Does the future of epilepsy care lie in eHealth?

An examination of attitudes and behaviours towards epilepsy self-management and eHealth from the perspectives of people with epilepsy, their carers and healthcare providers.

A thesis submitted to the School of Medicine in fulfilment of the requirements for the Degree of Doctor of Philosophy

by

Jack Banks, BSc. (Hons)

March 2022
Declaration Sheet

I, Jack Banks, declare that this thesis has not been submitted as an exercise for a degree at this or any other University. It is entirely my own work.

The Library of Trinity College Dublin may lend or copy the thesis upon request. This permission covers only single copies made for study purposes, subject to normal conditions of acknowledgement.

Jack Banks

Student No: 14319332
Acknowledgements:

I would like to thank all of the following individuals for making this thesis possible and for supporting me on my research journey.

My parents Orla and William. I am eternally grateful for all of the sacrifices you made in order for my third level education. You are my heroes and I love you both. My sister Lucy and brother Andrew, thank you for always being there for me.

My grandparents Eddie and Aileen. Thank you for all of your encouragement during my studies.

Manus, Laura, Cian and Fionn, my housemates. Thank you for being such wonderful friends and for all of your patience, particularly over the last year.

Professor Colin Doherty, my academic supervisor. I am so grateful for all of your advice, patience and guidance over the last number of years. From a personal and professional perspective you have been such a great mentor and I hold you in such high esteem.

Lauren, Corrina, Linda, Sean, Cara, Claire, Denise, Anne, Sinead, Sinead, Aisling, Smitha, Lorraine, Laura, Elisabeth, Aoife, Raluca and Lilia, the DML Epilepsy Service team in St. James’s. You were all so welcoming from my first day and I am so grateful to have worked with such an innovative, professional team.

Mary, Kevin, Zita, Tim, Laura, Rob and Derek, my fellow FutureNeuro eHealth team members since 2018. It has been such a pleasure working with you all and our Monday morning meetings certainly kept me on track.

Dale, Naomi and Ashleigh, my fellow PhD candidates. Our group was such an important source of solace for me during the last few years and it was lovely sharing the highs and lows of the PhD journey with you.

Rónan, Tomas, Niall, Eoghan, Eoin, Leon, Seamas, John, Cian, Roy, James, Ailish, Sarah,
Eleanor, Roisin, Katy and Hannah. Thank you for being such good friends and always being there for me.

Finally, to all of the individuals living with epilepsy and their families who took part in this body of work. It was a privilege to listen to your personal experiences and thank you so much for sharing your experience of living with epilepsy. I hope that the findings of this thesis will shape the way epilepsy care is delivered in this country going forward.
Table of Contents

Declaration Sheet ................................................................. i
Acknowledgements: ............................................................... ii
Table of Contents ................................................................ iv
Preface .................................................................................. xi
Abstract ................................................................................ xiii
Chapters Summary ............................................................... xv
List of Tables ........................................................................ xix
List of Figures ........................................................................ xxi
List of Key Abbreviations .................................................... xxiii
List of Publications Emanating from this Research ............... xxvi
List of Conference Presentations Emanating from this Research xxvi

CHAPTER I - Literature Review, Aims and Objectives of Research ............... 1

1. What is Epilepsy? ...................................................................... 1
   1.1.1 Historical Context ................................................................. 1
   1.1.2 Distinguishing Seizures and Epilepsy ........................................ 1
   1.1.3 What Causes Seizures? ............................................................ 2
   1.1.4 Seizure Types .................................................................... 2
   1.1.5 The Burden of Epilepsy .......................................................... 4

1.2 How is Epilepsy Treated? .......................................................... 5
   1.2.1 Historical Epilepsy Treatment Pathway ...................................... 5
   1.2.2 National Clinical Programme for Epilepsy (NCPE) ..................... 7
   1.2.3 Sláintecare ........................................................................ 9
   1.2.4 eHealth Ireland: Stay Left, Shift Left ......................................... 12
   1.2.5 Electronic Health Records (EHRs) and the Epilepsy Electronic Patient Record (EEPR) 14
   1.2.6 Providing Individualised Services and Care in Epilepsy (PISCES) .......... 14
   1.2.7 Telemedicine ..................................................................... 15

1.3 Epilepsy Self-Management ....................................................... 16
Chapter II - Self-reported anti-epilepsy medication adherence and its connection to perception of medication error

2.0 Abstract ................................................................. 37

2.1 Introduction .......................................................... 38

2.2 Methods ............................................................... 41

2.2.1 Study Design ...................................................... 41

2.2.2 Setting, Participants and Data Collection .................. 42

2.2.3 Data Analysis ..................................................... 43

2.2.4 Ethics ................................................................. 44

2.3 Results ................................................................. 44

2.3.1 Medication Adherence ......................................... 44

2.3.2 Medication Errors ................................................ 46

2.4 Discussion ............................................................ 48

2.5 Limitations ............................................................ 52

2.6 Conclusions .......................................................... 53

2.7 Acknowledgements .................................................. 53

2.8 Funding: ................................................................. 53
**Telemedicine for Chronic Epilepsy Management**

3.0 Abstract ........................................................................... 54

3.1 Introduction ....................................................................... 55

3.2 Methods ........................................................................... 57
   3.2.1 EEPR Data Capture and Analysis ................................. 57
   3.2.2 Clinical Audit – Data Capture ..................................... 58
   3.2.5 Data Analysis ............................................................ 60
   3.2.6 Ethics ....................................................................... 60

3.3 Results ............................................................................... 61
   3.3.1 EEPR Data Analysis .................................................... 61
   3.3.2 Survey of Clinician and Patient Experience .................. 63

3.4 Discussion .......................................................................... 70

3.5 Limitations ......................................................................... 72

3.6 Conclusion ......................................................................... 73

3.7 Acknowledgements ........................................................... 73

3.8 Funding .............................................................................. 73

**Chapter IV - Research Design and Methodology** .......................... 75

4.0 Introduction ........................................................................ 75

4.1 Research Design ............................................................... 75

4.2 Personal Characteristics and Reflexivity ............................. 78

4.3 Ethnography and Focused Ethnography ............................. 81

4.4 Data Collection .................................................................. 84

4.5 Participant Selection .......................................................... 87

4.5 Setting ................................................................................ 91

4.6 Data Collection Structure .................................................. 95

4.7 Data Analysis .................................................................... 98

4.8 Ethical Considerations ....................................................... 104

**Chapter V - Findings: An Exploration of the Perceived Challenges Faced by People With**
Epilepsy, their Carers And Healthcare Providers Surrounding Epilepsy Management and
eHealth Tools. ................................................................. 105

5.1 Introduction: ................................................................. 105

5.2 Methodology Summary .................................................. 106

5.3 Results ........................................................................... 107
  5.3.1 Final Sample .................................................................. 107
  5.3.2 Theme 1 - HCPs express doubt about their resources and capability to deliver comprehensive psychosocial care to each PWE and how new eHealth will integrate into their current workflow processes. ................................................................. 111
  5.3.3 Theme 2 - Epilepsy care needs to focus less on anti-seizure medications (ASMs) and more on psychosocial aspects of the condition ................................................................. 115
  5.3.4 Theme 3 - Family members and carers are heavily relied upon by PWE and HCPs to perform important self-management tasks. ................................................................. 119
  5.3.5 Theme 4 - HCPs doubt the willingness and capability of many PWE to engage in self-management activities. PWE difficulties with memory and recall and a lack of belief regarding the necessity for self-management prove to be barriers, particularly in the early stages following diagnosis ............................................................................................................................................... 124
  5.3.6 Theme 5 - A lack of data integration across eHealth platforms, the perception of digital interactions as being impersonal, privacy concerns and a lack of perceived utility are barriers perceived by PWE, carers and HCPs to using eHealth tools for self-management ....................................................................................................................................... 129
  5.3.7 COM-B Analysis of Data ................................................................................................................................. 136

5.4 Discussion ......................................................................... 138

5.5 Study Limitations .............................................................. 141

5.6 Conclusion ......................................................................... 142

Chapter VI - Findings: An Exploration of the Perceived Opportunities for Self-
Management and eHealth Within Epilepsy Care: Perspectives of People with Epilepsy,
their Carers and Healthcare Providers. ........................................ 143

6.1 Introduction ......................................................................... 143

6.2 Methodology Summary ...................................................... 143

6.3 Results ............................................................................... 145
  6.3.1 Final Sample .................................................................. 145
  6.3.2 Using knowledge as a tool to empower PWE to self-manage ................................................................. 149
6.3.3 Adopting a ‘whole family’ approach to care and providing support to family members and carers of PWE ................................................................. 152
6.3.4 Providing PWE with a choice as to whether they are seen virtually or face-to-face ........ 153
6.3.5 Upgrading the technical infrastructure within epilepsy services and creating an ‘eHub’ .... 156
6.3.6 Developing apps and wearables which integrate with current clinical systems and help navigate the challenges unique to each PWE .......................................................... 158
6.3.7 Utilising the lived experience of PWE, their carers and other HCPs to better effect ...... 163
6.3.8 Increased awareness of epilepsy among the general public and knowledge of the challenges faced in living with epilepsy ................................................................. 167
6.3.9 Establishing reliable eHealth resources to direct PWE towards ................................ 170
6.3.10 Take a more holistic approach to epilepsy care ...................................................... 172
6.3.11 COM-B Analysis of Data ....................................................................................... 173

6.4 Discussion .............................................................................................................. 175
6.5 Limitations ............................................................................................................ 178
6.6 Conclusions .......................................................................................................... 178

Chapter VII: General Discussion and Recommendations ........................................... 180

7.0 Introduction .......................................................................................................... 180
7.1 Scope Of Thesis and Research Outcomes ............................................................ 180
7.2 General Discussion .............................................................................................. 181
7.2.1 Perception of Medication Adherence And Medication Error Among PWE Attending the Epilepsy Service at SJH .......................................................... 181
7.2.2 Experience Receiving and Delivering Epilepsy Care via Telemedicine .......... 182
7.2.3 Challenges and Opportunities Associated with Self-Management and eHealth Usage for Epilepsy Care ......................................................... 184

7.3 Recommendations ............................................................................................... 187
7.3.1 Recommendation 1: Restructuring Epilepsy Services with enhanced communication with Primary Care and Non-Governmental Organisations ........................................... 187
7.3.2 Recommendation 2: Standardising the use of behavioural theory in the design of eHealth tools for epilepsy self-management and integrating data generated by such tools ........ 189
7.3.3 Recommendation 3: Creation of a platform that would allow PWE and carers to choose how they receive care ................................................................. 192
7.3.4 Recommendation 4: Acknowledging the role of family members and carers in epilepsy care more formally and including them to a greater degree in treatment management ............ 194
7.3.5 Recommendation 5: Understanding the priorities of each individual person living with epilepsy and making treatment and management decisions based on this understanding

Bibliography

Appendices

Appendix 1: Copyright Permission
Appendix 2: ‘Harriet’s’ testimonial as a participant in this research project
Appendix 3: Perceived Medication Adherence and Medication Error Questionnaire
Appendix 4: Letter from SJH-TUH JREC confirming ethical approval
Appendix 5: Letter from SJH-TUH confirming approval to conduct focus groups remotely
Appendix 6: PWE Participant Information Leaflet
Appendix 7: HCP Participant Information Leaflet
Appendix 8: Participant Consent Form
Appendix 9: PWE semi-structured interview topic guide
Appendix 10: HCP semi-structured interview topic guide
Appendix 11: Initial Codes and Descriptive Themes from Semi-Structured Interviews with PWE, Carers and HCPs
Appendix 12: Final Codes and Themes from Semi-Structured Interviews with PWE, Carers and HCPs
Appendix 13: PWE/Carer Focus group topic guide
Appendix 14: HCP Focus group topic guide
Appendix 15: Initial Codes and Descriptive Themes from Focus Groups with PWE, carers and HCPs
Appendix 16: Final Codes and Themes from Focus Groups with PWE, carers and HCPs
Preface

The basis for this research originally stemmed from my experience conducting a final year project within the Dublin Mid-Leinster (DML) Epilepsy Service in 2017-2018. This study involved auditing the medication adherence habits of people with epilepsy (PWE) attending the DML Epilepsy Service located in St. James’s Hospital, Dublin. For a three-month period, I distributed surveys to individuals sitting in the waiting area of the weekly outpatient epilepsy clinic. When collecting the completed surveys, patients or their family members often initiated conversations with me where they wished to expand upon answers they had written down, seeking to articulate why they had answered the way they did or to express frustration at an aspect of living with epilepsy. As is the case in many research projects, I came away from this experience with more questions than answers. I felt that the survey results merely reflected the ‘tip of the iceberg’ in relation to an aspect of managing epilepsy, and I wanted to conduct a more thorough body of research where patients could discuss more comprehensively how their epilepsy affected them and what they feel needs to change.

Around this time Professor Colin Doherty, my supervisor, informed me that funding for PhD research was available through an industry collaboration between FutureNeuro, Science Foundation Ireland’s Centre for Chronic and Rare Neurological Disease and S3 Connected Health, a small to medium sized medical technology enterprise based in Leopardstown, Dublin 18. The objective of this research was to develop an understanding of the self-management behaviours of PWE in order to inform where digital health or ‘eHealth’ tools could aid with managing the condition. Given the interest that I had developed in this area from my final year project, I was delighted to accept the position of PhD researcher when I received the offer.

From September 2018 through to August 2021, I was a fully-fledged team member of the DML Epilepsy Service. I sat in on weekly team meetings, distributed surveys at clinics, presented regularly at journal clubs, travelled to conferences and drank
thousands of cups of coffee with the doctors, nurses and dietitians who make up the service. Over this three-year period, I took an ‘ethnographic’ approach to conceptualising the lived experience of those delivering and receiving epilepsy care within the DML Service. This PhD thesis represents the fruit of this labour, and in the following chapters, I present both quantitative and qualitative findings of research into the attitudes and behaviours of PWE, their carers and healthcare providers (HCPs) towards the self-management of epilepsy and eHealth tools.
Abstract

An increase in chronic disease prevalence and ageing populations worldwide are forcing healthcare systems to seek alternatives to the outpatient model of care. It is proposed that eHealth could facilitate the movement of chronic disease care from acute hospital settings into the community, with a greater degree of independence provided to patients. Epilepsy is a chronic neurological disease where the majority of patients receive their specialist care via outpatient appointments. People with epilepsy (PWE) are required to engage in self-management behaviours in order to reduce seizure frequency and improve overall quality of life. A number of eHealth tools have been developed to aid with epilepsy self-management, however, uptake of these tools has been low. Reasons proffered for this low uptake include a lack of knowledge regarding the existence of these tools, a lack of integration of data across multiple platforms and concerns surrounding data privacy.

The objectives of this research were twofold. Firstly, it was to examine the perspectives of people with epilepsy (PWE), their carers and healthcare providers (HCPs) towards self-management and eHealth supports. The second objective was to conceptualise the experience of living with epilepsy and understand mechanisms through which eHealth usage can be promoted. An ethnographic research approach was adopted, with quantitative and qualitative data collected surrounding the self-management behaviour and attitudes of PWE, their carers and HCPs, with focus groups then conducted to ideate solutions for identified barriers to epilepsy self-management.

This research found that broadly, PWE, their carers and HCPs agreed that self-management needed to become a more prominent aspect of epilepsy care. Barriers towards using eHealth for epilepsy self-management that were identified included memory difficulties experienced by patients as a result of the condition, zero data integration between third party apps and wearable devices and the National Epilepsy Electronic Patient Record (EEPR) and a lack of perceived utility for digital tools,
particularly for patients whose condition was stable. Future opportunities for eHealth and epilepsy self-management that were identified included the rollout of telemedicine, the use of behavioural theory within eHealth tools to provide tailored self-management feedback to patients and carers and revisiting the National Care Programme for Epilepsy (NCPE) to ensure the systematic provision of self-management resources to PWE receiving care in Ireland.
Chapters Summary

The outpatient model of care currently utilised to treat most chronic illnesses is not seen as feasible going forward with ageing populations and increasing chronic disease prevalence. Healthcare systems and policy-makers are advocating for a shift towards models of care that promote and support self-management among patients. Within the realm of epilepsy care, eHealth is seen as having potential in facilitating patients to perform self-management tasks and moving care away from the current hospital-centric model of care.

In Chapter I, the literature surrounding epilepsy self-management, eHealth and the use of qualitative methods in health services research is examined. The current model of care for people with epilepsy (PWE) in Ireland is outlined and the essential principles driving new models of care towards models with an increased degree of self-management are introduced and discussed. Current approaches towards epilepsy self-management and the use of eHealth technology to support epilepsy care are outlined, with known challenges and barriers towards these concepts documented. The aims and objectives of this research project are then stated.

Medication adherence is widely viewed as the most integral self-management behaviour PWE should engage in. In Chapter II, the results of a clinical audit exploring perceived medication adherence and medication errors across a cohort of PWE attending the DML Epilepsy Service at St. James’s Hospital are described. The aims of this study were to establish baseline data surrounding adherence behaviours and perception of medication error using clinical audit. The development of a unique questionnaire for use in the audit is described. The major findings in this study are that 40.9% of respondents self-report that they feel to adhere optimally to their prescribed anti-seizure medication (ASM) regimen and 28.5% of the 186 respondents to the survey perceive that they have been exposed to a medication error. This understanding of perceived medication adherence and perception of exposure to medication error
developed as a result of this work identifies opportunities within epilepsy care delivery that need improvement.

With the arrival of CoVID-19 to Ireland in Spring 2020, the rollout of remote models of care across almost all disciplines of medicine was rapid. The Epilepsy Services at St. James’s (SIH) and Beaumont Hospital (BH) decided to conduct all outpatient appointments with PWE via telephone call. In Chapter III, a clinical audit of patient and clinician satisfaction with telemedicine for chronic epilepsy care is detailed. Data collected prior to the onset of CoVID-19 is compared to that collected in the three months after the pandemic struck. The audit documents how PWE, their carers and HCPs feel about receiving and delivering epilepsy care remotely and details where these populations feel improvement is needed. Results indicated that there was no loss of access to scheduled expert opinion and care between the pre- and post-CoVID eras in the Epilepsy Services in SIH and BH. HCPs largely feel that the patients with whom they conducted telemedicine encounters with are appropriate for this type of care. Clinicians are happy for the majority of patients to continue their care virtually going forward. PWE and their carers reported positive experiences with the overall experience of receiving care via telephone, both pre- and post-CoVID. PWE believe that telemedicine is most appropriate when an individual’s epilepsy is in a stable condition. PWE would like to see telemedicine more widespread.

The results of the two clinical audits described in Chapters II and III indicated the need for further exploratory research investigating patient, carer and clinician attitudes towards epilepsy self-management and using eHealth tools. In Chapter IV, the qualitative methodologies employed in the studies described in Chapters V and VI are detailed. Features of ethnography and focused ethnographies are described. The researcher’s background and how this informed the conceptualisation of ethnographically collecting data in the epilepsy clinic is described. A detailed description of the sampling, data collection and analysis processes are provided. Ethical considerations are described and the rigour associated with this methodology
is stated.

In Chapter V, a qualitative research study is presented. The aim of this study was to understand challenges faced by PWE, their carers and HCPs in relation to epilepsy self-management and using digital tools to facilitate this management. Results show that HCPs are concerned that the introduction of new eHealth innovations will increase their current workload. HCPs feel limited by a lack of personnel and time pressure to deliver comprehensive biopsychosocial care to each PWE they see. PWE expressed that memory, recall and concentration difficulties as a result of their condition limits their ability to perform self-management tasks. The heterogenous nature of epilepsy means that study participants understood that creating a ‘one-size fits all’ solution would be very difficult to create. A lack of data interoperability between current eHealth tools utilised for epilepsy care and self-management was identified as an issue by PWE, carers and HCPs. HCPs generally held a lack of belief regarding the efficacy of existing eHealth tools to make a meaningful difference to the lives of PWE. The cost associated with currently available eHealth tools is perceived as being beyond the financial means of many PWE. It is perceived that PWE who are capable and willing to use eHealth tools are already self-managing their condition appropriately, without the use of such tools.

While Chapters II, III and V examined challenges that PWE, their carers and HCPs perceive regarding epilepsy self-management and use of eHealth technology to enhance epilepsy care, Chapter VI describes how focus groups were utilised to provide PWE, their carers and HCPs an opportunity to ideate and express their opinions about how epilepsy self-management and eHealth usage could be enhanced in the future. The ideas generated by participants in the focus groups are presented across themes and areas where behavioural intervention could successfully improve eHealth-enabled epilepsy self-management are identified. Ideas generated by participants were diverse and targeted various aspects of living with epilepsy. Ideas included providing PWE with a more comprehensive education surrounding Anti-Seizure Medications (ASMs),
eHealth tools and self-management activities from HCPs, incorporating carers and family members of PWE into epilepsy care in a more formal manner and utilising the lived experience of PWE to better effect by including them in multi-disciplinary team (MDT) meetings and creating peer support groups. It was ideated that data could be integrated from multiple sources such as patient wearable devices or patient authored healthcare records into the National Epilepsy Electronic Patient Record (EEPR). The potential of an electronic patient portal associated with the EEPR linking with existing online resources to aid with self-managing epilepsy was highlighted by participants.

In the ultimate chapter, Chapter VII, the findings of the research thesis are generally discussed within the context of existing literature in the fields of epilepsy, self-management and eHealth. The author makes five recommendations through which self-management and eHealth can become more prominent in chronic epilepsy management in Ireland.
List of Tables

Table 1 - Definitions of medication adherence. medication non-adherence and the three categories of medication error.................................................................40
Table 2 - Table displaying the p value associations between eight different factors and whether respondents self-reported unintentionally or intentionally adhering to ASMs (n=186). ..................................................................................................................46
Table 3 - Table displaying significant (p<0.05) p value associations between patient factors and whether respondents self-reported being exposed to a prescribing error (n=186). ..................................................................................................................47
Table 4 - Table displaying significant (p<0.05) p value associations between patient factors and whether respondents self-reported being exposed to a dispensing error. (n=186). ..................................................................................................................48
Table 5 - Table displaying significant (p<0.05) p value associations between patient factors and whether respondents self-reported being exposed to an administration error. (n=186). ..................................................................................................................48
Table 6 - Questions common to the survey tools used to collect data from clinicians and patients both pre- and post-CoVID .................................................................59
Table 7 - Summary of qualitative research approaches used in health services research. ..................................................................................................................77
Table 8 - LeCompte and Schensul’s defining characteristics of ethnography........82
Table 9 - Main features of focused ethnographies as described by Muecke ..........84
Table 10 - Inclusion criteria for participants..................................................................................................................88
Table 11 - Steps involved in Braun & Clarke’s TA [269,272],.................................98
Table 12 - Characteristics of PWE sample (n=13)...............................................108
Table 13 - Characteristics of HCP sample (n=9)..................................................109
Table 14 - Characteristics of carer sample (n=3)...............................................109
Table 15 - Major themes which emerged from the interview data ......................110
Table 16 - Abbreviations used in results section .................................................111
Table 17 - Barriers identified at PWE/carer level to using eHealth for epilepsy self-management ........................................................................................................................................................................136
Table 18 - Barriers identified at HCP level to using eHealth for epilepsy self-management ..................................................................................................................................................................................................137
Table 19 - Abbreviations used in results section..........................................................................................................................146
Table 20 - Breakdown of participants in each focus group ............................................................................................................146
Table 21 - Characteristics of PWE sample (n=11)..............................................................................................................................147
Table 22 - Characteristics of HCP sample (n=9)..............................................................................................................................148
Table 23 - Characteristics of carer sample (n=3)..............................................................................................................................148
Table 24 - Themes which emerged following TA of focus group transcripts ..............................................................................149
Table 25 - Ideas generated by participants mapped onto the COM-B framework....173
List of Figures

Figure 1 - Diagram published on the Epilepsy Foundation website illustrating the 'new' classification of seizure types from the ILAE [6,7].

Figure 2 - The traditional model of epilepsy care [15]

Figure 3 - Graph outlining the 'Stay Left, Shift Left' concept on the eHealth Ireland website [38].

Figure 4 - Infographic created by Sara Riggare illustrating her annual time spent receiving care from her neurologist and the time she spends engaging in 'self-care' [71].

Figure 5 - Functions available through Epilepsy Ireland's mobile diary [125].

Figure 6 - Outline of PDSA cycle utilised to optimize clinical audit methodology.

Figure 7 - Diagram illustrating self-reported adherence to ASMs across all respondents (n=186).

Figure 8 - Breakdown of medication errors reported by respondents (n=186).

Figure 9 - Breakdown of Encounters by Encounter Type in BH and SJH from 23rd December 2019 to 23rd March 2020.

Figure 10 - Breakdown of Encounters by Encounter Type in BH and SJH from 24th March 2020 to 24th June 2020.

Figure 11 - Breakdown of Telephone Encounters by Issue Category in BH and SJH from 23rd December 2019 to 23rd March 2020.

Figure 12 - Breakdown of Telephone Encounters by Issue Category in BH and SJH from 24th March 2020 to 24th June 2020.

Figure 13 - Graphs outlining clinician response to questions surrounding patient appropriateness and future mode of care delivery.

Figure 14 - Graphs outlining patient response to questions surrounding interaction with clinician and overall experience using telemedicine.

Figure 15 - Comparison of features of focus groups and group interviews.[324]

Figure 16 - Procedure for arranging focus groups
Figure 17 - Screenshot of Miro board utilised during focus groups

Figure 18 - The Behaviour Change Wheel and Capability, Opportunity and Motivation Model of Behaviour (COM-B) [279,281].

Figure 19 - Data analysis process.
List of Key Abbreviations

AMAU: Acute medical admissions unit
ASM: Anti-seizure medication
ASMs: Anti-seizure medications
BCW: Behaviour change wheel
BH: Beaumont Hospital
CAG: Clinical advisory group
CDM: Chronic disease management
DML: Dublin Mid-Leinster
ED: Emergency department
EEPR: Epilepsy electronic patient record
GBEC: Group based epilepsy centres
GP: General Practitioner
HCP: Healthcare provider
HCPs: Healthcare providers
HSE: Health Service Executive
ILAE: International League against Epilepsy
MEW: Managing epilepsy well
MDT: Multi-disciplinary team.
NCHD: Non-consultant hospital doctor

NCPE: National care programme for epilepsy

PFCC: Patient and family centered care

PWE: People with epilepsy

RANP: Registered advanced nurse practitioner

SES: Socioeconomic status

SJH: St. James's Hospital

SUDEP: Sudden unexpected death in epilepsy

TA: Thematic analysis

TDF: Theoretical domains framework
List of Publications Emanating from this Research

'Self-reported antiepilepsy medication adherence and its connection to perception of medication error’ - Epilepsy & Behavior, Banks et.al, 2020 [1].

'LoVE in a time of CoVID: Clinician and patient experience using telemedicine for chronic epilepsy management’ - Epilepsy & Behavior, Banks et.al, 2020 [2]

These publications have been included as Chapters in this PhD thesis, making up Chapters II and III respectively. Full copyright permission has been obtained in order to include these publications in this thesis (Appendix 1).

List of Conference Presentations Emanating from this Research

‘An Exploration of the Perceived Challenges faced by People with Epilepsy, their Caregivers and Healthcare Providers surrounding Epilepsy Self-Management and eHealth Tools.’ American Epilepsy Society Annual Meeting, Chicago, December 2021 (Poster)

‘Does the future of epilepsy care lie in eHealth?’ International Conference for Integrated Care, Sibenik, Croatia, September 2020 (Poster)

‘From the Outside-In: Co-Designing Tools for Independence and Wellbeing in Epilepsy Care.’ Irish Street Medicine Symposium, Cork, Ireland September 2019 (Oral)

‘A Clinical Audit of Medication Adherence and Medication Error and Harm in People with Epilepsy.’ Irish Neurological Association Annual Scientific Meeting, Cork, Ireland, June 2019 (Poster)

‘A Clinical Audit of Medication Adherence and Medication Error and Harm in People with Epilepsy.’ Royal College of Surgeons in Ireland Research Day, Dublin, Ireland, March 2019. (Oral)
1. What is Epilepsy?

1.1.1 Historical Context

The word epilepsy is derived from the Greek word ‘epilambanein’ meaning to be seized or overwhelmed by surprise [3]. The earliest description of an epileptic seizure appears in a text from 2000 B.C. written in the Akkadian language, used in the region of Mesopotamia. The author describes a patient with symptoms resembling epilepsy ‘his neck turns left, his hands and feet are tense and his eyes wide open, and from his mouth froth is flowing without his having any consciousness’ [4]. Throughout the centuries, the association of seizures with mental health conditions, witchcraft, and demonic or divine possession has resulted in terminology with negative connotations and has led to cultural and societal beliefs, perceptions and stereotypes about epilepsy that are difficult to modify [5].

1.1.2 Distinguishing Seizures and Epilepsy

A ‘seizure’ is a paroxysmal alteration of neurologic function caused by the excessive, hypersynchronous discharge of neurons in the brain [6]. Epilepsy exists when an individual has an epileptic seizure and their brain demonstrates ‘a pathologic and enduring tendency to have recurrent seizures’ [7]. The definition of epilepsy has received many updates over time, with various task forces being commissioned by the International League Against Epilepsy (ILAE) to refine or improve upon previous iterations. The most recent update occurred in 2014, with a person now being considered to have epilepsy if they meet any of the following conditions:

1. At least two unprovoked (or reflex) seizures occurring greater than 24 hours apart.
2. One unprovoked (or reflex) seizure and a probability of further seizures similar to the general recurrence risk (at least 60%) after two unprovoked seizures, occurring over the next 10 years.
3. Diagnosis of an epilepsy syndrome [7].

'Epileptic seizure' is used to distinguish the abnormal neuronal firing in epilepsy from a non-epileptic seizure, or an event that may resemble an epileptic event but is not due to abnormal electrical discharge. A seizure provoked by a reversible insult such as fever or hypoglycaemia is also not classified as an epileptic seizure because it is a short lived secondary condition, not a chronic state [6].

1.1.3 What Causes Seizures?

A seizure can be conceptualised as occurring when there is a distortion of the normal balance between excitation and inhibition of the brain, with this imbalance resulting from an alteration at many levels of brain function, from genes and subcellular signalling cascades to widespread neuronal circuits [6]. The factors that alter the balance between excitation and inhibition can be genetic or acquired [6]. Genetic pathologies leading to epilepsy can occur anywhere within the brain from circuit level (e.g. abnormal synaptic connectivity in cortical dysplasia) to the receptor level (e.g. abnormal GABA receptor subunits in Angelman syndrome) to abnormal ionic channel function (e.g. potassium channel mutations in benign familial neonatal epilepsy) [6]. Similarly, the function of neuronal circuits can be altered by events such as head trauma, brain infection, stroke or prolonged febrile seizures [6].

1.1.4 Seizure Types

There are three major groups of seizures; focal onset, generalised onset and unknown onset [8] [9].
Focal onset seizures, previously known as partial seizures, begin in a single area of the brain. At first, the person may notice minor symptoms which is referred to as an ‘aura’, during which they may have altered feelings or sense that something is about to happen [10]. As the seizure spreads across the brain, more symptoms appear. If the abnormal electrical activity involves a large area of the brain, the person may feel confused or dazed, or experience minor shaking, muscle stiffening or fumbling or chewing motions [10]. Focal seizures that cause altered awareness are called focal unaware seizures and were previously known as complex partial seizures. If the electrical activity of the seizure remains in a single sensory or motor area of the brain, the person can be aware of what is happening and consciously notice unusual sensations and movements [10]. These are known as focal aware seizures, previously they were known as simple partial seizures. Focal onset seizures may progress to involve the entire brain, in which case they are termed partial seizures with secondary generalisation [11].

Generalised onset seizures result from surges of abnormal neuronal discharges throughout the brain’s cortex [10]. A ‘post-ictal’ period following the seizure of confusion, followed with a gradual return to baseline is common [11]. Tonic-clonic seizures are the classic generalised seizures characterised by loss of consciousness.
and full-body rigidity (tonic phase) and rhythmic convulsions (clonic phase) [11]. Other generalised seizures include absence seizures, previously known as petit-mal seizures, during which an individual stares and stops responding appropriately. Individuals generally have no motor activity during absence seizures but the post-ictal period still occurs. Tonic seizures, which are rigid without convulsions, and atonic seizures, characterised by a complete and sudden loss of muscle tone, are other less common generalised seizures [11].

When the location of a seizure’s onset within the brain is not known, it’s called an unknown onset seizure [8]. A seizure can also be referred to as an unknown onset if it is not witnessed by another individual. As more information is learned, an unknown onset seizure may be later be diagnosed as a focal or generalised seizure.

People with epilepsy (PWE) can be classified into different syndromes based on specific clinical features [12].

1.1.5 The Burden of Epilepsy

Epilepsy is estimated to affect more than 65 million people worldwide, with more than 80% of PWE living in developing countries [13]. In Ireland, it has been shown that up to 40,000 people suffer from epilepsy, and this number may be increasing [14].

Individuals with epilepsy are at risk not only for seizures, but also for a myriad of comorbid health conditions. Often the comorbidities that accompany epilepsy outweigh the burden of the seizures themselves. Common comorbidities that occur in epilepsy include cognitive dysfunction, such as memory, attention or concentration problems; mental health conditions, such as depression or anxiety; and somatic comorbidities, such as sleep disorders, migraines or cardiovascular disease [5]. Other health problems can occur as a result of ongoing seizures, the cause of the epilepsy or problems associated with the treatment, such as fractures and other injuries, osteoporosis, reproductive problems and even death, in an event known as sudden unexpected death in epilepsy (SUDEP) [5].
Epilepsy is a costly disorder in terms of its impact on individuals and their families, as well as on society. Seizures and seizure medications may affect cognitive ability, including in young children whose brains and cognitive functions are still developing. For young and middle-aged adults, epilepsy can impact the ability to live and function independently, drive to and from school and work, maintain employment, have children and participate in social life. For older adults, epilepsy may contribute to the health burden of other neurological disorders, such as stroke or dementia, and may hinder safety and independent living. These limitations can pose considerable economic, social and emotional burdens on individuals with epilepsy and their families [5].

