**Patient perspectives on the acceptability of mHealth technology for remote measurement and management of epilepsy: a qualitative analysis**

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**Abstract**

**Background**: Innovative uses of mobile health (mHealth) technology for real-time measurement and management of epilepsy may improve the care provided to patients. For instance, seizure detection and quantifying related problems will have an impact on quality of life and improve clinical management for people experiencing frequent and uncontrolled seizures. Engaging patients with mHealth technology is essential but little is known about patient perspectives on their acceptability. The aim of this study was to conduct an in-depth qualitative analysis of what people with uncontrolled epilepsy think could be the potential uses of mHealth technology and to identify early potential barriers and facilitators to engagement in three European countries.

**Method**: Twenty people currently experiencing epileptic seizures took part in five focus groups held across the UK, Italy and Spain. Participants all completed written consent and a demographic questionnaire prior to the focus group commencing and each group discussion lasted 60-120 minutes. A coding frame, developed from a systematic review of the previous literature, was used to structure a thematic analysis. We extracted themes and subthemes from the discussions, focusing first on possible uses of mHealth and then the barriers and facilitators to engagement.

**Results**: Participants were interested in mHealth technology as a clinical detection tool, e.g. to aid communication about seizure occurrence with their doctors. Other suggested uses included being able to predict or prevent seizures, and to improve self-management. Key facilitators to engagement were the ability to raise awareness, plan activities better and improve safety. Key barriers were the potential for increased stigma and anxiety. Using familiar and customisable products could be important moderators of engagement.

**Conclusion**: People with uncontrolled epilepsy think there is scope for mHealth technology to be useful in healthcare as a detection or prediction tool. The costs will be compared with the benefits when it comes to engagement and ongoing work with patients and other stakeholders is needed to design practical resources.

**Key words**: epilepsy; mHealth; acceptability and feasibility; qualitative analysis.

**1 Introduction**

Epilepsy is a neurological condition characterised by recurrent unprovoked and unpredictable seizures. Most people with epilepsy also suffer from a range of other problems including mood disturbance, memory impairment and medication side-effects that have a further impact on quality of life [1-3]. Treatments for epilepsy primarily focus on the management of seizures occurrence. Current methods for assessing treatment outcomes, focus on the reduction of seizure activity but self-reported seizure occurrence has been found to be unreliable [4]. With developments in mobile health (mHealth) technology that tracks physiological signals (including electro-dermal activity and heartrate) and patterns of activity (accelerometery), there is potential for more objective and frequent health assessment that might help identify seizure activity early [5, 6], particularly for people with uncontrolled, frequent seizures. Identifying such indicators in a more timely and effective way could lead to more efficient treatment and management. In addition to the use of wearables, there is an emerging interest in the use of other mHealth tools such as smartphone applications (apps) to aid self-management [7-10], including the continued monitoring of patient-reported factors thought to be associated with seizure activity [11].

While mHealth tools provide the opportunity for real-time measurement and management, this process requires user engagement. Engagement has been defined as the extent and way people actively use resources, e.g. wear a device, and interact with a smartphone app [12]. Preliminary research supports the acceptability of mHealth resources for people with epilepsy with a recent survey reporting that 80% of people with epilepsy were willing to use a wearable device for seizure tracking [13]. A large proportion (69%) were also willing to use smartphone apps. That study touched on some potential barriers to engagement, including fears about data confidentiality and need for technical support. A recent systematic review of eHealth technology suggested that factors influencing engagement may be complex and multifactorial with many other aspects to consider [12]. This study builds on these results. We first investigate patient preferences for uses of mHealth resources in healthcare and then consider the barriers and facilitators to engagement, including how engagement may be influenced by the cultural context with the aim of maximising the value of interventions across three European countries (Italy, UK, and Spain).

**2 Methods**

**2.1 Design**

A qualitative study was conducted with the aim of identifying potential uses, and barriers and facilitators to the engagement with mHealth technology for people with a diagnosis of epilepsyin three European countries (Italy, UK and Spain). The topic guide and coding frame built on barriers and facilitators to engagement with remote measurement technology identified in a recent systematic review [12]. This coding frame included several pre-established major and minor codes, as well as subthemes that emerged beneath these codes following grounded-theory methods.

