Developing and assessing the acceptability of an epilepsy first aid training intervention for patients who visit UK emergency departments: A multi-method study of patients and professionals

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ABSTRACT

Epilepsy affects around 1% of the UK population; 40% of whom experience two or more seizures annually. However, most Emergency Department (ED) visits by people with epilepsy (PWE) are clinically unnecessary. Evidence highlights that with correct training, seizures can be safely managed by patients and their families within the community. Arguably therefore, PWE who frequently visit the ED might benefit from a self-management intervention that improves their own and their families' confidence and ability in managing seizures. Currently, no such intervention is available for PWE attending the ED. A collaborative approach (patients, carers, health professionals) was adopted to develop a patient-focused, self-management intervention. An existing group-based seizure management course, offered by the Epilepsy Society, was adapted. Collaborative feedback was sought via a base-line document review, one-to-one semi-structured interviews, and focus group discussions. The applied framework provided a systematic approach from development through to implementation. Participant feedback overall was extremely positive. People with epilepsy who visit the ED reported a positive view of epilepsy seizure first aid training and associated educational materials. Their feedback was then used to develop the optimized intervention presented here. Strengths and perceived barriers to successful implementation and participation, as well as the practical and psychosocial benefits, were identified. We describe the developed intervention together with the process followed. This description, while being project-specific, provides a useful template to assist in the development of interventions more generally. Ongoing evaluation will determine the effects of the training intervention on participants' behavior.

1. Introduction

1.1. Background

Epilepsy is common, with a prevalence of ~1% in Europe [1]. Self-management is a key component of living with the condition [2]. Despite this, models of care in many countries fail to equip all patients with sufficient self-care knowledge, skills, and confidence [2]. In the UK, there remains no routine course that patients or carers can take as there are for other chronic conditions [3–7] and time within routine appointments to obtain information is limited [8,9]. Patients have summarized the lack of support following diagnosis as: "I was left high and dry"

and "They didn't give me anything…just said, please take these tablets" [10]. Evidence from around the world now suggests that such a lack of support contributes to a significant minority of people with epilepsy (PWE) utilizing costly hospital emergency services.

1.2. Use of hospital emergency services and the link to self-management

In the UK, one-fifth of PWE visit hospital EDs each year, with 60% attending multiple times [11,12]. The cost of ED care for epilepsy in England alone in 2012/13 was £56 million [13]. Detailed information on the support needs of those who visit ED is not available. It is known, however, that compared to those in the wider epilepsy population, they have more seizures, report poorer quality of life, are more anxious, and feel more stigmatized [12,14]. They are also more likely to live in socially deprived areas [15].

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Emergency care for epilepsy can be important, even life-saving. However, UK-wide evidence shows ED visits by PWE are often clinically unnecessary or avoidable. Most are by those with known rather than new epilepsy and most have experienced uncomplicated seizures [16, 17]. While distressing to observe, such seizures can be safely managed by PWE and carers within the community [18–20]. Emergency Department visits in such instances do not typically lead to patients receiving any additional care [21] and there may be iatrogenic harms [22].

A recent study by our group showed sub-optimal self-management accounted for many of these visits. A sub-group of 20 adults with established epilepsy from London EDs were interviewed about the circumstances of their visits. Patients who had visited the most explained how they and their family and friends (to whom care decisions were often delegated) were unsure how to manage seizures, were uncertain about their effects, could not educate others about first aid, and feared death [23,24]. This led them to call for an ambulance when they were about to have, or had had, a seizure. Quantitative evidence reinforced what patients said, with epilepsy first aid knowledge being especially low amongst ED attendees [25]. This makes a case for an epilepsy first aid intervention for PWE who frequently visit the ED and informal carers. No such intervention currently exists [26–28]. However, self-management courses hold the potential to improve self-management skills, and in turn reduce fears and ED utilization [28–33].

1.3. Aims

We aimed to develop and evaluate a complex service intervention — epilepsy first aid training for PWE who frequently visit the ED. Complex interventions, as defined by the Medical Research Council (MRC) [33], constitute several interacting components. As such they present a number of evaluation challenges; not least in relation to the difficulty of standardizing intervention design and delivery. To assist with the development–evaluation–implementation process we drew guidance from the MRC Framework [33], key components of which are outlined in Supplementary File 1. Most self-management interventions to date reported within the epilepsy literature have been derived from limited expert opinion and have not involved PWE in the planning process. To ensure maximum benefit, acceptability to users, and ultimately support from the wider epilepsy community, we in contrast worked collaboratively with patients, carers, and health professionals to identify needs and delivery preferences and ultimately develop our package. Our aims were to:

1) fully detail the process of intervention development and assessment; 2) describe the content and organization of the resulting intervention; and 3) increase the evidence available on those who visit ED.