A major challenge for PWE has been the multitude of ways that epilepsy is misperceived. The unpredictable nature of seizures, the feelings of helplessness of those who witness them, and the centuries of misperceptions and misinformation about epilepsy have resulted in PWE being stigmatised and isolated [5]. One study found that 36% of students with epilepsy said that they felt that they had to keep their epilepsy a secret as they did not want to be treated differently and 23% of parents did not disclose diagnosis as they did not want their child to face the potential stigma associated with the disease [15]. This type of internalised stigma can reduce quality of life even when seizures are well controlled by medication or other treatments [5]. In a history of epilepsy, Eadie and Bladin wrote 'It can be safely said that epilepsy has been one of the least understood and most maligned of medical conditions' [16].

1.2 How is Epilepsy Treated?

1.2.1 Historical Epilepsy Treatment Pathway
The diagnosis of epilepsy is not straightforward. The core of accurate diagnosis of the disorder is the clinical history, along with crucial contemporaneous witness accounts. However, the availability and accurate recall of both patient and witness accounts decays over time [17]. In time-pressured environments such as primary care and emergency settings where patients first present, diagnostic accuracy may be little
better than chance [17][18][19].

Following a diagnosis of epilepsy, patients receive epilepsy care from specialist epilepsy centres located within the neurology departments of hospitals. In Ireland, six group based epilepsy centres (GBEC) exist which are staffed by registered advanced nurse practitioners (RANPs) who work in tandem with neurology consultants with special training in epilepsy and non-consultant hospital doctors (NCHDs) [20]. In these epilepsy centres, routine epilepsy care is provided for PWE including in and outpatient care, rapid access service for general practice and emergency department referrals plus telephone and email advice [20].

![Figure 2 - The traditional model of epilepsy care [15]](image)

Studies have shown that PWE experience significant difficulties accessing epilepsy
specialists in emergency settings [21].

For the majority of PWE, their primary contact with their epilepsy service is through routine outpatient appointments. Patient follow-up takes place at intervals decided by the clinician, typically three, six, nine or twelve months depending on the severity of the patient’s epilepsy. During these appointments, the clinician and patient discuss the patient’s seizure activity and response to treatment. Treatments for epilepsy focus primarily on the management of seizure occurrence, with anti-seizure medications the first line treatment in the vast majority of cases. Approximately 70% of PWE can become seizure free following adherence to an appropriate ASM regime [22]. For the remaining 30% of PWE for whom medication is ineffective at reducing seizures, non-pharmacological treatments such as surgery, vagus nerve stimulation (VNS) and the ketogenic diet are utilised in attempt to reduce seizure activity [23][24]. Epilepsy outpatient appointments typically conclude with the clinician either altering or maintaining the patient's prescription based on the clinician's impression of the patient's condition based on their discussion. A follow-up appointment is then arranged, and this cycle of treatment continues until the optimal management regime is found.

1.2.2 National Clinical Programme for Epilepsy (NCPE)

Epilepsy care in Ireland is guided by the National Clinical Programme for Epilepsy (NCPE). In 2010, the Health Service Executive (HSE) sought expressions of interest from groups of clinical teams, community clinicians, carers and patients who were interested in delivering safe, effective care in a resource constrained environment. The HSE coined this advent the ‘National Clinical Programmes’. Those working in the field of epilepsy in Ireland welcomed the emergence of the National Clinical Programmes and in May 2010, the Clinical Advisory Group (CAG) of the National Clinical Programme for Epilepsy (NCPE) was inaugurated. Over a six-year period from 2010 to 2016, the CAG of the NCPE developed and published a vision document in determining the best way of delivering epilepsy care in Ireland. The document provides an outline of the
building blocks that are required to create the conditions to realise this vision.

There are three core objectives of the NCPE: improving access to expert care and information; improving the quality of care across the healthcare spectrum from prevention, through managed primary care to complex surgical care for difficult epilepsy; and improving value conscious care by shifting care, where possible, from expensive hospital-based care to the community. In order to achieve each of these objectives, the NCPE recommends addressing each aspect of care with a specified care pathway.

(a) Managed primary care is delivered by General Practitioners (GP) with the support of Registered Advanced Nurse Practitioners (RANP), a cohort of epilepsy experts with a nursing background.

(b) Group Based Epilepsy Centres (GBEC) are staffed by RANP, who work in tandem with non-consultant hospital doctors (NCHD) and consultant neurologists to provide routine epilepsy care. There are six GBEC based around Ireland and every PWE has access to one. The care provided in GBEC includes in and outpatient care, a rapid access service for community and emergency department referrals, telephone, email and virtual advice. Transition clinics introduce adolescent PWE moving from paediatric to adult care to the staff working on the adult service.

(c) Through the use of integrated care pathways by emergency departments (ED) and acute medical admissions units (AMAU), front line physicians use an evidence-based algorithm to help with the management of patients who come to hospital with first seizures or breakthrough events.

(d) The 15% or so of highly complex epilepsy patients who need to be assessed for possible epilepsy surgery are dealt with through pre-surgical evaluation beds spread across three sites.

The NCPE's vision for epilepsy care is: ‘To provide the best value care for all people
with epilepsy in the right place, at the right time, sharing the best available information’. Underpinning this vision is an ethos of ‘Person and Family Centred Care’ (PFCC). PFCC focuses on ‘putting the patient and family at the heart if every decision and empowering them to be genuine partners in their care’ [25]. In adapting this approach to healthcare delivery, the NCPE wishes for PWE and their carers to be recognised within the full context of their lives, not just their health condition [26,27]. Through PFCC, the NCPE wishes for patients to become activated and empowered partners in their care and for clinicians to provide care that is responsive to individual patient preferences, needs and values [26,27].

While the goals of the NCPE are generally agreed upon and welcomed by stakeholders, cultural and infrastructural difficulties within Ireland’s healthcare system present obstacles in making the NCPE vision a reality. The effects of neoliberalism on healthcare, similar to all public service delivery, have demanded the measurement of efficiency with outcomes based on quantifiable measures [28]. Work by Byrne et al indicated that HCPs working in epilepsy care in Ireland felt tension existed within the current system between the time required to identify and respond to individual patient needs and the pressure to meet workload targets [29]. HCPs felt that boundaries were perpetuated within and between professions, disciplines, organisations and sectors which was resulting in missed opportunities for collaborative practice in epilepsy care, limiting the optimal co-ordination of care [29]. These boundaries, combined with the demand for pace and productivity, highlight the challenges of introducing changes within a hard-pressed healthcare system. Shifting to a care model where individuals receive extra attention from HCPs, particularly in relation to more holistic aspects of their care or self-management, will be very difficult without appropriate resourcing and support to HCPs.

1.2.3 Sláintecare

Health reform has been at the centre of political and societal discourse in Ireland for decades. Efforts have been made by successive governments to improve and enhance
health services. Examples of success have emerged over the years, however the reality has fallen short of expectations with deep-rooted and fundamental problems failing to be addressed across the system.

In 2016, there was a consensus across all political parties that these problems needed to be addressed comprehensively on a cross-party basis. The Oireachtas Committee on the Future of Healthcare was established and was tasked with developing an agreement on a long-term vision and policy direction for the health and social care system over the next decade. This long-term strategy would continue to be implemented irrespective of the political parties in power. The committee published its report titled ‘Sláintecare’ in May 2017, setting out a vision for the development of the Irish health service over the next decade. In order to help translate the Sláintecare vision into a reality, the Government published the Sláintecare Implementation Strategy in May 2018 with strategic goals set in place to realise this vision.

A major tenet of Sláintecare is the realignment of how chronic conditions such as epilepsy are dealt with by the health system. For chronic diseases such as epilepsy the search is very much on for new and affordable ways of delivering care [30]. High ‘did not attend’ (DNA) rates at hospital appointments and poor patient engagement are common, resulting in poorer health outcomes and greater use of emergency care [30–32]. Over 60% of individuals in the nation aged over 50 report at least one chronic condition [33]. Chronic disease currently accounts for a significant portion of hospital activity, including 40% of hospital admissions and 75% of hospital bed stays [34]. The increase in chronic diseases leads to a higher workload in health care, a substantial impact on society and an enormous burden on patients’ lives which results in a growing need for structural changes of the organisation of healthcare [35–39]. Sláintecare states that an increased emphasis needs to be placed on preventative care and ongoing management for chronic disease, and these services are better provided closer to patients’ homes in the community. It is posited that the current health system
remains overly hospital centric, with hospitals too often representing the first port of call when an individual with chronic disease requires attention. Sláintecare reports that if this does not change, acute hospitals will soon become overwhelmed from dealing with exacerbations of chronic conditions. One of the strategic actions of the report is to accelerate implementation of integrated care programmes focused on chronic conditions and older people, to provide appropriate and effective care in the community. Chronic disease management (CDM) is cited as an ‘immediate priority’, with any barriers to CDM occurring in the community to be tackled and resourced appropriately [40]. The strategy aims to amend the GP contract to provide incentives to work in the community in increasing numbers and to adopt new approaches and ways of working. This reform will be jump started through acceleration of the existing national clinical programmes, such as the NCPE.

Another core objective of Sláintecare is the accelerated roll-out of eHealth systems and infrastructure throughout the health system. New digital initiatives will provide integration capability and patient information systems needed to support new models of care. Electronic health records (EHR) are a core component of this and a particular focus will be placed on growing eHealth capabilities in the community. The success of this will rely on the effective delivery of advances in technologies and ICT capabilities, such as telemedicine and eHealth initiatives. It is stated that digital health systems can support more efficient processes, empowering patients in managing their care and accessing their own medical records, as well as facilitating the provision of services in more appropriate care settings closer to the patients home [40].

Sláintecare states that investing in eHealth systems and ICT based systems will allow for the provision of the required infrastructure to make ‘the right information available about the right patient in the right place and at the appropriate time’, an almost identical vision to that of the NCPE. Many processes in the health system are currently paper-based and this is not in line with international best practice. Investing in eHealth will allow current manual processes such as ordering prescriptions, accessing
centralised waiting lists and managing complex hospital functions to be supported through ICT, similar to other knowledge-intensive sectors of the economy. Sláintecare posits that the widespread implementation of EHRs will allow patient information to follow the patient, thus providing the data to underpin care in the most appropriate care setting and also empowering patients to participate in the management of their own healthcare. A ‘shared care’ record will provide the necessary integration between community-based care and the acute hospital sector, allowing a more seamless approach to sharing patient data and underpinning planning and development of service improvements.

1.2.4 eHealth Ireland: Stay Left, Shift Left

With the creation of Sláintecare, eHealth Ireland launched their ‘Stay Left, Shift Left’ strategy to support its integration.

Moore’s Law is a statement attributed to Gordon Moore, co-founder of Intel. In 1965, Moore forecast that the number of components on an integrated circuit would double every year. When it proved correct in 1975, he revised what became known as Moore’s Law to a doubling of transistors on a chip every two years [41]. Moore’s prediction has come to define the trajectory of technology and the exponential growth of computing power of time.

Doug Busch and Andy Grove of Intel introduced the original Shift Left concept to support the application of Moore’s Law for Healthcare [42]. It addresses the traditional paradigm of using solutions to make people better by imagining a ‘shift left’ in healthcare policy and practice.
The 'Stay Left, Shift Left' strategy builds upon the Sláintecare strategy to extend preventative healthcare. Stay Left wishes for the health system to move to a new model where technology-based innovations facilitate an increased focus on keeping healthy people well, as opposed to making sick patients better. In shifting care 'left', a fundamental idea is that patients and their carers will not have to travel to acute hospitals to receive their treatment. This shift could be considered both theoretical and practical. Theoretical, in the sense that care is moving to a more independent model where patients self-manage their conditions, but also practical, as patients will not have to travel to hospital settings to take part in clinical appointments. It is posited that this will support the provision to patients of the best quality of life and quality of care in the most cost-efficient format. This will lead to better quality and extended lives. When individuals do get sick, Shift Left advocates technology solutions to support specialised, integrated care from acute settings to community to a home setting more quickly, or to avoid trips to hospitals at all [42]. Digital health technologies can support a shift left through the promise of increasing access, increasing reach, maintaining quality and delivering on outcomes.
1.2.5 Electronic Health Records (EHRs) and the Epilepsy Electronic Patient Record (EEPR)

A core component of both Sláintecare and Shift Left are the use of electronic health records (EHRs) to enhance and integrate patient care across multiple settings. EHRs are a classic example of eHealth infrastructure. They are developed using medical informatics processes to complement, or in some cases, replace traditional paper records [43]. In addition to improving patient care, they provide opportunities for research by providing a rich source of clinical information in a readily available format [43]. EHRs also provide opportunity for business activity, with growing markets for development, management, and enhancement of EHR solutions [43].

The most significant technological development in epilepsy care in Ireland in the last twenty years has been the creation of the National Epilepsy Electronic Patient Record (EEPR). The EEPR is a bespoke system which underpins the NCPE [20,44]. The EEPR is a point of care system that currently contains the longitudinal epilepsy care records of approximately 10,000 individuals [45]. It supports a range of clinical tasks including inpatient and outpatient care, outreach services, telephone/virtual clinics, epilepsy surgery, and vagus nerve stimulation (VNS) treatment [44]. The EEPR is continuously evolving with a core objective of making epilepsy care more patient and family centred [43–46].

The design, development and implementation of the EEPR respected the inter-relatedness of human, organisational and technological dimensions. The EEPR developers worked closely with the end-users to realise a solution that could be developed safely and effectively. Aware that human behaviour is more likely to follow the principle of least effort, a balance between mandatory and optional EEPR fields was judiciously established [46].

1.2.6 Providing Individualised Services and Care in Epilepsy (PiSCES)

The growing adoption of electronic patient records worldwide is being accompanied by an increasing international interest in the use of electronic portals (ePortal) to provide people with access to, and engage them as co-authors of their own medical
In recent years, an ePortal titled Providing Individualised Services and Care in Epilepsy (PiSCES) to the EEPR has been created through a co-design process involving PWE, their carers, clinicians, researchers and engineers. PiSCES includes a number of features which allows patients to view and update their own medical records, including: 'My Epilepsy Care Summary', 'My Epilepsy Care Goals', 'My Epilepsy Clinic Letters', 'Help us Measure Your Progress', 'Prepare for Your Clinic Visit' and 'Information for Your Healthcare Provider' [44]. PiSCES is not yet a widespread operational tool within epilepsy care. It is currently being implemented with a core group of PWE and care partners, nurses and consultant and non-consultant neurologists to fully understand how and where it can be of benefit to each of these stakeholders. It is hoped that this research will ultimately lead to PiSCES effective and successful deployment across each of the nation’s GBEC. Early results indicate that the ePortal is capable of providing personal, proactive and precision epilepsy care [44].

1.2.7 Telemedicine

The concept of ‘telemedicine’ is highlighted in both Sláintecare and the eHealth strategy for Ireland as an effective eHealth tool for improving efficiency and reducing cost in the delivery of chronic disease management in acute hospital settings. Telemedicine refers to the practice of medicine using technology when the clinician and patient are not in the same location [52]. It encompasses a range of information and communication technologies that support delivery of remote or long-distance clinical care such as telephone, video or email consultations [52], store and forward systems [53] and mobile applications [54]. There is a growing evidence base across a number of neurological conditions indicating that telemedicine for routine clinical appointments has benefits in terms of reducing cost, improving health outcomes and diagnostic accuracy compared to face-to-face encounters [55–59]. A telemedicine model for delivering clinical neurophysiology services in Ireland was evaluated by Breen et al in 2010, with results indicating improved satisfaction with waiting times, availability of results and impact on patient management [60]. In Ireland, like many jurisdictions worldwide, the uptake of telemedicine to provide chronic epilepsy care
has been slow. Clinicians and patients have persisted with onsite appointments in spite of the potential feasibility of remote visits, especially for stable chronic patients.

1.3 Epilepsy Self-Management

1.3.1 Defining Self-Management and Theory

As indicated in Sláintecare and Shift Left, there are growing calls to restructure the way in which chronic disease care is delivered. Within the proposed structural changes in both of these visions, patients and their carers will have a greater degree of responsibility for managing their condition and the manner in which they interact with the healthcare system will primarily be facilitated through ICT. For these visions to be successful, patients must feel empowered and supported to fulfil requirements pertaining to their health - a concept reflected as self-management.

Disease self-management originated in social cognitive theory, which addresses the cognitive, emotional and behavioural aspects of behaviour change and is relevant to managing chronic illness [61–63]. Self-management of chronic illness is defined as 'the daily actions that people take to keep their illness under control, to minimise its impact on physical health status and functioning, and to cope with psychosocial sequelae’ [64]. These actions include making informed decisions about care, performing activities intended to manage the condition, and applying the necessary skills to maintain adequate psychosocial functioning [64]. Related to self-management is self-efficacy, which refers to people's confidence in their ability to engage in these actions [64]. Evidence-based self-management and self-efficacy strategies are recognised as central in managing a variety of chronic diseases [65].

1.3.2 Self-Management and Epilepsy

Within the traditional model of routine outpatient epilepsy care, PWE spend almost all of their time coping with their condition outside of hospital settings. While clinicians can prescribe treatments at appointments, they cannot monitor treatment adherence, mood, or enhance their patients quality of life on a daily basis [66]. This fact has long
been acknowledged and various approaches have been developed, implemented and tested to help PWE maximise their quality of life away from hospital settings [61]. Sara Riggare, a researcher and patient living with Parkinson’s disease, created an infographic breaking down the time she spends annually receiving care from her neurologist and the time she spends engaging in ‘selfcare’ (Figure 4). Dilorio et al. defined epilepsy self-management as the ‘ability of patients to adapt and adhere to the behavioural adjustments needed to reduce seizure frequency and improve overall health’ [67][68]. The underlying principle of epilepsy-self management is that the condition is managed by the patient rather than by a clinician, with a positive relationship between clinicians, patients and their families integral to promoting comprehensive care and improved outcomes [69,70].

![Figure 4 - Infographic created by Sara Riggare illustrating her annual time spent receiving care from her neurologist and the time she spends engaging in 'self-care' [71].](image)

**1.3.3 Epilepsy Self-Management**

As Dilorio’s definition states, effective epilepsy self-management does not solely
surround seizure freedom. The inherent refractoriness of the seizure disorder as well as the appropriateness of medical therapy are pivotal determinants of a PWE’s ability to eliminate seizures from their life [72]. Epilepsy self-management encompasses a set of skills and behaviours one can enact in order to improve their overall health and lessen the impact of seizures on their lives. In practice however, evidence suggests that effective self-management is exceptionally difficult for PWE, the reasons for which are myriad. Issues such as medication non-adherence, cognitive dysfunction as a result of epilepsy, poor understanding of the need for treatment routines, lack of belief in medication efficacy, side-effects concerns, and practical barriers in getting prescriptions filled, picked up or delivered, are all well documented barriers to optimal epilepsy care [73][23].

1.3.3.1 Antiseizure Medication (ASM) and Medication Adherence

When a neurologist or a physician has made the diagnosis of seizures or epilepsy, the next step is to select the best form of treatment for the patient. Antiseizure medication (ASM) therapy is the mainstay of treatment for most PWE [74]. ASM therapy has four goals: to eliminate seizures or reduce their frequency to the maximum degree possible; to evade the adverse effects associated with long-term treatment; to aid patients in maintaining or restoring their usual psychosocial and vocational activities; and in maintaining a normal lifestyle [75,76].

ASMs are considered to be an integral modality of epilepsy treatment, with adherence to these medications greatly affecting seizure management [77,78]. The first general principle applied in ASM choice and usage is to employ ASM monotherapy, whenever possible, since monotherapy can be just as effective, or even more effective than polytherapy [79]. Following an individual being diagnosed with epilepsy, a neurologist will employ pharmacological knowledge and clinical wisdom to select an appropriate ASM to commence treatment with. Characteristics such as a patient’s age, sex, co-morbidities and co-existing medications are important determinants of proper drug selection and use [79]. These factors guide which ASM may have the most desirable
pharmacokinetic and pharmacodynamic properties to avoid the development of undesirable adverse effects [79].

To prevent further seizures, clinicians typically seek to begin ASM therapy in patients earlier rather than later. The probability of seizure recurrence after initiating ASM therapy varies among patients, depending on the type of epilepsy and any associated neurological and medical problems [76]. The response to ASMs is considered to be an important indicator in the prognosis of epilepsy [80].

Historically, clinicians have stressed adherence to ASM therapy as the most important self-management behaviour that PWE need to undertake [61,81]. Medication adherence is defined as the extent to which a person takes their medication as prescribed with respect to dosage and dosing intervals [82]. Non-adherence to medication can take many different forms: reduced or increased amount of a single dose; decreased or increased amount of daily doses; extra dosing; incorrect dosing intervals; a lack of awareness of the need for medication; taking duplicate or discontinued medication; and regularly forgetting or intentionally not taking medication [83].

Despite almost 70% of PWE being able to achieve seizure freedom following an appropriate anti-epileptic drug (ASM) regime, research evidence suggests that between 29% and 66% of PWE are non-adherent to their prescribed medication [84,85]. Non-adherence to ASMs is associated with increased emergency department visits, hospitalisations, fractures and head injuries [84,86]. Reduced adherence also correlates with lower quality of life, decreased productivity, seizure related job loss and seizure related motor vehicle accidents [87]. Seizure risk is 21% higher in non-adhering PWE when compared to those who adhere, and they exhibit reduced seizure control [84,88]. Epilepsy mortality has been associated with failure to collect repeat prescription for epilepsy medication [89].
1.3.3.2 Cognitive impairment as a result of epilepsy

Individuals with epilepsy are at risk not only for seizures, but also for a myriad of comorbid health conditions. Common co-morbidities that occur in epilepsy include cognitive dysfunction, such as memory, attention, or processing difficulties; mental health conditions, including depression or anxiety, and somatic co-morbidities, such as sleep disorders and migraines [90]. Epilepsy co-morbidities are common and often severe and for many PWE, the co-morbidities are more burdensome than the seizures.

Among the comorbidities associated with epilepsy, cognitive abnormalities are among the most common and troublesome [90]. In PWE, there is an associated high rate of cognitive difficulties that compromise educational progress and achievement throughout life [91]. Children who have poorly controlled seizures are more likely to have lower IQ scores than children with well controlled seizures [91]. Adults with chronic epilepsy are more vulnerable for cognitive regression [92].

Much of the cognitive impairment that occurs in PWE is related to the underlying aetiology of the epilepsy. Both acquired disorders such as trauma, hypoxia, ischemia, and mesial temporal sclerosis secondary to prolonged seizures and genetic disorders, including tuberous sclerosis, fragile X, Rett and Dravet syndromes can lead to significant cognitive impairment in addition to causing epilepsy [90]. In addition to these static deficits caused by the underlying aetiology, cognitive impairments can be more dynamic or transient, occurring as a result of the seizures, EEG interictal spikes and ASMs [90].

Cognitive impairment and functional disability as a result of epilepsy have been cited as important challenges to self-management [23]. Both children and adults with epilepsy frequently complain of memory disorders [93]. Individuals with epilepsy may have transient epileptic amnesia, in which the sole or main feature of the epilepsy is accelerated ling-term forgetting, in which newly acquired memories fade over days to weeks and remote memory impairment in which autobiographical or public facts are forgotten [93]. Accelerated forgetting has been demonstrated in both adults and
children living with epilepsy [94,95].

The nature of these cognitive co-morbidities, unsurprisingly research has shown that PWE struggle with accurate seizure recall, either due to the nature of an individual’s seizure types or simple recall bias [96,97]. PWE have also cited that cognitive difficulties they experience can make communication with HCPs more difficult and grasping evolving terminology relating to their condition can lead to frustration and the feeling of being experimented upon [23].

1.3.3.3 Health Literacy, Self-Efficacy and Locus of Healthcare Control
As with many chronic health conditions, challenges to self-management for adults with epilepsy include low health literacy, poor social support, low levels of education, medication and disease-related side effects, and low socioeconomic status [98,99]. Further complicating self-management for PWE are high levels of disease related stigma, driving or mobility restrictions, and social isolation which all serve as barriers to a sustained time commitment towards carrying out behaviours which may reduce seizure frequency and improving quality of life [100–102].

In addition to adhering to an appropriate ASM treatment regime, there are a number of behavioural and psychosocial adjustments that PWE must undertake to optimize their health and improve their quality of life. These include being able to describe and document one’s seizures, practicing safety precautions, having adequate rest and managing one’s stress levels [67]. Research surrounding PWE engagement with these non-adherence related skills and behaviours have shown important indicators for performing such tasks; health literacy, self-efficacy and locus of healthcare control.

Health literacy is defined as the ‘cognitive and social skills that determine the motivation and ability of individuals to gain access to, understand, and use health information in ways that promote and maintain good health’ [103]. Health literacy is considered to be a determinant of health behaviours and outcomes and is considered to be positively associated with self-management among people living with chronic
disease [104,105].

Self-efficacy is defined by Bandura as 'beliefs in one's capabilities to organize and execute the courses of action required to produce given attainments' [62]. The findings of several studies across chronic diseases such as diabetes, arthritis and asthma indicate that people with high levels of self-efficacy are more successful at managing self-care tasks such as avoiding triggers for symptoms and monitoring health status [106–109]. Studies investigating self-management in epilepsy indicate that self-efficacy is a primary determinant of general epilepsy management and medication management [110].

Work by Squiers et al indicated that various mediators may affect the relationship between health literacy and health behaviours and outcomes [111]. Others suggest that self-efficacy doesn't entirely explain how health-literacy influences how an individual engages in self-management behaviours [112,113]. What is known is that people with lower levels of health literacy tend to be less interested in social engagement [114] and greater health literacy has been linked to favourable social contacts and lesser social isolation [115,116]. Social isolation has been suggested to negatively influence health behaviours. Those without regular interpersonal contact and involvement in social organisations are likely to perform more adverse health behaviours such as poor diet or insufficient physical activity [117,118].

An internal sense of personal control is related in positive ways to psychological and physical adaptation to illness, as well as engagement in beneficial health behaviours [119]. PWE are also known to have strong perceptions of external locus of health control [120]. Work by Asadi-Pooya et al. indicated that the belief that powerful other people, such as doctors, nurses, family and friends, have control over their health status is strong among PWE [120]. In this study, patients with good seizure control, with better treatment success, had higher internal locus of healthcare control scores than patients with uncontrolled seizures. In one study, PWE had coping styles different
from those of the general population and used less active strategies in coping with their problems. [121]. This suggests that PWE might adapt less effectively to their illness and have lower levels of engagement in beneficial health behaviours and active coping strategies than others [120].

1.3.3.4 Family and Carers Supporting Self-Management

The nature of chronic disease management is very complex, with each patient holding a different view of their disease, life priorities, hope, support and how to carry out self-management tasks for their condition [122]. Up to 25% of individuals with chronic conditions report being non-adherent to medical recommendations, with higher rates of non-adherence for lifestyle changes, such as exercise and diet, compared with more specific and narrowly defined behaviours such as taking medications [123]. Social support from family members and carers is a way to overcome these barriers and improve self-management outcomes in individuals living with diabetes [124], heart disease [125] and epilepsy [126]. Family members have a role to play in supporting self-management by carrying out various kinds of tasks related to the activities of daily life, including maintaining cleanliness, preparing food, household chores, giving attention, providing comfort, socialising and following up with medical care [127].

Self-management behaviours often take place in a shared environment and in the context of relationships, naturally involves individuals beyond the patient [128]. Family support is associated with better self-management and health outcomes particularly when it’s encouraging, enhances patient autonomy or fosters family cohesion [129]. Support needs for PWE vary depending on the person’s seizure type, severity and triggers [130]. As described in Section 1.3.2, the cognitive and memory difficulties associated with epilepsy can impede on an individual’s ability to perform self-management tasks. Relatively little research exists surrounding the support PWE receive for self-management, evidence suggests primary support persons are involved in medication reminders and monitoring, supporting strategies for reducing stress and improving sleep and providing emotional support [130].
From the first diagnosis of epilepsy, families are encouraged to help by monitoring seizures and medication and be involved in the initial explanation of the importance of adherence [131]. Clinicians often recommend family members and friends to learn seizure first-aid and practice what to do during seizures with PWE [67]. A stressor unique to families of PWE is the unpredictability of when seizures occur [132]. This can make it difficult for caregivers to plan activities.

Families form the core of a patient’s social support system, and strong social support results in significantly less debilitation from the disorder [133]. A study by Lua et al. indicated that patients with good awareness, knowledge and attitudes towards epilepsy had a better health-related quality of life (HRQoL) [134]. A comparison study showed that impaired HRQoL and low self-esteem were intensified by seizures themselves and the clinical trajectories of the disease [135]. In both studies, familial support was shown to influence HRQoL. After controlling for illness duration, seizure frequency and depression, patients who had better HRQoL scores often had effective family involvement.

Saburi et al. interviewed adults with epilepsy and found that fear, individual isolation, secrecy and concealment were negative strategies often used by PWE and their family members in the course of their interactions [136]. Many caregivers and parents of PWE have unfounded concerns about the condition, which leads to the formation of overly negative attitudes [137]. A study by Ellis demonstrated that stigma within the family is responsible for triggering some of the behavioural problems in PWE [138]. Another consequence of caring for PWE is the tendency of family members to become overprotective. This has the deleterious effect of heightening the feelings of depression, emotional immaturity and poor social skills among PWE [137,138]. Support can lead to poorer self-management when it’s critical, overprotective, nagging or controlling [129].

Studies on the psychological effects of epilepsy and their impact on management skills
have focused primarily on PWE [137]. It has been shown that having a family member with epilepsy is an unfavourable predictor for a successful family life, primarily because family members bear much of the caregiving responsibility and its accompanying stress [139]. Somatic and psychological health, emotional health, quality of life and well-being have all been shown to deteriorate among caregivers of those with epilepsy [140,141]. The negative impact of caring for a loved one with epilepsy on family members is widespread and has been seen across a wide variety of cultures [136,141,142]. Understanding how families are affected by epilepsy allows caregivers to address specific family needs, help families improve medical management, and practice strategies for maintaining their own wellbeing [137].

Despite the difficulties and challenges facing families who care for PWE, it is also important to point out that such experiences have positive effects. Thompson et al’s survey indicated that families caring for PWE resulted in a heightened sense of closeness among family members and an increase in their resolve to support one another [132]. Family members also reported having other siblings benefitting from a family member with epilepsy by developing close family ties, achieving harmony, and adapting in order to accommodate a family member with epilepsy. These families described how their situation has fostered closer family dynamics and increased satisfaction when witnessing the stability of their family member with epilepsy [132].

1.3.4 Clinicians Supporting Self-Management

Most conceptions of self-management of chronic disease have evolved to envision a partnership between the patient and the clinical care provider [143]. This formulation of self-management recognises a) that chronic conditions require medical services and assistance from a clinician and b) that the experts in the day-to-day challenges of management are the patients [144]. It is clear that physicians need to be aware of the strong role that they play in determining their patients’ health related beliefs and behaviours and be more solicitous of their thoughts and desires. If PWE can successfully self-manage their condition, it plays a huge role in the ‘ownership’ of their
care, transferring from healthcare provider to patient [145][146].

Dilorio et al. demonstrated that patients who were more satisfied with their clinicians expressed higher levels of self-efficacy in relation to epilepsy management tasks [147]. It is understandable that physicians play an important role in enhancing a patient’s confidence in managing his or her epilepsy. Despite the undoubted importance of clinicians in fostering self-management, work by Clark et al. indicated that it is not sufficiently covered in most clinical epilepsy encounters [81]. In this body of work, significant perceived barriers to providing effective self-management guidance included the severely limited time with patients in clinical appointments. Clinicians believed that they do not see enough of these patients to fully understand holistically their treatment challenges or have insufficient training on how to promote effective self-management to them [81]. As a result, selecting the best treatment plan, effectively engaging the patient in his or her own care, and linking to needed support services can fall outside their areas of expertise [148,149]. Clinicians who fail to recognise the way epilepsy affects all aspects of day-to-day functioning of PWE and their families will too often provide treatment plans and support services which are inadequate for the range and intensity of problems that patients face [81].

1.4 Can eHealth support self-management of epilepsy?

1.4.1 What is eHealth?

Technology has had quite a pervasive influence on the modern world, and there is an increasing acceptance of ‘electronic first’ approaches to communication and interaction among human beings [17].

eHealth is a relatively new practice which utilises electronic processes in the healthcare of patients. A study in 2005 found 51 unique definitions of the term [150]. An accurate definition of eHealth enjoyed by this author is: ‘eHealth is an umbrella term incorporating any area that combines healthcare and technology to improve efficiencies and reduce costs’ [151].
1.4.2 eHealth and Self-Management

The use of technology is seen as integral to the implementation of self-management programs today [152]. Self-management is not only a convenient way to organise differently, it also offers patients significant benefits by providing them with more knowledge about their disease and involvement to be able to accept and maintain a healthier lifestyle. eHealth provides the means to facilitate communication between healthcare providers and patients, to transfer information and to facilitate the patient being more self-managed [152].

1.4.3 Can eHealth aid with Self-Management of Epilepsy?

As mentioned earlier, the heterogenous nature of epilepsy means that a number of treatment methods are used to treat patients based on their symptoms, no ‘one size fits all’ cure exists for epilepsy and a number of treatments are in use to reduce seizure activity in patients. In the last two decades, eHealth developed for PWE have appeared with varying aims and functions to support treatment.