**2.2 Context**

***2.2.1 Researcher characteristics***

The focus groups were facilitated by native speakers in all countries. Co-ordination was agreed via face-to-face, telephone and e-mail contact prior to commencing with all sites following the same research protocol. The groups were facilitated by two clinicians (who were either a psychologist or a neurologist); one led the discussion (primary facilitator) and the other (secondary facilitator) provided support with recruiting and consent procedures and listened during the discussion. None of the primary facilitators were directly involved in the clinical care of the participants. All facilitators were female, apart from those in Spain which involved a man and a woman.

***2.2.2 Participant characteristics***

Participants were eligible if they were over the age of 18 and had a diagnosis of epilepsy which required ongoing, active management. Participants were only included if they were experiencing at least one seizure per month. This was the protocol across all countries involved who went through an inclusion criteria checklist with each potential participant whether they were recruited through clinics or charities. All participants needed to be able to give written informed consent to take part in this study. People with a diagnosis of exclusive psychogenic non-epileptic attacks (dissociative seizures) or severe behavioural difficulties that prevented them from attending a focus group were excluded.

**2.3 Ethics approvals**

Local research ethics committees for each country approved procedures. Ethics code UK: 16/LO/1513; Italy: 88/2018/PO; Spain: PIC-149-16. In the UK, potential participants were approached through a charity newsletter. In Spain and Italy, clinicians selected patients attending neurology services.

**2.4 Focus group procedure**

A pre-specified topic guide (available on request) was used to structure an open discussion about potential uses of mHealth and the barriers and facilitators to engagement with these resources in the context of living with a long-term health condition. The open-discussion format allowed people to share a range of examples. Each group discussion lasted 60-120 minutes. Participants all completed written consent and a demographic questionnaire prior to the focus group commencing.

**2.5 Data analysis**

Descriptive statistics were calculated for the age, gender, ethnicity and time post diagnosis for participants in each country (presented in Table 1). Each focus group discussion was audio recorded and transcribed verbatim. The Italian and Spanish transcripts were then translated into English by a native speaker. This enabled a combined analysis in English. All transcripts were coded by two researchers working independently. The coding frame was used to structure the data extraction (themes presented in bold in Table 2 and 3) and variable subthemes emerging from the data were identified in the final analysis, which were reviewed by those who ran the focus groups in other countries.

**3 Results**

Focus groups were conducted with 20 people across three countries (UK N7; Spain N5; Italy N8). In the UK and Italy, participants were invited to a second focus group where they were given the opportunity to provide feedback on the themes identified. Some additional themes were identified through this process, but the majority (80% for uses of mHealth and 83% for barriers and facilitators to engagement) of themes were identified in the first group with the second group serving as a validation. The age and gender distribution of participants was similar across countries (see Table 1), however, participants in the UK were, on average, slightly older. Participants from the UK and Italy group had on average been living with epilepsy longer than in Spain.

**Table 1.** Participant characteristics separated by country.

|  |  |  |  |
| --- | --- | --- | --- |
|  | **UK (n=7)** | **Spain (n=5)** | **Italy (n=8)** |
| **Gender: n female (%)** | 5 (71.4) | 3 (60.0) | 5 (62.5) |
| **Age: mean (SD)** | 44.5 (15.7) | 37.3 (9.2) | 32.6 (10.7) |
| **Time since diagnosis (years): mean (SD)** | 19.1 (16.1) | 8.4 (11.3) | 17.5 (12.5) |
| **Ethnicity: n (%)****White****Asian** | 6 (85.7)1 (14.3) | 5 (100.0) | 5 (100.0) |