2. Methods and materials

2.1. Design

2.1.1. Intervention

The UK epilepsy voluntary sector has long been offering epilepsy-related training within the third sector to other audiences. Of particular relevance is a 3-hour group-based training course titled 'Epilepsy awareness and seizure management' [34] (see Supplementary File 2). It has been delivered on a small scale since 1998 by the Epilepsy Society to a fee-paying group (e.g., teachers, care staff, patients and carers).

It had not been formally evaluated for use within a health service, but appeared to have potential for PWE who have visited ED and their carers. For example, one of its aims was to increase recipients' confidence in seizure management, emphasizing how most seizures are self-limiting, and providing a practical understanding of when seizures do, and do not, require emergency treatment. We therefore decided to adapt this course for the ED patient and carer population. Materials for the course included presentation slides, a video of seizure types, and first aid, as well as copies of the slides and additional information

booklets (such as on risk management, emergency medication). It was delivered by educational facilitators from the charity's training section who had experience of working in epilepsy.

2.1.2. Adapting the intervention

To identify the changes required, we utilized a collaborative framework, underpinned by a philosophy of experience-based co-design (EBCD) [35], which is an approach to improving healthcare services that combine participatory and user experience design and processes to bring about quality improvements in healthcare [35]. It enables professionals, patients, and carers to reflect on their experience of a service/intervention, identify improvement priorities, and devise and implement changes. In the current study this co-design process comprised three iterative stages (Fig. 1): (i) Qualitative interviews with health professionals about the existing intervention; (ii) optimization of its behavior change potential; and (iii) focus group discussions with service users as a coordinated strategy to use patient feedback to improve the intervention and evaluate subsequent changes.

The process was overseen by an intervention development panel. Its co-design meetings enabled professionals, patients, and carers to engage in the process of gathering experiences and considering the feedback from the interviews and focus group discussions. The panel included a psychologist (AN), neurologist (LR), patient and carer representatives, a medical sociologist (MM), a research nurse with specialist qualitative training (DS), and a representative from the Epilepsy Society training division. Patient and carer representatives were active in all decision making and reimbursed for travel and time in line with guidance [36].

The National Research Ethics Committee North West—Liverpool East approved the study (15/NW/0225) and informed consent was obtained from all participants.

2.2. Procedure

2.2.1. Stage 1: qualitative interviews with health professionals

2.2.1.1. Purpose. To tailor the intervention for delivery with the UK health service, maximize the likelihood that the intervention could be supported by health professionals in the future, and ensure the medical information presented was correct [37].

2.2.1.2. Recruitment. The starting point was the establishment of a multidisciplinary, consultative group comprising nine health professionals supporting PWE. A number of different health disciplines can be involved in the care of PWE. Some will identify a GP as the main provider of their ambulatory care, while others (particularly those with uncontrolled epilepsy) will identify a specialist, such as a neurologist or epilepsy nurse. The voluntary sector is also frequently identified as being an important support structure for many PWE. When someone seeks emergency care for a seizure, other parts of the health system also come into contact with the person with epilepsy — including paramedics and ED staff. All parties were considered as being able to offer potential insights into the support needs of those with epilepsy who attend for seizures. We therefore chose to adopt a broad approach and use purposive sampling so as to recruit informed individuals from the main parts of the care pathways encountered by PWE. As a means to increasing the reliability of the results, our sample was geographically diverse.

Most professionals were nominated by their discipline's professional body. Each representative was offered a consultancy fee of £200.

2.2.1.3. Process. Data were collected from each of the nine health professionals via audio-recorded, face-to-face or telephone, semi-structured interviews.