1.4.3.1 Educational Programmes

Self-management programmes for PWE historically have involved formalised programmes conducted face-to-face with other patients, professional moderators and often carers. These programmes depended entirely on in-person educational sessions and in-person support groups and were found to be very effective in improving self-management skills, though they were labour intensive and logistically challenging for both practitioners and patients [61].

Since the advent of the internet and mobile connectivity, many programmes have incorporated the same elements in more accessible form. One of the first programmes to implement this digital strategy was the WebEase platform (www.webease.org). The WebEase tool includes three educational modules - medication adherence, sleep, and stress, that can be completed online. The original clinical trial demonstrated improvements in epilepsy self-efficacy, self-reported adherence and stress levels in an intervention patient group compared with a wait list control group [153].
The Managing Epilepsy Well (MEW) network provides comprehensive digital resources for PWE. Programmes such as PEARLS, UPLIFT, HOBCOTCH and MINDSET exist with slightly different clinical focuses for patients that aim to identify specific self-management challenges and craft individualised educational programmes [154–156]. Currently these programmes are only available at dedicated epilepsy centres in the U.S.

1.4.3.2 Self-Management ‘Apps’

Mobile diaries designed for epilepsy management have been available for many years. The basis for the development of many self-monitoring applications (‘apps’) was that giving PWE a platform to continually monitor or log seizure activity will allow more accurate epilepsy information to be presented to their clinicians, thus allowing more informed management and treatment.

A number of mobile applications on different operating platforms are available, although most are commercial products that have not been critically studied [17,96,157]. Reviews have identified a large and growing number of epilepsy specific mobile applications, with most being related to seizure and medication tracking [157,158]. Common features of epilepsy management smartphone apps include an interface to record seizures occurring, share information with caregivers or healthcare providers, and graphical summaries to examine seizure trends over time [159].
One of the better-known mobile diaries is the product supported by the international Epilepsy Foundation, My Seizure Diary [160]. The latest version of the app offers users a notification based method for reporting seizures and includes customisable reminders for seizure monitoring, medication dosing and refills [161]. Earlier versions of the app have been successfully used in clinical trials for capturing self-reported data [162,163]. Another popular epilepsy-specific diary is EpiDiary, which also offers seizure tracking, medication adherence data and advanced graphing features, in addition to being available in multiple languages [161].

1.4.3.3 Patient Portals

Electronic patient portals (ePortals) are web-based platforms that are linked to
patient’s electronic patient record (EPR). ePortals offer patients secure access to their own medical information and the ability to manage several aspects of their healthcare at any time of day or night through interactive tools [164]. Common features of ePortals include clinic visit summaries, tools for patient-reported outcomes and goal setting, aids for education surrounding chronic conditions and the means to securely message and communicate with HCPs [44,164–168]. As outlined earlier, PiSCES is an ePortal linked to the Irish EEPR which is currently in transition from a research phase with a small cohort of PWE and carers, to becoming an operational tool used across each Irish GBEC. The Dorset Epilepsy Service in the United Kingdom has successfully developed and trialled a portal tool to facilitate reporting of seizures by PWE to clinicians involving the use of a smartphone app and wrist-worn device connected together [17,169].

1.4.3.4 Wearable Devices

The use of devices in the management of health conditions, including epilepsy, is expanding rapidly. Devices have the potential to provide reliable biomarkers for comorbidities and possibly sudden unexpected death in epilepsy (SUDEP) as well as offering novel insights into the relationship between seizures and various environmental and internal factors [170].

Wearable automated seizure detection devices have been developed and are commercially available to PWE [171]. The detection of seizure activity either occurs directly or indirectly by these devices. The ‘Embrace’ and ‘E4’ wristbands developed by Empatica are equipped with accelerometers and electrodermal activity sensors in order to detect hallmark physiological seizure signals in patients [171].

The potential for devices to assist in managing risk in epilepsy is significant, but technologies developed thus far are varied, frequently complex, inconsistently validated and often confusing [170]. Concerns exist surrounding the validity of data generated by wearable devices and generation of true and false positive alarms [170]. In Rugg-Gunn’s 2019 review, ‘The role of devices in managing risk’, the criteria for an
‘ideal’ wearable device is outlined: detect and abort preictal or ictal epileptic activity thereby reducing seizure frequency and severity and also monitor and reduce cardiorespiratory impact and autonomic dysfunction, provide a preictal warning, summon assistance if required, and store biometric data for later interrogation and integration [170]. Devices should also have an impact on risks associated with seizures, such as SUDEP [170]. PWE have indicated that devices must be safe, unobtrusive, easy to use and comfortable [170][172][173]. To date, all of these characteristics do not exist in a single device [170].

In addition, the scientific evidence for the diagnostic utility of wearable devices is limited. This has impacted their integration into rational medical decision making [170].

1.4.5 Challenges to eHealth Implementation for Self-Management
Research indicates that while PWE appear willing to utilise eHealth for epilepsy management [174], the uptake of eHealth supports among the populations with epilepsy is low [175]. A number of barriers at patient level have been proffered to explain this.

1.4.5.1 Perceived Burden of Disease
Work by Runz-Jorgensen et al found that across a cohort of individuals living with multimorbidity, participants’ assessment of the significance of their experienced challenges appeared to be the main reason for the differences in assumptions and expectations about eHealth [176]. Those with a greater burden of illness and treatment, who were more likely to be socially isolated and housebound due to physical restrictions, and who assessed their experienced challenges as more significant, had more positive perceptions of eHealth. They also had a greater intention and interest to use eHealth and believed they could benefit from using it.

In contrast, those with less complex disease patterns and less treatment were more likely to perceive eHealth as something worthless and undesirable. Individuals with
more 'stable' conditions were able to highlight expected consequences and limitations of eHealth and did not express an intention to use it while in their current state of health [176]. Venkatesh et al conducted an empirical comparison of eight information technology models and found that the strongest determinant of intention to use technology is the degree to which the individual believes that using the system will help attain gains [177]. When applied to an epilepsy context, the spectrum of perceived severity of challenges associated with the condition would influence eHealth use, with individuals experiencing less frequent seizure patterns or who perceive their epilepsy as having less of an impact on their lives would be less likely to use eHealth tools.

1.4.5.2 Lack of Awareness
For PWE and their carers, a lack of awareness and exposure to helpful digital resources is a significant barrier to their use [157,178]. Newly diagnosed patients are often ill-prepared to immediately evaluate and adopt chronic disease management practices in the context of a flood of new information, medical treatment recommendations, further diagnostics, and lifestyle modifications. For patients with less frequent seizures, tools that require daily maintenance may actually confer added complexity to their treatment plan [154]. Some PWE with psychiatric or medical co-morbidities have limited ability to use more intensive programs i.e. self-management modules, diary interfaces and wearables. Frustratingly, these are often the same patients who would benefit the most from these tools [23]. In order for these PWE to engage with digital tools, a significant degree of intervention is required from carers or HCPs. Alternatively, the digital tools need to offer very simple interfaces or limited feature sets to improve usability [154]. Non-adherence has been cited as an issue with digital resources. Patients often do not fully complete self-management programmes and may not be able to understand the goal of these efforts [23]. Current wearables available require a significant degree of patient or carer maintenance and face the same challenges, if not more, as daily medication regimens [179].
1.4.5.3 Smartphone Usage and Health Literacy

A survey of 571 PWE in the Netherlands showed that PWE are less likely to own a smartphone or computer compared to the general population [175]. 43% of participants in this study used a paper diary to self-monitor their epilepsy, compared to 16% who used a digital diary [175].

It is common in eHealth studies for a substantial proportion of users to drop out before completion, or to stop using the application under research [180]. Talboom Kemp et al. proffer that patients must experience practical added value to their daily life to stay motivated to use an eHealth platform. Work by Compos et al. illustrated that lower socioeconomic status (SES), older and male US adults were less likely to engage in several eHealth activities compared to their counterparts [181]. ‘Health literacy’ refers to an individuals’ capacity to obtain, process and understand basic health information and services that are needed to make appropriate health decisions [182]. Talboom Kemp et al stress that health literacy means more than transmitting information and developing skills to be able to read folders and make appointments and that in the future, emphasis should be given to more personal forms of communication and community-based educational outreach, as well as more focus on equipping patients to overcome structural barriers to health.

1.4.5.4 Privacy concerns

Patients also have concerns surrounding the potential risks to data security and confidentiality associated with digitally connected tools and devices. Patients report needing to establish a certain level of trust with their healthcare teams to feel more comfortable with the safety of these tools and the use of these data to inform treatment plans [23,183].

1.4.5.4 Lack of integration with current care pathways

The lack of uptake of eHealth by PWE has been attributed to the lack of integration with current clinical care pathways [17]. While many eHealth supports exist for PWE, they often do not communicate with software utilised by HCPs when providing
epilepsy care, resulting in an increased workload for clinicians and not delivering on their potential. These include the inadequate consideration of the relevant attitudes and possibly skills of healthcare professionals, the obstacles of time and competing priorities and because of the plurals of all necessary factors to enhance self-management [152,184].

1.5 Aims and Objectives of Research

The overall aims of this research thesis are summarised as follows:

- Examine the perspectives of people with epilepsy (PWE), carers and healthcare providers (HCPs) towards self-management and eHealth supports.
- Conceptualise the experience of living with epilepsy and understand mechanisms through which eHealth usage can be promoted.

The overall objectives of this research thesis are summarised as follows:

- Collect data surrounding medication adherence and medication error across a cohort of PWE receiving their routine outpatient epilepsy care from the DML Epilepsy Service at SJH.
- Understand the perceptions of PWE, carers and HCPs receiving and delivering chronic epilepsy care via telemedicine.
- Understand the challenges PWE, their carers and HCPs perceive as existing with regard to epilepsy self-management behaviour and using eHealth tools.
- Ideate solutions for identified barriers to epilepsy self-management and eHealth usage.

1.6 Discussion

The predominantly face-to-face model of outpatient follow-up for epilepsy care has existed since the 19th century. It is acknowledged that in-person outpatient care is expensive, increases staff workload and often fails to reliably provide responsive care when patients need intervention. In an epilepsy specific context through the NCPE,
and in a broader national context through Sláintecare and Shift Left, there are growing calls to fundamentally change how chronic disease management is approached both in Ireland and internationally. Given that we live in a ‘technology first’ society, it is proposed that through the empowerment and engagement of patients with appropriate digital health tools, individuals can receive and clinicians can deliver chronic disease care when and where it is needed remotely. While these proposals are undoubtedly progressive, their visions are broad and lack granular detail surrounding how individuals will behave differently in relation to their healthcare through increased use of eHealth.

Self-management and epilepsy are topics which have been explored for decades. Historically, adherence to ASM treatment has been viewed as the most important behaviour for PWE to engage in between appointments by clinicians. While ASMs remain the primary treatment route for PWE achieving seizure freedom and increasing quality of life (QOL), there are a number of other skills and behaviours that PWE need to perform to limit the impact of epilepsy on their lives. Factors influencing the engagement of PWE have been explored and it is acknowledged that PWE struggle with performing self-management tasks. Clinicians currently are unsure of how to foster self-management among the PWE they treat.

There are a number of eHealth tools which have been developed to help with epilepsy self-management, including educational programmes, smartphone applications, patient portals and wearable devices. PWE appear interested in using eHealth for epilepsy management, however uptake of eHealth thus far has been low. The cognitive impairment, social isolation and stigma associated with the condition and levels of self-efficacy and health literacy among PWE have not been adequately taken into consideration in the design and implementation of eHealth tools for epilepsy thus far. Clinician concerns regarding data privacy and perceived ineffectiveness of eHealth have not been alleviated by developers working in the epilepsy and eHealth fields, and consequently scepticism exists among HCPs regarding the use of eHealth for
chronic epilepsy management.

The field could benefit from the usage of mixed or qualitative methodologies to better understand the lived experience of stakeholders and barriers and facilitators to eHealth usage for self-management among PWE, their carers and HCPs. This PhD project seeks to scratch beneath the surface to understand the perspectives of PWE, carers and HCPs towards self-management and eHealth supports to conceptualise their lived experience and understand where eHealth usage can be promoted.

1.7 Conclusion

If epilepsy care wishes to move to a model where PWE, their carers and HCPs interact for routine care in a primarily digital manner, research is needed to conceptualise the lived experience of each of these stakeholders. Deficits currently exist in the understanding of the factors influencing important epilepsy self-management behaviours and the provision of self-management information from HCPs. This PhD project wishes to address these deficits by carrying out two clinical audits and two qualitative research studies exploring how PWE, their carers and HCPs perceive the world around them. This will enable an understanding of the key mechanisms through which each of these groups can be empowered to engage with eHealth usage for epilepsy management.
Chapter II - Self-reported anti-epilepsy medication adherence and its connection to perception of medication error

Jack Banks a,c, Jarlath Varley b, Mary Fitzsimons c, Colin P. Doherty a,c,d

a Academic Unit of Neurology, School of Medicine, Trinity College Dublin, Dublin 2, Ireland

b School of Nursing and Midwifery, Trinity College, Dublin 2, Ireland

c FutureNeuro SFI Research Centre, The Royal College of Surgeons in Ireland, 123 St. Stephen’s Green, Dublin 2, Ireland.

d Department of Neurology, St.James’s Hospital, James’s Street. Dublin 8, Ireland.

This chapter was published in journal article form in the eminent journal *Epilepsy & Behavior*, Volume 104 in March 2020.

DOI: 10.1016/j.yebeh.2019.106896

2.0 Abstract

Although 70% of people with epilepsy (PWE) achieve seizure freedom following an appropriate Anti-Seizure Medication (ASM) regime, evidence suggests that adherence to ASMs by PWE is sub-optimal. Non-adherence to ASMs is associated with increased morbidity, mortality, emergency department visits and hospitalisations with reduced adherence also correlating to a lower quality of life, decreased productivity and loss of employment. Furthermore, research indicates that medication errors which are widespread in chronic disease are less well studied in epilepsy but are likely also to contribute to avoidable disease morbidity and mortality.

The goals of this project were to determine rates of medication adherence by self-reported questionnaire and its links to perceived medication error in a cohort of PWE attending a general epilepsy outpatient clinic. Following a plan-do-study-act cycle, it
was found that the most appropriate methodology for conducting was in the form of a bespoke nine-item self-administered questionnaire. 186 PWE completed a nine-question questionnaire asking patients about their own medication adherence habits and their perception that they were previously exposed to medication error.

This study found that 41% of respondents reported sub-optimal adherence to ASM therapy, while 28.5% of respondents self-reported that they unintentionally do not take their ASM medication on an occasional, regular or frequent basis. 5.9% of respondents self-reported that they intentionally do not take their medication as prescribed. 6% of respondents self-reported that they are both unintentionally and intentionally, non-adherent to their ASM therapy. No significant associations were demonstrated between age, sex, perceived effectiveness of medication, feelings of stigma/embarrassment, side effects or additional neurological co-morbidities and unintentional or intentional non-adherence.

28.5% of respondents to the questionnaire reported that they perceived themselves to have been subjected to medication error. Prescribing errors were the most common form of perceived medication error, followed by dispensing errors, then administration errors. Significant associations were found between ineffective medication and feelings of stigma or embarrassment about epilepsy with perceived prescribing errors. Intentional non-adherence to medication was significantly associated with perceived dispensing errors.

2.1 Introduction

Medication adherence is defined as the extent to which a person takes their medication as prescribed with respect to dosage and dosing intervals [82]. Non-adherence to medication can take many different forms (see Table 1).

Despite almost 70% of people with epilepsy (PWE) being able to achieve seizure freedom following an appropriate anti-seizure medication (ASM) regime, research evidence suggests that between 29% and 66% of PWE are non-adherent to their
prescribed medication [84,185]. Non-adherence to ASMs is associated with increased emergency department visits, hospitalisations, fractures and head injuries [84,86]. Reduced adherence also correlates with lower quality of life, decreased productivity, seizure related job loss and seizure related motor vehicle accidents [87]. Seizure risk is 21% higher in non-adhering PWE when compared to those who adhere, and they exhibit reduced seizure control [84,88]. The most serious impact of epilepsy is death, whether through accidents, trauma or the syndrome known as sudden unexpected death in epilepsy (SUDEP) [186]. Epilepsy mortality has been associated with failure to collect repeat prescription for epilepsy medication [89].

From a health economics perspective, non-adherence can involve additional costs to the health care service due to the extra staff and resources required to deal with additional hospital admissions caused by seizures and seizure related injuries [187]. Data indicates that all medication non-adherence across EU health systems costs governments an estimated €125 billion and contributes to the deaths of nearly 200,000 Europeans annually [188].

Medication errors are defined as any error occurring in the medication use process, from prescribing to dispensing to administration of an inappropriate or incorrect drug or dose, irrespective of whether such errors lead to adverse consequences [189]. As the definition suggests, errors can occur at any stage in the drug use process, however medication errors can be broadly categorised into three different types: prescribing, dispensing or administration errors (see Table 1).
Medication Adherence | The extent to which a person takes their medication as prescribed with respect to dosage and dosing intervals [82]
---|---
Medication Non-Adherence | Involves reduced or increased amount of a single dose, decreased or increased amount of daily doses, extra dosing, incorrect dosing intervals, a lack of awareness of the need for medication, taking duplicate or discontinued medication and regularly forgetting or intentionally not taking medication [83].
Prescribing Error | Incorrect drug selection for a patient, be it the dose, the strength, the route, the quantity, the indication or the contraindication [190].
Dispensing Error | Discrepancy between a prescription and the medicine that the pharmacy delivers to the patient or distributes to the ward on the basis of the prescription [191].
Administration Error | Discrepancy between the drug therapy received by the patient and the drug therapy intended by the prescriber [192].

Table 1 - Definitions of medication adherence, medication non-adherence and the three categories of medication error.

While the issue of medication adherence in epilepsy patients has been acknowledged and relatively well explored, the issue of medication errors relating to ASMs and the impact on patients and families is less well understood [193–195]. In this study, the concept of PWE feeling/perceiving that they were exposed to a medication error, and how this might influence their ASM compliance behaviours, was explored. The objective of this work was to collect data surrounding medication adherence and medication error across a cohort of PWE receiving their routine outpatient epilepsy care from the DML Epilepsy Service at SJH.

In terms of continuous quality improvement in clinical epilepsy care, promoting ASM adherence and reducing medication errors are important activities. Prior to designing interventions to increase ASM adherence and reducing medication errors, the Epilepsy Department of St. James’s Hospital wanted to establish baseline data surrounding adherence behaviours and perception of medication error using clinical audit. A number of established instruments measuring self-reported medication adherence exist such as the Morisky medication adherence scale – 8 (MMAS-8), medication possession ratio (MPR) and the epilepsy self-management scale (ESMS). Rather than use one of these instruments, a unique questionnaire was developed for this audit as we wished to include questions about perception of medication error.
2.2 Methods

The audit was carried out in the form of a self-administered questionnaire. The questionnaire investigated the influence of eight factors – sex, age, number of medications, current perceived effectiveness of medication, prior perceived effectiveness of medication, perceived side effects, perceived stigma and additional neurological co-morbidities – on whether a PWE intentionally or unintentionally was non-adherent to ASMs through a self-reported questionnaire.

2.2.1 Study Design

Legend

Blue = Pilot PDSA cycle
Black = Final methodology employed

Figure 6 - Outline of PDSA cycle utilised to optimize clinical audit methodology.

Initially, the idea of the audit being carried out as an oral interview by the epilepsy staff was considered. The interaction would take place in an interview style, with the
nurse asking a series of 20 questions to the participant in a conversational manner and recording their answers. This methodology was trialled during the first two weeks of the study. This was seen to place a heavy burden on already strict time constraints and two further PDSA cycles were undertaken. This resulted in the creation of a nine question self-administered survey completed in the waiting room recording self-reported medication adherence and perceived exposure to medication error. The questionnaire (see Appendix 3) included questions about the patient’s current ASMs, rate of forgetting to take medication, intention to adhere to ASMs, belief in effectiveness of medication, experience of ASM side-effects, feelings of epilepsy related stigma, co-morbidities and perception of being subject to prescribing, dispensing and administration errors. The questionnaire provided options to select coded responses as well facility for respondents to provide free-text comments. The questionnaire was paper based and was designed to be self-administered by patients while they were in the waiting area of the general epilepsy outpatient clinic.

2.2.2 Setting, Participants and Data Collection

This study was carried out in the Epilepsy division of the Department of Neurology, St. James’s Hospital (SJH), Dublin, Ireland between January and October 2018. There is one general epilepsy clinic per week run by the service. This clinic serves to provide chronic disease management in a population of 2,500 established PWE. A presenting sample of PWE who attended a weekly outpatient epilepsy clinic were invited to complete the questionnaire. All established PWE over the age of 18 who were prescribed ASMs and attend this clinic were eligible for inclusion in this study.

Participants were approached prior by a member of the epilepsy care team while they were in the waiting room of the outpatient clinic to their appointment. The epilepsy team member provided general information about the study, how it was intended to develop an intervention for driving improvement of medication adherence and safety, before the content of the questionnaire was explained. Where relevant, a friend/relative/carer who accompanied the patient to the clinic was asked to complete
the questionnaire on the patient’s behalf.

Information on whether the respondents unintentionally were non-adherent to their medication was determined from responses to the question ‘How often do you forget to take your medication?’. Respondents could choose between the following alternative answers to this question: ‘never’, ‘occasionally’, ‘regularly’ and ‘frequently’. Information on whether the respondents were intentionally non-adherent to ASMs was determined from responses to the question ‘Have you ever intentionally not taken your medication as prescribed?’. Respondents could answer ‘yes’ or ‘no’ to this question, and if they answered ‘yes’ they were asked to report the reasons for such non-adherence. In addition, respondents could provide comments in a free text section at the end of the questionnaire.

Information on whether respondents perceived they had been exposed to a form of medication error was determined from responses to the following question ‘As far as you are aware, have you ever been subject to any of the following medication errors: (i) Prescribing Error (Incorrect selection of drug/dose/strength/route by prescribing doctor) (ii) Dispensing Error (Incorrect drug dispensed by pharmacist) or (iii) Administration Error (Drug taken incorrectly by patient or administered improperly to patient)?’. Respondents could answer ‘yes’ or ‘no’ to these questions.

2.2.3 Data Analysis

There were eight independent variables that were tested for unintentional and intentional non-adherence: sex, age, number of current ASM medications prescribed, current perceived effectiveness of medication, previous perceived effectiveness of medication, perceived side effects of medication, experiencing stigma / embarrassment about epilepsy and presence of additional neurological co-morbidities. Each of these eight independent variables were also tested for perception of exposure to prescribing errors, dispensing errors and administration errors among participants. Unintentional and intentional non-adherence were also tested for exposure to each of
these forms of medication error i.e. is there a relationship between non-adherence to medication and exposure to medication errors?

Microsoft Excel and IBM SPSS were used to conduct data analysis. To test possible group differences, Pearson’s chi squared tests were performed. P< 0.05 is considered statistically significant. P values were subject to the Bonferroni correction where possible.

2.2.4 Ethics

This body of work, described in this chapter, was classified as a clinical audit by the SJH Research and Innovation (R&I) Office. The purpose of this body of work was to collect data surrounding perception of medication adherence and error with a view to understanding where deficits currently exist in these practices within the DML Epilepsy Service and where improvements were needed. While this body of work was not subject to a full institutional ethical board review, a clinical audit registration form detailing the reasons for choice of audit, objectives, methodology and sharing of audit results were reviewed and accepted by the SJH R&I Office. A data protection impact assessment (DPIA) describing the nature and processing of data for this audit was also reviewed and accepted by the data protection officer within the SJH R&I Office.

2.3 Results

2.3.1 Medication Adherence

During the study period, 186 PWE completed the questionnaire. 59.1% of patients reported no medication adherence issues, while 40.9% of respondents fail to adhere optimally to prescribed ASMs. The results suggested that medication adherence was more often unintentional than intentional.

28.5% of respondents self-reported that they unintentionally forget to take their medication on an occasional, regular or frequent basis. 5.9% of respondents admitted to intentional non-adherence to ASMs. 6.5% of respondents stated that they have both
unintentionally forgot and intentionally did not take their prescribed ASMs in the past (see Figure 7).

No significant (p<0.05) associations were demonstrated when a chi-squared test was used to compare whether eight different factors influenced respondents' self-reported unintentional or intentional non-adherence to ASMs (see Table 2). None of sex, age, number of ASMs prescribed, current perceived effectiveness of medication, previous perceived effectiveness of medication, perceived side effects, experiencing stigma or embarrassment about epilepsy or the presence of additional neurological conditions appeared to influence whether respondents unintentionally or intentionally non-adherent to ASM therapy.
<table>
<thead>
<tr>
<th></th>
<th>Unintentional Non-Adherence</th>
<th>Non-Adherence</th>
<th>Intentional Non-Adherence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex</td>
<td>0.267</td>
<td>0.825</td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>0.296</td>
<td>0.251</td>
<td></td>
</tr>
<tr>
<td>Number of ASMs</td>
<td>0.281</td>
<td>0.536</td>
<td></td>
</tr>
<tr>
<td>Unintentional Non-Adherence</td>
<td>-</td>
<td>0.106</td>
<td></td>
</tr>
<tr>
<td>Intentional Non-Adherence</td>
<td>0.106</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>Current perceived effectiveness of medication</td>
<td>0.057</td>
<td>0.464</td>
<td></td>
</tr>
<tr>
<td>Previous perceived effectiveness of medication</td>
<td>0.758</td>
<td>0.656</td>
<td></td>
</tr>
<tr>
<td>Side effects</td>
<td>0.356</td>
<td>1.000</td>
<td></td>
</tr>
<tr>
<td>Experiencing stigma or embarrassment about epilepsy</td>
<td>0.224</td>
<td>0.241</td>
<td></td>
</tr>
<tr>
<td>Presence of neurological co-morbidity</td>
<td>0.895</td>
<td>0.777</td>
<td></td>
</tr>
</tbody>
</table>

Table 2 - Table displaying the p value associations between eight different factors and whether respondents self-reported unintentionally or intentionally adhering to ASMs (n=186).

2.3.2 Medication Errors

Of the 186 participants, 28.5% of respondents reported a perceived medication error. Prescribing errors (18.81%) were the most common form of perceived error reported by this cohort of PWE, followed by dispensing errors (14%) then administration errors (9.15%). A small number of PWE perceived that they were subject to some combination of 2 or 3 different forms of medication error (see Figure 8).
Figure 8 - Breakdown of medication errors reported by respondents (n=186).

Significant (P<0.05) associations were seen between four factors and perception of exposure to prescribing errors; poorer perceived effectiveness of current ASM medication, experiencing stigma or embarrassment because of epilepsy, self-reported exposure to dispensing errors and self-reported exposure to administration errors. This information is summarised in Table 3.

<table>
<thead>
<tr>
<th></th>
<th>Have you ever been subject to a prescribing error?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Effectiveness of Current Medication</td>
<td>0.004</td>
</tr>
<tr>
<td>Experiencing Stigma / Embarrassment</td>
<td>0.041</td>
</tr>
<tr>
<td>Exposed to Dispensing Error</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Exposed to Administration Error</td>
<td>&lt; 0.001</td>
</tr>
</tbody>
</table>

Table 3 - Table displaying significant (p<0.05) p value associations between patient factors and whether respondents self-reported being exposed to a prescribing error (n=186).
Significant (P<0.05) associations were seen between three factors and perception of exposure to dispensing errors; intentional non-adherence to ASM medication, perception of exposure to prescribing errors and perception of exposure to dispensing errors. This information is summarised in Table 4.

<table>
<thead>
<tr>
<th></th>
<th>Have you ever been subject to a dispensing error?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intentional Non-Adherence to Medication</td>
<td>0.035</td>
</tr>
<tr>
<td>Exposed to Prescribing Error</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Exposed to Administration Error</td>
<td>0.002</td>
</tr>
</tbody>
</table>

*Table 4 - Table displaying significant (p<0.05) p value associations between patient factors and whether respondents self-reported being exposed to a dispensing error. (n=186).*

Significant (P<0.05) associations were seen between three factors and self-reported exposure to administration errors; unintentional non-adherence to ASM medication, self-reported exposure to prescribing errors and self-reported exposure to dispensing errors. This information is summarised in Table 5.

<table>
<thead>
<tr>
<th></th>
<th>Have you ever been subject to an administration error?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unintentional Non-Adherence to Medication</td>
<td>0.035</td>
</tr>
<tr>
<td>Exposed to Prescribing Error</td>
<td>&lt; 0.001</td>
</tr>
<tr>
<td>Exposed to Dispensing Error</td>
<td>0.002</td>
</tr>
</tbody>
</table>

*Table 5 - Table displaying significant (p<0.05) p value associations between patient factors and whether respondents self-reported being exposed to an administration error. (n=186).*

### 2.4 Discussion

The major findings of this study were that 40.9% of respondents to a self-administered questionnaire reported sub-optimal adherence to ASMs, 28.5% perceived that they were subject to a medication error and patients who perceive errors to be occurring are less adherent than those who don’t.

In previous studies examining the reasons for non-adherence to ASMs, ‘forgetfulness’ appeared as the main self-reported reasons for non-adherence to medication
This study is no different, with unintentional non-adherence reported by 35% of all participants compared to 12.4% of respondents who reported intentional non-adherence to medication. A recent study by Henning et al. utilised an anonymous online questionnaire to question PWE about their medication habits and found that 40% of PWE 'sometimes' or 'often' forgot to take their medication [197]. The same study reported that 30% of PWE intentionally did not follow the treatment plan with their physician. The different intentional non-adherence rates reported in this study and Henning et al.'s study could be explained by the lack of anonymity in our survey.

Previous studies examining medication adherence rates across populations of PWE have predominantly used methods such as the Morisky medication adherence scale (MMAS), medication possession ratio (MPR) and the ESMS (epilepsy self-management scale) [198–200]. Our PDSA cycle informed the researchers that a short, bespoke self-administered questionnaire including questions relating to perceived error, extending the time scale for data beyond 2 weeks was the most appropriate methodology for conducting this first pass audit. Such a tool has not been used in this population previously. The overall non-adherence rate of 41% obtained in this study via self-report lies within the non-adherence rates of 29-66% among adult PWE reported in a recent systematic review by O’Rourke and O’Brien [185].

No significant links were found between sex, age, number of medications, current perceived effectiveness of medication, previous perceived effectiveness of medication, experiencing stigma or the presence of additional neurological conditions and non-adherence to medication. This demonstrates the complexity of non-adherence to ASMs and undoubtedly there are several reasons behind a patient’s decision not to take their medication as prescribed. This points us to the idea that non-adherent behaviour is a dynamic process with many psychosocial, physical, cognitive and personal factors involved, evidence for which is provided in Smithson et al.'s 2012 study which sought to identify at risk PWE for medication non-adherence. [201] Despite the many reports of the prevalence of non-adherence and complex causation in epilepsy care, there are
few studies of interventions to address this issue. While non-adherence is problematic in all chronic conditions, one might argue that the consequences in epilepsy care may have more wide ranging physical and psychosocial consequences given the unpredictable nature of seizures.

To our knowledge, this is the first study which explores rates of perception of medication errors in a cohort of adult PWE. The number of participants who believed that they were subject to all three forms of medication error were high – 18.8% of participants perceived that they were subject to a prescribing error, 14% believed that they were subject to a dispensing error and 9.1% felt that they were subject to an administration error. As this study did not set out to measure the rate of “actual” medication error, the veracity of the PWE error perception is not known. Furthermore, it is challenging to assess and compare these rates with other studies examining medication errors across epilepsy, neurological disease or chronic disease in general given the lack of research in this area. A recent systematic review highlighted the lack of uniformity in examining medication errors and error-related adverse event rates in primary care and ambulatory settings. Across 60 different studies medication error prevalence estimates ranged from 2% to 94% [202]. We assume that there are important differences in patient perception of medication error and true and validated errors. Exploring medication diaries, reconciliation reports and pharmacy records to obtain this data was beyond the scope of this clinical audit. Nonetheless, understanding perception of medication errors is important in understanding where patients feel their service can improve, which was the aim of this project with respect to continuous quality improvement in epilepsy care.

Analysis showed that respondents who perceived exposure to one type of medication error were significantly more likely to believe they had been exposed to the other two forms too. This tells us that it is likely that respondents who believe that medication errors are occurring along their medication use process are likely to believe they are occurring at multiple stages, not solely at the prescribing, dispensing or administration
stage. The significant association between respondents perceiving current medication to be not effective and perceiving prescribing errors is interesting and suggests that ineffectiveness of ASMs could be linked to prescribing errors by clinicians. The association between intentional non-adherence to medication and perceived dispensing errors suggests a putative link between dispensing errors by pharmacists and PWE intentionally not taking their medication as prescribed. Patient perception may give rise to their belief that the prescriber or pharmacist is responsible for medication error leading to their sense of victimisation and consequent reduced compliance with ASM treatment. A next step for this research will involve developing an audit tool for monitoring adherence and error data, in addition to generating a 'true' sample of medication adherence rates through interrogation of prescription refill data and diaries. Prospectively looking at participants who reported intentional non-adherence to medication or perceived exposure to medication errors and qualitatively examining the reasons for their perception of these phenomena will also occur.

Increased accountability for medication error and safety is leading to more studies such as this one, where individual patient factors are being assessed to determine which patients are at most risk of being subject to a medication error. A number of solutions have been proposed to minimise the impact of medication errors. A systematic review of 38 studies of primary care interventions designed to reduce medication-related adverse events found that the most successful interventions included a medication review conducted by a pharmacist or another clinician [203].

The impact of medication safety education with both healthcare providers and patients on reducing medication error rates have been reviewed. It was found that educational interventions may impact on clinician adherence to prescribing guidelines [204]. Another review found that patient self-administration of medication can be seen as safer than usual care following appropriate education and preparation [205]. An eHealth solution to improve medication safety has also been reviewed. Computerized provider order entry (CPOE), a clinical decision support system is designed to alert
clinicians of inappropriate medications. In a review of 10 randomised control trials of CPOE, a reduction in medication errors was found in only half of the studies [206].