**3.1 Potential uses of mHealth technology**

Participants raised a multitude of ideas about how mHealth technology might be useful in their daily life. These responses are summarised in Table 2. Using mHealth technology to better **remember and communicate with doctors** about seizure occurrences was the only category mentioned across all groups. Someone who had already had experience of using an app said: ‘*in terms of collating all that information and remembering it, my app did that for me. So, I just logged it throughout the months, and then I went back, when I was at the hospital, and then I could present all of that information to her*’ (UK6). In general, there was less discussion about potential uses of mHealth technology in Spain; few participants expressed an awareness of the use of medical devices to monitor their condition and only one commented on the utility of technology to adequately diagnose epilepsy. However, other similarities across the UK and Italy included value in being able to **detect seizures at night** and, going further, to **predict or prevent seizures**. One person said: ‘*The key word for me is preventing. In everything. If you can prevent, everything is solved*’ (IT6). Self-management to support **regulation of activity and rest** also arose as an important potential use of mHealth technology. A participant from the UK expressed: ‘*I get warnings before my seizures but they’ re not very long, so if I can predict it even before that, it might change the way I plan my day…if we can find anything, any kind of technology that would support me in day to day life, of knowing when it’s going to happen, then I would welcome it*’ (UK6).

**Table 2. Potential uses of mHealth technology.**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | **UK (Group 1a)** | **UK (Group 1b)** | **Spain (Group 1a)** | **Italy (Group 1a)** | **Italy (Group 1b)** |
| **Clinical detection/prediction (circumstances that provoke seizures)** | Predicting seizures (4) |  |  | Predicting seizures (3) |  |
|  |  |  |  | Predicting falls (1) |  |
|  |  | Detection at night (3) |  | Detection at night (1) |  |
| **Communication and memory aid** | Communicate with doctors (2) | Communicate with doctors (1) | Communicate with doctors (2) | Communicate with doctors (3) | Communicate with doctors (3) |
|  |  |  | Communicate (e.g. GPS location) with close others (1) | Communicate with close others (3) |  |
| **Self-management**  | Managing sleep (1) | Managing sleep (including seizures during sleep) (3) |  | Managing sleep (1) | Managing sleep (2) |
|  | Managing activity (planning) (1) | Managing activity (1) |  | Managing activity (3) | Managing activity (2) |
|  |  |  |  |  | Managing medication (2) |
|  |  | Tracking days when well (1) |  |  |  |
| **Intervention** | Seizure prevention (1) |  |  | Seizure prevention (4) |  |

a Groups followed the same topic guide developed to identify uses of mHealth technology and the barriers and facilitators of engagement; b for the UK and Italy, participants met for a second time to provide feedback on the themes extracted in the initial discussion – these columns represent repeated discussion of themes and any additional ideas emerging.

**3.2 Barriers and facilitators to engagement with mHealth**

Table 3 details the themes of barriers and facilitators to engagement with mHealth that emerged across countries and groups. These have been sub-divided into health-related, user-related and technology-related themes to guide understanding of where in the system we need to target to improve engagement.

**3.2.1 Health-related themes**

It was noted in all countries that awareness of seizures may be influenced by periods of **reduced consciousness**. One person, in the context of absence seizures, said, ‘*I couldn’t tell you, because I don’t know I’ve had them*’ (UK1). This may result in challenges for recording seizure activity if measurement is based on self-report. The other sub-themes emerged for groups in specific countries. The impact of emotions such as **fear and shame** were mentioned in Italy and the UK, respectively; and in Italy one participant highlighted that the nature of seizures may **change over time**, posing a question about how measurement tools could be designed to consider this variation. There was no discussion about the impact of physical health or other areas of cognition on the use of mHealth resources.

**3.2.2 User-related themes**

**Perceived costs.** A theme related to some of the negative emotions of fear and shame evoked by use of mHealth tools was a concern across all countries about **stigma**. Some participants questioned whether wearing a device would mean disclosing their condition to others. IT7 said: ‘*if you walk wearing the watch, it’s like it is written all over your face. They would label you straightaway*’. These experiences included self-stigma: ‘*It’s not just other people, you know, see that there is, you know, a strange thing on you but you’re constantly looking at something. I mean that’s why I don’t wear a medic alert either, because it’s like a constant reminder that, and sometimes you just don’t want to be thinking about it every time*’(UK4). Participants across all countries also expressed concern about **increased anxiety for self and others**, e.g. SP3 said: ‘*I think you’d start obsessing about it*’ and went on to explain that this might disrupt sleep, and SP4 said: *‘if it lets your Dad know, and your Dad is at the back of beyond somewhere and unable to come and help you, he’s going to be so upset about it’*. **Involving family members and carers in monitoring** was seen to be beneficial in the UK and Italy but there was also some concern raised about **relying on others** for support. Potential **financial costs** were only raised in Spain and Italy but mHealth devices were referred to as ‘*expensive*’ (SP1) and one person was worried about them not being supported through health services.