The task of this multidisciplinary, professional group was to conduct a baseline document and audio-visual review of course materials currently offered on a small scale by the charity, Epilepsy Society. The
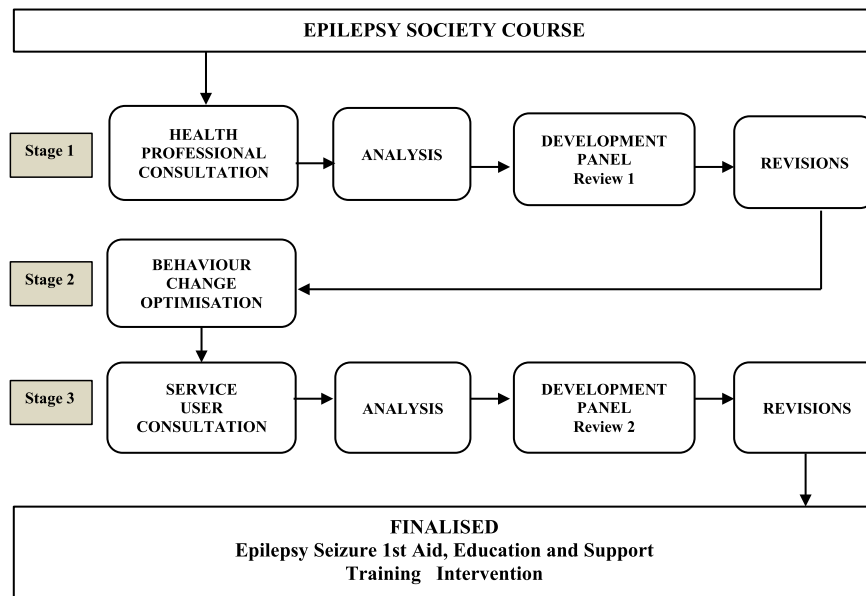
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Fig. 1. Study stages 1–3.

duration of the original course was approximately 3 h. Course content is outlined in Supplementary File 2. In brief, it comprised learning topics around diagnosis; seizure causes, types and triggers; management, risk and when to call an ambulance; treatment, medication and side effects; and demonstrating the recovery position. This information was delivered with the aid of slides, a video, and participant information packs. Participants were sent the original course materials to review. Two weeks later they provided feedback via individual, semi-structured interviews. (Topic guide is Supplementary File 3).

A topic guide was developed to reflect the intended purpose of the stage (outlined at Section 2.2.1.1) and on the basis of the literature. It was refined through the iterative process of conducting each of the interviews [38,39]. The interviews were introduced to participants as looking to explore professionals' views of the existing intervention for delivery to those with established epilepsy who have attended ED and their carers. Consensus already exists on what constitutes appropriate seizure first aid [18–20,33] and so one of the objectives of the stage was to (i) seek feedback from the professionals, where expertise permitted, about the accuracy of the medical information presented by the programme. We also sought their (ii) views about the idea of the course; (iii) the potential of the course to improve seizure management skills; (iv) the potential of the course to help patients make fewer clinically unnecessary ED visits; (v) their views in relation to course content and delivery; (vi) how to maximize its benefit and; (vii) how the intervention might be best implemented within the National Health Service (NHS) — including identification of barriers and facilitators to success. Each category was supplemented by probe questions to assist participants in providing focused and detailed information based on their experiences and beliefs.

It was considered important to seek feedback from professionals in the first instance in order to prevent potentially vulnerable PWE (and carers) being exposed to possibly incorrect information. Moreover, it would allow us to identify from the start broadly what sort of seizure first aid intervention was considered to be feasible for delivery within the context of a publically-funded health service.

2.2.1.4. Analysis. Interviews were audio-recorded and transcribed verbatim. QSR International's NVivo 10 [40] – a qualitative data management and analysis software package – was used and enabled the data to be organized into different data types and sources, in context, throughout the consultation phases. This allowed data to be coded and cross referenced

within and across individuals. Lower level codes were then grouped into themes.

2.2.2. Stage 2: optimization of behavior change potential

2.2.2.1. Purpose. It was anticipated that the intervention's provision of information about epilepsy and seizure first aid could reassure participants and increase seizure management confidence and competence. However, for some, the information might highlight that their prior use of ED conflicted with medical guidance (e.g., that of their own volition they had visited an ED for an uncomplicated seizure). This might reduce the ability of the intervention to change behavior since Self-Affirmation Theory [40,41] states people are fundamentally motivated to preserve a positive, moral, and adaptive self-image. As such, health messages which threaten one's sense of self-image can be subject to defensive processing (e.g., motivated scepticism, unrealistic optimism) [42].