2.5 Limitations

There are a number of limitations associated with this study. Initially, it was envisaged that a mixed methods approach would be used to investigate medication adherence and medication errors in this population, similar to Smithson et al. [201]. A methodology where semi-structured interviews were conducted by clinicians during clinical appointments was trialled for a two-week period. It was seen to prolong appointments and place a burden on already strict time constraints given the large number of patients who attend the weekly clinics. This meant that a new methodology was required, leading to the design of a questionnaire.

Logistically, the questionnaire proved effective in allowing as many patients as possible to take part in the study, as it could be completed while they were seated in the waiting area of the clinic. The self-reported nature of the questionnaire was suitable for this study as it was examining what participants testify about their medication adherence and their perception of exposure to medication errors. Although the questionnaire designed specifically for this study was unvalidated, it is important to note that overall observed non-adherence rate of 41% among participants lies within the 29-66% rate for adult PWE reported in a recent systematic review by O'Rourke and O'Brien and suggests a reliability of the questionnaire instrument.

Data was collected at a specialist out-patient clinic at St. James’s Hospital, Dublin, Ireland. After a period of approximately nine months, it was found that almost all patients attending these clinics had either completed the questionnaire at a previous clinic or declined to take part. Opting to collect data from one clinical setting limited the number of potential participants in this study and led to data saturation occurring with less than 200 participants over the timescale of the project.
2.6 Conclusions
Non-adherence to ASMs by PWE likely stems from a combination of personal, medical and psychosocial issues. A number of PWE believe that errors are being made in the medication use process, particularly at the prescribing and dispensing stages. PWE who perceive that they have been subject of a medication error are significantly more likely to not-adhere to ASMs. These findings open the door to future research being conducted with PWE to evaluate their attitudes and behaviours towards epilepsy treatment and the healthcare professionals that provide it. It also suggests the urgent need to consider interventions; institutional, educational, electronic-enabled and others that might mitigate these numbers.

2.7 Acknowledgements
The authors thank all of the staff of the Dublin-Mid Leinster Epilepsy Service and all the patients who participated at St. James’s Hospital who facilitated this study taking place in their clinic.

2.8 Funding:
This study was funded by a research grant from Science Foundation Ireland (SFI) under grant number 16/RC/3948 and is co-funded under the European Regional Development Fund and by the FutureNeuro industry partners.
Chapter III - LoVE in a Time of CoVID: Clinician and Patient Experience using Telemedicine for Chronic Epilepsy Management

Jack Banks a,c, Derek Corrigan a, Roger Grogan c, Hany El-Naggar a,c, Maire White c, Elisabeth Doran d, Cara Synnott d, Mary Fitzsimons c, Norman Delanty Colin P. Doherty a,c,d

a FutureNeuro SFI Research Centre, The Royal College of Surgeons in Ireland, 123 St. Stephen’s Green, Dublin 2, Ireland.

b Academic Unit of Neurology, School of Medicine, Trinity College Dublin, Dublin 2, Ireland

c Department of Neurology, Beaumont Hospital, Dublin 9, Ireland

d Department of Neurology, St.James’s Hospital, James’s Street. Dublin 8, Ireland.

This chapter was published in journal article form in the eminent journal Epilepsy & Behavior, Volume 115 in February 2021.

3.0 Abstract

As part of our ongoing interest in patient and family centred care in epilepsy, we began, before the onset of the CoVID-19 pandemic, to evaluate the concerns and preferences of those delivering and receiving care via telemedicine. CoVID-19 arrived and acted as an unexpected experiment in nature, catalysing telemedicine’s widespread implementation across many disciplines of medicine. The arrival of CoVID-19 in Ireland gave us the opportunity to record these perceptions pre and post-CoVID. Data was extracted from the National Epilepsy Electronic Patient Record (EEPR). Power BI Analytics collated data from two epilepsy centers in Dublin. Analysis of data on reasons for using the telephone support line was conducted. A subset of patients and clinicians who attended virtual encounters over both periods were asked for their perception of telemedicine care through a mixed methods survey. Between 23rd December 2019 and
23rd March 2020 (pre-CoVID era), a total of 1180 patients were seen in 1653 clinical encounters. As part of a telemedicine pilot study, 50 of these encounters were scheduled virtual telephone appointments. 28 surveys were completed by clinicians and 18 by patients during that period. From 24th March 2020 to 24th June 2020, 1164 patients were seen in 1693 encounters of which 729 (63%) patients were seen in 748 scheduled virtual encounters. 118 clinician impressions were captured through an online survey and 75 patients or carers completed a telephone survey during the post-CoVID era. There was no backlog of appointments nor loss of care continuity forced by the pandemic. Clinicians expressed strong levels of satisfaction, but some doubted the suitability of new patients to the service or candidates for surgery receiving care via telemedicine. Patients reported positive experiences surrounding telephone appointments comparing them favorably to face-to-face encounters. The availability of a shared EEPR demonstrated no loss of care contact for patients with epilepsy. The survey showed that telemedicine is seen as an effective and satisfactory method of delivering chronic outpatient care.

3.1 Introduction.

Epilepsy is a chronic, noncommunicable disease of the brain characterised by recurrent seizures [207]. In Ireland, it is believed that up to 37,000 people suffer from epilepsy, and this number may be increasing [208]. The traditional model of chronic disease management involves episodic, reactive and hospital centric care being delivered to patients via face-to-face encounters [209]. The establishment of the Irish National Care Programme for Epilepsy (NCPE) in 2010 sought to drive clinical service improvements in Ireland through improved; patient experience, access to care and value [20,210]. At the core of the NCPE was an emphasis of delivering truly person-centered care (PCC) to people with epilepsy (PWE) nationwide, which would be achieved through continuous meaningful engagements between the health system and PWE [29,211]. In the last number of years, extensive engagements with PWE have resulted in the roll-out of nurse-led epilepsy services.
supported by a point of care, web-based national epilepsy electronic patient record (EEPR) and dedicated emergency department seizure care pathways across Ireland [44,212,213].

Telemedicine refers to the practice of medicine using technology when the clinician and patient are not in the same location [214]. It encompasses a range of information and communication technologies that support delivery of remote or long-distance clinical care such as telephone, video or email consultations [214], store and forward systems [53] and mobile health (mHealth) applications [54]. There is a growing evidence base across several conditions indicating that telemedicine has benefits in reducing cost, improving health outcomes and diagnostic accuracy [54,215–219]. When deployed correctly, telemedicine can lead to Low-cost high Value E-care (LoVE) and provides an opportunity to improve patient health service engagement choices, promote self-care and reduce face-to-face clinician contact where relevant and appropriate - all core objectives of the NCPE.

St. James's Hospital (SJH) and Beaumont Hospital (BH) are large teaching hospitals in Dublin, hosting two of the country’s largest epilepsy services. In December 2019, SJH began a pilot study to explore the provision of care through the creation of ‘virtual clinics’ and utilisation of telemedicine for chronic epilepsy management. These virtual clinics were held monthly and consisted of pre-selected PWE receiving their care via a telephone call by an advanced nurse practitioner (ANP), a specialist registrar in neurology or a consultant epileptologist. The rest of the clinics were delivered in the form of face-to-face appointments in the outpatient department (OPD) clinic.

From the end of March 2020, the coronavirus (CoVID-19) pandemic forced a rapid-reorganisation of chronic disease care delivery. Social distancing and self-isolation, introduced by governments to limit the spread of viral infection, dramatically reduced face-to-face encounters. Changes that typically would have encompassed months of planning, pilot testing and education were compressed into days [220]. CoVID-19
reached the Republic of Ireland in the spring of 2020. On 12\textsuperscript{th} March, the government shut all schools, colleges and universities, childcare facilities, and cultural institutions, and advised cancelling large gatherings. On 24\textsuperscript{th} March, almost all businesses, venues and amenities were shut. Three days later, the government banned all 'non-essential' travel outside one’s home (including visits to family and partners). Scheduled outpatient clinics were largely cancelled across the health system [221].

Both SJH and BH made the decision to facilitate as many epilepsy outpatient department (OPD) clinic appointments as possible through telephone calls. It was decided to continue the evaluation of telemedicine which began pre-CoVID in SJH and expand it across the two centres.

This project, therefore, began before the CoVID-19 era with a carefully planned implementation of a telehealth solution based on the use of a point of care electronic patient record and telephone contact in selected patients. As part of the implementation, we sought to understand the perceptions of chronic epilepsy management via telephone consultations from a clinician and patient perspective. The objective of this clinical audit was to understand the perceptions of PWE, carers and HCPs receiving and delivering chronic epilepsy care via telemedicine.

In this manuscript, an audit of the following aspects of epilepsy patient care is reported:

(1) The impact of the pandemic declaration on the mode of care for patients with epilepsy.

(2) The experience of those delivering and receiving care via telemedicine-enabled epilepsy care.

3.2 Methods

3.2.1 EEPR Data Capture and Analysis

A quantitative approach was taken to extract data from the Irish National Epilepsy Electronic Patient Record (EEPR) and assess the readiness of epilepsy clinical services
to adopt a telemedicine model in the face of CoVID-19.

The EEPR is a custom-designed, web-based point of care clinical record that is shared across geographical and institutional boundaries [222]. The EEPR has approximately 9,000 unique patient records from all over Ireland, over 100 clinician users with more than 700 encounters every month.

Power BI software (Microsoft) was used to extract quantitative data collected in the three months prior to CoVID-19 up to 23rd March 2020 and for the three months during and immediately after the society-wide lockdown to June 24th, 2020. As part of the recording in the EEPR, the encounter type is recorded indicating how that encounter took place, such as in the outpatient clinic or as part of a scheduled virtual encounter. Quantitative data showing the overall numbers of encounters by encounter type was extracted and analysed for both reporting periods, pre and post- CoVID.

3.2.2. Clinical Audit – Data Capture

3.2.2.1 Survey Tools

Both quantitative and qualitative approaches were taken during this evaluation to understand the experience of clinicians and patients delivering and receiving epilepsy care via telemedicine.

Patients attending ‘pre-CoVID virtual clinics’ at SJH were identified by the EEPR and a subset were surveyed by a researcher (JB) from 23rd December 2019 to 23rd March 2020 in order to capture the experience of clinicians and patients receiving their care in this manner.

We sought to capture the experience of clinicians and patients in a short and effective manner using semi-structured surveys. In order to minimise disruption to clinical appointments and ease the burden of clinicians and patients, we limited the survey to one page. As a tool specifically existing for epilepsy management via telemedicine does not exist, questions from the Telehealth Satisfaction Questionnaire [223] and
Telemedicine Satisfaction Questionnaire [224] were adapted to create clinician and patient surveys for use in this study (Table 6). Uniquely, we also collected qualitative data from epilepsy patients receiving care through telemedicine, which had not been reported in the literature previously.

<table>
<thead>
<tr>
<th>Clinician Questionnaire</th>
<th>Patient Questionnaire</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. With whom did you conduct this telephone appointment?</td>
<td>Do you typically have to take time off work, school or college to attend a face-to-face appointment in the hospital?</td>
</tr>
<tr>
<td>2. Did you experience any technical difficulties during this encounter?</td>
<td>How do you typically travel to face-to-face appointments in the hospital?</td>
</tr>
<tr>
<td>3. Did you feel this patient was appropriate for a telephone appointment?</td>
<td>How was your experience interacting with the clinician during this appointment?</td>
</tr>
<tr>
<td>4. Are you happy for this patient to continue their routine care virtually?</td>
<td>How was your overall experience having this appointment over the phone?</td>
</tr>
<tr>
<td>5. Did you discharge this patient?</td>
<td>Do you have any other thoughts or opinions surrounding telephone appointments for epilepsy care?</td>
</tr>
</tbody>
</table>

Table 6 - Questions common to the survey tools used to collect data from clinicians and patients both pre- and post-CoVID

3.2.2.2 Pre-CoVID Quantitative Data Capture

In the pre-CoVID audit, the researcher (JB) placed paper questionnaires on the desks of the clinicians working at the virtual clinic. Following each appointment conducted over the phone they were requested to complete it. The researcher collected the completed questionnaires 1-2 days after the clinic from the administrative staff and manually inputted this data on Microsoft Excel. The researcher then contacted all patients who had an appointment via telephone. If the patient was busy and not in a position to speak on the phone, they were called at a later time. Telephone survey data was recorded on Microsoft Excel.

3.2.2.3 Post-CoVID Quantitative Data Capture

In the post-CoVID era, the methodology of collecting data from clinicians and patients needed to be adapted to facilitate social distancing. The clinician feedback, therefore, would be collected through the Qualtrics online survey tool. Again, patient contact details were gathered from the National EEPR. These patients were contacted via telephone within 48 hours of the virtual encounter, and if they agreed they would
complete a survey over the telephone. In the same manner as pre-CoVID, patients were called at a later time if the timing of the initial call did not suit them.

3.2.2.4 Pre- and Post-CoVID Qualitative Data Capture

At the end of each telephone survey with patient participants, we collected qualitative impressions from patients about the use of telemedicine for receiving epilepsy care. Participants were asked if they had any additional thoughts or impressions about telemedicine not expressed in the previous survey questions. This oral data was transcribed verbatim by the researcher.

3.2.5 Data Analysis

Survey data collected from clinicians pre-CoVID was manually inputted and analysed on Microsoft Excel. Post-CoVID, clinician data was exported from Qualtrics to Microsoft Excel to facilitate data analysis.

Patient data collected via telephone surveys was inputted and analysed on Microsoft Excel. Qualitative impressions recorded by patients at the end of surveys were coded and common codes were organised into themes surrounding experience of telemedicine.

3.2.6 Ethics

This body of work, described in this chapter, was classified as a Clinical Audit by the SJH Research & Innovation Office and the Beaumont Hospital (BH) Clinical Audit Department. The purpose of this body of work was to collect data surrounding perception of telemedicine with a view to understanding where deficits currently exist in this practice, in a similar fashion to the clinical audit described in Chapter II. While this body of work was not subject to a full institutional ethical board review, a clinical audit registration form detailing the reasons for choice of audit, objectives, methodology and sharing of audit results were reviewed and accepted by both the SJH R&I Office and the BH Clinical Audit Department. DPIA’s describing the nature and processing of data for this audit were also reviewed and accepted by the data
protection officers within the SJH R&I Office and BH's audit office.

3.3 Results

3.3.1 EEPR Data Analysis

Quantitative data for all encounters from 23rd December 2019 to 23rd March 2020 were compared to data from encounters from 24th March 2020 to 24th June 2020. Despite the abruptness of the deployment of telehealth, the numbers show that there was practically no loss of access to scheduled expert opinion and care between the pre and post-CoVID eras.

Pre-CoVID, 1180 patients were seen across 1653 encounters. Post-CoVID, 1164 patients were seen across 1693 encounters. In both instances, some patients had more than one encounter during these periods which explains the greater number of encounters relative to the number of patients.

Figures 9 and 10 show the massive increase in virtual encounters between the two periods without the loss of continuity of care. Furthermore, 433 patients had unscheduled telephone encounters using dedicated helpline numbers pre-CoVID compared to 488 patients post-COVID, indicating no loss of access to unscheduled care support. It should be noted that four clinicians in one of the centers (SJH) contracted the virus and four other clinicians were sent into self-isolation due to contact tracing for 14 days. For that period, none of the epilepsy clinic staff were at work. Similarly, across the two centres, four nurses who had intensive care unit (ICU) experience were also redeployed to manage the surge in admissions during that time. Despite this, there was no accrual of missed encounters, as the staff were able to deliver care from their homes. Figures 11 and 12 show data pertaining to the reasons for the use of unscheduled telephone and email services between the pre and post-CoVID eras. The overall concerns of patients using the advice lines did not dramatically differ. This indicates that the CoVID pandemic did not substantially change the requirement for expert advice.
Figure 9 - Breakdown of Encounters by Encounter Type in BH and SIH from 23rd December 2019 to 23rd March 2020.

Figure 10 - Breakdown of Encounters by Encounter Type in BH and SIH from 24th March 2020 to 24th June 2020.
3.3.2 Survey of Clinician and Patient Experience

3.3.2.1. Clinician Experience

From 23rd December 2020 to 23rd March 2020, 50 scheduled telephone encounters took place. 28 questionnaires were completed by 8 clinicians following these telephone encounters. From 24th March 2020 to 24th June 2020, 729 scheduled telephone encounters took place. 118 questionnaires were completed by 13 clinicians.
following these telephone encounters during this period. Clinicians did not repeat the survey if they had previously completed a virtual telephone appointment with the same patient.

Pre-CoVID, in 52% of telephone encounters clinicians spoke directly to patients. In the other 48% of telephone encounters, clinicians spoke to either a family member or a carer. Post-CoVID, 77% of telephone encounters were directly with patients and 23% were with family members or carers. Clinicians reported experiencing technical difficulties in 24% of encounters pre-CoVID and 8% of encounters post-CoVID. The most common difficulties cited were poor telephone signal and disconnections occurring during the appointments.

Clinicians largely felt that the patients they conducted telemedicine appointments with were appropriate for this type of care both pre- and post-CoVID. Results indicated that clinicians were happy for the majority of the patients to continue their care virtually. These results are illustrated in Figure 13.
3.3.2.2. Quantitative Data surrounding Patient Experience

Pre-CoVID, 18 patients who had a virtual appointment were followed up with and they or a family member or carer completed a survey via telephone to record their experience. Post-CoVID, 75 patients or their family members or carers completed a
survey via telephone. In both the pre- and post-CoVID populations, no patient who answered the phone call from the researcher declined to take part in the survey. No patient completed the survey with the researcher more than once.

Pre-CoVID, 44% of respondents to the telephone survey stated that they needed to take time off work, school or college to attend a face-to-face appointment. Post-CoVID, 55% of respondents stated they need to take time off to attend appointments.

Patients and carers reported similarly positive responses pre- and post-CoVID with regard to interaction with their clinician and overall experience receiving their care via telephone. These results are illustrated in Figure 14.
3.3.2.3 Qualitative Data surrounding Patient Experience

Patients expressed a range of responses, both positive and negative, in response to the question 'Do you have any other thoughts or opinions surrounding telephone
appointments for epilepsy care?’ both pre- and post-CoVID.

3.3.2.3.1 Similarities to Face-to-Face Appointments

Many patients remarked at how similar the telephone call was to a face-to-face appointment. A number of patients stated that the nature and conversation of the virtual appointment was the same as previous face-to-face encounters.

P70 – ‘I got the exact same treatment as I would if I had gone in to BH’

P43 – ‘Unless you need a test done, it’s the same as sitting across from them really’

P48 - ‘There’s no physical contact on any of my appointments anyway so the phone is fine’

3.3.2.3.2 Convenience

Many patients highlighted the convenience of not having to travel to the hospital for an appointment that can often be quite brief.

P13 - ‘I was quite impressed by it. There was no waiting around for a ten-minute appointment’

The convenience of not having to travel to the hospital for an appointment was highlighted in particular by carers of patients who have intellectual or physical disabilities.

P69 - ‘Going to the hospital is usually horrendous. Waiting areas, toilet facilities and all that. This is so great’

3.3.2.3.3 Stability of Condition

The large number of respondents stated that their willingness to engage with telemedicine in the future would depend on the stability of their condition. Many patients expressed that they would be happy to continue with telemedicine for a routine ‘check-up’ with clinicians if their seizure frequency remains the same or if epilepsy presents no new problems in their lives.
P47 - ‘If it’s a routine check-up, there’s no need for me to be in wasting the clinician or my time’

P42 - ‘When there’s nothing urgent this is a great way of doing things’

However, a number of respondents stated that if their seizure frequency increased or their epilepsy began to impact their lives in a new manner, they would rather be seen in person rather than virtually.

P36 - ‘If someone is having active seizures, a phone call might not be the best idea’

P75 - ‘If everything is going smoothly then phone is grand. If you’ve a problem you’d want to be seen face-to-face though’.

3.3.2.3.4 Video Appointments

Many respondents reported that they would like to see the clinician’s face in future virtual appointments through the use of video-conferencing software.

P51 - ‘It would be great if you could see the clinician’s face, I’d love to do a video call’

P1 - ‘Facetime or Zoom would be better than the phone call’

3.3.2.3.5 Concentration and Appointment Flow

Some patients expressed that this new style of appointment required more concentration and preparation compared to face-to-face appointments.

P66 - ‘You’ve to think more on your feet… You’ve to do a bit more thinking than if you were there in person’

P8 - ‘Questions come up more easily (In face-to-face appointments). It’s easier to develop conversation… If you’re doing it on the phone have your questions written down beforehand’

3.3.2.3.6 Preference for Face to Face

Other patients stated that telemedicine was something they did not wish to utilise in
the future, and they would prefer face-to-face.

*P15 - ’This was not very satisfactory to be honest. I’d prefer face-to-face’*

*P35 - ’If I’d a choice, I’d prefer face-to-face. I feel more comfortable chatting in person’*

*P58 - ’I’m not great at talking on the phone I don’t think. I can explain things more in depth in-person. I like getting out of the house and going to the hospital for the appointments’*

3.4 Discussion

The predominantly face-to-face model of outpatient follow up for epilepsy care has existed since the 19th century [17]. In-person outpatient care often fail to reliably provide responsive care when patients need intervention [30]. Despite this, telemedicine has not been widely used to provide chronic epilepsy care for patients. Clinicians and patients persisted with onsite appointments in spite of the potential feasibility of remote visits, especially for stable chronic patients [225,226].

The CoVID-19 pandemic has forced health administrators and clinicians to adopt and implement telemedicine in a short space of time to continue caring for patients during society-wide travel restrictions. It is already clear that patients are apprehensive about the risk of coronavirus exposure and a study on severe psychological distress conducted in China during the initial CoVID-19 outbreak revealed that PWE showed higher psychological distress scores than otherwise healthy individuals [227]. Furthermore, epilepsy tends to be more severe in patients with intellectual disability whose daily routines have been severely disrupted by the pandemic. A hastily or poorly implemented telehealth system could add to these difficulties.

In this study, quantitative data garnered from the National EEPR shows that the switch to telehealth coincided with a nationwide social lockdown on the 24th of March 2020. The switch was comprehensive, and the data reveals that the two large epilepsy services in large urban centers caring for more than 7,000 epilepsy patients managed
to avoid any backlog, seeing almost the same number of cases in the 3 months up to the end of March compared to the 3 months after. The agility of the services was in our view largely to do with the dynamic capability of the EEPR which was able to enable and facilitate the switch with its point of care capability and remote access.

The other finding from the quantitative data is that the use of telephone and email support services showed that in the number of enquiries increased slightly from 433 to 488 but in general, the concerns of epilepsy patients were only marginally different comparing pre- and post- CoVID periods. This suggests that there may not have been a significant increase in care requirement for epilepsy patients during the pandemic, although this is being analysed separately [61].

Studies which compare the experiences and outcomes of telemedicine vs face-to-face visits for neurological conditions have consistently displayed positive results for telemedicine [52,228,229]. This audit is unique in that not only does it provide quantitative data reporting positive experience, it provides qualitative insights into what aspects of telephone appointments patients did and did not enjoy. To our knowledge, this is the first time such qualitative data has been reported.

Survey data collected, both pre- and post-CoVID, displayed high levels of satisfaction with telemedicine from both a clinician and patient perspective. Importantly, patients who received their care via telemedicine pre-CoVID were carefully selected for these types of appointments based on the impression clinicians had of their condition from previous appointment history. Post-CoVID, all patients, not just pre-selected ones, were subject to telemedicine care – which raises concerns about the suitability of unselected cohorts, however the high levels of clinician and patient satisfaction seen in both cohorts indicate that telemedicine is a viable process for all, not just a select few who clinicians believe are suitable for it.

Interestingly clinicians were more likely to express concerns about the suitability of certain patients for using telemedicine for their care going forward than the patients
themselves (25% vs 9%). Clinicians described concerns that patients experiencing their first clinic visit; those with unclear seizure frequencies and those who were surgical candidates are not appropriate for receiving care via telemedicine. While patients in general were more predisposed to telehealth, some expressed more concern that if their condition were to worsen, they would prefer to receive care in person than over the phone.

It is important to implement the learnings of epilepsy care delivery during this pandemic in a post-CoVID world. A number of publication and policy documents have stated that we must maintain remote models of care for patients with chronic conditions and not return to 'business as usual' once this pandemic ends [44,218,220,226,230,231]. Our results, in particular the qualitative data garnered from patients indicate that a majority of patients with epilepsy are happy to continue their care virtually if their condition remains stable or no new issues arise between appointments. If structures were to be created which allow patients or their carers to submit their preference for a telemedicine or face-to-face visit in advance of an outpatient appointment, this would likely decrease the number of patients who are unnecessarily travelling to hospitals to receive their epilepsy care. Our group has recently reported the introduction of a patient portal which has the capability to indicate these preferences and even alter the notion of scheduled visits [44]. The use of video consultations has become quite common during CoVID across many disciplines of medicine [232]. The utilisation of video as opposed to telephone could provide additional visual cues to clinicians and therapeutic presence to patients, which could allow more difficult consultations to take place remotely [232].

3.5 Limitations
The number of completed surveys by clinicians and patients in the pre-CoVID era is low. Data was collected following 50 clinical encounters from clinicians and 18 patients completed surveys via telephone over a 3-month period from December 2019 to March 2020. During this period of data collection, clinicians were inconsistent in
completing surveys following each appointment and patients proved difficult to reach in the days following the clinic. Nonetheless, we feel it is important to include the pre-CoVID data because it serves to illustrate the similarities in clinician and patient experience of telemedicine from an era when it was voluntarily being employed for selected patients to when it was employed out of necessity for continuing to provide care to all patients during a pandemic. It is also understood that the eligible participants for this audit were those who completed a telephone appointment with a clinician. This excluded those who were unable to connect with their clinician or those who did not have the physical or psychological capability to have a successful appointment via telephone. The exclusion of these individuals from the sample may alter the satisfaction rates with telemedicine described in this audit.

3.6 Conclusion
The switch to telemedicine during the CoVID pandemic in the Irish Epilepsy Service, as in many centers around the world, was rapid and comprehensive. The availability of a shared agile web based EEPR allowed us to demonstrate no loss of care contact for this vulnerable group across two large urban epilepsy centers. A mixed methods survey allowed us to demonstrate that telemedicine is seen to be an effective and satisfactory method of delivering chronic outpatient care. This was true regardless of the CoVID-19 pandemic indicating the long-term potential of telemedicine as a method of care delivery.

3.7 Acknowledgements
The authors would like to thank the clinicians working in SJH and BH Epilepsy Departments for facilitating this audit of care delivery and experience. The authors would also like to thank the patients, family members and carers who were contacted and completed the survey as part of this audit.

3.8 Funding
This publication has emanated from research supported in part by a
research grant from Science Foundation Ireland (SFI) under Grant Number 16/RC/3948 and co-funded under the European Regional Development Fund and by FutureNeuro industry partners.
Chapter IV - Research Design and Methodology

4.0 Introduction

The purpose of this chapter is to detail the rationale for employing qualitative research methods in this body of work. This chapter will describe the rationale for employing a qualitative methodology, critically evaluate existing qualitative methods and describe the final methodologies employed in the studies outlined in Chapters V and VI.

4.1 Research Design

Literature in the fields of self-management behaviours and eHealth have primarily employed quantitative methodologies, such as those used in Chapters II and III, when researching attitudes and behaviours of participants towards these concepts. Evidence-based practice is the dominant treatment philosophy within medicine and is based largely on a tradition of quantitative methods and their resulting data. This has meant that qualitative or mixed methods are often overlooked in the design of studies in the field [233]. Qualitative research starts from a fundamentally different set of beliefs - or paradigms - than those that underpin quantitative research. Quantitative research is based on positivist beliefs that there is a singular reality that can be discovered with the appropriate experimental methods. Post-positivist researchers agree with the positivist paradigm, but believe that environmental and individual differences, such as the learning culture or the learners’ capacity to learn and influence this reality, and that these differences are important. Constructivist researchers believe that there is no single reality, but that the researcher elicits participants’ views of reality. Qualitative research generally draws on post-positivist or constructivist beliefs [234].

Researchers select designs based on considerations such as the audiences’ familiarity with one approach or another, the researchers’ training and experiences with different forms of qualitative designs, and the researchers’ and departments’ partiality to one approach or the other [235]. Also involved in the selection are researchers’ comfort
levels with structure, writing in a more literary or scientific way and the final written 'product' that the design type produces [235]. When researching phenomena and their meaning to participants, qualitative methods are often more favourable than quantitative [236]. It has been noted that utilising qualitative research techniques enables the clarification of meanings that are not experimentally captured using quantitative tools [237]. This study was particularly interested in what it is like for participants to experience a certain phenomenon i.e. living with epilepsy, caring for someone with epilepsy or providing epilepsy care and what this experience means to them. In health research, qualitative methods provide an excellent means of revealing the 'lived experience' of participants – lived experience meaning a personal, self-reflexive awareness [237][238]. Traditional quantitative research has been criticised previously for failing to capture the impact of epilepsy on the lives of patients and their families, focusing primarily on quality-of-life issues and generic health surveys [239]. During data collection for Chapter II’s clinical audit of perceptions surrounding medication adherence and error and Chapter III’s clinical audit of perceptions surrounding telemedicine, the PhD researcher felt that the number of variables at patient, healthcare provider and wider system levels would lend themselves well to be analysed in a more open-ended approach rather than answering survey questions or interrogating hospital or clinical databases. It was concluded that adopting a qualitative approach in designing the study would enable participants to give a fuller, richer account of their experiences with self-management and digital tools for epilepsy care rather than a quantitative instrument which would be less flexible in probing this area of interest. A summary of popular qualitative methodologies utilised in health research is presented in Table 7.
<table>
<thead>
<tr>
<th><strong>Type of problem best suited for</strong></th>
<th>Ethnography</th>
<th>Grounded Theory</th>
<th>Phenomenology</th>
<th>Case Study</th>
<th>Narrative Research</th>
</tr>
</thead>
<tbody>
<tr>
<td>Studying a specific group of people about a specific topic and drawing conclusions only about what is studied.</td>
<td>When no theory exists, or existing theories are inadequate.</td>
<td>When the researcher seeks to understand the lived experiences of people about a phenomenon.</td>
<td>When the researcher has a case bounded by time / place that can inform a problem.</td>
<td>When detailed stories help understand a problem.</td>
<td></td>
</tr>
<tr>
<td><strong>Unit of analysis</strong></td>
<td>Individuals who form a part of a group or culture,</td>
<td>A process, action or interaction involving many individuals.</td>
<td>Several individuals who have shared the experience.</td>
<td>An event, programme, or activity, or more than one individual.</td>
<td>One or more individuals.</td>
</tr>
<tr>
<td><strong>Data collection</strong></td>
<td>Interviews, participant observation and fieldnotes.</td>
<td>Interviews</td>
<td>Primarily interviews but documents, observations and art can all be used.</td>
<td>Multiple forms, interviews, observations, documents and artefacts.</td>
<td>Interviews and documents.</td>
</tr>
<tr>
<td><strong>Data analysis strategies</strong></td>
<td>Thematic analysis (TA).</td>
<td>Open coding</td>
<td>Bracketing</td>
<td>Description of case and themes, as well as cross-case themes.</td>
<td>Chronology, elements of a story, restorying.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Axial coding</td>
<td>Statements</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Selective coding</td>
<td>Themes</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Textual description</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Structural description</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Essence of phenomenon</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Research outcomes</strong></td>
<td>Understanding of attitudes and behaviours of group under study.</td>
<td>General explanation of a process, action or interaction shaped by views of a large number of participants.</td>
<td>Insight into how a given person, in a given context, makes sense of a given phenomenon.</td>
<td>Interpretation of meaning and lessons learned from cases.</td>
<td>Chronological ordering of the meaning of stories collected.</td>
</tr>
</tbody>
</table>

*Table 7 - Summary of qualitative research approaches used in health services research.*
The above approaches have been utilised in previous research studies investigating the lived experiences of PWE, their families and HCPs [101,240–242].

Qualitative research methods were deemed most suitable for this research study, as it sought to scratch beneath the surface about patient, carer and clinician perceptions and attitudes about epilepsy care, their thoughts about epilepsy self-management the challenges they face and the opportunities they perceive as existing. It was also considered important to listen to the experiences of the family members and carers of PWE, as well as HCPs providing specialist epilepsy care. This would allow a picture to be painted of the current ecosystem of epilepsy care and where epilepsy self-management and digital support tools fit into this. While the literature review highlighted several studies relating to the use of eHealth in managing epilepsy, the relevance of an exploratory and inductive study into this area cannot be doubted. This body of work sought to reveal insights into how each of these populations approach epilepsy self-management to identify where challenges and opportunities lie. The aims of this portion of the PhD study were to understand challenges faced by PWE, their carers, family members and HCPs in relation to epilepsy self-management and using digital tools to facilitate this management and to ideate solutions to these identified challenges.

4.2 Personal Characteristics and Reflexivity

Jack Banks (JB), the PhD researcher, conducted all of the data collection associated with this study.

As the primary individual responsible for gathering and analysing data for this study, JB’s background and assumptions informed and shaped the process. According to Denzin and Lincoln [260], reflexivity refers to a process by which ‘researchers are obliged to delineate clearly the interactions which have occurred among themselves, their methodologies, and the settings and actors studied’. Murphy et al. [261] stated that: ‘Qualitative research calls for a level of self-conscious reflection upon the ways
in which the findings of research are inevitably shaped by the research process itself and analysis which takes such factors into account’. Reflexivity is focused on making explicit and transparent the effect of the researcher, methodology and tools of data collection on the process of the research and the research findings [252]. This focus contrasts with quantitative research, where efforts are made to minimise or eradicate the effects of the researcher on the research [261]. Many qualitative researchers question the extent to which the latter is truly achievable. Although rules and principles exist surrounding the design of research, individuals process and synthesise information in different ways. Furthermore, we are imbued with ideologies, values and belief systems that are not necessarily salient to our thinking and may be difficult to deconstruct. The aim of reflexivity is to acknowledge this influence in a transparent fashion. This is of particular importance in focused ethnographies, particularly for a researcher who is familiar with, or who may have personal experience of, the culture being studied [261]. Reflexivity will allow the researcher to establish the validity of the phenomena being studied and that it is not just an expression of his or her ideology [262].