**Perceived rewards.** Despite the identified costs, people could see benefits to the use of mHealth technology, including measurement that contributes to **raising awareness**, for oneself to learn about their condition as well as to help others, e.g. doctors and family members, to understand. One person in Italy expressed that ‘*finally I can explain*’ (IT2). There was a sense that for the information gathered to be useful it must be shared with others. A small group of participants in Italy highlighted that this **feedback would be helpful**. In terms of data sharing, the people in Italy and Spain suggested that this information would be useful to **share with their doctor and family**. This topic was not explored in the UK where there was a greater emphasis on **problems with privacy**. UK6 said: ‘*for me, it feels similar to that idea of taking away your independence, like that invasion of privacy. I still want the same level of privacy as everyone else, so I’d be keen to know what data it is, that they’re tracking, and how it is being used, as well, like who has access to it*’. In other countries issues around privacy and disliking data sharing were also raised, if not discussed at great length.

**Technology acceptance.** Across all countries there was a degree of **scepticism**, and for some dislike, of technology. One person explained that ‘*it all seems like quite an inexact science with epilepsy and it’s really difficult to know what triggered this one, and you’re always trying to figure out, was I over tired, was I stressed that day, you know, what’s going on. And because it’s such an inexact science, I probably have less confidence in the fact that some kind of tracking device would be able to predict it*’ (UK4). Even if a device was able to predict a seizure, another person expressed that they would have difficulty trusting it in certain situations: ‘*I wouldn’t feel confident to use this tool that says to me “you can drive”*’ (IT3). **Uncertainty**, more broadly, may impact on engagement. In the UK only, it was raised that social acceptance may reduce some of the anxieties around using technology in health management, but they also highlighted the importance of maintaining human contact.

**Overall value.** Participants in Italy, Spain and the UK all expressed the need to balance different features of the system, in some cases the **costs against the rewards**. One person said the most important thing was that it was helping in some clear way: ‘*personally I wouldn’t mind about how it looked if it was helping me. But if it wasn’t doing anything then you know there’s absolutely no point of wearing it*’ (UK6). There was a theme spanning all groups suggesting that **improved safety** was valued about the potential to predict seizures using mHealth technology. In the context of beingfearful about sudden unexpected death in epilepsy (SUDEP), one person said: ‘*if I could do anything that would make it safer I would be happy to*’ (UK5). The ability to **reassure others** as well as oneself was also touched upon in Italy and the UK. A related, frequently occurring, theme was the potential for mHealth technology to **increase independence** in some contexts of daily activities but **increase dependency** in others, e.g. on the technology itself.

**3.2.3 Technology-related themes**

**Convenience.** Different themes emerged in the different countries. Only participants in the UK suggested practical problems with wearing a device at night, for example, one person said: ‘*it would need to be very comfortable for me to sleep with it*’ (UK3). A group of participants across the UK and Italy suggested that it was important for the device to **serve a function** beyond the potential for seizure detection or prediction: ‘*Perhaps making it more similar to a watch*’ (IT8). Similarly, participants in these two countries spoke about the importance of **flexibility**, be it when an intervention occurred or placement of the device. In Italy and the UK there was a more in-depth discussion about the **timing of feedback**, with some preferring feedback during appointments and others in real-time, especially if there was scope to predict when a seizure was likely to occur. Another topic that arose only in Italy included the convenience associated with **automatic data sharing with a doctor**.

**Usability.** Across every group there were points raised about the potential for **customisation and choice** related to personal preferences. Some of these choices have already been touched on in the context of who to share data with and when to receive alerts or feedback but also included the ability to switch the system off and choose the **aesthetics** (colour etc.) of the device and **data visualisation**. **Accuracy** was also another clear facilitator with participants highlighting that the system may need some ‘*serious fine-tuning*’ (SP1). The UK group spoke about other practicalities including the need to **charge** mHealth tools and need for them to be **waterproof**.