2.2.2.2. Process. Self-Affirmation Theory provided the means to modify the intervention so as to mitigate against this potential biased processing and so maximize the possibility that the information being relayed would change behavior [43]. Specifically, a large body of evidence shows that having a person complete a 'self-affirming' activity prior to receipt of health risk messages, such as reflecting on the values one holds in high regard, reduces resistance to dissonant information and increases behaviour change. It appears that this is because self-image can be maintained by self-affirming in one domain (e.g., recalling one's acts of kindness) even if one is being threatened in another domain (e.g., health) because people can defend their global sense of self-worth [44]. Therefore, we introduced Reed and Aspinwall's [45] self-affirming 'Kindness Questionnaire'. This is brief (~5 min), effective [46,47], and does not need to be delivered by specialists. Its 10 questions require the person to recall past acts of their own acts of kindness (e.g., "Have you ever been concerned with the happiness of another person?"; "Have you ever forgiven another person when they have hurt you?"). The intention was that PWE and carers would each complete it, privately, at the start of the intervention.

2.2.3. Stage 3: focus groups with service users

2.2.3.1. Purpose. To ensure the intervention addressed users' needs, was acceptable, and that its delivery was optimized.

2.2.3.2. Recruitment. To allow service users to critically review the intervention, two courses were run in November 2015 using the adaptation resulting from the first two stages. Participants attended a course and gave feedback via focus groups.

Sampling was purposive and PWE were invited to take part along with an informal carer. Potential participants were identified via usergroups. They were eligible if aged ≥16 years (no upper age limit), lived in North West England, and could provide informed consent and participate in the intervention in English. People with epilepsy needed to also have an established diagnosis of epilepsy (≥1 year), be prescribed antiepileptic medication and have visited an ED in the past 2 years. People were excluded if they reported acute symptomatic seizures, as were those with severe current psychiatric disorders or life-threatening medical illness.

Participants each received a £10 shopping voucher and were reimbursed for travel costs.

2.2.3.3. Process. The practice courses were delivered on weekdays to groups of ~10 patient/carer dyads. A facilitator from the Epilepsy Society, who was an epilepsy nurse specialist with experience of delivering the original version of the course, delivered the courses. She underwent a period of familiarization with the new version by reviewing the new materials and a trainers' manual, and by meeting the development panel.

The focus group model of user involvement required a trained qualitative researcher (DS) to facilitate data collection. Using this model had the potential to identify insights to strengthen the intervention, which, arguably, might be lost with more conventional models of user involvement — such as sitting on steering groups [48]. At the end of each course, DS conducted a focus group. The topic guide (Supplementary File 4) reflected the discrete sections of the course enabling feedback to be sought in relation to each of the sections. Each category was supplemented by probe questions to assist participants in providing feedback. They were asked about issues related to both the course content and delivery, as well as for views around perceived strengths and barriers to its successful implementation. The researcher also observed

each course and recorded her impressions of participants' engagement with the materials, the group, and the facilitator.

2.2.3.4. Analysis. The analysis procedure was similar to that for the health professional with focus group discussions being audio-recorded, fully transcribed and, along with the researcher's field notes, uploaded to NVivo.

3. Results

3.1. Participants

3.1.1. Health professionals

Nine health professionals were recruited. They were dispersed across the UK and included two consultant neurologists, one with a specialist interest in epilepsy, two consultants in emergency medicine, a consultant paramedic, an epilepsy nurse specialist, a general practitioner with a specialist interest in epilepsy, a service commissioner with a healthcare background, and an educational representative from another epilepsy charity.

3.1.2. Service users

Twenty-three service users were recruited. This comprised 13 PWE (7 males/6 females) and 10 informal carers (4 males/ 6 females).

3.2. Feedback

3.2.1. Health professionals

Analysis of responses highlighted three key themes: initial impressions, barriers and drivers to effective participation in training, and course delivery. Full quotes are provided in Table 1.

3.2.1.1. Initial impressions. There was consensus on the need for such an intervention, and that it could ultimately prove cost-effective. The existing intervention was seen to provide a useful starting point and participants liked the video and associated information booklets but

Table 1
Themes within health professional feedback and quotes illustrating them.