JB was a full time PhD researcher at the time of the study in Trinity College Dublin. JB identifies as male and uses the pronouns he/him. Prior to the commencement of this PhD project, JB had no prior qualitative research experience. JB received training in qualitative research methods from members of the Consulting Department of S3 Connected Health, a small to medium sized medical technology enterprise based in Leopardstown, Dublin 18. S3 Connected Health provided funding for a proportion of this PhD research under a targeted project within the Science Foundation Ireland (SFI) FutureNeuro research centre for rare and chronic neurological disease. JB received mentorship from members of S3’s Consulting Department with expertise in qualitative research and behavioural science. JB also completed a taught module in Medical Anthropology from Maynooth University prior to the commencement of data collection. Through this mentorship and coursework, JB became familiar with various
qualitative research methodologies.

JB was primarily based in the Trinity Centre for Health Sciences at St. James's Hospital during his PhD. JB was familiar to all the staff working within the DML Service since January 2018, when the audit assessing perception of medication adherence and error (as described in Chapter III) commenced. Consequently, JB had existing relationships for almost two years with all the staff interviewed as part of this study. JB attended weekly operations team-meetings, presented at journal clubs, travelled to conferences, and ate lunch with the doctors, nurses, and dietitians of the DML Service daily. Through each of these encounters with staff working in the Epilepsy Service, it is not unreasonable to think that their opinions regarding epilepsy care elicited during team-meetings or conversations did not influence JB’s impressions of challenges which exist in providing care to PWE. However, the frequent interaction with the DML Service’s staff enabled a strong rapport to be built between JB and staff. This proved advantageous in that it enabled thorough interviews and focus groups to be conducted where participants felt comfortable in JB’s presence and could discuss the topics of interest at ease. JB’s physical presence among the DML team during this PhD project allowed him to develop intuitions regarding the culture within the service and conceptualise the qualitative data findings in the context of what he had witnessed.

Some of the PWE and carers who took part in this qualitative study had previously met JB when he assisted with a research project being conducted in the RCSI in the summer of 2019. However, each interview was the first time that JB had a one-to-one conversation with any of the participants in these populations. The participants were aware that JB was completing this body of work in fulfilment of a PhD programme which involved researching epilepsy self-management and using eHealth tools. When recruitment of participants for the first phase was taking place, JB outlined to potential participants that there would be two qualitative methodologies employed, interviews and focus groups, that they would be invited to and they could take part in one, both, or neither if they did not wish to do so. Participants were informed at the initial
recruitment stage that the focus group sessions served the purpose of generating ideas about problems experienced by PWE could be solved.

4.3 Ethnography and Focused Ethnography

The term 'ethnography' is derived from the Greek word 'ethnos' meaning nation [243]. It is a mode of social research typified by inductive reasoning. Leung describes ethnography as 'a social research method occurring in natural settings characterised by learning the culture of the group under study and experiencing their way of life before attempting to derive explanations of their attitudes or behaviour' [244]. Ethnography is 'the work of describing culture' using 'a process of learning about people by learning from them'. Ethnographers essentially study situations in real time, thus as they occur in their natural setting, to gain an in-depth perspective. What distinguishes ethnography from other qualitative research genres and makes it valuable for researching healthcare issues and makes it valuable for researching healthcare issues, is its link between the macro and the micro, thus between everyday interactions and wider cultural formations through its emphasis on context (Savage, 2006).

'Classical' ethnographic methods are those that ethnographers have traditionally used, such as carrying out fieldwork and living in the communities of their hosts, observing activities of interest, recording fieldnotes and observations, participating in activities during observations (participant observation), and carrying out various forms of ethnographic interviewing. Other methods that anthropologists have traditionally used include the physical mapping of the study setting, conducting household censuses and genealogies, assessing network ties, and using audio/visual methods [245]. The defining features of 'classical' ethnographies based on LeCompte and Schensul characteristics of ethnographic research [246] are listed in Table 8.
Carried out in a natural setting, not in a laboratory.

Involves intimate, face to face interaction with participants.

Presents an accurate reflection of participant perspectives and behaviours.

Utilises inductive, interactive and recursive data collection to build local cultural theories.

Uses both qualitative and quantitative data.

Frames all human behaviour within a socio-political and historical context

Uses the concept of culture as a lens through which to interpret study results.

| Table 8 - LeCompte and Schensul’s defining characteristics of ethnography |

Ethnography is not used for developing generalised conclusions, but rather studying a data-specific group of people regarding a specific topic and drawing conclusions only about what is studied [247]. This methodology involves relative submersion into the setting to be studied, and is an appropriate methodology for a wide variety of research topics within healthcare and medical education. While, to some extent, ethnography has been applied in healthcare settings and in the medical education environment, many are of the opinion that there is a general lack of research employing this methodology itself or ways in which the method may be applied [233,244]. Getting to the root issues about patient care rather than tracking behaviour leads to real solutions, rather than a trial and error process. Undoubtedly, cultural factors continue to be a major factor in the delivery of healthcare. Patients make decisions through this lens, creating a dynamic in the healthcare system with a wide variance of options for the various cultures served [233]. Through ethnography, behaviours are understood and used to treat the patient through means that fit the patient [248].

Some limitations are associated with an ethnographic approach. Ethnography is laborious and detailed in the collection of data. The time required being involved in participant observation and conducting long interviews greatly limits the sample size. When researching a certain culture, the results cannot necessarily be generalised to other populations. Because the results are based on the cultural responses, the outcome of the study cannot be applied beyond where the study was conducted. The
interpretation of the cultural experience will vary among researchers. There is not a list of answers from which to choose, but rather the investigator makes, interprets, and categorises the notes made. The entire project is subject to the processes and interpretations developed by the researcher and the research team.

Nonetheless, it was decided that an ethnographic approach most suited the needs for studying attitudes and behaviours towards self-management and eHealth within a cohort of PWE, carers and HCPs that form a part of the ecosystem of epilepsy care in Ireland. However, instead of using a classical ethnographic approach, this research adopted the form of a ‘focused ethnography’ - an applied research methodology that has been widely used in the investigation of fields specific to contemporary society which is socially and culturally highly differentiated and fragmented [249]. It is particularly useful in evaluating or eliciting information on a special topic or shared experience [249]. A focused ethnography is also of particular use to health researchers who emphasise a distinct issue, situation or ‘problem within a specific context among a small group of people’ living in a bigger society [250]. Focused ethnographies may target the shared features of individuals in groups, so that they can focus on common behaviours and experiences [251]. Because of its nature, focused ethnography allows the researcher to better understand the complexities surrounding issues from the participants’ perspectives (‘emic’ view) while bringing the outsiders framework to the study (‘etic view’) [250].

The main features of focused ethnographies as described by Muecke [255] are listed in Table 9. Focused ethnography is an applied and pragmatic form of ethnography that differs from other ethnographic forms in that it tends to explore only one particular problem or topic and has a focused field of enquiry. Compared to a ‘classical’ ethnographic approach, it involves shorter term and targeted data collection in which the visits to the field are tailored to a particular timeframe or events so that relevant results can be obtained. Focused ethnographies are very suitable for healthcare research as they can be pragmatic and efficient ways to capture data on a specific topic
of importance to clinical specialties and determine ways to improve care and care processes [252].

<table>
<thead>
<tr>
<th>Problem-focused and context specific</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus on a discrete community or organisation or social phenomena.</td>
</tr>
<tr>
<td>Conceptual orientation of a single researcher.</td>
</tr>
<tr>
<td>Involvement of a limited number of participants.</td>
</tr>
<tr>
<td>Participants usually hold specific knowledge.</td>
</tr>
<tr>
<td>Used in academia as well as for development in healthcare services.</td>
</tr>
</tbody>
</table>

*Table 9 - Main features of focused ethnographies as described by Muecke*

4.4 Data Collection

4.4.1 Semi Structured Interviews

For this focused ethnography, the first qualitative methodology employed were semi-structured interviews. These were conducted with participants with the aim of elucidating the challenges participants perceive as existing towards epilepsy self-management and using eHealth tools. Interviews are ways of listening to and gaining an understanding of people’s stories [256]. Stories have been the way people have made meaning of their experiences throughout recorded history and they provide a context for their behaviour [257]. Interviews allow interviewees to express their viewpoint and the researcher can adopt the line of questioning to explore topics which emerge from the participant’s responses – an approach that is not possible with quantitative methods such as surveys, for example [256]. The semi-structured interview allowed the agenda to be relatively set, but allowed room for the interviewee to explore tangential areas that their train of thought produced [256][258].

Observation and participation, typically regarded as the characteristic features of the ethnographic approach [253], were not utilised. With the application of ‘new’ ethnographic methods such as focused ethnography in unique settings, researchers
have become interested in particular questions among groups that may already be familiar to them and that may differ from the bounded, foreign cultural groups of interest to traditional ethnographers [253]. With researchers conducting focused ethnographies more commonly focusing on specific issues that are experienced by individuals who do not necessarily live in the same area, the fieldwork customary in conventional ethnography is not considered a necessity [252]. Despite methodological adaptations such as the removal of observation that make it possible to use ethnography in new ways, the method’s fundamental purpose - to understand and describe culture - has not changed. As Wolcott states in the book, ‘Ethnography: A Way of Seeing’, ‘In the end, it’s not the data collection techniques that make a study ethnographic; it’s the intent of the research that legitimises the use of the label’ [254]. As this focused ethnography had pre-selected topics of enquiry - epilepsy self-management and eHealth - interviews and focus groups with participants were structured around these topics. Collecting ethnographic data via interviews and focus groups for this focused ethnography was deemed sufficient to reveal the experiences of patient and carer self-management behaviour and impressions of work and professional culture from a HCP perspective.

4.4.2 Focus Groups

The second qualitative methodology employed in this study were focus groups. This second phase of qualitative research wished to bring participants who took part in a semi-structured interview together in an environment where they could collaborate to ideate solutions about how epilepsy care could change to facilitate a greater degree of self-management and use of eHealth tools. It was decided that focus group discussions would be an appropriate method to facilitate collaboration and ideation among participants.

Focus groups are a well-established method for collecting data to explore participants’ opinions, experiences and perspectives [296]. The hallmark of focus groups is to produce data and insights from a group interaction that would be less pronounced in
an interview setting [297].

Focus group discussion is a technique where a researcher assembles a group of individuals to discuss a specific topic, aiming to draw from the complex personal experiences, beliefs, perceptions and attitudes of the participants through a moderated interaction [298–302]. The technique emerged as a qualitative data collection approach and a bridging strategy for scientific research and local knowledge [298]. Focus-group discussion is perceived to be a ‘cost-effective’ and ‘promising alternative’ in participatory research, offering a platform for different paradigms and worldviews [302,303] Sociologists and psychologists have used the method since the 1940’s [304,305]. However, its popularity and application has since grown across a wide range of disciplines including education [306], communication and media studies [307] sociology [302] feminist research [308] and marketing research [309]. Focus groups have been shown to be an effective method for exploring people’s opinions and experiences regarding illness and healthcare, both from a patient and provider perspective [310–313].

Focus groups have previously been utilised successfully to explore issues surrounding epilepsy and provide unique insights into the shared experiences of PWE [239,314–317]. As the aim of this second portion of the research was to ideate solutions to perceived barriers existing for self-management and eHealth, focus groups were preferred to further one-to-one research with participants. In focus groups, it was thought that participants might provide more data when given the opportunity to hear others’ perspectives and stories, add their own stories and perspectives in agreement or disagreement and share additional topics on hearing other participants’ stories, building onto what they would have thought of in an individual interaction with a researcher [239,318].
4.5 Participant Selection

4.5.1. Semi-Structured Interviews

Purposive sampling was undertaken. In ethnographic terms, all of the participants would essentially come from the similar subculture and would be having specific experiences of interest to the researcher [243]. As is the case with sampling in the majority of qualitative research studies, the sample size was not determined by the need to ensure generalisability, but by a desire to investigate fully the chosen topic and provide information rich data [266]. A sample size of 30 was estimated to achieve data saturation and maximum phenomena variation in the sample regarding lived experience receiving and delivering epilepsy care [267].

Based on the literature review and understanding developed by the researcher of epilepsy care in Ireland, it was concluded that people with epilepsy (PWE), carers of PWE and clinicians involved in the delivery of epilepsy care each needed to take part in this study. For these three target populations, the inclusion criteria were defined as follows:
People with epilepsy

Patients are 16 years of age or over.

Have a diagnosis of epilepsy or suspected epilepsy (e.g., have had a seizure type event that is being investigated).

They must provide written informed consent of their willingness to participate based on clear information provided by the PhD researcher.

Carers, families and friends of people with epilepsy with experience interacting with people with epilepsy.

Family/carers are 18 years of age or older.

Provide support to a PWE. This can range from accompanying the patient to clinical appointments to being a full-time carer.

The PWE whom this family member/carer is participating in relation to must have consented to their family member/carer participating (where the PWE has capacity and is over 18) if that PWE is also a study participant.

A family member/carer of a PWE may participate even where that PWE is not a participant in this project. In this situation, the consent of the PWE to their family member/carer will not be sought.

Provide written informed consent of willingness to participate.

Health care providers (HCP) working in the epilepsy care sector.

They must be engaged in the delivery of a relevant epilepsy service.

They must provide written informed consent of their willingness to participate based on clear information provided by the PhD researcher.

<table>
<thead>
<tr>
<th>Table 10 - Inclusion criteria for participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>PWE and carer participants were recruited from three main settings within the Dublin Mid-Leinster (DML) Epilepsy Service at St. James’s Hospital:</td>
</tr>
</tbody>
</table>

A) **Group Clinic:**

The group education clinic is an annual event hosted by the DML Epilepsy Service.

It serves to provide chronic disease management for patients who are seizure free, suffering infrequent seizures or who are deemed to be successfully managing their epilepsy and achieving a good quality of life. Clinicians act as gatekeepers for selecting
patients to attend the group education clinic. If a patient is presenting to the general epilepsy clinic and is not outwardly struggling with their epilepsy, clinicians can refer them to the group clinic as their new touchpoint with the service. During the group clinic, patients are invited to share their own experiences of living with epilepsy. Patients or their families can ask questions to clinicians and other patients who are present. The PhD researcher planned with the group clinic coordinator to personally introduce and present the study at the Group Clinic held in October 2019. The researcher introduced himself and provided some background to his research and qualifications. Some general background of the study was provided, and the aim of the study was fully articulated, yet without any reference to his personal assumptions or background findings from other studies. Following the presentation, the researcher welcomed questions and patients who expressed an interest in taking part in the research were provided with a pack containing a participant information leaflet (PIL), a consent form and a stamped addressed envelope they could send to the researcher containing the consent form if they decided to take part.

**B) Teenage Transition Clinic.**

The DML Epilepsy Service hosts two ‘teenage transition clinics’ annually, typically in Spring and Autumn. Patients in their late teenage years who will soon have their epilepsy care transferred from one of Dublin’s paediatric hospitals to the DML Service are invited to these events. The transition clinics primary purpose is to familiarise new patients and their families with the staff who will now be providing their care. In a similar fashion to the group clinic, patients and their families are encouraged to ask questions to staff present. The researcher planned with the transition clinic coordinator and interested patients and family members could consent to take part in the research using the same procedure as the group clinic.
C) General Outpatient Epilepsy Clinic.

Each Wednesday afternoon, the DML Epilepsy Service hosts a general chronic epilepsy management clinic in the outpatient department of St. James’s Hospital. Patients are scheduled for appointments generally every three, six, nine or twelve months depending on the severity of their condition.

The researcher presented the study background and aims to the clinical staff of the DML Service. For an eight-week period, clinicians working in the general epilepsy clinic acted as ‘gate-keepers’ in introducing the researcher to potential study participants. On a weekly basis prior to clinic, clinicians were reminded to inform patients of the study being conducted. If they were interested in taking part, they could approach the researcher who positioned himself in the waiting area for further information about the study.

It is acknowledged that limitations exist within the sample. As is the case in focused ethnographic studies where relatively long-interviews are conducted with participants, the sample size is generally small. In employing HCPs as gatekeepers for recruitment of participants, their biases could have influenced which PWE and carers they directed to JB to take part in the study. It is possible that participants may have indicated specific knowledge regarding an aspect of self-management or eHealth which may have triggered HCPs to direct them to JB when they otherwise may not have. The recruitment of PWE, carers and HCPs from one location - the DML Epilepsy Service - also serves as a limitation as the attitudes regarding receipt and delivery of epilepsy care are based on experiences from a single setting. However, ethnographic research seeks primarily to understand the culture of the setting in which the study participants come from and apply learnings to this setting, which suited the nature of this project.

4.5.2. Focus Groups

As described in Section 4.5.1. PWE and carers were initially recruited from three
locations within the DML Epilepsy Service; Group Clinic, Teenage Transition Clinic and General Outpatient Epilepsy Clinic. All of the HCPs recruited were employed as staff within the DML Service.

Each of the participants who completed a semi-structured interview and provided their consent to be contacted for the second phase of the qualitative research study received an invitation to take part in a focus group. An email containing information about the aims of the focus groups and what would be required of participants was sent to each participant. If participants were interested in taking part, they responded to the email and completed an attached Google Form to indicate when they would be available to take part in a group. PWE, carers and HCPs were then divided into eight groups of between two and four participants. A Zoom link was emailed to participants the day before the group was due to be held.

4.5 Setting

4.5.1 Semi-Structured Interviews

Interviews were conducted in a number of locations. All HCP participants were interviewed onsite in SJH. Interviews took place usually in a private meeting room in Hospital 5, the hospital wing in SJH where the DML Service is located.

PWE and carer participants were interviewed in SJH or FutureNeuro offices in RCSI. The time and location were agreed upon via email correspondence or telephone call by the researcher and participant.

There was no one else present during the interviews besides the researcher and the participants. On one occasion, a PWE and their carer were interviewed together.

4.5.2 Focus Groups

Focus groups are traditionally organised as in-person discussions of a given topic with between six and eight participants and guided by an in-person moderator with audio-recordings for analysis [297]. When this research was originally designed during the
first year of JB’s PhD studies in 2018-2019, it was envisaged that these focus groups would take place in-person on-site at St. James's Hospital. It was planned that participants would be seated in a function room, presented the results of the first phase through a Microsoft PowerPoint presentation and their ideas generated during the group would be written on a paper flip-chart by the moderator and presented back to them.

Since the onset of the CoVID-19 pandemic in the Spring of 2020, the conduct of patient-centred research, particularly those that require face-to-face interactions such as qualitative research, has been challenged [297]. In the Republic of Ireland, like most other jurisdictions worldwide, the government have discouraged individuals meeting indoors for non-essential purposes in order to prevent the spread of infection. This meant that in order for this research study to continue while the pandemic was ongoing, a format in which participants and the moderator were located remotely from one another would need to be utilised.

With the advent of technologies such virtual and internet-based meeting platforms, JB viewed the enforced pivot to online as an opportunity to creatively engage the participants in this particular study for the PhD project. Interest in conducting focus groups through online platforms has existed for well over ten years prior to the onset of CoVID-19 [319]. Researchers began to look for new ways of conducting group research at a time when researchers were being assailed by recruitment problems, declining response rates, and rapidly rising costs for focus group discussions [319]. Independent of the setting, patient recruitment is often a bottle-neck in research and a considerable number of projects need much more time than planned to obtain a significant number of patients [320].

The widespread adoption of technology now supports the potential conduct of virtual focus groups, which may benefit participants with geographical barriers to in-person participation [297]. Work with remote participants dispersed across Australia
suggested that virtual focus groups using web-based video chat platform is an appropriate platform to collect qualitative data [321]. Similar research from Sweden has also shown that focus group discussions held online are a feasible mode of qualitative data collection [322]. Online focus groups have been shown to be a useful way of eliciting public views related to matters of health and medicine, particularly from diverse and geographically dispersed participants [319,323].

While larger sized focus groups benefit from heterogeneity among participants and potential for stimulation of discussion, literature indicates that focus groups with a greater number of participants are often not conducive for vulnerable groups, with participants often finding the process intimidating [324,325]. Focus groups with a greater number of participants also have limitations surrounding management of group dynamics, potential conflict and social anxiety [326,327].

When designing these focus groups, attempts were made to mitigate these limitations of focus groups by incorporating elements of group interviewing methodology, specifically through the use of ‘nominal group technique’ (NGT). The NGT was developed in management as an organisational decision-making technique to compensate for the limitations of focus groups [328]. NGT interviewing consists of two to six people, typically known to each other, where the interviewer directs questions at each participant, enabling each person to contribute [328]. The features of online and in-person focus groups are compared in Figure 15.
Within each focus group, JB sought to create an environment where participants felt their voices were heard and felt free to discuss a wide range of issues without feeling intimidated. It was hoped that each participant would have ample time to describe their lived experience and articulate their ideas regarding the future directions of epilepsy self-management and eHealth tools. As such, it was decided to limit the number of participants in each focus group to a maximum of four participants with JB as moderator.

Zoom is a web-based collaborative video conferencing tool that provides audio, video, and screen sharing [329]. Other similar software packages include Skype, Google Meet, WebEx, Microsoft Teams and WhatsApp [330]. After the onset of CoVID-19, Zoom software was the choice of many government agencies, universities, non-profit organisations, and individuals to host online forums as an alternative to face-to-face ones [331]. Zoom was chosen as the video conferencing tool that would be utilised for conducting the focus groups associated with this study as it was the recommended
platform from the School in which this PhD was conducted.

4.6 Data Collection Structure

4.6.1 Semi-Structured Interviews

One-to-one, semi-structured interviews were conducted with consenting participants guided by open-ended questions. This type of interviewing allows the researcher and participant to engage in a process whereby initial questions may be modified and restructured in response to initial participant answers while simultaneously the investigator can probe interesting and important areas that arise [268].

Guided by open-ended questions, the interviewer invited the participant to describe and reflect upon their attitudes and behaviors surrounding epilepsy care, epilepsy self-management and digital support tools.

Three unique interview scripts were designed to guide the interviews with these three participant cohorts. These interview scripts were devised through a combination of literature review and the intention of elucidating behavioural factors which influence the participants’ engagement with eHealth and epilepsy self-management.

The interviews with PWE and carers began with the participant introducing themselves and describing their first time experiencing or witnessing a seizure event. Interviews with HCPs began with the participant describing how they began providing treatment for PWE. In the exploration of epilepsy self-management, epilepsy care and digital health, certain responses could prompt the interviewer to ask certain questions in a different order if it followed on from what the participant has just said. Similarly, how a question was phrased depended on the participant responsiveness and how the interviewer felt the participant was responding. Where necessary, the interviewer probed and sought clarification from the participant or repeated or rephrased the question if indicated. In addition to tape-recording the interview, the interviewer took field notes. At termination of the interview each participant was advised that revision, clarification and/or deletion of the interview or part of the interview were possible.
4.6.2 Focus Groups

Each group met remotely via Zoom. Participants joined using both video and audio.

In switching to online, research practices had to be adapted in a manner which made it engaging for participants. Miro software was utilised as a platform to display information to participants during the focus groups. While functionality exists within Miro for multiple users to access whiteboards at the same time, for this research study the software solely functioned as a platform to display information to participants and JB was the only person editing the whiteboard on display during the focus groups. The board was for the display of data and visualisation of ideas.

Once participants joined, JB shared his screen where a Miro board was visible to all participants.
An icebreaker was conducted in which participants were asked to introduce themselves and describe what they understood as self-management of epilepsy. JB then presented an overview of the major themes which emerged from the semi-structured interviews. Images relating to the major themes were displayed on the Miro board and were visible throughout each focus group. Participants were invited to comment or share opinions on these results. After the results were discussed, participants were given five minutes to consider and write down their responses to the following two questions:

1. How might we balance face-to-face and virtual care going forward?

2. How might we do things differently to encourage more active self-management?

After five minutes had elapsed, participants shared their contributions. JB presented all of them together and summarised what was said. Once participants were happy and had nothing further to say, JB stopped sharing his screen and recording of the
group interview ceased. Audio recordings of the groups were transcribed.

4.7 Data Analysis

4.7.1 Thematic Analysis

Within qualitative data analysis, thematic analysis (TA) is the process of identifying patterns or themes within qualitative data [269]. TA is sometimes claimed to be compatible with phenomenology, in that it can focus on participants’ subjective experiences and sense-making [270]. There is a long tradition of using TA in phenomenological research [271]. A phenomenological approach emphasises the participants’ perceptions, feelings, and experiences as the paramount object of the study. Rooted in humanistic psychology, phenomenology notes giving voice to the ‘other’ as a key component in qualitative research in general.

Braun & Clarke’s (2006) 6-step framework (Table 11) is a widely used and popular approach for analysing qualitative data, probably because it offers such a clear and usable framework for doing TA. The goal of TA is to identify themes i.e. patterns or data that are important or interesting, and to use these themes to address the research questions. Braun and Clarke intended for their approach to TA to reflect their view of qualitative research as creative, reflective, and subjective, with researcher subjectivity understood as a resource rather than a potential threat to knowledge production.

<table>
<thead>
<tr>
<th>Step 1: Become familiar with the data</th>
<th>Step 4: Review themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Step 2: Generate initial codes</td>
<td>Step 5: Define themes</td>
</tr>
<tr>
<td>Step 3: Search for themes</td>
<td>Step 6: Write-up</td>
</tr>
</tbody>
</table>

*Table 11 - Steps involved in Braun & Clarke’s TA [269,272]*

4.7.2 Behavioural Theory and COM-B

Theory provides an explicit statement of the structural and psychological processes that are hypothesised to influence behaviour and, as such, is useful for investigating implementation difficulties, informing the design of practice change interventions and
contributing to the evidence base on which to select interventions [273,274]. Theory can provide information about mechanisms involved in behaviour change and these mechanisms can be systematically investigated and targeted with behaviour change techniques and components to bring about change [275]. If assessments of implementation difficulties are not undertaken within a theoretical approach, then the resulting interventions are likely to be limited to pragmatic rather than generalisable solutions, and opportunities to investigate the mediating pathways of behaviour change and optimise interventions will be limited [276]. Michie and colleagues addressed the challenges associated with applying theory in implementation science by using a consensus approach to develop the Theoretical Domains Framework (TDF) [277]. This brings together 33 models of behaviour or behaviour change and includes 128 separate constructs [277]. The TDF has 11 theoretical domains that explain the potential determinants of behaviour; knowledge, skills, social / professional role and identity, beliefs about capabilities, beliefs about consequences, motivation and goals, memory attention and decision processes, environmental context and resources, social influences, emotion and action planning. Latterly, the Behaviour Change Wheel (BCW) was developed as a behaviour system designed to link from identification of determinants of behaviour using the TDF to the mapping of appropriate behaviour change techniques (BCTs) to inform interventions. It consists of 'COM-B' (Capability, Opportunity and Motivation to Behaviour) at the hub of the wheel (Figure 18). Domains of the TDF have been mapped to the COM-B. For example, 'Capability' includes the domains knowledge and skills, 'Opportunity' includes social influences and environmental context / resources and 'Motivation' includes beliefs about capabilities and emotions. The COM-B hub of the BCW is encircled by nine intervention functions; education, persuasion, incentivisation, coercion, training, restriction, environmental restructuring, modelling and enablement) and the outer of the three rings seven policy categories; communication, guidelines, fiscal, regulation, legislation, environmental / social planning and service provision.
The COM-B model was chosen as the behavioural framework through which this qualitative research would be conducted as it would enable the encapsulation of the individual and context factors that hinder and facilitate using eHealth for epilepsy self-management that emerged from the themes within the qualitative data. The model was also deemed valuable to facilitate the subsequent translation of findings into actionable recommendations for interventions that target specific barriers or opportunities. This behavioural framework has been used effectively by others to evaluate healthcare implementation challenges and to design theory informed strategy [280,282–288].
4.7.3 Data Analysis Process

4.7.3.1 Semi-Structured Interviews

For the semi-structured interview data, qualitative data analysis was conducted using a combination of Braun and Clarke’s TA and COM-B mapping. The data analysis process is described in Figure 19.

JB solely performed the coding of the transcribed data. While it undoubtedly can be helpful to code data with another researcher to discuss and identify emerging categories, to reflect on assumptions and what might have been overlooked in the data, it can be argued that this doesn’t necessarily result in ‘better’ coding, just different coding. For this body of work, JB adopted the position that coding should be flexible and organic, and coding should evolve throughout the coding process. JB understood coding as an active and reflexive process that inevitably and inescapably bears the mark of the researcher.

Interview transcripts were analysed using NVivo 12 and Miro software.

NVivo is a software programme developed by QSR International which is designed to support researchers to manage research data. The software has tools which enable the researcher to import data, index and code it with thematic or conceptual labels, write memos and track ideas, run searches and generate reports [289]. This software was selected to analyse the interview transcripts as it enabled coded data from multiple transcript files to be grouped into broad, descriptive themes. These initial codes and themes are included in Appendix 10.

After the organisation of codes into broad, descriptive themes using NVivo, Miro software then used to review and refine themes. Miro is an online platform which facilitates the creation of whiteboards which can be accessed by multiple authorised users. It is versatile and can be used in multiple ways, with users being able to create sticky notes, shapes and text. Miro was selected for this step in the process as it would facilitate the seamless organisation of a large number of quotes from a number of
codes in both a functional and aesthetic visual manner, allowing for the final organisation and definition of themes.

The PhD researcher JB conducted data analysis alongside data collection. JB regularly met with his supervisor, Colin Doherty (CD) to discuss interpretation of data which was being collected and themes which were emerging from the data. Data saturation was deemed to have occurred when no new themes were emerging from the data. Both JB and CD deemed saturation to have taken place following the completion of interviews with 13 PWE, 3 carers and 9 HCPs.

These final themes and codes are included in Appendix 11.

After themes were defined, they were mapped onto the COM-B framework by JB. This additional step in the TA process facilitated the identification of future behavioral intervention functions to address the barriers and challenges which were identified in the interviews. The themes and ideas which emerged from the semi-structured interviews were presented to participants in the focus groups, as described in Section 4.6.2., which served as a platform for ideating solutions to the challenges identified for epilepsy self-management and eHealth use.
4.7.3.2 Focus Groups

The audio recordings from each of the focus groups were transcribed by JB. Braun and Clarke's reflexive method of thematic analysis was conducted in the same manner as described in Section 4.7.3.1; initial coding and creation of broad descriptive themes took place using NVivo and then final themes were arranged and described using Miro software. The initial and final codebooks are included as Appendices 15 and 16.

JB solely performed the coding of transcribed data. As was described in Section 4.7.3.1, after themes were defined in the data analysis process, JB mapped them onto the COM-B framework. This additional step in the analysis process allowed the identification of behavioural interventions which could possibly facilitate the introduction of ideas generated by participants about improving self-management and eHealth usage in epilepsy care.

4.7.3.3 Rigour

The COREQ (COnsolidated criteria for REporting Qualitative research) Checklist was consulted in writing up the qualitative methodology employed [263]. To ensure
trustworthiness of data, the principles of credibility, dependability, confirmability and transferability created by Lincoln and Guba were enforced [264]. Credibility was ensured through the detailed capturing and description of the approach to sampling, data management, analysis and interpretation [265]. Consideration of issues regarding reflexivity and transferability were considered throughout. In the findings reported in Chapters V and VI, quotations were chosen to provide readers the opportunity to interpret data, establish confirmability and to show the richness of the data.

4.8 Ethical Considerations

Formal ethical approval for this study was sought and sanctioned by the St. James’s Hospital and Tallaght University Hospital Joint Research Ethics Committee (SJH-TUH JREC) (Ref 2019-08 List 31 (08). As was outlined in Section 4.5.2, it was originally envisaged that this focus group research would take place in person. In light of CoVID-19 and the enforced pivot to online focus groups, permission was sought from the SJH-TUH JREC to conduct this body of research through an online format. Permission was granted by the SJH-TUH JREC for this research to take place via Zoom.

It is also noted that title of the thesis does not match with the title of the project included in the approval letter from SJH-TUH JREC. The original title of ‘From the outside-in: Co-designing tools to promote independence and wellbeing in epilepsy care’ was devised in the first year of the PhD programme. This title served as a placeholder title during the ethics application process. While the studies conducted for this PhD incorporate elements of co-design methodology and represent a shift from the traditional paradigm within health services research of inadequate patient involvement - hence service design being described as from the outside-in rather than the inside-out - it was decided that the final title ‘Does the future of epilepsy care lie in eHealth? An examination of attitudes and behaviours towards epilepsy self-management and eHealth from the perspectives of people with epilepsy, their carers and healthcare providers’ more accurately captured the essence of this PhD research than the original title.
Chapter V - Findings: An Exploration of the Perceived Challenges Faced by People With Epilepsy, their Carers And Healthcare Providers Surrounding Epilepsy Management and eHealth Tools.