**Intrusiveness.** Again, across all groups some themes emerged. The first was that use of mHealth tools to predict or detect seizures may be **annoying**. Wearable devices may be an awkward size or shape and disruptive in terms of too many alerts. Some people in the UK group already had experience of these difficulties. UK7: ‘*I’ve got an alarm system in my flat and that came with a wrist band as well. But the wrist band was the most awkward part of it…it just never worked for me. I mean the alarm system in my bed, that sets my alarm off constantly, um, I mean, I got the police called to my house*’. The second main theme emerging was that participants want mHealth tools to be **discreet**. One person in Italy told the group that they thought an app would be easier to conceal than a wearable device as ‘*the app could be inserted in a device made for other things*’ (IT5). Other comments were restricted to people in one single country and are detailed in Table 3.

**Table 3. Barriers and facilitators to engagement with mHealth technology**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **A: Health-related**  | **UK (Group 1a)** | **UK (Group 1b)** | **Spain (Group 1a)** | **Italy (Group 1a)** | **Italy (Group 1b)** |
| **Symptom intensity or severity** |  |  |  | Seizures change over time (1) |  |
| **Emotional resources** |  |  |  | Fear (1) |  |
|  |  | Shame (1) |  |  |  |
| **Awareness/cognition** | **Reduced consciousness (1)** |  | **Reduced consciousness (1)** |  | **Reduced consciousness (2)** |
| **B: User-related**  | **UK (Group 1a)** | **UK (Group 1b)** | **Spain (Group 1)** | **Italy (Group 1a)** | **Italy (Group 1b)** |
| **Technology acceptance for self** | **Scepticism or dislike of technology (2)** |  | **Scepticism or dislike of technology (1)** | **Scepticism or dislike of technology (2)** |  |
|  | Type of wearable (1) |  | Some types of technology more acceptable than others (1) |  |  |
|  | Preference for human contact (1) |  |  |  |  |
|  |  |  |  | App more acceptable (1) |  |
| **Technology acceptance within system** | Social acceptance reduces anxiety (1) | Social acceptance reduces anxiety (2) |  |  |  |
|  |  | Dress codes/policies (2) |  |  |  |
| **Perceived rewards for self** | **Raise awareness (4)** | **Raise awareness (1)** | **Raise awareness (2)** | **Raise awareness (2)** |  |
|  | Take mind off seizures (1) |  | Take mind off seizures (1) |  |  |
|  |  |  |  | Feedback would be helpful (2) | Feedback would be helpful (3) |
|  |  |  |  | Not alone (1) |  |
|  |  |  |  |  | Protection (1) |
| **Perceived rewards within system** | Help services (1) | Help services (1) |  |  |  |
|  |  | Help research (1) |  |  |  |
| **Perceived costs: self** | **Stigma (6)** | **Stigma (5)** | **Stigma (1)** | **Stigma (5)** |  |
|  | **Increased anxiety (4)** | **Increased anxiety (1)** | **Increased anxiety (2)** |  | **Increased anxiety (1)** |
|  |  |  | Financial costs (1) |  | Financial costs (1) |
|  |  |  | Others not available to help (1) |  |  |
| **Perceived costs: others** | **Worry others (2)** | **Worry others (2)** | **Worry others (2)** | **Worry others (4)** | **Worry others (1)** |
| **Data sharing**  | Problems with privacy (4) | Problems with privacy (1) |  |  | Problem with privacy (1) |
|  |  |  | Ambivalence about privacy (1) |  |  |
|  |  |  |  | Dislike data sharing (1) |  |
|  |  |  | No problems sharing data e.g. helpful to share with doctor (2) | No problems sharing data e.g. helpful to share with doctor (2) | No problems sharing data e.g. helpful to share with doctor (3) |
|  |  |  | Helpful sharing data with family or close others (2) | Helpful sharing data with family or close others (1) | Helpful sharing data with family or close others (2) |
|  |  |  |  | Optional sharing (1) |  |
| **Support** | Relying on others (1) |  |  |  |  |
|  |  | Involving relatives or caregivers in monitoring (1) | Involving relatives or caregivers in monitoring (2) |  | Involving relatives or caregivers in monitoring (2) |
|  |  |  |  | Level of helpfulness depends on the person (1) |  |
|  |  |  |  | Support needed from health organisations (1) |  |
| **Overall value** | **Improved safety (4)** | **Improved safety (1)** | **Improved safety (3)** | **Improved safety (3)** | **Improved safety (2)** |
|  | **Costs vs rewards (4)** | **Costs vs rewards (2)** | **Costs vs rewards (3)** | **Costs vs rewards (1)** |  |
|  | Increased independence (1) |  |  | Increased independence (1) | Increased independence (1) |
|  | Reassuring others (3) | Reassuring others (1) |  | Reassuring others (2) | Reassuring others (1) |
|  | Dependency (1) |  |  | Dependency (1) |  |
|  | Uncertainty (4) | Uncertainty (3) |  | Uncertainty (1) |  |
|  |  |  |  |  | Useless if it cannot predict seizures (1) |
|  |  |  |  |  | Not seizure free but well (1) |
| **C: Technology-related**  | **UK (Group 1a)** | **UK (Group 1b)** | **Spain (Group 1)** | **Italy (Group 1a)** | **Italy (Group 1b)** |
| **Convenience & accessibility** | Serves a function (4) | Serves a function (2) |  | Serves a function (2) |  |
|  | Not practical (1) | Not practical: sleep (3) |  |  |  |
|  |  | Flexibility (of intervention) (1) |  |  | Flexibility (interoperability, device placement) (2) |
|  |  | Timing of feedback (2) |  | Timing of feedback (1) | Timing of feedback (2) |
|  |  |  |  | Automatic data sharing (2) |  |
| **Usability** | **Customisation or choice (2)**  | **Customisation or choice (2)** | **Customisation or choice (4)** | **Customisation or choice (5)** | **Customisation or choice (2)** |
|  | **Accuracy (2)** | **Accuracy (2)** | **Accuracy (1)** |  | **Accuracy (2)** |
|  |  |  |  | Aesthetics (4) | Aesthetics (1) |
|  |  |  |  | Data visualisation (1) | Data visualisation (3) |
|  | Waterproof (1) |  |  |  |  |
|  | Charging (1) |  |  |  |  |
|  |  | Recognised (1) |  |  |  |
|  |  | Device may not always be worn (1) |  |  |  |
| **Intrusiveness** | **Annoying (4)** | **Annoying (1)** | **Annoying (1)** | **Annoying (1)** | **Annoying (1)** |
|  | **Discreet (4)** | **Discreet (3)** | **Discreet (1)** | **Discreet (2)** |  |
|  | Passive data collection (1) | Passive data collection (1) |  |  |  |
|  | Feeling monitored (1) |  |  |  |  |
|  |  | Comfort (1) |  |  |  |
|  |  |  |  | Pressure to use technology (1) |  |