Area	Theme	Illustrative quote
Initial impressions	Need for such an intervention and potential cost-effectiveness	"[I]t will be a powerful tool to upskill and reassure(…)The clearer they are about what constitutes that person's normal epileptic fit and what maybe a bit unusual, the more(…) appropriate the response the better their… overall experience, privacy, dignity and everything to follow (…) [I]t's a fairly easy case to make for the commissioners (…)Resources directed by commissioners to pay for this really unnecessary attendance could be re-directed… win–win." (ED Consultant).
	Existing course good foundation for adaptation	"There's a solid foundation in there which you can build on to then create the course to make sure it reaches the kind of outcomes that you are after. … It's just making sure that it hits all those objectives along the way." (User group representative).
Changes needed	Practical challenges of hosting a group-based course	"Getting people together may be a difficulty, with distance and timing a factor to be considered so it is important to think about local delivery and minimising travel time." (Epilepsy Nurse Specialist)
	Revise language level and presentation style	"(…) it's written in quite a wordy way and probably a few more pictures and a few less words…would be better. This is probably a very good presentation to new health care professionals…but probably not great for people that…have no training whatsoever." (Consultant Paramedic)
	Emphasize the benefits of the course to patient and carers	"It's about helping people manage their epilepsy better. What will the course do for you? What can you get out of the course? (…)The course should focus on behavioral change, but the impression should not be given that the focus is about reducing A&E admissions — that would be counter-productive. Rather, it is about highlighting the benefits, such as better management will reduce inconvenience in having to go to A&E." (General Practitioner)
	Need to elicit and address patient concerns and address them	"[S]eizure management, what you should do and what you wouldn't do…I'd make that part interactive…get them to tell, you get their opinion and their views before and then you show them what they probably should do afterwards but find out. Because you'll probably (…) challenge them (…) that's the point where you really get them I think." (Consultant Neurologist)
	Need to support patients regarding epilepsy identification and care plans	"[I]f we [the ambulance service] tip up and we don't know anything about you we are taking you to hospital (…) we're tipping up to what we consider to be a first time fit until proven otherwise. Have a care plan written or something on you that says I'm an epileptic and this is what happens to me normally." (Consultant Paramedic)
Course delivery	Attributes and skills of ideal course facilitator	"The facilitator is someone who should have knowledge of epilepsy and be good at leading groups. They need the ability to keep the course on track and to time especially when participants may want to talk a lot!" (Epilepsy Nurse Specialist)

substantial changes were seen to be needed to make the intervention appropriate for its new audience and to achieve the aim of attenuating unnecessary/avoidable ED use.

3.2.1.2. Areas of intervention in need of revision. A more focused and "*clear message*" on the need or not for ED after a seizure was required at the start (Consultant Paramedic) and the language reduced to the average UK reading age [49]. There were suggestions to also revise the style of presentation so that it was less for people who might be involved in epilepsy due to their profession.

It was considered that a "*behavioral change focus*" (Emergency Medicine Consultant; 1) should be brought to the fore and that the benefits to the patient and carer of avoiding unnecessary ED visits should be emphasized.

A recurring theme was that patient and carer participation should be promoted through more interactive exercises, the inviting of questions, and the discussing of fears as this was when "*true education happens*" (Emergency Medicine Consultant; 1).

It was highlighted that when seizures happen in public places the decision to seek emergency care was not necessarily that of the patients or carers. As such, it was recommended that the intervention should support patients to develop and carry with them personalized care plans on paper or on their 'smart phones'.

3.2.1.3. Course delivery. Participants observed that to make the course suitable for delivery within the health service and to promote quality and consistency across trainers, the intervention should become fully standardised and a trainer's manual, including recommended times for each topic/activity, developed.

With respect to who would be suitable to deliver the course, some identified epilepsy nurse specialists. However, others felt the epilepsy voluntary sector was well-developed and as such commissioning organizations from it could help avoid shortfalls where specialist staff were not available.

3.2.1.4. Changes made by intervention development panel to create version 1.1. The panel agreed that the intervention's content needed to be revised so it was better directed towards the intended goal of attenuating unnecessary ED use. They specified the following aims for the new intervention: i) to help participants feel more confident to manage their seizures/the seizures of someone they know; ii) know how to tell others how to help; iii) know some things that may reduce the chances of a seizure; and iv) know some things that may reduce the chances of injury from a seizure. In addition, it was suggested that didactic materials for learning in small groups, an information pack to remind participants of what was talked about, as well as some further information on other related topics and a manual for group trainers should also be developed.

In line with these requirements, AN and DS revised the intervention generating new presentation materials for each section of the training session. New content (see Supplementary File 2) was introduced and a training manual for facilitators generated. In doing this, attention was given to presenting information in an easy-to-understand style and included the use of video materials with the support of Epilepsy Society.

To promote more interaction, scenarios and tasks for the group teaching process were designed to address not only the educational but also the behavioral aspects of epilepsy. Four new activities were introduced. One involved practicing the recovery position; another required subgroups to find answers to different questions concerning seizure first aid from amongst a group of laminated cards and to present these. This was designed to help identify participant beliefs and fears and for these to be discussed. The final two activities centered on case studies. This involved participants being read illustrated stories of patients and asked to consider what things the patient in the story might have done to have achieved a better outcome. The carrying of epilepsy

ID was one way in which the outcome of one of the stories could have been changed.