5.1 Introduction:
As outlined in Chapter I, it is proposed that through the empowerment and engagement of patients with appropriate digital health tools, individuals can receive, and clinicians can deliver chronic disease care remotely. While these proposals are undoubtedly progressive, their visions are broad and lack granular detail surrounding how individuals will behave differently in relation to their healthcare through increased use of eHealth. As discussed in Chapter II, a clinical audit explored and documented perceptions of medication adherence and medication error across PWE receiving their care in St. James's Hospital. The major findings of Chapter II were that 40.9% of respondents to a self-administered questionnaire reported sub-optimal adherence to ASMs and 28.5% perceived that they were subject to a medication error. Participants who perceived medication errors to be occurring are less adherent to those who do not. No significant links were found between sex, age, number of medications, current perceived effectiveness of medication, previous perceived effectiveness, experiencing stigma or the presence of additional neurological conditions and non-adherence to medication. This demonstrates the complexity of non-adherence to ASMs and undoubtedly there are several reasons behind a patient’s decision not to take their medication as prescribed. In Chapter III, a clinical audit assessing patient and clinician perception of telemedicine revealed high levels of satisfaction with remote models of care both before and after the onset of CoVID-19. PWE and HCPs both felt that telemedicine was a more than adequate manner to receive and deliver chronic epilepsy care when the condition of the patient was ‘stable’, however both populations expressed doubt about the viability of this method should a patient present with increased seizure frequency or problems relating to their epilepsy.
With these results in mind, the next phase of this research study sought to scratch beneath the surface about patient perceptions and attitudes about epilepsy care, their thoughts about epilepsy self-management and the challenges they face. It was also considered important to listen to the experiences of the family members and carers of PWE, as well as HCPs providing specialist epilepsy care. This would allow a picture to be painted of the current ecosystem of epilepsy care and where epilepsy self-management and digital support tools fit into this. While the literature review highlighted several studies relating to the use of eHealth in managing epilepsy, the relevance of an exploratory and inductive study into this area cannot be doubted. This body of work sought to reveal insights into how each of these populations approach epilepsy self-management to identify where challenges lie. The objective of this study was to understand challenges faced by PWE, their carers, family members and HCPs in relation to epilepsy self-management and using digital tools to facilitate this management.

5.2 Methodology Summary

As outlined in Chapter IV, this research study took the form of a focused ethnography. This Chapter V will outline the findings of the semi-structured interviews conducted during this focused ethnography. Semi-structured interviews were conducted with participants with the aim of elucidating the challenges participants perceive as existing towards epilepsy self-management and using eHealth tools. Purposive sampling was undertaken and PWE, carers and HCPs were recruited from three locations within the DML Epilepsy Service at SJH: Group Clinic, Teenage Transition Clinic and the General Outpatient Epilepsy Clinic. All HCP participants were interviewed onsite in SJH. PWE and carer participants were interviewed in SJH or FutureNeuro offices in the Royal College of Surgeons in Ireland (RCSI). Interviews were audio recorded and transcribed verbatim. Interview transcripts were analysed by the PhD researcher JB using Braun & Clarke’s six-step TA with an additional COM-B mapping step. The major themes and challenges identified in the semi-structured
interviews are outlined in this chapter and were presented to participants in the focus groups (described in Chapter VI) as the foundation for the ideation of solutions to identified problems.

5.3 Results

5.3.1 Final Sample

Following recruitment from the three locations (Transition Clinic, Group Clinic and General Epilepsy Clinic), thirty-five participants expressed an interest in taking part in the study and were given participant information leaflets. Thirty-two participants agreed to take part in the study and provided their written consent to take part in the study. Seven participants were unable to take part in an interview. Reasons proffered for non-attendance at interviews included bereavement, illness and no longer being interested in taking part. In the end, a total of twenty-five participants completed semi-structured interviews with the researcher.

Participants were assigned a code in sequential order as consent forms were returned to the researcher. Each individual carried the prefix PWE for person with epilepsy, C for carer or HCP for healthcare provider. In this manuscript however, pseudonyms were used instead of codes when presenting quotes attributed to participants. Pseudonyms were chosen to make it easier for readers to follow individual narratives.

Recruitment was discontinued when data saturation occurred i.e., no new themes were emerging from the data collected. The participants' demographic profiles were diverse. Demographic information was not stratified as part of data analysis. Demographic information relating to the participants are presented in Tables 12, 13 and 14.
### Age of Participant (Years) (n=13)

<table>
<thead>
<tr>
<th>Mean</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>39.08</td>
<td>17</td>
<td>66</td>
<td>14.63</td>
</tr>
</tbody>
</table>

### Age of Seizure Onset (Years) (n=13)

<table>
<thead>
<tr>
<th>Mean</th>
<th>Minimum</th>
<th>Maximum</th>
</tr>
</thead>
<tbody>
<tr>
<td>21.62</td>
<td>9</td>
<td>54</td>
</tr>
</tbody>
</table>

### Education Level (n=13)

<table>
<thead>
<tr>
<th>Junior / Intermediate Certificate 1 (7.7%)</th>
<th>Technical / Vocational Qualification 2 (15.4%)</th>
<th>National Certificate / Diploma 4 (30.8%)</th>
<th>Bachelor’s Degree 4 (30.8%)</th>
<th>Postgraduate Degree 2 (15.4%)</th>
</tr>
</thead>
</table>

### Working Status (n=13)

<table>
<thead>
<tr>
<th>Working for payment / profit 5 (38.5%)</th>
<th>Student / Pupil 3 (23.1%)</th>
<th>Retired from employment 1 (7.7%)</th>
<th>Unable to work due to sickness or disability 4 (30.8%)</th>
</tr>
</thead>
</table>

### Current Living Situation (n=13)

<table>
<thead>
<tr>
<th>Living with parents 6 (46.2%)</th>
<th>Living with partner and/or children 6 (46.2%)</th>
<th>Living alone 1 (7.7%)</th>
</tr>
</thead>
</table>

### Seizure Frequency (n=13)

<table>
<thead>
<tr>
<th>Daily 2 (15.4%)</th>
<th>Less than daily but more than once a week 4 (30.8%)</th>
<th>Less than weekly but more than once a month 1 (7.7%)</th>
<th>Less than monthly but more than once a year 4 (30.8%)</th>
<th>Less than once a year 2 (15.4%)</th>
</tr>
</thead>
</table>

### Prescribed Epilepsy Treatment (n=13)

<table>
<thead>
<tr>
<th>1 ASM taken daily / twice daily 3 (23.1%)</th>
<th>2 or more ASMs taken daily / twice daily 10 (76.9%)</th>
</tr>
</thead>
</table>

### Supplementary Epilepsy Treatment (n=13)

<table>
<thead>
<tr>
<th>Dietary Treatment 2 (15.4%)</th>
<th>Vagus Nerve Stimulation (VNS) 2 (15.4%)</th>
<th>Dietary Treatment and VNS 1 (7.7%)</th>
<th>No Secondary Treatment 8 (61.5%)</th>
</tr>
</thead>
</table>

*Table 12 - Characteristics of PWE sample (n=13)*
<table>
<thead>
<tr>
<th>Position (n=9)</th>
<th>Nurse 5 (55.6%)</th>
<th>Dietitian 1 (11.1%)</th>
<th>Non-consultant hospital doctor 1 (11.1%)</th>
<th>Consultant hospital doctor 2 (22.7%)</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Years Providing Epilepsy Care (n=9)</th>
<th>Mean 10.78</th>
<th>Minimum 2</th>
<th>Maximum 25</th>
<th>Standard Deviation 8.26</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Gender (n=9)</th>
<th>Male 2 (22.2%)</th>
<th>Female 7 (77.8%)</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Provided care in another jurisdiction (n=9)</th>
<th>Yes 6 (66.7%)</th>
<th>No 3 (33.3%)</th>
</tr>
</thead>
</table>

Table 13 - Characteristics of HCP sample (n=9)

<table>
<thead>
<tr>
<th>Age of Participant (Years) (n=3)</th>
<th>Mean 54</th>
<th>Minimum 49</th>
<th>Maximum 61</th>
<th>Standard Deviation 6.25</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Gender (n=3)</th>
<th>Male 1 (33.3%)</th>
<th>Female 2 (67.3%)</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Current Working Status (n=3)</th>
<th>Working for payment / profit 2 (66.7%)</th>
<th>Looking after home / family 1 (33.3%)</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Years Caring for PWE (n=3)</th>
<th>Mean 19</th>
<th>Minimum 7</th>
<th>Maximum 30</th>
<th>Standard Deviation 11.53</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Seizure Frequency of PWE they Care for (n=3)</th>
<th>Less than daily but more than weekly 2 (66.7%)</th>
<th>Less than yearly but more than monthly 1 (33.3%)</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Prescribed Treatment of PWE they Care for (n=3)</th>
<th>2 or more ASMs taken daily / twice daily 3 (100%)</th>
</tr>
</thead>
</table>

Table 14 - Characteristics of carer sample (n=3)

A final table of major themes was developed when all transcripts had been thematically analysed using Braun & Clarke’s process (Table 15). It must be remembered that these themes were not selected on the basis of their prevalence
within the data. Through the TA process, it became clear that the most pertinent data relating to epilepsy self-management and eHealth were emerging from questions asked in the latter half of interviews. While the introductory questions surrounding the participants’ background, initial seizure experiences and reaction to diagnosis served a purpose in 'breaking the ice' and beginning conversations surrounding epilepsy management with participants, the primary objectives of the interviews and focus groups were to elucidate the attitudes, perceptions and behaviours of PWE, their carers and HCPs towards self-management and eHealth. For this reason, data specifically pertaining to these topics are the primary findings reported. Each theme is supported by various direct quotations from the individual texts to illustrate and support their inclusion however for practical reasons not all supporting material that emerged during the TA process could be included.

| Theme 1 | HCPs express doubt about their resources and capability to deliver comprehensive psychosocial care to each PWE and how new eHealth will integrate into their current workflow processes. |
| Theme 2 | Epilepsy care needs to focus less on anti-seizure medications (ASMs) and more on psychosocial aspects of the condition. |
| Theme 3 | Family members and carers are heavily relied upon by PWE and HCPs to perform important self-management tasks. |
| Theme 4 | HCPs doubt the willingness and capability of many PWE to engage in self-management activities. PWE difficulties with memory and recall and a lack of belief regarding the necessity for self-management prove to be barriers, particularly in the early stages following diagnosis. |
| Theme 5 | A lack of data integration across eHealth platforms, the perception of digital interactions as being impersonal, privacy concerns and a lack of perceived utility are barriers perceived by PWE, carers and HCPs to using eHealth tools for self-management. |

*Names provided with quotations below are pseudonyms to protect identity of participants.*
Table 16 - Abbreviations used in results section

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>HCP</td>
<td>Healthcare provider</td>
</tr>
<tr>
<td>CfPWE</td>
<td>Carer for a person with epilepsy</td>
</tr>
<tr>
<td>PWE</td>
<td>People with epilepsy</td>
</tr>
<tr>
<td>ANP</td>
<td>Advanced nurse practitioner</td>
</tr>
<tr>
<td>RD</td>
<td>Registered dietitian</td>
</tr>
<tr>
<td>CHD</td>
<td>Consultant hospital doctor</td>
</tr>
<tr>
<td>NCHD</td>
<td>Non-consultant hospital doctor</td>
</tr>
</tbody>
</table>

5.3.2 Theme 1 - HCPs express doubt about their resources and capability to deliver comprehensive psychosocial care to each PWE and how new eHealth will integrate into their current workflow processes.

HCPs emphasised that within the current model of epilepsy care, there are three primary locations that can be accessed by PWE or their carers: clinical appointments, the telephone advice line (TAL) and email. The TAL and email services serve as avenues for PWE or their carers to seek help with any aspect of their lives relating to epilepsy between clinical appointments. Deirdre, a PWE, describes below how the TAL operates:

*Deirdre (Patient) - ‘They’re Mondays and Thursdays, 8 to 12, half 12. So you can ring them in that time, actually speak to them. But they will go off, talk to the doctor and ring you back. If you email them they’ll go talk to the doctor and email you back. Unless you ask them to call you back. And that’s a very handy way of getting immediate attention of them and immediate answers. It’s a very, very good way of doing it.’*

While the HCPs acknowledged that the advent of the TAL and email advice lines increased accessibility for PWE to seek counsel if they are experiencing problems or have questions, they largely felt that this still was not enough to get a meaningful indication of how a PWE was coping with self-management or other aspects of their lives.
Andrea (ANP) - 'It's more that they rely on kind of crisis management. Rather than long term planning management of their condition.'

Freya (ANP) - 'On paper that person looks like they have really stable epilepsy, you know, not having seizures, they're fine. They're not coming to clinic regularly but actually they are really struggling with the condition.'

Freya (ANP) - 'They should be able to report back to us in a significant way that means something to us and them.'

One sentiment that was expressed was that PWE can have difficulties outside of normal office hours and that telephone and email supports limited to one to three days a week during office hours may not be adequate.

Freya (ANP) - 'Patients don’t just ring around seizures, they ring around stressors or side effects...They ring us around other aspects of their life that they may be struggling with...We are very much a signposting service in that the nurses try to signpost people to all aspects of living with chronic disease.'

Some PWE did mention that if they needed urgent information or help, that the TAL or email service was not suitable.

Harriet (Patient) - 'If it were an emergency, well then I’d call the department, I’d go into the website and call the number first. Just call around, phone calls until I got through to somebody eventually.'

Deirdre (Patient) - 'That's fine for me. And anything I need I get on the nurses line. But the next day is fine for me. That's okay for me but there are patients who can't wait that long. Even a day they can't wait. Unless they go to A&E.'

Freya expressed that she would like to see a service set up that would allow PWE access outside of the DML's business hours.

Freya (ANP)- 'I think we would all love to have a resource that we could give to patients to help them navigate outside of the business hours that we work on'

Some HCP participants mentioned that the service website needed to be improved. Having the website updated with information that would allow patients to access
information 24/7 was seen as important in facilitating patients to be empowered and to take charge of managing their own condition.

Donna (NCHD) - 'Like what I think we are really missing in our service is a website. So that you can access the information in your own time when it suits you. Like when you are at home in the evening and you just had a seizure, not when our phone line is on between 8 and 12 in the morning. There’s certain things that we say to patients all the time, that you know could be better I think, we could get it out there better in a website format.'

HCPs were conscious of introducing changes which might interrupt or increase their workload. There was a scepticism to how data generated by users would not result in an increased workload for them.

Ivan (CHD) - 'I’m not going to be looking down at a device for two hours on one patient. That’s not going to happen. We’ve got a life to live. I want to go home. I want to read a book. I want to see the match.'

Holly (RD) - 'I think we have to be careful, you know, because it has to be taken into our workflow. And our work pathway and processes. And I think at the moment it isn’t really.'

HCPs felt that resources in the service were very stretched. Nurses and doctors felt that the range of care they delivered was limited by the number of staff that were employed. The low number of staff relative to the number of queries received and patients that had to be cared for means that the care delivered to patients tends to be quick and prioritises physiological aspects.

Glen (CHD) - ‘But the medication stuff takes so much, so long sometimes to try and understand and get right. That you don’t have enough time really to do the other stuff.’

Ellen (ANP)- 'I could have more of an impact if I had more help, but I don’t have more help...Everybody that works in the health service is overwhelmed. The last thing they want is to implement any new change that you’re going to introduce any kind of extra service for PWE.'

Some PWE and carers recognised how resources were stretched within the service. Lisa said that this affected how she engaged with it,
Lisa (Patient) - 'I kind of nearly have this moral issue in that I’m taking up someone else’s time. You know another patient’s time. I understand like how bad some people are and it kind of gives you a reality check here, like here ‘there’s really nothing wrong with you, you know.’

Within the DML Service, it is common for ANPs to provide individual education to PWE and their families following diagnosis of the condition.

Beatrice (ANP) - ‘So for me, I would do first one-to-one education for newly diagnosed patients with epilepsy, and key to them having I suppose, a well-rounded and a stable handle on their chronic disease is education and lifestyle. We’re in a good position with our ability to educate and then I think all of us have our own individual interests in different aspects of the chronic disease.’

Freya (ANP) - ‘And we do provide education and self-management supports in our day-to-day interaction over the phone or in face-to-face visits and they are sort of periods or snapshots in the times of their visits where we might touch on aspects of living with the condition.’

Group education sessions and group clinics are also hosted by the DML Service, PWE and carers reported positive experiences of these group sessions. Some HCPs mentioned the topics that they brought up in education sessions. These ranged from explaining to PWE why they needed to adhere to prescribed medication to discussing lifestyle issues.

Donna (NCHD) - ‘And so I think it’s a lot about communication explaining to patients why we think it’s important that they take their medication and I always tend to give them ways to remind themselves like setting alarms or you know signing up to a website and reminding you of it.’

It was mentioned by Andrea that attendance at the group education is not as high as the Service would like.

Andrea (ANP) - ‘I think we do try; we try and do a lot of education. We don’t have as a good take up on our education sessions as we would want. A lot of people don’t show up.’

Ellen was of the opinion that some individual’s personality types would not lend
themselves to benefitting from a group session.

Ellen (ANP) - ‘You know they also don’t want to go to education in front of other people you know. And again, if you put yourself in an individual’s shoes you know. Like I’m a quiet person, I wouldn’t speak up in a group and I would have no interest in going to a group about any condition I may or may not have’

5.3.3 Theme 2 - Epilepsy care needs to focus less on anti-seizure medications (ASMs) and more on psychosocial aspects of the condition.

Within the ecosystem of epilepsy care, the prescription of anti-seizure medications (ASMs) is viewed as the cornerstone of treatment. As Glen puts it;

Glen (CHD) - ‘Prescribing medication is a big part of what we do. If you were trying to put a percentage on it, it’s probably 70% of what we do. But it probably should be 50%.’

The reason for this proffered by Glen is the training that HCPs receive.

Glen (CHD) - ‘What we have is a hospital based service of clinicians who are trained in the biology of a disease. So we end up talking about the thing that we know about’

Glen believed that discussing medication with PWE was the most concrete way of establishing how an individual was managing their condition. The difficulty in assessing the impact of other lifestyle or holistic measures taken by a patient meant that clinicians often tracked progress through medication outcomes.

Glen (CHD) - ‘You know, taking their medication is the most concrete one, to be able to talk to a patient about. Because they’ll either admit or not that they’re not taking it. It’ll be clear that over time that they’re missing it. We have the capacity to measure levels in their blood. I just wonder whether if they did all those other things right. Whether they really need to be on as much medication, or as frequent use of their medication.’

There have been times when PWE have been frustrated by HCPs solely wanting to discuss ASM related issues in appointments. Patients have been frustrated at times when they have wanted to discuss lifestyle issues together with ASMs and HCPs have
not engaged with them in the manner that they would like them to.

Lisa (Patient) - ‘And I said what’s your opinion on lifestyle changes you know sugar and whatever. And she put her head in her hands.’

Deirdre (Patient) - ‘You can tell them something and they’d say “well okay, if you’re feeling this way we’ll try this medication” or whatever. But some of them go “ah sure, you’ll be alright once you take the tablets”. And I have one doctor that does that. And honest to God I’ve never really liked him and I just feel like giving him a punch.’

Freya expressed some doubt about the capability of nurses to deliver comprehensive education surrounding self-management of chronic disease.

Freya (ANP) - ‘We don’t have anybody providing the background tools...As nurses we try and signpost people but there is a huge lack of resources in that part of living with a condition. We don’t really have any expertise in patient motivation, all these things that are really important in bringing patients along in their chronic disease’

It was common across PWE interviewed to have experienced times when they did not take their medication as prescribed to them by HCPs. The rationale for not adhering as prescribed was often attributed to not perceiving medication as important to maintaining wellness. Over time, as the chronic nature of the condition sets in, PWE stated that they started to understand the importance of medication;

Lisa (Patient) - ‘I suppose I’ve always been prescribed it and had it. but sometimes I’d be like, I know when I was like in my early twenties I’d be like, “oh did I take it for two days”. And then I might take two days’ worth at once or something like that. Now I’m really strict about it you know like on top of things.’

Keith (Patient) - ‘I think maybe with the reaction of some of the staff in the hospital also helped me come to terms with the fact that it’s not something to be taken lightly, especially with medication as well. I know it was explained that I was just going to keep repeating the same process of seizure, injury, hospital, over and over again if I didn’t take the medication.’

Monica (Patient) - ‘I stopped taking it to see if I truly needed it. But I kind of - they’ll be so proud of me - I reduced it gradually, instead of
being like, “okay I’m not going on this anymore”.

There was a consensus across PWE, carers and HCPs that prescribing and adhering to ASMs were not the only factors required to lessen the impact of seizures.

Beverley (CfPWE) - ’Got to balance but you know up to how much medication you take versus being able to function.’

Lisa (Patient) - ’Right on that dosage you would never have seizures again. I said, “no. Because I want to have a life”.

Donna (NCHD) - ’For the patients I don’t think that’s everything, some patients have frequent seizures but they are not affecting them very much and they might be happy to live with them compared to having all the side effects of medication, that we are more understanding of, you know, accepting of that too.’

Freya (ANP) - ’I do certainly recognise that patients input into their care certainly makes them have more ownership of what happens with their epilepsy care. So I very much want patients to tell us that they can live with seizures if there’s not the burden of medication.’

HCPs acknowledged that non-ASM matters needed to be discussed more in clinical encounters.

Ellen (ANP) - ’You know when they go to doctors it’s very much the medication management and seizure and that’s it. But there’s a lot more to epilepsy than medications and seizures do you know.’

Glen (CHD) - ’If you asked me is it more important that they get that (adhering to medication) right or should they get plenty of sleep, no stress and a proper diet. I couldn’t tell you what’s more important. I just wonder whether if they did all those other things right. Whether they really need to be on as much medication, or as frequent use of their medication. Now that’s not the general line that we give, we always go ‘oh you have to take your medication’. But that’s because we can’t control these other things. The only one we can control is the medication that’s why it takes up 70% of our time, instead of less than that’

Donna (NCHD) - ’Service that is more holistic and comprehensive that we can actually address patients wellbeing and patients overall quality of life and not just the seizures which is what we are doing at the
The role of primary care in management of epilepsy was mentioned in a number of the interviews with clinicians. HCPs felt that general practice was important in the provision of some aspects of epilepsy care, particularly in relation to lifestyle and how ASMs interact with other medications. There was a consensus that an improved relationship between the DML Service and GPs would be beneficial, but it was not clear what this relationship might look like.

Freya said that the DML Service encourages PWE to get in touch with their GP's with issues they are having in between appointments with the DML Service.

Freya (ANP) - 'We would be very much encouraging people to go to their GP for a lot of the times in between, because we don't have the resources to bring someone in straight away after a phone call'

A number of HCPs mentioned that they did not believe GPs, by and large, were interested in taking over aspects of epilepsy care.

Ivan (CHD) - 'GPs don't want to look after PWE. There's a few GPs out there who are interested in epilepsy. Most GPs are s**** scared of neurological disease and epilepsy. And they don't want it shifted back to them...To expect GPs to take over the management of epilepsy or even a significant proportion of epilepsy, it's not going to happen.'

HCPs mentioned that an enhanced relationship with GPs could reap large benefits for all parties involved. It was proffered that the DML Service and GPs could work together to create self-management and holistic plans for PWE.

Glen (CHD) - 'Because even if we had you know, some resource around lifestyle and that sort of stuff. It has to be in concert with what's going on in the community. You know there has to be a sense that the community doctors are working with us on that, you have epilepsy, oh yeah we know them you know, you need to take onboard now that there's a whole special programme of exercise and diet that people with epilepsy have'

Glen (CHD) - 'The GPs talk about this holistic stuff all the time, and we do mention these other things but I guess, if we were working more
closely with GP we might say, well look your GP should have a plan for you around your holistic life’

Andrew, a carer for a PWE, said that he would like to see more of a link between different care practices.

Andrew (CfPWE) - ‘And everybody has a role to play but the important thing is to make sure that it all interconnects and dovetails. Because if all has to work together, if it doesn’t work together it doesn’t work, it’s as simple as that. I think that’s really important. And I think we need more of that kind of really proactive interconnected and joined up thinking.’

5.3.4 Theme 3 - Family members and carers are heavily relied upon by PWE and HCPs to perform important self-management tasks.

PWE spoke of how their carers and family members helped them to manage many aspects of their lives while living with epilepsy.

Family members and carers were said to protect PWE during seizures to prevent injuries. Keith and Elaine below describe how people look after them when they experience seizures.

Keith (Patient) – ‘I’m lucky that my housemates understand and they know what to do. A few of my seizures have happened in like the living room or my kitchen. So my housemates are able to look after me and lie me on the floor and move things away from me.’

Elaine (Patient) – ‘Yeah, I have to sometimes behave because other people have done so much for me. And sometimes I’d be out (of consciousness) and then not realise and then I’m coming back home because I’m having a seizure. And I don’t realise it.’

PWE cannot drive under Irish law unless they have been seizure-free for at least a year. As a result, they often rely on family members or carers for transport to and from locations. Deirdre, Fiona and Harriet below describe how their families have provided transport for them.

Deirdre (Patient) – ‘The fact that I can’t even drive to the shop. So if the weather’s bad and my husband’s not there and I need to go to the shop,
I can't go, you know. And I hate asking other people.

Fiona (Patient) - 'Like from bringing me, constantly being a taxi because I can no longer drive. You know if I ask, normally they go and like trip over themselves, in fairness, to like take care of me. At the same time as a thirty-seven year old adult I don't want to ask them either you know'

Harriet (Patient) - 'When I was living with the parents before I moved in with the boyfriend. My wonderful Dad would be up every morning getting me to the bus early and I always felt terrible about it.'

Circumstances often mean that carers and family members are the people who end up performing most of the management activities for a person with epilepsy's condition. Beverley described how she records her son’s seizures using an app on her phone.

Beverley (CfPWE) - 'I have downloaded an app just on my phone that I record Gary's seizures on but he probably needs to start doing that himself.'

Very often family members are the primary reminders to PWE to adhere to their medication daily. Conor humorously mentioned below that his wife is his reminder to take his medication.

JB: Do you have any mechanisms or habits to help you remember to take your medication? Conor (Patient): "Yeah, the wife" (laughs)

Beverley indicated that she is the person who manages Gary's medication and that without her input he has forgotten to take his medication on a number of occasions.

JB: Have you ever had difficulty remembering to take medication? Gary (Patient): "No". Beverley (CfPWE):"Yes you have. Several times you forgot to take it".

Beverley (CfPWE): ‘He’s managing his own meds, or he has been managing his own meds until the latest change. So until the change is complete, I've just taken over doing them.'

Monica indicated that her mother stresses the importance of taking her medication to her.

JB: 'Yeah and taking the tablets, did you ever have any problems
Gary spoke of the importance of his family members in noticing his reaction to new medications, his seizure frequency and overall wellbeing. He believed that he was not able to notice these things, whereas his family members would from being around him.

Gary (Patient) - ‘Because I don’t like necessarily notice a change most of the time, I just off people who are like family they would notice a change in things I think.’

Andrew has conducted research into self-management behaviours that will help his son live with epilepsy. Here he describes sleep’s role in maintaining wellness with epilepsy.

Andrew (CfPWE) - ‘Sleep deprivation, you don’t get a good night sleep and because of that you’re more likely to have a seizure. And when you actually think about it...when you actually break it down and actually you know, try and manage it.

Ciara said that she ‘micro-manages’ everything surrounding her son’s condition. She keeps information about all of his investigations that she can bring to clinical appointments and tell the HCP should they ask.

Ciara (CfPWE) - ‘I micro-manage everything and I go “well he hasn’t had his bloods done or when is the last time he had an EEG”, it would be you know “oh I’ll have a look”.

The negative manner in which epilepsy affects relationships within families was discussed in many interviews. Deirdre spoke of how she felt that her husband was affected following her diagnosis.

Deirdre (Patient) - ‘The seizures were just so frequent, so fast, so hard. And my husband wasn’t even, now he was coping but you could see it was getting to him. You know he spent more time out of the house trying to unwind, you know.’

Beverley spoke of how difficult it was to witness her son experience a seizure.
Beverley (CfPWE) - ‘He had another tonic clonic seizure which was the first time I had ever seen anybody having a tonic clonic seizure. Unfortunately for me it was my son which was really tough.

Keith mentioned that when he experienced seizures in public, it made him feel a sense of guilt and was conscious of how distressing it might be for his family, friends or others who may witness them.

Keith (Patient) - ‘I was a bit confused more so than embarrassed or anything. And then not long after waking up, you get a feeling of, I get a feeling at least of guilt, like guilty like I’ve done something wrong. And in that incidence with other people being there it felt, I felt that even more so.’

Many of the patients want to be independent adults, however participants expressed that they feel their families are over-protective and limit the activities that they can do as a result of epilepsy. Deirdre found it frustrating when her family were frequently asking how she was.

Deirdre (Patient) - ‘It was terrible like everybody was very sort of “are you okay? Do you need anything?” and it was very, it was annoying because I’m the sort of person that’s like, “if I want something I’ll ask you, leave me alone”, you know. And with people sort of fawning all over me I was like “oh”, I was like “leave me alone”, you know.’

Fiona also became annoyed when her family would ask to help her.

Fiona (PWE) - ‘But I’m like you’re just doing this just to help me out, stop doing, stop doing things just to help me out.’

Monica and Elaine spoke of how their families influenced the activities she could and couldn’t do.

Monica (Patient) - ‘In my mind I find it hard to do a lot of things and those around me would really object to me doing a lot of things.’

Elaine (Patient) - ‘I think it’s just got so bad over the past year that they think that curtailing me in the house is the easiest way. But I feel like it’s the most dangerous way for me. Because I just feel like I could hit my head off the coffee table.’
Both Lisa and Conor felt that their families either did not want to be involved in helping them manage their epilepsy or could not offer anything more to them.

*Lisa (Patient)* - ‘Well I would say generally my parents are a little bit, I’m starting a rant about my parents now (Both laugh), are a bit like disconnected in general from the whole health and epilepsy situation.’

*Conor (Patient)* - ‘There’s nothing they can do, you know. What could they do, you know? Not anything really. I never told a lot of them. Most of them I didn’t tell, most of them. Just never think about it really, you know. I never had a seizure when they were there.’

Most interviews with PWE and carers had an element of discussion surrounding the role family members and carers play in helping PWE manage their condition or how epilepsy has affected family dynamics and relationships. The role of family members and carers was not as widely discussed in interviews with HCPs. Donna spoke of their role in collecting information surrounding a PWE’s condition and communicating this information to clinicians.

*Donna (NCHD)* - ‘Often if it’s a patient who has a carer and the carer cares and they write it all down and then you get a good record and that’s very helpful. Patients usually don’t know what their seizures look like and they are not aware when they are having a seizure, you always need to have the story from someone else of what’s actually happening.’

Freya acknowledged that the importance of their role was understated and they required more support.

*Freya (ANP)* - ‘I think that they are huge safe guarders for us as in we rely heavily on them to report when things aren’t going well... I’m talking about people with complex epilepsy, so we rely heavily on them to become the expert living with that person at home. We rely on them to do an awful lot, without any real tools other than using the phone and email services to drop us a line’
5.3.5 Theme 4 - HCPs doubt the willingness and capability of many PWE to engage in self-management activities. PWE difficulties with memory and recall and a lack of belief regarding the necessity for self-management prove to be barriers, particularly in the early stages following diagnosis.

Glen believed that a PWE’s philosophy surrounding how severely has epilepsy has affected their life is a predictor of how heavily they will engage in self-management activities for their condition.

Glen (CHD) - ‘My feeling is the most important self-management point is the patient’s philosophical view of their epilepsy. I use the word philosophy of mind, rather than psychology. I think philosophy of mind is probably more open to intervention...There’s behavioural modification you can do to manage the psychology of mind. But the philosophy is usually how a person thinks, some of it is open to manipulation. But some of it is not you know. You know when you’re talking, I just know when I’m talking to somebody that they’re philosophically, people talk about these concrete thinkers. Everything has to be black and white. Probably that person with the one seizure in their life, who feels their life is trashed, is not immediately open to, not easily open to change. Certainly not by me or the team here you know. Maybe there’s some way, like you know that...That might change them a little bit. It probably wouldn’t change them philosophically. But it would make them accept this more easily. But I think it is hard to change someone’s outlook.’

We see this variation in how PWE philosophically view their own epilepsy with the perceived level of restriction epilepsy has placed on their own lives. Alan, Lisa and Conor did not believe epilepsy was holding them back significantly in their lives.

Alan (Patient) - ‘It hasn’t held me back with anything. If someone said “Why can’t you do that?”, I’d go and say “Why?” and we’d see how we go from there. Most of the time I don’t have many problems’

Conor (Patient) - ‘Well it’s no issue with me. If somebody asked me I’d say “ah yeah, they told me I have epilepsy” you know.’

Lisa (Patient) - ‘Also I’m a pretty high functioning person with epilepsy you know. I’m pretty like you know, I’ll bounce back after a few days for the most part.’
Conversely, Jane and Elaine felt that epilepsy was holding them back in various aspects of their lives.

Jane (Patient) - ‘It’s funny, I’ve got upset about it recently. When I say recently... I think about it every single day. And I could be in work, I may not be in work, but it’s something that is just there all of the time. I never thought I would be the type of person that would let this get in the way. Never, ever thought it, but I have let it just suck the life out of me. Like my family have said it, that I’ve let this take over my life and I never thought it would. You know, because I was fine for years but is that why I never let it take over my life because I was fine. I knew right, give it a year and I’ll be back driving. Do you know, it’s grand I can cope with that. Maybe stupidly I thought it would be the same this time. But it’s been five, over five years now and nothing has changed. Nothing.’

Elaine (Patient) - ‘I suppose it’s just made my life more and more difficult you know. I’ve wanted to do more and more and more. And it’s just, like I wanted to be a community worker and I wanted to do more with homeless people. And that was always my aim. But I just started getting sick...Lately I’ve just felt...ah it’s like it’s really impacted on me. Because I’ve always kind of seen myself as a person that was strong and outgoing and just wanted to do and have fun. But now it’s kind of hiding away, because I think I’m going to die at any moment.’