a Groups followed the same topic guide developed to identify uses of mHealth technology and the barriers and facilitators of engagement; b for the UK and Italy, participants met for a second time to provide feedback on the themes extracted in the initial discussion – these columns represent repeated discussion of themes and any additional ideas emerging.

**4 Discussion**

In the context of living with unpredictable seizures, people with epilepsy may have little control over their health condition. For some, medication may help reduce the occurrence of seizures, but not for all. We asked people about ways in which mHealth technology (e.g. wearables and smartphone apps) may be able to supplement treatment and health management. Taking a cross-national perspective, we invited people from Italy, Spain and the UK. This paper highlights similarities and some, albeit few, differences between the responses of people in these countries. Summarised here are the key requirements to consider when trying to understand the processes that may impact on user acceptance and engagement with novel mHealth technology.

**4.1 Key requirements of epilepsy**

**The relationship with doctors and the need to allay the fears of others should be emphasised.** A clear message from the focus groups was that people with uncontrolled epilepsy do not live with their health condition in isolation. Previous research suggests an external locus of control for people with epilepsy [14, 15] with perceptions of reliance on the people in the system supporting them, in some cases to maintain safety. This may include the support of close others (friends and family members) when experiencing a seizure (e.g. during periods of reduced consciousness) and the care of doctors to help with the medical management of their condition. Technology that could support others to care for the person with epilepsy was endorsed. Important values were being able to improve safety for the person with epilepsy and provide reassurance for others. However, issues of choice and control around the sharing of data will be crucial for maintaining high levels of privacy.