Within the revised intervention, 114 min (47.5%) now comprised interactional/networking elements; 114 min (47.5%) taught slides; and 12 min (5%) were video.

3.2.2. Service users

All patient and carer participants identified the need for such a course with a lack of prior support in self-management being a recurring topic.

Participants described three areas of perceived need, namely; knowledge acquisition around epilepsy, emotional and/or practical support, and dealing with isolation and stigma.

Carer concerns centered on the "*need to know I'm doing the right thing*" (Carer 4, F, FGD1). People with epilepsy expressed concerns in relation to disclosure and how best to tell others around them how they should help if a seizure happened; they wanted information and advice on how best to manage this.

3.2.2.1. Initial impressions. Overall, the content of the revised course was felt to be "*excellent*" (Patient 3, FGD 2) and appropriate (see Table 2).

Of particular importance to users was the relatively straightforward guidance that an ambulance was required when seizures lasted for 5 or more minutes. This information alone was found to be helpful and reassuring and some said they would no longer always call straightaway for an ambulance: "*I think I will wait longer than I did before picking up the phone*" (Carer 3, F, FGD 2).

There was consensus, for the most part, that the need to feel informed and reassured on what to do when seizures occurred had been met. Participants expressed how they had "*learned a lot*" (Carer 5, F, FGD1) from the session. The balance between taught and interactive components was felt appropriate and the opportunity to practice the recovery position was valued.

The training session was though considered to cover more than implied by its title. Participants said the "*wider remit*" (Patient 10, F, FGD2) was desirable, but that a more accurate title was needed to engage future service users — 'Managing seizures: epilepsy first aid training, information and support' — was identified as more suitable.

3.2.2.2. Barriers and drivers to effective participation in training. Service users' perceptions of barriers and drivers to successful training were explored. One barrier was the use of the self-affirmation 'Kindness Questionnaire' [46]. Its positioning and purpose to the session was not understood by most participants, "*(…) just coming into the session the questionnaire seemed inappropriate*" (Carer 3, F, FGD1). It was also found by some to be threatening, "*(…) it felt like a test and a bit off putting*" (Carer 4, F, FGD1).

Another was that some service users reported "*There's a lot of information to take in*" (Patient 4, M, FGD1) and issues relating to memory difficulties were highlighted. Participants therefore supported the use of handouts, and requested an online copy of the materials that they could access and share with others.

With respect to content, important feedback from service users was that they appreciated that attention was given to what the types of seizures are and managing them and that the focus was not simply on "*grand mal seizures*" (Carer 5 F, FGD1). However, they suggested that more time be given to exploring triggers and auras and to explain that not everyone has triggers, which in itself, is a potential risk. It was also suggested that new sections should be included to discuss the risks associated with post-ictal states and how best to deal with them. Finally, some suggested that "*dealing with an injury as well as dealing with the seizure can be difficult*" (Carer 7, F, FGD2). As such, information and advice was said to be needed on how to deal with common seizure injuries.

Table 2
Themes within service user feedback and quotes illustrating them.

Area	Theme	Illustrative quote
Learning needs	Information and self-management support	"The consultants they just presume that you know [about epilepsy]...but for all the years he got put on tablet or tablets...you didn't see or hear any of this [information presented by course]. So its suddenly all of an 'eye-opener' and talking here you realise we are not on our own" (Carer 1, F, FGD1)
		"I always think of epilepsy as the poor relation (…) not much on TV or adverts about epilepsy support (…) A course like this helps to develop that sense of support as well as improve knowledge." (Carer 2, M, FGD1).
	Need for support specifically for carers	"It can be quite overwhelming I think for your partners. It's like 'all on their shoulders' what happens. I think your carer needs a lot of support to" (Patient 3, M, FGD1)
	How to tell others about epilepsy and how to help if a seizure happens	"Like when you go somewhere you need to remember to like tell people that you have seizures" (Patient 1, M, FGD1)
		"I need to know how best to share with others [family/friends/workplace] the implications of having epilepsy" (Patient 2, F, FGD1)
Initial impressions	Information reassuring	"I think I will now wait longer than I did before picking up the phone (to call an ambulance)… I think I will wait rather than when he has a seizure going for the phone straightaway" (Carer 7, F, FGD2)
	Practical tasks (e.g., practicing recovery position) valued	"Watching a video would just go straight over me head, but actually putting [patient name] on the floor and putting him in the right position will help. For me that's very useful...something like that I won't forget" (Patient 5, F, FGD1)
Course delivery	Benefits of group format	"[R]eally glad I came. I think it's just being around people who know exactly, exactly how you feel and that's why this should have been put on a long, long time ago." (Carer 1, F, FGD1)

3.2.2.3. Course delivery. Participants valued the group format of the course and that both PWE and carers were present. The size of the group (n = ~20) was considered appropriate and encouraged discussion. Participants valued meeting other people in the same situation as them. It allowed them to share experiences and helped them "*realise you are not on your own with it*" (Patient 6, M, FGD1).