HCPs found that often the PWE they engage with on the TAL and email services are ones who have bought into their diagnosis and are actively self-managing their condition on a day-to-day basis. HCPs said that some PWE who are in a sense of denial or unwilling to accept that they have epilepsy do not want to engage with the DML Service.

Ellen (ANP) - ‘There’s so much that individuals can do themselves...There are systems out there, but I suppose some people, some individuals with epilepsy don’t want to link in with these services. They don’t want to admit they’ve epilepsy’

Donna (NCHD) - ‘The problem is I think you always get the ones that are already interested that have bought into the diagnosis and have bought into looking after themselves. I think we provide a lot of services that can help, like the telephone line, the emails services, but the patient will have to want to engage. If someone doesn’t want to engage with their diagnosis all those services are great but you know, if you don’t want to know about
PWE spoke of the difficulty that can be involved in accepting their diagnosis and making adjustments to their lifestyle afterwards.

Fiona (Patient) - 'Because I refused to accept it for so long. And I went out and I did the things that I used to do before. I didn’t want to accept, I wanted to be on holidays away from the condition as much as like, you know, work, or anything like that. I actually wanted to escape the fact that I have to deal with that. So by accepting it, it’s probably better psychologically mentally for me. So that I could deal with that and that could go away. And like there’s constant in my life. That I can come to an acceptance of that.

Lisa (Patient) - ‘When I was younger I used to go out a lot and just be kind of, you know, pretty I suppose carefree. And I kind of look back and think was I maybe avoiding like just worrying about anything. You know you just want to be normal. Yeah so I didn’t really have any kind of plan or management (Laughs) in place.’

Donna empathised with the difficulty PWE experience following their diagnosis and their reasons for not wanting to engage in management activities or adjusting their lifestyle.

Donna (NCHD) - ‘I think I could see my own struggle with that, because it reminds you twice a day that you have a condition that you don’t want to be thinking of. And often patients don’t have seizures for months and months and then it’s very easy to think “oh maybe it just won’t happen again. Maybe it will just go away” which is probably a normal human thing to do.’

Misconceptions of epilepsy that PWE had at the beginning of their epilepsy journeys informed how some participants said they managed their condition.

Keith (Patient) - ‘I don’t even know if it was the denial, maybe denial was the wrong word, I didn’t realise the seriousness maybe of the condition, I’d never seen somebody else take, have a seizure, I’d never, I don’t know anybody else with epilepsy. So yeah I probably just didn’t take the condition seriously enough to warrant taking medication.’

Conor (Patient) - ‘When they told me I was epileptic I didn’t believe
them “they don’t know what they’re talking about” you know what I mean...The wife’s uncle had it and I remember him falling into, at the fire nearly, you know, and pulling him up and you know. And another chap I used to go to school with, and he used to bite his tongue. That’s what epilepsy was to me, you know, never thinking that mild, like I have, that it’s a different form of epilepsy I suppose...’

Some PWE questioned why they needed to manage the condition in the first place.

Andrew (CfPWE) - ‘That doesn’t make him stand out because he’s becoming conscious of the fact that there are limitations on what he can and can’t do. So he’s starting to kick back, he’s at that age where he’s starting to kick back, “do I have to take these meds?”.

Keith (Patient)- ‘Like I was being told “you’re going to have to take this for the rest of your life”, I think that was more so why I was reluctant. Yes, I was still in denial but it was more so the commitment to taking the medication for the foreseeable future that turned me away from the medication initially.’

Beverley (CfPWE) - ‘I think what happens is, so when you are feeling okay you’ll tend to let it drift.’

Memory difficulties were mentioned by numerous PWE interviewed. Several PWE perceived their memory as being poor and impacting their ability to manage various aspects of their day-to-day lives.

Harriet (Patient) - ‘My long term memory is very, very poor.’

Hannah (Patient) - ‘Like when I was younger I had such good memory. I used to remember what happened, who was there for my seizures. Now I completely, it’s not that I still know them, but it’s just gone out of my mind like.’

PWE spoke of how they often have no recollection following seizures.

Jane (Patient) - ‘Complex seizures, isn’t that it? Yeah, where you don’t remember. I remember nothing of them. So they’re the more unusual ones. So they can happen equally as frequently, shall we say. But they’re the ones where I do sort of embarrassing stuff or you know, I have to be told about them as well obviously, because I don’t remember.’
Brenda (Patient) - ‘No, I don’t remember any of them. I’ve never even been told, my memory would be extremely foggy for a couple of days after them. And I would constantly ask those around me what happened, same question over and over again, what time is it, all those things’

PWE also mentioned their difficulty in concentrating or recalling information as a result of their condition.

Keith (Patient) - ‘And with college work it is a bit annoying, just my ability to recall information or retain information sometimes. And concentration, so sometimes in a lecture no matter how hard I try I’m not, I have a lot of trouble concentrating and again that was never a problem before.’

Deirdre (Patient) - ‘If he asked me to do something, if I don’t write it down, I forget. And that’s one of the things we actually argue over, is me forgetting stuff. And I don’t want my memory, like a problem with my health, to be an issue with us arguing. I don’t want it, you know.’

Lisa spoke of how she does not have the ability to remember when her seizures occurred and consequently cannot record when they happen.

Lisa (Patient) - ‘So I can’t record absences, I wouldn’t know when I have an absence generally. And that’s always been a bit of a difficulty in telling my doctor. You know he’ll be like “how many?” and I’m like “I’ve no idea”.’

Lisa (Patient) - ‘Like I think what’s hard for me in tracking them is generally that like they want you to input like specific numbers. Where I, you know, because I don’t know with my absences how many I’m having.’

Keith said that memory issues are a bigger deal to him than seizures and it is something he would like to address.

Keith (Patient) - ‘I would love to be able to do something about concentration or memory, I have issues with now. I know there’s not like a magic tablet that I can take to stop it but I think that’s a bigger deal for me than stopping the seizures, is fixing that.’

HCPs acknowledged that memory certainly was an issue for many PWE and it affected
their ability to manage their condition.

*Beatrice (ANP)* - ‘Sometimes there can be cognitive issues with their medication, with their seizure control, with their ability to retain information.’

*Donna (NCHD)* - ‘They also have lots of side effects from their medications which can also affect their lives a lot. It can make them depressed, it can make them drowsy, it can make them not able to concentrate’

*Donna (NCHD)* - ‘Some patients have too many seizures to record it all, some patients live on their own they don’t know they are having these seizures. It’s very hard to find out how many seizures they are actually having. But often it’s just not, I mean if you think about it yourself having to write a diary of every time you had a seizure. I wouldn’t be able to do it. I can totally understand people don’t do it’

**5.3.6 Theme 5** - A lack of data integration across eHealth platforms, the perception of digital interactions as being impersonal, privacy concerns and a lack of perceived utility are barriers perceived by PWE, carers and HCPs to using eHealth tools for self-management.

In the field of epilepsy self-management, an area that has been targeted in the past by developers has been apps or platforms which facilitate PWE or carers to record information relating to a PWE’s seizures.

Freya and Camile perceived that many PWE are not capable of engaging with eHealth tools such as these

*Freya (ANP)* - ‘And people with complex epilepsy, I think then sometimes apps don’t speak to them, as in they may be dealing with severe cognitive issues, they may be dealing with very frequent seizures that kind of lends (to a situation) that other people are caring for their epilepsy and not them’

*Camila (ANP)* - ‘I personally like to see seizure diaries but I don’t think they’re great at that. The vast majority probably aren’t super at that.’

It was mentioned in some interviews that younger PWE would be more likely to engage with digital tools in order to self-manage their condition. Ellen provided the age range she believed would be willing to engage with eHealth.
Ellen (ANP) - ‘My opinion it would be young like teenager, sixteen, up maybe to the age of forty. Like digital tools would suit people of a generation but it won’t suit maybe older people who are not as technology savvy or younger kids say, you know, with access to internet and stuff like that.’

Holly agreed that she also felt older groups might be less likely to use such a tool. She also said however that younger PWE might not want to engage either because they do not want to, rather than lacking capability or having the opportunity to do so.

Holly (RD) - ‘Maybe some of the older groups mightn’t be, and it could be a younger patient, or maybe it’s a carer doing things. And they might be elderly and yeah, they’re just not comfortable with computer stuff. But not necessarily, there are some young people that just don’t want to email, technology savvy people who use apps day-to-day for everything’

Camila felt that while younger PWE might use apps for different aspects of their lives, this did not mean they were more informed about self-managing their epilepsy compared with older individuals. From her experience providing care, some older PWE who are concerned about their condition come to appointments equipped with data to provide their HCP with as much information as possible to help treat them.

Camila (ANP) - ‘I think we would have some younger patients who are there with their iPhone throughout the consultation and clearly savvy enough with stuff like that and I’m sure use apps for lots of things but they can be really vague about what their seizure frequency is and you can have an older person who may be, you know, it comes with a lot of anxiety so they’re very much, they can give you facts, figures, when it happened, what happened, dates, times.’

In terms of willingness to use eHealth, PWE highlighted some challenges they perceived as existing to consistently using such tools. Lisa highlighted that the vast number of ways epilepsy manifests makes it difficult to create a digital solution that would help everyone living with the condition.

Lisa (Patient)- ‘But for a normal, inverted commas, person with epilepsy, again like you’re talking about such a broad range of people. That it’s hard to just get one fits all. It’s impossible to get one fits all.’
Monica mentioned that feelings of hopelessness or despair have impacted her engagement with eHealth in the past.

Monica - ‘I only looked into downloading the app when I came in here. I wasn’t bothered downloading before I came in, because I was just, I thought I was depressed, but the psychiatrist just thinks I’m in mental despair, not from being in here. But from having my illness.’

Keith mentioned that his seizures would need to be detected automatically for him to engage in a meaningful way.

Keith (Patient) - ‘I don’t think I would do it every day. I mean if I wake up tomorrow morning and the app tells me that I had a seizure during the night, then I will just look back, I will remember what I did the day before, I hope, provided I don’t fall and bang my head with the seizure. But I hope, yeah I presume I’ll remember what happened during the day and I will go and log maybe just that day. And then I can see from each of them if there’s any similarities, there might not be but yeah.’

With regard to wearable devices, Keith felt that a subtle device would be required. As he prefers to keep the management of his condition a private matter, he does not wish for eHealth tools to draw questions from people around him about what they are.

Keith - ‘Something that looks more like a watch is going to get less questions, if I’m wearing something that just has a metallic face and there’s nothing really there, you’re obviously going to get questions and I can’t say oh it’s a whatever watch because people, like nowadays will look at that up, they’ll be interested for themselves so they will go and look it up and you’re not going to find whatever rubbish I’ve tried to pass them off with.’

Both Brenda and Lisa highlighted a concern they had with increased technology usage. They both believed that it could cause anxiety and stress for PWE and carers.

Brenda (Patient) - ‘I think for me, because I’m reasonably well, that I just started looking at it and analysing it and like what is this, like have the opposite, it’s like if you have a sleep App on your watch or something you know people can have a tendency to over analyse it. If they didn’t have it they may not.’

Lisa (Patient) - ‘But by becoming obsessed with looking out for research
and screens and you know that clearly goes against trying to take care of yourself from an epilepsy seizures point of view.’

Currently, data inputted into these eHealth tools is not integrated with the national epilepsy electronic patient record (EEPR) or any other electronic health record (EHR) accessible to clinicians. Donna outlined this below

Donna (NCHD) - ‘Yes, other than the patients being asked or told to think about things like seizure apps which we don’t have access to, we can’t look up someone’s seizure app at the moment, you know we can’t do anything like that.’

Beverley mentioned how the lack of integration was frustrating because she had to repeat the ‘story’ of Gary’s condition to HCPs when he received care from different providers.

Beverley (CfPWE) - ‘You are telling the same story over and over again and it’s true of other people I know who are into hospital for many different things you know, always having to repeat, whereas if you have everything online or in some kind of technology space. You know you can say “well look this is actually my history and this is all of it and it’s a hundred per cent accurate”.

Lisa mentioned that if there was integration of information across multiple platforms such as Google Calendar for PWE, it would be great, however the regulatory challenges she understood which existed surrounding integration of patient data from multiple sources was cited as a challenge for her and other patients.

Lisa (Patient)- ‘Well I suppose you could like, in that if someone were to download the app and maybe they’d be happy to pay for it you know to download the app that it could gain access to your Google calendars, it’d get access to, what else do I use, an alarm. It could gain access to you know and you could have reminders like just before you go to bed. Where you’re saying oh Google can I get information from this calendar? Is it okay? And then you’re into GDPR b******t and like it’s so annoying.’

Some PWE and carers raised issues surrounding privacy and consent in relation to technology usage. Brenda was concerned about how her personal information could
be made available to third parties without her permission if she used an app.

*Brenda (Patient)* - ‘But you know just as long as my information is not out there un denounced to me and gleaned off somewhere it shouldn’t be. That’s the key things I’d look for.’

Deirdre stated that any information you input onto an app should only be shared with anyone else with your consent.

*Deirdre (Patient)* - ‘This app with your permission and only with your consent, there would have to be a consensual thing on it as well, saying “yeah, I consent to them being able to see this”.’

Hannah said that if she was experiencing frequent and dangerous seizures, privacy issues would be of less concern to her if it meant that she would be safe.

*Hannah (Patient)* - ‘You could get the mat on the bed. You know you could get stuff like that. You could get CCTV in; you know like a baby alarm, it might alert you. But you’re very much crossing a privacy line there. Now certainly I have no problem crossing it if we were back where we were two years ago and you really needed the vigilance.’

In some interviews the prospect of conducting appointments via telephone call or video conferencing software was discussed. A number of PWE expressed some concern about appointments taking place via telephone and not video call if they were taking place virtually. Below, Monica outlined how she felt that it would be easier to think of questions if you could visually see the HCP. She also thought that more fruitful discussions would take place if you could see the HCP and it would not just be a series of questions from the HCP to the PWE.

*Monica* - ‘Because I think when you’re looking at someone one to one, you can think of more questions. Rather than on the phone call. Because I think when we use our phone people normally ask us questions like, “hi how are you, have you any plans today”, this that and the other. Rather than on Skype you kind of have discussions more than just direct questions. Because I think I’ve learned from having a phone myself, this could just be me, people run out of credit. People don’t want to talk to someone on a different network. So it’s kind of a just check in thing.’
Holly said that miscommunication was possible if more interaction between PWE and HCPs was to take place virtually.

_Holly (RD) - ‘You know, I suppose the way we, when we communicate in person, we have a lot more verbal and non-verbal communication. Whereas with the written word on e-mail, or messaging on an app it’s a little bit more open to interpretation. So that can pose its own challenge.’_

Ivan said that he had PWE coming from around Ireland to attend his clinic. He believed that these patients enjoyed seeing him in person for several reasons.

_Ivan (CHD) - ‘I have patients from all over the country who want to come physically and see me, I would think. They want to come. They like coming and patients like coming to see their doctor. I have patients, I have a big private practice of patients from all over the country, I think two patients, they’re related, from [location in South of Ireland]... they love coming up to Dublin to see me. Not because we have good banter and they come up and it’s an excuse for them to go in town shopping.’_

A number of HCPs expressed that, on the whole, they were not overly impressed by the quality of eHealth tools available commercially.

_Donna (NCHD) - ‘The little I do know about them, I’m not overly, massively impressed. I think the challenges outweigh what benefits they’re giving at the moment but I would be happy to be proved wrong in that.’_

_Glen (CHD) - I’m not convinced there’s anything. Like if somebody said to me “oh is there an app you would recommend?” the one that I know that I’ve seen in action and it hasn’t been a bad addition is a thing called Seizure Tracker.’_

_Beatrice (ANP) - ‘In some cases they may be redundant, they may not offer them anything in addition to their treatment.’_

_Ivan (CHD)- ‘I don’t know. I don’t still have a feel for it. And again, as I said, I’m supposed to know about this stuff and I still don’t. And I’d say I’m not the only one. I don’t have a good feel for where we are with devices and how much they’re going to impact on the quality of epilepsy care, I really don’t’_
A grievance held by HCPs with regard to commercially available eHealth tools was their associated cost. Both Beatrice and Camila said that this acts as a barrier to them promoting eHealth usage among PWE they provide care to.

Beatrice (ANP) - ‘I don’t tend to talk about that because, number one, I haven’t got that much experience with it and, number two, you have a monthly cost and I suppose I don’t think that’s necessarily right for a patient to feel that they need to have a subscription to a company. Not everyone will be able to have full-time employment and as a clinician, I wouldn’t want to have a patient feel that they needed to have this watch in order to manage their condition at a cost to them when they may not be able to afford it’

Camila (ANP) - My issue with it is patients can be really keen on it, it’s not subsidised, it’s expensive to buy, so the reality is it’s not within the means of a lot of our patients so I find that very frustrating

A number of HCPs expressed the notion that PWE who will use new eHealth tools are already self-managing appropriately and it is merely ‘preaching to the converted’.

Glen (CHD) - ‘You know that whole adherence question. So what device do we currently think will take care of that. And I don’t think they’re good enough. I think they’re clunky, they rely on a certain amount of smarts that the patient who uses them already has. Now you’re speaking to the converted and people who like to use those do it for convenience rather than real information.’

Donna (NCHD) - ‘The problem is I think you always get the ones that are already interested that have bought into the diagnosis and have bought into looking after themselves. They are the ones that will be happy to use it, it’s like people who want to wear their Fitbit are probably people who want to be fit.’

Holly (RD) - ‘The people who would be more likely to use it, are they more likely to get information online anyway? And how are we going to capture the people who don’t, how are we going to engage with them?’

Ivan (CHD) - ‘There’s going to be a place for eHealth and digital health but again, it’s basically the good things about all of the stuff that we talked about for a proportion of the patients who need that’

Donna (NCHD)- ‘I think that the people we are really trying to reach they are usually quite removed from technology, not all. I think there’s
probably a gap where you know even if you had the technology you
probably still wouldn’t engage them'

5.3.7 COM-B Analysis of Data

After defining each of the five themes, the challenges identified in relation to using eHealth for epilepsy self-management were mapped onto their associated COM-B constructs.

The barriers identified at the level of PWE and carers are summarised in Table 17. While barriers exist in terms of the social and physical opportunity, automatic motivation and physical capability constructs, the primary barriers to using eHealth for epilepsy self-management appear to lie in their psychological capability and reflective motivation.

<table>
<thead>
<tr>
<th>Reflective Motivation</th>
<th>Lack of belief regarding the necessity of carrying out self-management activities.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Lack of data integration across currently available eHealth mobile 'apps', wearable devices and EHR’s used by HCPs.</td>
</tr>
<tr>
<td></td>
<td>Perception of eHealth as being less personal than face-to-face interaction.</td>
</tr>
<tr>
<td></td>
<td>Privacy concerns surrounding how an individual’s healthcare data is used.</td>
</tr>
<tr>
<td>Psychological Capability</td>
<td>Memory issues experienced by PWE and an inability to recall seizures.</td>
</tr>
<tr>
<td></td>
<td>Lack of knowledge surrounding self-management tasks from PWE and carers.</td>
</tr>
<tr>
<td></td>
<td>Lack of experience using eHealth to consistently monitor health.</td>
</tr>
<tr>
<td>Physical Capability</td>
<td>Prolonged screen-time perceived as dangerous for PWE.</td>
</tr>
<tr>
<td>Automatic Motivation</td>
<td>Viewing one’s own healthcare data on an eHealth platform perceived as a source of stress.</td>
</tr>
<tr>
<td>Social Opportunity</td>
<td>Lack of subtlety perceived as existing with commercially available wearable devices.</td>
</tr>
<tr>
<td>Physical Opportunity</td>
<td>N/A</td>
</tr>
</tbody>
</table>

Table 17 - Barriers identified at PWE/carer level to using eHealth for epilepsy self-management

The barriers identified at the level of HCPs are summarised in Table 18. Barriers spread across the social and physical opportunity, reflective motivation and psychological
capability domains. In terms of the social opportunities, the training of HCPs and cultural norms existing within the delivery of epilepsy care means that treating physiological symptoms rather than psychosocial ones. A lack of integration with general practice is also viewed as a barrier to promoting care with an increased emphasis on self-management and eHealth. At the level of physical opportunity, the lack of staff, an ‘out of hours’ care service, information on website and integration of existing eHealth apps and wearables with the EEPR. In terms of reflective motivation, HCPs expressed concerns with eHealth tools disrupting workflow processes and doubts about how useful current eHealth tools that are available for epilepsy self-management actually are. From a psychological capability perspective, barriers were identified in terms of the lack of perceived expertise in the areas of self-management and holistic care and knowledge surrounding the functionality of eHealth tools.

<table>
<thead>
<tr>
<th>Reflective Motivation</th>
<th>Concerns about new eHealth disrupting current workflow processes.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Lack of perceived utility of current eHealth tools for epilepsy self-management.</td>
</tr>
<tr>
<td></td>
<td>Perception of eHealth as being less personal than face to-face interaction.</td>
</tr>
<tr>
<td>Physical Opportunity</td>
<td>Lack of staff.</td>
</tr>
<tr>
<td></td>
<td>Lack of ‘out of hours’ care.</td>
</tr>
<tr>
<td></td>
<td>Lack of self-management information available on the DML Service’s website.</td>
</tr>
<tr>
<td></td>
<td>Lack of integration of commercially available eHealth apps and wearables with the EEPR utilised by HCPs.</td>
</tr>
<tr>
<td>Psychological Capability</td>
<td>Lack of expertise among DML Service’s staff in the areas of self-management and holistic care.</td>
</tr>
<tr>
<td></td>
<td>Lack of knowledge from HCPs surrounding what functionality exists within currently available eHealth tools.</td>
</tr>
<tr>
<td>Social Opportunity</td>
<td>The delivery of care from HCPs tends to focus on physiological symptoms rather than psychosocial ones.</td>
</tr>
<tr>
<td></td>
<td>Lack of integration with General Practice surrounding self-management support for PWE.</td>
</tr>
<tr>
<td>Automatic Motivation</td>
<td>N/A.</td>
</tr>
<tr>
<td>Physical Capability</td>
<td>N/A.</td>
</tr>
</tbody>
</table>

Table 18 - Barriers identified at HCP level to using eHealth for epilepsy self-management
5.4 Discussion

This study demonstrates that a number of barriers exist at patient, carer and healthcare provider levels towards increased self-management of epilepsy and use of eHealth to facilitate this.

A diverse sample of PWE and carers shared their experiences of living with epilepsy and the challenges they faced in managing their condition. The inclusion criteria in all three populations were not strict. It did not matter what syndrome of epilepsy the patient had been diagnosed with, nor how frequently they had seizures. Family members and carers who played any role in the care of PWE were invited, not just those who provide care full-time for a PWE. HCPs who deliver relevant dedicated epilepsy treatment were invited to take part. The heterogenous nature of the epilepsies means that it affects individuals and those around them in many ways.

While previous studies have used similar qualitative research methodologies in capturing the lived experience and attitudes of PWE [101,240,241,290–292], this study uniquely included the participation of carers for PWE, HCPs delivering specialist epilepsy care and a behavioural framework to identify future intervention functions to address the challenges identified.

Broadly, sentiment existed that PWE and carers are open to the idea of eHealth and technology playing a greater role in their day-to-day lives to aid the management of epilepsy. However, barriers primarily exist in terms of the psychological capability and reflective motivation of PWE and carers to engage with digital tools for self-management.

From a psychological capability perspective, PWE expressed how their condition has affected their memory and ability to recall information, which hinders their ability to document when seizures have occurred and if they have taken their medication or not. From a reflective motivation perspective, PWE also displayed a perceived low-level of confidence in their memory ability, often using disparaging language to describe their
ability to remember tasks, objects or events. Studies indicate that the prevalence of memory problems in people with refractory epilepsy is between 20-50% and more than half of patients referred for neuropsychological assessment reported memory difficulties in their daily lives [293]. For some PWE, a large discrepancy exists between the severity of the observed memory disturbances as indicated with memory tests and the severity and impact of these memory problems in daily life. Patients may have mild memory disturbances but experience such extensive memory problems that they are hardly able to function in their daily lives. In cases such as these, it is likely that these memory problems are more related to a loss in memory confidence instead of a loss of memory competence [294]. Poor memory performance in PWE can often become more of a function of self-doubt than actual lack of ability, even if these abilities are mildly disturbed. An intervention to aid PWE with memory could focus on boosting lowered memory self-efficacy beliefs which could aid their confidence in performing self-management tasks.

PWE expressed an openness towards using eHealth tools to manage their condition, however they identified a number of challenges that they perceived with existing tools that would prevent themselves and other patients from engaging. Concerns were expressed surrounding the lack of integration of existing tools with other digital aspects of their lives, excessive eHealth usage causing stress and data protection. Previous research has found that PWE’s perceived disadvantages of self-care include confrontation with their condition, emotional stress, being defined as a patient and privacy concerns [175]. A lack of equity was also cited as a disadvantage to increased eHealth usage in previous research, and the notion that PWE are concerned that not everyone is able to work with eHealth tools was seen in the results of this study too, with PWE and carer participants believing eHealth may not be suitable for older patients in particular. The long term engagement of users has been cited as the key to the successful adoption of eHealth technology in chronic health conditions [101]. As will later be outlined in Chapter VI, participants in this study were invited to further
discuss and ideate about the role they would like eHealth to play in self-management of their epilepsy.

Family members and carers were shown in this study to play an integral role in the self-management of epilepsy. In numerous interviews, PWE described various ways in which their carers helped them navigate living with epilepsy and HCPs outlined the value of carer insight into clinical decision-making. Carer participants shared their experience of the distress caused by witnessing seizures, the learning they undertook to help them manage the condition and the lengths they go to accurately capture data relating to their family members’ epilepsy. Previous research has explored emotional and quality of life impacts on family members following a diagnosis of epilepsy [137,138,142]. The results of this study uniquely contribute the perceived practical challenges faced by carers and family members performing the management of another individual’s epilepsy to this area.

Many of the challenges relating to the beliefs of capability or consequences surrounding eHealth tools were shared by HCPs and PWE. HCPs expressed doubt surrounding the perceived ability of PWE to engage with eHealth, the meaningful value eHealth adds to current self-management practices and disruption to work practices. Research has indicated that HCPs often hold negative views regarding the introduction of new eHealth to their care delivery, with clinicians commonly holding beliefs that electronic systems would disrupt the delivery of care; doubts that these systems can improve patient care, clinical outcomes or improve the quality of medical practice; and distrust in the systems as well as a more general resistance to change [295]. Unlike results yielded from PWE and carers, HCPs perceived challenges as existing in their physical and social opportunities in providing care. A lack of staffing, restricted time with patients and a lack of integration of eHealth data across different platforms were seen as barriers to using digital tools and providing increased self-management discussions with PWE. In addition to an intervention surrounding education, persuasion and modelling, environmental restructuring is necessary to
facilitate HCPs being able to deliver care that focuses on more aspects of self-management than medication prescription and provision.

PWE and carers spoke of their concern at the possibility of increased eHealth usage and emphasis on self-management reducing their opportunity to meet in-person at appointments. These interviews were conducted between November 2019 and March 2020, prior to the onset of the CoVID-19 pandemic when face-to-face interaction was forced to cease as much as possible across society. Chapter V will explore the experiences of PWE, carers and HCPs interacting via eHealth during a pandemic.

5.5 Study Limitations

As is the nature with focused ethnographic research, participants were recruited from a single site where individuals within a group or culture share features, so common behaviours and experiences can be explored. As a result, participants in this study were recruited from one hospital site, limiting the generalisability of the results across other jurisdictions in which epilepsy care is provided.

Data coding was solely performed by JB. It is acknowledged that the collection and interrogation of data by a single researcher potentially limits the validity of the study findings. It is also possible however that data collection and interrogation by multiple researchers could have created significant multiple biases between the researchers based on individual personnel assumptions or their own life experiences. Unintentional research bias was minimised by regular meetings between the PhD student and supervisor in which feedback was provided to identified themes presented.

The original goal sample size of thirty participants was not achieved, with twenty five participants completing interviews. Nonetheless, data saturation occurred following completion of interviews with thirteen PWE, three carers and nine HCPs, indicating the additional five interviews would not have yielded significant additional data.
5.6 Conclusion

This study documented the challenges perceived as existing for increased eHealth usage in the self-management from PWE, carer and HCP perspectives. With little exception, the participants in this study felt that barriers existed to moving to a model of care where the patient performed self-management tasks relating to their epilepsy and using digital tools to do this. In describing their lived experiences, attitudes and behaviours, a number of common grievances were found across these three populations about digital health tools for epilepsy management. The identification of these grievances, concerns and perceived challenges will serve as targets for the development of eHealth solutions for epilepsy self-management going forward. In the final chapter, Chapter VI, study participants ideate solutions to the challenges which were expressed as existing towards using eHealth tools for epilepsy self-management.
Chapter VI - Findings: An Exploration of the Perceived Opportunities for Self-Management and eHealth Within Epilepsy Care: Perspectives of People with Epilepsy, their Carers and Healthcare Providers.

6.1 Introduction

This was the final research study associated with this PhD project. The studies outlined in this thesis thus far have focused on perception of medication adherence and medication error, barriers to epilepsy self-management and eHealth usage and attitudes towards telemedicine for chronic epilepsy care. In Chapter II, the major findings were that 40.9% of respondents to a self-administered questionnaire reported sub-optimal adherence to ASMs and 28.5% perceived that they were subject to a medication error. Audit data collected in Chapter III displayed high levels of satisfaction with telemedicine from both a clinician and patient perspective, with some concerns from clinicians about the suitability of certain patients for using telemedicine for their care going forward. Chapter V indicated that behavioural barriers exist in terms of the psychological capability and reflective motivation of PWE and carers to engage with digital tools for self-management, with additional environmental barriers existing in the social and physical opportunities for HCPs to provide self-management care and resources to PWE.

This objective of this study was to provide participants with an opportunity to ideate solutions to overcome perceived barriers or challenges identified in these earlier studies. This study took the form of focus group research, where participants were provided with an environment to express their ideas about how epilepsy care can be improved going forward in relation to self-management and digital health usage.

6.2 Methodology Summary

The methodology employed for this study is outlined in Chapter IV. This research took the form of focus groups, the second qualitative methodology employed in the focused ethnographic approach taken during the qualitative portion of this PhD research. The
first qualitative methodology, as outlined in Chapter V, consisted of semi-structured interviews with participants recruited from the DML Epilepsy Service at SJH. During this first phase, participants outlined the challenges they perceived as existing with current approaches to self-management and using eHealth for epilepsy related management tasks. This second phase of research wished to bring participants from the first phase together in an environment where they could collaborate to ideate solutions about how epilepsy care could change to facilitate a greater degree of self-management and use of eHealth tools. It was decided that focus group discussions would be an appropriate method to facilitate collaboration and ideation among participants. Each of the participants who completed a semi-structured interview and provided their consent to be contacted again received an invitation to take part in a focus group. With the ongoing CoVID-19 pandemic, in the interest of participant safety and adherence to public health guidelines, focus groups took place online via Zoom. Participants joined via audio and video. Miro software was utilised as a platform to display information to participants during the focus groups. Following an icebreaker, JB presented an overview of the major themes which emerged from the semi-structured interviews. After the results were discussed, participants were given five minutes to consider and write down their responses to the following two questions:

1. How might we balance face-to-face and virtual care going forward?

2. How might we do things differently to encourage more active self-management?

After five minutes had elapsed, participants shared their contributions. JB presented all of them together and summarised what was said. Once participants were happy and had nothing further to say, JB stopped sharing his screen and recording of the group interview ceased. Audio recordings of the groups were transcribed verbatim. In the same manner as the semi-structured interviews, focus group transcripts were analysed by the PhD researcher JB using Braun & Clarke’s six-step TA with an additional COM-B mapping step.
6.3 Results

6.3.1 Final Sample

Each of the twenty-five participants who took part in a semi-structured interview during the first phase of the qualitative research project were contacted and invited to take part in this focus group phase.

Three PWE who took part in a semi-structured interview declined to take part in a focus group, the reasons for which being unavailability in their schedules and sickness. Four HCPs who took part in a semi-structured interview declined to take part in a focus group, the reasons for which included maternity leave, sickness, starting a new position in a new jurisdiction and unavailability in their schedule.

One PWE who consented to take part in an interview and focus group but did not take part in an interview due to unavailability, reached out to JB expressing an interest in taking part in a focus group, thus was included in the final sample for the focus groups.

Four new members of staff who joined the DML Service between semi-structured interviews ending and the focus groups beginning expressed an interest in taking part in the focus groups. After being provided with the full details of the project by JB, these four HCPs provided written consent and were included in the final sample for the focus groups.