**Scepticism and concerns about technology need to be addressed directly.** While there were many positive ideas about how mHealth technology may be able to help with the detection, and even prediction and prevention of seizures, people still raised concerns about potential negative impacts. There was a sense that if devices were used to predict or warn people of seizures occurring, accuracy and timing would be paramount. False alarms and short-term prediction could serve to increase distress rather than allay fears, and visibility could lead to heighted experiences or stigma. Stigma associated with epilepsy is well documented within the previous literature [16, 17] and was a strong theme emerging in our focus groups. Raising awareness could be a ‘*double-edged sword*’ (IT3) and there is a need to balance the costs with the potential benefits. There is a clear advantage of being able to gather data and feed information back in ways that are discreet.

**Practical issues need to be considered in the design of mHealth technologies.** A long-term engagement of the users is key to the successful adoption of mHealth technology in chronic health conditions, such as epilepsy. There may be advantages to technologies that serve multiple functions and can become integrated into a person’s daily life beyond that of a health monitoring device. Use of consumer-grade wearables in healthcare that may be more socially acceptable, able to integrate with other technological devices (e.g. for entertainment) and serve another purpose (e.g. as a watch), may enhance acceptability. As consumer-grade devices are customisable, there may be an expectation that devices used in healthcare should be able to meet this standard. Choice and flexibility in the design of systems may not only be important for engagement but also accuracy of measurement as parameters may need to be modified to track changes in types of seizures over time. These recommendations map onto the framework used to structure the analysis from Simblett et al’s systematic review of engagement with remote measurement technology [12], highlighting the importance of convenience and usability in the design of mHealth resources.

Overall, the results reported here support previous findings in the literature that people currently experiencing epileptic seizures may be very willing to use mHealth tools to supplement health management [13] but that there are still some clear potential barriers. Our focus groups did not discuss the details in terms of the technical support that would be needed to assist people to use mHealth technology. Moreover, the adoption of mHealth and its implementation in a conventional healthcare system might present challenges. Although one person in the UK had already used an app to track seizures and communicate this information with their doctor, this experience was not common, and they reported that their engagement in this system was not maintained. This is an area that needs greater exploration, with actual user experience investigated. It may be important to note that experiences reported across the countries may have differed due to the open nature of the questions, which were only semi-structured. While all the analysis was undertakenby researchers in the UK, groups were facilitated, and transcripts written by different individuals who spoke the native language in each country. Broad comparisons were made across themes emerging from each of the groups but some of the details may have differed due to the variations discussed.

**Strengths and limitations**

The strength and uniqueness of this study is the cross-national approach taken to investigate patients’ ideas about the value as well as the challenges of using mHealth technology. The views summarised represent individual experiences, especially those experiencing a high frequency of seizures. This concentration was deliberate as this is the group most likely to benefit from wearable technology. In order to generalise these findings to people with epilepsy more broadly these results need to be considered in combination with quantitative research. Bruno et al [13] found that age and disease-related factors do not influence access to digital technology. Even though there were some differences between countries our results echo those findings that despite some perceived costs there is a willingness to consider the use of wearable devices in the clinical care of epilepsy. The qualitative methods employed allow for a rich and in-depth exploration of the potential barriers and facilitators to engagement with tools such as smartphone apps and wearable devices for measurement and management of symptoms associated with epilepsy. It is important to note that this was in the context of hypothetical scenarios and more work is needed to understand actual user experience.

**Conclusions**

People with epilepsy agree that there may be scope for mHealth technology, including wearable devices and smartphone apps, to measure and help manage seizures and associated experiences of epilepsy. Common views on the uses of this technology and specific requirements were shared by the focus groups cross-nationally, and, although not univocal, the attitude towards mHealth appeared comparable. Researchers need to continue to work with people with epilepsy, along with other important stakeholders (including their family members and healthcare professionals) to understand their concerns better and the practical steps that can be taken to improve acceptability and engagement. This study paves the way for further research that assesses actual experiences of mHealth technology for use in healthcare.

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**Conflict of Interest**

The authors declare no conflict of interest.

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