In terms of who would be best to facilitate the course, many felt it should be a health professional as they believed this would make the course "*credible*" (Patient 8, F, FGD2) and promote uptake. Others however, argued it could be facilitated by a representative from a user group as what was most important was that the trainer was knowledgeable and empathetic and had the skills to facilitate discussions. Either way, it was argued that standardized training for the facilitators themselves was important.

3.2.2.4. Changes made by intervention development panel to create version 1.2. The users' feedback led to a refashioning of a number of details in the way the intervention was to be delivered (see Supplementary File 2).

To increase the acceptability to users of the self-affirmation 'Kindness Questionnaire', it was agreed that this would not be introduced to participants until ~30 min into the session and would follow the 'ice-breaker', rather than immediately at the start. Given the main aim of the intervention was to help patients and families manage uncomplicated seizures, the panel revised the intervention so information on managing common post-ictal states was included.

However, for the same reason, training patients and carers in dealing with seizure injuries as requested was deemed to be beyond the intervention's scope. As such, the intervention was modified to simply acknowledge the possibility of injuries and direct participants to some external resources on this.

The length of the training intervention at Version 1.2 was extended from 3 to 4 h. The additional time facilitated a more interactive approach to the training to include: discussion of participant expectations, course tasks, quizzes, lifestyle scenarios, practical demonstrations of how to place someone in the 'recovery position' following a seizure, and question and answer sessions.

Finally, a website associated with the course that would allow participants to access course materials, including the videos, was developed (see Acknowledgements). Both the service users and clinicians acknowledged the need to recognize the potential of memory difficulties existing within the epilepsy population. It was also considered that an online copy of the materials would have the added advantage of enabling participants to easily share the information with others in their social network.

4. Discussion

We undertook a project to develop an epilepsy first aid training intervention that met the needs and preferences of PWE who frequently visit hospital EDs and their carers. There is international momentum for such an intervention.

To promote adequate development and piloting [33], we worked collaboratively with service users and other key stakeholders. Qualitative approaches to data collection enabled the systematic exploration of participant views of the intervention, from a number of perspectives. Information gathered in Phases 1, 2, and 3 were used both sequentially and iteratively to define definitive components of the intervention. We have described the process we followed. Such an account is rare, but important.

Firstly, it provides the epilepsy community and beyond with detailed information about the intervention which we are now trialling [50]. Outcome papers are frequently criticized for not providing readers with sufficient information to interpret trial results [51].

The second reason is that in doing so we provide information on a methodology that is frequently recommended, but for which researchers have little guidance on how to do it and to know how benefits might be derived. We anticipate that our description will provide a useful template for the development of other interventions. The applied, collaborative framework we employed permitted us to move beyond the criticized "tokenistic" approach of involving service users [52] and allowed us to complete a practicable "co-design" project whereby health professionals, patients, and carers reflected on their experiences of a service and worked together to create a complex intervention [35].

4.1. Addressing the support needs of PWE attending ED and their carers

Self-management interventions have two main aims: to increase relevant knowledge around the condition and to promote patient responsibility and confidence to manage life-style decisions effectively [53,54]. Contrary to earlier findings [55,56] suggesting PWE attending EDs may be reluctant to accept and participate in the provision of additional epilepsy support, we found participant acceptance of the training and associated educational materials to be positive. Many carer and family member participants expressed feeling ignored and alone. The benefit of meeting with others and learning from the experiences of others was perceived as a positive outcome; participants said it enabled them to apply the experience of peers to improving or consolidating their own epilepsy management decisions [57]. Peer support was further facilitated with the use of refreshment breaks enabling participants to informally interact with others about issues of interest or concern. Our

findings lend support to wider evidence indicating that PWE do want to receive this sort of support [58–62] and that there is widespread recognition for a self-management intervention [24,60,61].

In addition, a number of positive training outcomes could be discerned across two domains; 'intervention-context interactions' and 'epilepsy-specific management'. To promote group interaction, course facilitation began by asking participants to identify their expectations of the day. This introductory section encouraged group participation and enabled the trainer to shape subsequent learning to the needs of group members. Throughout involvement in the learning process participants asked questions about epilepsy, openly discussed various related topics, shared stories, experiences, and feelings about their epilepsy amongst themselves, and requested more information concerning epilepsy.

Participant comments demonstrated that much information was derived through the participation of significant others [60] and as such, the intervention was not only suitable for PWE but also for their informal carers.

Epilepsy-specific management included discussion around a number of topics. First, as noted in prior research, many seizures leading to emergency visits by PWE do not require emergency care or are potentially avoidable [21,62–64]. Thus, in line with previously identified epilepsy self-management models [27,65], strategies to assist with AED management were discussed as part of the course content. To support learning, supplementary materials were available for participants to take away.

As in an earlier epilepsy self-management study [21], our intervention discussed the possibility of wearing an epilepsy identification (ID) bracelet and/or carrying an epilepsy ID card/care plan. Anecdotal evidence, such as that from online forums (see http://forum.epilepsysociety.org.uk/viewforum.php), indicates some objections to carrying ID including, for example, being labelled and/or setting oneself apart. Conversely, other PWE have reported these items as giving them more confidence which meant that they did not feel the need to be accompanied by a carer who could explain their diagnosis to others should a seizure occur. Consequently, epilepsy did not restrict them as before. The perceived challenges associated with epilepsy ID and recommendations for PWE to carry such an item have been raised in the paramedic literature before, but not much attention has been given how to support patients. The degree of use of IDs by PWE appears low [66]. To address this issue we used a case story to help illustrate the possible advantages that ID could bring and provided copies. Patients did not express dislike of this.

4.2. Benefits and challenges of working with stakeholders to develop an intervention

The process enabled us to access the unique perspectives of service users and health professionals. Clear, tangible changes to the intervention were made in response to this. The intervention is now better positioned to be implemented within the UK's health service, should trial evidence justify this. Examples abound, including from epilepsy [67], showing just how important it is to ensure that any new intervention is supported by those who will be asked to ultimately refer their patients to it, deliver it, or allocate resources to it.

A concern of some researchers is that the process of engaging service users and other stakeholders will be unwieldy and that stakeholders will be challenging to engage [68]. To this point, we would note that this process is not one that should be entered into lightly as it required careful planning, expertise, resources, and ethical approval. It took 9 months to complete, with a team including four experienced academics, two at the professional level.

We would argue though that the length of the feedback sessions and the quality of consideration given by the stakeholders goes some way to demonstrating just how willing stakeholders are to contribute to such processes. In terms of recruitment, we note that those with epilepsy

can often have low self-esteem and confidence [69–71]. This meant we needed to be mindful from the start of the need, when bringing people into this process, to clearly emphasize to participants what we were doing, why we wanted them involved and that it was their views, however critical, that we needed to learn from. In terms of the health professionals, the main challenges were that they were geographically dispersed and typically busy clinicians. As such, there was a need to be flexible with regards to the arranging of interviews.

4.3. Current research activity

In line with the MRC's Evaluation Framework [33], the training intervention is now being piloted by means of an external pilot randomized controlled trial [71]. This will provide systematic evidence on the uptake of the training and estimates of its effect. The proposed primary outcome being used in the trial is ED use in the 12 months following randomization. Secondary outcomes include patient and carer confidence in and knowledge of seizure first aid, quality of life, psychological distress, and wider service use. Such evidence will be used to inform the optimal design of a definitive trial of the intervention.

5. Conclusion

We have described the development of an epilepsy seizure first aid training intervention that has been tailored to the unique needs of PWE who visit EDs and their carers. This activity was underpinned by the MRC's complex intervention guidance [33]. By doing this, the acceptability of the intervention within the target population has been increased. Stakeholder collaboration has arguably maximized the intervention's potential benefit and better positioned the intervention for future, sustained use within the health service. We now await results from the pilot trial.

Supplementary data to this article can be found online at http://dx.doi.org/10.1016/j.yebeh.2017.01.006.

Department of Health disclaimer

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Ethical standards

The manuscript does not contain clinical studies or patient data. The National Research Ethics Committee North West—Liverpool East approved the study (15/NW/0225) and informed consent was obtained from all participants.

Conflict of interest

The authors declare no conflict of interest.

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