Each of the three carers who took part in a semi-structured interview also took part in a focus group. In total, twenty-three participants took part in one of eight focus groups. These eight focus groups were held between November 2020 and April 2021. The make-up of each of these focus groups is described in Table 20 and the demographic characteristics of the PWE, HCP and carer participants is outlined in Tables 21, 22 and 23.
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>HCP</td>
<td>Healthcare provider</td>
</tr>
<tr>
<td>PWE</td>
<td>People with epilepsy</td>
</tr>
<tr>
<td>CfPWE</td>
<td>Carer for a person with epilepsy</td>
</tr>
<tr>
<td>ANP</td>
<td>Advanced nurse practitioner</td>
</tr>
<tr>
<td>RD</td>
<td>Registered dietitian</td>
</tr>
<tr>
<td>CHD</td>
<td>Consultant hospital doctor</td>
</tr>
<tr>
<td>NCHD</td>
<td>Non-consultant hospital doctor</td>
</tr>
</tbody>
</table>

Table 19 - Abbreviations used in results section

<table>
<thead>
<tr>
<th>Focus Group</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus Group 1</td>
<td>2 PWE</td>
</tr>
<tr>
<td>Focus Group 2</td>
<td>3 PWE</td>
</tr>
<tr>
<td>Focus Group 3</td>
<td>2 PWE, 1 CfPWE</td>
</tr>
<tr>
<td>Focus Group 4</td>
<td>3 PWE</td>
</tr>
<tr>
<td>Focus Group 5</td>
<td>4 HCPs</td>
</tr>
<tr>
<td>Focus Group 6</td>
<td>3 HCPs</td>
</tr>
<tr>
<td>Focus Group 7</td>
<td>1 PWE, 2 CfPWE</td>
</tr>
<tr>
<td>Focus Group 8</td>
<td>2 HCPs</td>
</tr>
</tbody>
</table>

Table 20 - Breakdown of participants in each focus group
<table>
<thead>
<tr>
<th>Age of Participant (Years) (n=11)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean 41</td>
<td>Minimum 18</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age of Seizure Onset (Years) (n=11)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean 21.55</td>
<td>Minimum 9</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Education Level (n=11)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Junior / Intermediate Certificate 1 (9.1%)</td>
<td>Technical / Vocational Qualification 1 (9.1%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Working Status (n=11)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Working for payment / profit 5 (45.5%)</td>
<td>Student / Pupil 2 (18.2%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Current Living Situation (n=11)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Living with parents 6 (54.5%)</td>
<td>Living with partner and/or children 5 (45.5%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Seizure Frequency (n=11)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily 1 (9.1%)</td>
<td>Less than daily but more than once a week 4 (36.4%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Prescribed Epilepsy Treatment (n=11)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1 ASM taken daily / twice daily 1 (9.1%)</td>
<td>2 or more ASMs taken daily / twice daily 10 (90.9%)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Supplementary Epilepsy Treatment (n=11)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Dietary Treatment 1 (9.1%)</td>
<td>Vagus Nerve Stimulation (VNS) 2 (18.2%)</td>
</tr>
</tbody>
</table>

*Table 21 - Characteristics of PWE sample (n=11)*
### Table 22 - Characteristics of HCP sample (n=9)

<table>
<thead>
<tr>
<th>Position (n=9)</th>
<th>Nurse 4 (44.4%)</th>
<th>Dietitian 1 (11.1%)</th>
<th>Non-consultant hospital doctor 3 (33.3%)</th>
<th>Consultant hospital doctor 1 (11.1%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Years Providing Epilepsy Care (n=9)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>8.94</td>
<td>Minimum</td>
<td>1</td>
<td>Maximum</td>
</tr>
<tr>
<td>Gender (n=9)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male 1 (11.1%)</td>
<td>Female 8 (88.9%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provided care in another jurisdiction (n=9)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes 5 (55.6%)</td>
<td>No 4 (44.4%)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Table 23 - Characteristics of carer sample (n=3)

<table>
<thead>
<tr>
<th>Age of Participant (Years) (n=3)</th>
<th>Mean</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean 54</td>
<td>Minimum 49</td>
<td>Maximum 61</td>
<td>Standard Deviation 6.25</td>
<td></td>
</tr>
<tr>
<td>Gender (n=3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male 1 (33.3%)</td>
<td>Female 2 (67.3%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Current Working Status (n=3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working for payment / profit 2 (66.7%)</td>
<td>Looking after home / family 1 (33.3%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years Caring for PWE (n=3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean 19</td>
<td>Minimum 7</td>
<td>Maximum 30</td>
<td>Standard Deviation 11.53</td>
<td></td>
</tr>
<tr>
<td>Seizure Frequency of PWE they Care for (n=3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than daily but more than weekly 2 (66.7%)</td>
<td>Less than yearly but more than monthly 1 (33.3%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Prescribed Treatment of PWE they Care for (n=3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 or more ASMs taken daily / twice daily 3 (100%)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
A final table (Table 24) of major themes was developed when all focus group transcripts had been thematically analysed using Braun & Clarke’s process (Table 11). As with the presentation of themes in Chapter IV, it must be remembered that these themes were not selected based on their prevalence within the data. Each theme is supported by various direct quotations from the individual texts to illustrate and support their inclusion. For practical reasons, not all supporting material that emerged during the TA process could be included. The data presented in the themes below primarily relates to the data generated during the ideation phase of the focus groups.

<table>
<thead>
<tr>
<th>Theme 1</th>
<th>Using knowledge as a tool to empower PWE to self-manage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Theme 2</td>
<td>Adopting a ‘whole family’ approach to care and providing support to family members and carers of PWE.</td>
</tr>
<tr>
<td>Theme 3</td>
<td>Providing PWE with a choice as to whether they are seen virtually or face-to-face.</td>
</tr>
<tr>
<td>Theme 4</td>
<td>Upgrading the technical infrastructure within epilepsy services and creating an ‘eHub’.</td>
</tr>
<tr>
<td>Theme 5</td>
<td>Developing apps and wearables, which integrate with current clinical systems and help navigate the challenges unique to each PWE.</td>
</tr>
<tr>
<td>Theme 6</td>
<td>Utilising the lived experience of PWE, their carers and other HCPs to better effect</td>
</tr>
<tr>
<td>Theme 7</td>
<td>Increasing awareness of epilepsy among the general public and knowledge of the challenges faced in living with epilepsy</td>
</tr>
<tr>
<td>Theme 8</td>
<td>Establishing reliable eHealth resources to direct PWE to</td>
</tr>
<tr>
<td>Theme 9</td>
<td>Taking a more holistic approach to epilepsy care</td>
</tr>
</tbody>
</table>

*Table 24 - Themes which emerged following TA of focus group transcripts*

6.3.2 Using knowledge as a tool to empower PWE to self-manage

Many PWE expressed that they would like HCPs to provide them with further information about treatments and other aspects of epilepsy.

Monica mentioned that having informational videos readily available to show PWE or their families would alleviate anxiety or fear that they may be experiencing.

_Monica (Patient) - ‘I think if they had more videos and things on hand to what is going on, as in I don’t know if you were shown for your surgery, but when I was getting my vagal nerve simulator put in for my_
Conor said that he would like HCPs to provide further information about medication to patients.

Conor (Patient) - ‘I would like the doctors to explain how the medication works...I am on the Lamictal now, why does other medication not suit me but it would suit other people? I was on Tegretol in the beginning, I had a terrible time with Tegretol but they just didn’t tell me why at all’

Conor (Patient)- ‘They didn’t explain it to me how the medication works really, now I know it’s stop the seizures, but they just [don’t] actually explain to you how this medication is going to work in your brain and tell you what about what it does and why does it not agree with some people. Why did the Tegretol not agree with me what is the difference between me and someone else?’

Alan agreed with Conor and felt that HCPs providing more information about medication to patients would be beneficial.

Alan (Patient) - ‘The medication side-effects should be dealt with at an early stage - that is the one of the notes I made here and I know I was on Tegretol like Conor there and Lamictal and on a higher dosage of both. And they both clashed off each other and I wasn’t allowed to take it and eventually I had to be taken off the Tegretol altogether, it’s things like that. Why is that happening to me, you know there are things probably I didn’t think of asking at the time but yes Conor makes a good point of it there why is this medication not suiting me and why is it doing this to me you know and your balance etc. etc. you know.’

Lucy was of the opinion that more information and education about medication for PWE would certainly be beneficial for self-management and adherence.

Lucy (NCHD) - ‘And [they] need to know about their medication - that they might be facing a situation when people don’t know them. And obviously they don’t know what medication they are on. Sometimes they rely on, “oh you have on the notes what I’m taking, I don’t
remember’. So I would encourage the opposite, to learn what the medication is and what the side-effects are. So basically encourage them to learn about their condition, about their medication. Set reminders, like phone reminders to take their medication in this way to encourage them to take ownership of taking their medication.’

Kate felt that educating PWE was important to fostering an understanding of self-management activities PWE and their families can do to help them with their condition.

Kate (NCHD) - ‘I think education sessions would be important. Particularly if you’re a new diagnosis. And then sessions for you know, women of childbearing age or young women to understand some of the issues there. New diagnosis, to talk about what epilepsy is, why they’re being put on a certain treatment. You know, if that treatment doesn’t work, it’s not necessarily the end of the world. And we’ll do something else. And just so they really understand and what they can do with their lifestyle to help manage it.’

Ellen felt that empowerment of PWE was integral in getting PWE to engage with self-management activities.

Ellen (ANP) - ‘Trying to empower the patients to more self-manage. So that they would probably need us less. Because then their seizures would be well controlled. They’d sort of be on top of it. They’d know what triggered, like have they their lifestyle under the perspective of maybe alcohol, drugs, etc. And also as well they’d link into the relevant services from that perspective...basically to get them to take more responsibility about their condition. And I think once they do that that would actually reflect on the appointments, virtual, face-to-face whatever. Because they’ll only be ringing us when they really need us like kind of thing. And they would have actually managed their condition.’

Lucy felt that it was integral to educate PWE about the importance of self-management activities at their first appointment.

Lucy (NCHD) - ‘In terms of empowering patients, so educate at the first appointment when they are given the diagnosis, educate about the condition. And about how important it is to keep a diary, to learn about their own condition and their own body. About their own triggers.’
6.3.3 Adopting a ‘whole family’ approach to care and providing support to family members and carers of PWE.

Beverley said that she would like to see epilepsy care approached from a whole family perspective, not just as a condition an individual patient is treated for.

*Beverley (CfPWE)* - ‘But one thing I would like to see more going forward, is a whole family approach to the care of somebody who has epilepsy and the reason I say that is because it can be very difficult for the whole family as we said. Like we had two children only a year and half and three years older than Gary at the time, so they were all very young really when Gary was having seizures and it was quite distressing for them to see their brother obviously having seizures. And then as parents, we were dealing with something that we didn’t really have any familiarity with.’

When probed about what this whole family approach might look like, Beverley said that psychological support could play a role.

*Beverley (CfPWE)* - ‘There could be more for the whole family. I’m not really sure what that is but I suppose I’m thinking more in terms of, you know, psychological supports as well, you know, access to people who can talk you through things. I’m not talking about more from the neurologist necessarily because obviously they have a role which is very specific in this in terms of the patient and the nurses similarly, even though the nurses were fantastic from a parents perspective. But anyway that’s one thing I feel quite strongly about.’

Fiona said that she would like to see more recognition given to the role family members play in the management of epilepsy. She spoke of how family members who care for PWE need psychological support as well as patients.

*Fiona (Patient)* - ‘More support for the psychological management with epilepsy where both the patient and their carers or family members for those who are close to them...I was stressed out by my mum and all that she was carrying for me or trying to carry for me. She also couldn’t do that, she can’t change me, she can be there in a supportive sense. In that she can write all the information in the world down she can search for everything and it was in fact you know her searching rather than me again sometimes you are just too tired to research. I can’t deal with it.’
Fiona also said that she would like some support to help PWE manage their relationship with other family members while living with the condition.

_Fiona (Patient)_ - 'It’s an entirely separate thing the carers also, as much as they love you and want to be there for you and to fix everything to make your life perfect, they also have to realise that that can be really suffocating and stressful.'

6.3.4 Providing PWE with a choice as to whether they are seen virtually or face-to-face.

In balancing telemedicine and face-to-face care going forward, Jennifer suggested that offering a face-to-face appointment to each patient annually would be appropriate for keeping more ‘stable’ patients engaged with the service.

_Jennifer (ANP)_ - 'Offer a face-to-face once a year for everybody. Now not everybody will want that. But I guess my fear is someone who only needs the twelve month appointment, they’re automatically managing well enough. So I think I have a fear that they’re going to be just put to virtual forever more. But that shouldn’t be the case. We should be offering them either once a year with their clinical team.'

_Jennifer (ANP)_ - 'I think Zoom really should be the way we should be doing all our virtuals. But yeah, technology on the patient side is the issue there. But that was what I would think.'

Ellen also felt that maintaining an element of face-to-face care was important going forward.

_Ellen (ANP)_ - 'I thought from the point of view of virtual and face-to-face. I thought like you could alternate it, because it is nice to see the patient as well. Like as Jennifer said, it’d be awful if they were just constantly on the phone like you know. So I was thinking maybe alternate virtual one, face-to-face the next.'

Ellen spoke of the positives associated with providing telemedicine appointments for patients with intellectual disability (ID) living in residential centres. She said that she would like to see a predominantly virtual model of care continued for this population going forward.

_Ellen (ANP)_ - 'For people with ID I was thinking, especially for people in
Lucy believed that face-to-face care was still necessary for some PWE.

*Lucy (NCHD)* - 'And then face-to-face is still needed for some groups of patients. For those who need the education, for those who will need neurological assessment, say the first assessment.'

Ellen spoke of how she thought it was important to ask patients or their carers how they would like their care to continue, virtually or face-to-face.

*Ellen (ANP)* - 'I think it’s important to ask the patient what they would like. Would they like virtual, would they like face-to-face. And you’d be surprised how many people are saying “this is fantastic, virtual’s brilliant. I don’t have to pay the car park. And I don’t have to pay childminding. I don’t have to take a day off work, it’s just brilliant and this is the way I want to continue”. And people have said that to me - for me in outreach this is all brand new, in my outreach. So therefore patients weren’t used to this. So therefore they really, really like it, they think it’s a fantastic idea.'

Holly agreed that giving PWE a choice about how they received their care would work well going forward.

*Holly (RD)* - 'I think when you’re trying to balance it going forward its offering both options and maybe giving the patient a choice. So I can see in my own service that it would definitely be a blended approach. I suppose I’ve always used kind of tele health, but more telephone rather than video calls. And maybe there was a little bit of my own discomfort with the video calls where now that I’m more used to them I can see the value of being able to see each other’s reactions and see each other’s faces, not having met them before, which is different on the phone...So yeah I suppose the balance is offering them both and having maybe a discussion about why I’d say come in to the clinic this visit or actually a video call will be fine for this one. And I think patients really like the
Ciara spoke of her positive experience with telemedicine during CoVID and recognised the value of not having to travel to the hospital to receive care, particularly for patients who live far away.

Ciara (CfPWE) - ‘We’ve all had virtual appointments this year because of COVID...I remember having my first one and thinking “ugh”, but it was actually fantastic. You know, some people that live down the country and they have to travel all the day to get into Dublin to see you know it’s the way forward.’

Andrew said that based on his experience with telemedicine during CoVID, he feels a blend of virtual and face-to-face appointments would be great going forward.

Andrew (CfPWE) - ‘Because of the pandemic there’s been a blend of virtual and in-person appointments. I think what that would allow people to do, two things, is there’s huge time saving if you have a virtual or a Zoom appointment. Your appointment time and date is precise. You don’t have to travel, sit in a waiting room for hours and then have your appointment which is usually about what, 10 to 15 or 20 minutes long. From that point of view, it gives greater flexibility to people to actually have those type of appointments. And then having in person appointments when it’s needed.’

Mary and Lucy felt that it was important to get an initial impression of the PWE’s condition or capability to manage their condition remotely prior to deciding if they are suitable for receiving their care via telemedicine.

Mary (NCHD) - ‘So for the virtual versus face-to-face. So if they’re new patients I suppose we need to triage it first to see if we can manage with phone calls. But I think one face-to-face at least to meet the patient once if they’re new. It’s a good idea. And then if everything is stable to go ahead with phone calls.’

Mary (NCHD) - ‘If they’re stable, phone calls definitely, but if something happens that needs a neurological exam, or mostly a neurological exam. Then obviously a change to face-to-face. But triage and then a review of the needs to change from phone call to face-to-face is needed. Depending on what’s going on I suppose.’
Lucy (NCHD) - ‘So going forward, virtual versus face-to-face. In carefully
selected patients, virtual is preferred. As it would avoid travel
arrangements and travel costs, work disruptions for patients, or carers.
For those who are knowledgeable about their condition and are
comfortable to manage their condition with assessments over the
phone.’

6.3.5 Upgrading the technical infrastructure within epilepsy services and creating an ‘eHub’
Camila understood that some PWE faced distractions during telemedicine discussions.
She thought a good idea to allow patients or carers to eliminate distractions would be
the creation of a virtual platform for appointments which would involve checking in
and waiting before their appointment, similar to how it would be if they were having
their appointment in the outpatient clinic in the hospital.

Camila (ANP) - ‘The first thing I wrote down was an entirely virtual
platform. I suppose one of the things that I noticed from virtual
interactions is sometimes the patient doesn’t schedule it as an
appointment. So if they’re coming to the hospital, they’re focused on
just being in the hospital. They sit there with a book, they wait to be
seen. Sometimes I find when it’s a phone call, there’s children in the
background, or they’re on a bus, or they haven’t kind of scheduled that
time specifically to focus. So there can be distractions in the
background. So an entirely virtual platform would mean that they
would need to check into a room and they stay there.’

Camila also felt that increased use of video-based platforms should take place.

Camila (ANP) - ‘But it is a video based platform, which I think we don’t
use enough of. I think the phone is great and helpful. But I do think the
video offers a lot more.’

Freya similarly ideated about the possibility of creating an ‘eHub’ which would
facilitate delivery of telemedicine to PWE. This eHub would include appropriate
working spaces for HCPs and flexible slots for PWE to book an appointment through
video conferencing software.

Freya (ANP) - ‘Thinking about our own space to be able to manage
these patients virtually, you know, flexible working spaces for clinicians
and for patients. Engaging the hospital to be much more approaching
chronic disease as an eHub maybe. Providing us an eHub within the hospital that patients can know that they can facilitate a Zoom meeting with their clinician at four o’clock in the evening. If they just ring in that morning maybe they want a quick chat over a meeting that someone could be sitting at a Zoom platform, maybe at four o’clock. Because it’s open to them over in an eHealth hub.’

Freya felt that the DML Service’s extensive engagement with eHealth historically would mean that they are in a strong position to apply for grants and secure funding for plans to expand virtual care.

Freya (ANP) - ‘Is there something within the HSE’s plan that we could be part of, given that we really have engaged in virtual care? Maybe we could be part of a project that would give us the resources to use some of those platforms. So, thinking on our feet, when those sort of funding things come up, we could be putting our patients forward as an empowerment exercise to be part of those eHealth programmes.

Camila said she would see the value in developing an algorithm which would allow PWE to be directed to the most appropriate resource depending on the query they present with.

Camila (ANP) - ‘if there was a body of algorithms that a patient [says] “I have this problem”. And they can work through that algorithm so again, a bit of a self-management tool. Or just the first port of call that “I’ve had a seizure” - did you forget to take your medications?, yes, okay. “You don’t need to do anything else, just take your medications”. Like an algorithm that they have for lots of acute things that would arrive into the emergency department. Or if you ring an online clinician with your VHI or whatever it might be. They work through algorithms, I think it would be really nice for our service. So we just need loads of cash for all of that.’

Camila ideated a virtual outpatient department (OPD) which included a multidisciplinary discussion room. In this virtual OPD, different members of the healthcare team would interact with the patient as deemed necessary in order to provide each patient with comprehensive biopsychosocial care.

Camila (ANP) - ‘it’s basically like your OPD but it’s virtually and there’s an MDT discussion room. That the different clinicians can all go into
discuss the patient. They’re separate rooms. So there are rooms for like Epilepsy Ireland personnel, OT, physio, whatever it might be. And the person goes from room to room as is required.

Andrew alluded to this concept in an idea he had where PWE or their families could create appointments through telemedicine at short notice.

Andrew (CfPWE) - ‘I think also you’re looking at technology, it blends in with the first one insofar as you know, having appointments, virtual appointments, and using technology in that way in order to, you know, if you have a worry, you can set up a Zoom appointment or have a phone call or whatever. And that can be done at relatively short notice, you don’t have to wait weeks for an appointment.’

Kate and Ellen mentioned that having the appropriate hardware would be integral to delivering high quality eHealth enabled care. Both wished for increased investment in hardware to facilitate this.

Kate (NCHD) - ‘Then technology, I kind of thought about it more for if it actually just wasn’t the phone. You know if you were using, doing something like this. Then you’re going to need the technology. So you’ll need you know the tablets, you need a proper internet connection as well. Which is then just a wider issue beyond healthcare. You know a wider sort of governmental issue.’

Ellen (ANP) - ‘I think resources are required. Because to get, like it’d be nice, I do everything on the phone. So I don’t see their faces. So it would be nice to actually see their faces...but for me it’s all face-to-face, because currently at the moment in outreach, I think there’s only two PCs with cameras. So a lot of its resources as well.’

6.3.6 Developing apps and wearables which integrate with current clinical systems and help navigate the challenges unique to each PWE

On the topic of apps and wearables being developed to aid with epilepsy self-management, Holly felt that for PWE to use them they needed to be relevant and specific to their needs and help improve outcomes for them, which PWE often can’t see.

Holly (RD) - ‘I think for any self-management piece or for any kind of app or anything, like it just has to be simple and it has to be convenient
for people to engage with it. It also has to be relevant, like what we were saying earlier about like relevant to their needs to what they want to do... I suppose when you’re thinking about self-management it has to address their needs or improve their experience or improve outcomes for them. Which sometimes they might not see that it does.’

Jane spoke of how she would like to see apps and wearables of the future being easier to use than what is currently available.

Jane (Patient) - ‘if technology was easier to use than what I’ve been shown so far. So in other words I’ve mentioned the seizure tracker, this American seizure tracker, essentially what I’ve done, I’ve done myself as far as, I wouldn’t even like to call it technology but you know the way that I’ve managed to track my seizures.’

Andrew believed that technology had a large role to play in PWE becoming more independent and facilitating greater self-management.

Andrew (CfPWE) - ‘In terms of technology, technology is huge, you know. I think the Embrace watch, for example, is a huge help. It’s not perfect but I think as we go forward things are going to get better, they’re going to get more accurate and I think it’s going to help people with epilepsy to become much more independent and self-aware and self-reliant instead of having to depend on other people to actually manage their condition.’

A desire commonly expressed by participants across the three populations was the need for future eHealth developments to integrate the data generated across different platforms. Deirdre ideated the possibility of all hospitals having access to a patient’s data in the emergency cases.

Deirdre (Patient) - ‘I know it won’t happen for a long time but I think there should be sort of a central computer what all the hospitals can if you are in an emergency have access to it. To have access to being a patient and their medication etc. what doctor they are under things like that would be great you know...Save you answering questions like not having to answer questions like that if you are not well you have had a seizure, or like myself, you have had a fall or whatever and that the hospital can just say ok, get this so St. James’ they have your password and they can see your whole history so they know what is going on with you.’
Lisa spoke of how she would like to be able to share her medical history with HCPs abroad if a situation was arise when she was overseas.

Lisa (Patient) - 'If we could share the info internationally or download like a fuller picture, for example this just came to mind quickly because a friend in Spain asked me for my record or my most recent admission to show a neurologist friend of hers. And I realised I couldn’t actually get to it so that would have been really useful...So you could, rather than just you accessing it, if you could also share it with doctors abroad if you’re travelling or that kind of thing, it could be useful.'

Many ideas were generated regarding the future of an epilepsy patient portal or enhancements to the existing PiSCES portal which some of the participants had experience with previously. Harriet added to Lisa’s sentiment above about sharing medical information internationally, with the portal being the means of doing this. Harriet also said that the portal could be used to facilitate communication with clinicians instead of phone calls.

Harriet (Patient) - 'Make the portal fully active, used nationally, internationally. Maybe a chance to connect with the HSE, we spoke about, directly, you know having contact other ways. I mean if it were to become, I don’t know some sort of platform, you know a little pop up, you know how can we help you kind of thing, wouldn’t that be amazing for some people. Rather than having to make that phone call, you know.'

Alan spoke of his positive experience using the portal in the past, highlighting the features which allowed him to write down questions before appointments and the ability to see what medications he was taking.

Alan (Patient) - 'I couldn’t find any faults in it, at least like that if you had a problem and you wanted to type it in, you would turn on your computer and type the problem in and what’s your question and you could only think of your questions there and then. Because sometimes you are in the surgery you just can’t think of your question you would forget them, so you would type it onto your computer, it’s sent in and plus you can see your medications there in front of you.'

Noel was not aware of the PiSCES portal prior to his participation in the focus group.
He said that would be open to the idea of using a smartphone app like this to help manage his condition.

Noel (Patient) - ‘The next one was technological advances...Something as we were saying like an app on your phone or something we could manage it better, at the moment we can’t manage it like, as I say like e-portal, I didn’t know about e-portal.’

Alan hoped that the portal project would continue to operate and that virtual appointments would continue to take place virtually.

Alan (Patient) - ‘I think the portal project part, with everything going online, I think would suit an awful lot of people. I think it should be continued. I know it was only it was a study and all this sort of thing, but I think it worked out very well. On my side, I thought it worked out very well and I think it should continue with that, you have access to your files etc. and also your appointments should continue online with your clinician and I think that should be the way to go forward.’

Deirdre said that she had experience with the portal and found it was not suitable for her. However, she sees no reason why some of the features of the portal such as enhanced communication with clinicians and symptom-monitoring could not be carried out by patients in a non-technological format.

Deirdre (Patient) - ‘I used to use the portal but then I would get a hell of a lot of migraines unfortunately and it got to the stage where I was, just I just couldn’t handle using it you know, so I couldn’t, and then another thing I was saying, if we got more frequent phone calls like we were speaking about earlier should be looked at by every specialist.’

Deirdre (Patient) - ‘I think it would be a good idea if you were given like a questionnaire after appointments so for your next appointment like they would just put down medication effects or whatever. And then you could write them down as you go on from the few months till your next appointment, I think that even if they gave you a little booklet give out a booklet and you could just rip out the page and bring it with you to your next appointment.’

Freya expressed her desire for the national epilepsy electronic patient record (EEPR) to be enhanced.
Freya (ANP) - 'Enhancing our EPR, you know it really needs work; the portal doesn't work for every patient. And it doesn't work for clinicians either. So thinking about that in the long term.'

Camila spoke of how she would like a portal which integrates with all of the clinical systems she uses to deliver care.

Camila (ANP) - 'A portal that works, that talks to all our systems that we have at the moment. I think fundamentally really, I like the idea of the portal. But it's clunky, it's difficult to navigate, it adds more time for a clinician. So one that would work would be really nice.'

Holly ideated that the portal could link or signpost patients to existing eHealth apps for self-management.

Holly (RD) - 'I wonder sometimes like with the portal, like I know there's a goal-setting part in it, would that be a way of signposting to maybe other apps or other ways of monitoring, tracking sleep, all those kind of things, that if this is an issue for you, this might be something else that you can do, but that be a way of signposting them to the more reputable kind of apps for doing certain things.'

Holly (RD) - 'Would a combination of the portal with kind of app based technology, would that work better? Because it might engage them with the portal but then it could also help them self-manage certain aspects that maybe are important to them.'

Deirdre and Alan both wished that an appropriate eHealth app or functionality was created to deal with emergency situations.

Deirdre (Patient) - 'If there was some sort of thing like an app or an emergency app so that you have it on the phone but even if you have say, your hospital number on it or something like that and we just put it in, but in every hospital to sort of connect their computers or whatever, so they just put on say James' hospital number and they will know the history of it.'

Alan (Patient) - 'I think it could help because that time that I was admitted to the hospital they were asking me what medication was I on I had to tell them that I was epileptic, they didn't know and then they were asking me what medication was I taking. And could I remember it? no I couldn't remember anything at all. I just couldn't remember, and if
they had that on file they could just go to the computer, look it up, and that is the problem solved. I may not have needed to be admitted to the hospital at all, I could have went down the other line you know.’

Deirdre (Patient) - ‘Like Alan was saying there they should look for an ICE App - in case of emergency, and you download that and you just put in all your information so when you go into hospital you just show them your phone.’

Some PWE spoke of challenges that they experience that they would like technology to help them with. Harriet spoke of how she would like a tool developed to aid with memory.

Harriet (Patient) - ‘Have a tool developed to help manage bad, long term or short-term memory. Nearly everyone I’ve spoken to who has epilepsy has memory issues and that seems to be an area that’s kind of overlooked a little bit.’

Hannah spoke of how she would like an eHealth development which would enable her seizures to be timed.

Hannah (Patient) - ‘From technology side I’d love if I could time the seizures but other than that that’s all.’

Ciara said that she would like to see a feature within the EEPR or an eHealth development which would order medication for her.

Ciara (CfPWE) - ‘I mean you’d wonder could the EPR do that, your meds, you ordered your meds on the 4th December so therefore by the 4th January or whatever you need to, and send a link to the pharmacy and say these meds need to be updated. Because your meds are, like I’ve seen myself in situations where on a Friday evening I’ve realised ‘bugger I forgot to collect the medication’. And you are panic stations. So the EPR will be, the portal would be amazing to have access to that.’

6.3.7 Utilising the lived experience of PWE, their carers and other HCPs to better effect

Many of the HCPs who took part in these focus groups mentioned that they would like to see additional personnel involved in the care of PWE to improve provision of self-management. Kate felt that the presence of psychologists and pharmacists would improve self-management across PWE attending the service.
Kate (NCHD) - ‘Okay so I have in terms of improving face-to-face to help self-management, so if they’re coming to clinic, is it an idea to have not only the neurologist but a psychologist at the clinic too? You know, they saw the neurologist and then they could go and see them for a chat. A sort of multidisciplinary team at the clinic, even the pharmacist to go through meds and things. Or a dietician, or representative from Epilepsy Ireland.’

Camila spoke of how a ‘care co-ordinator’ could prove useful in forming management plans for PWE.

Camila (ANP) - ‘The other thing was a care coordinator for each patient. It could be based virtually as well. But they have a person, a person that’s their person. That they go to initially if there are issues and that person coordinates them around the hospital. So that’s for, if they have to have ECGs, bloods, levels, whatever it might be. That that’s the person that coordinates those. So it doesn’t necessarily need to be a clinical person. It could be any person, from any background. But that they coordinate. I think the health service in Ireland is really difficult to navigate. And I think a care coordinator would, care coordinators for everybody. And you know that could manage expectations, could make a twelve month plan, this is what we want to achieve and they work them through it.’

Kate mentioned that she would like to see extra resources dedicated to helping PWE who present to the service with behavioural issues.

Kate (NCHD) - ‘When I think about the behaviours, you know sometimes we meet patients who have behavioural issues. So they’ve epilepsy, but also because of their intellectual disability there’s huge behavioural issues. And while we can manage some of those medications, it can be tricky too, I think for the neurologist. And the psychiatry sometimes don’t really want to take ownership of them either. I always think there should be this you know special, like this behavioural speciality. They sort of fall between sort of pASMiatics and adult and it’s just I don’t know, nobody really seems to take responsibility for them. So you know somebody like that at clinics for those difficult patients.’

Camila mentioned that she would like to see an intellectual disability specialist added to the team of HCPs.

Camila (ANP) - ‘An intellectual disability specialist. Again, I think they’re
really poorly accounted for, or resourced within our health service. Within our acute hospital and also virtually, I don’t think there are any provisions for trying to manage virtual interactions with a patient with an intellectual disability. And maybe it’s just a standard that we do all of them by video. So that we can eyeball someone, if they’re not going to be able to communicate virtually, then they’re not partaking in the phone. Or if they can’t communicate verbally then they’re not partaking in the phone appointment at all. At least if it was video you could see them.’

Camila said that making the MDT more diverse in terms of its make-up could facilitate PWE choosing who they needed to speak to if a problem arose.

Camila (ANP) - ‘Self-referral to clinician of choice. So I’d really like to see the patients being able to self-refer themselves if they feel that they need to see OT. And I suppose that at the start of their clinical journey they are briefed on the roles of the different people involved in a multidisciplinary team. So that they can decide themselves, ‘oh I think [I need] some OT input, my self-management is poor’. Or ‘I need to see the nurse’, or I need to see whoever. And that also they would self-select as opposed to us deciding whether they’re appropriate for face-to-face or virtual. That they self-select. Meaning that maybe they do think ‘I just need a quick update, or a quick input’ and that would be via phone. Or actually ‘no, I really need to sit down with someone, because I need to talk to them more deeply about something’. So that they just decide themselves.’

Both Camila and Kate said that they would like to see the lived experience and expertise of PWE and families utilised within the service. Camila spoke of how she would like PWE to form a part of their MDT when patients are going forward for neurosurgery.

Camila (ANP) - ‘I’d really like to see them being part of their neurosurgery MDT. Their Wednesday case discussions, if they’re up that they can log in and they can be a part of that. Because I think they would have a lot to add. And maybe they would interrupt what’s discussed a little bit differently than we might communicate afterwards. So I think that would be nice.’

Kate had knowledge of ‘expert patients’ who provided support to individuals with similar health issues in France and saw this is a potential avenue for helping PWE help
each other.

Kate (NCHD) - ’I know in France they have these patients called expert patients, who are just very well versed in their condition. They just you know and they and sometimes patients will interact, or maybe have questions that they’re more comfortable asking another person who has epilepsy with.’

Fiona felt that as a PWE, she sees the potential of support groups and listening to the experience of other individuals living with epilepsy.

Fiona (Patient) - ‘Or a travel situation anyone has, is a local support group and this is maybe a suggestion for Epilepsy Ireland and maybe there already are loads of support groups that I wasn’t aware of, maybe it’s good to chat with them. Or chat with those around a similar situation, because you can kind of bounce things off people and say this is pure s*** for me today, or I had a great day, people who are in a similar situation, perhaps they can empathise.’

Fiona (Patient) - ‘Sometimes it’s just impossible to do, it depends on the situation, because we are all so very different, and we all, I think no matter what the condition is, we each kind of approach it, no matter who you are or what kind of support groups you have or if you have nobody. Or if you are intellectual disabled and you have epilepsy then this is …I don’t know to be honest (laughs) the only person I can look after is me, and I can’t give solutions to everybody. And even me looking after me- sometimes I do a great job and sometimes I do a s*** job (laughs)’

Both Noel and Ciara said that they would like to see greater involvement at GP level for epilepsy management and for epilepsy care to be brought into the community.

Noel (Patient) - ’I’d like to see more epilepsy management at GP level.’

Ciara (CfPWE) - ‘I suppose one of them is slightly similar to Noel and I’m not sure exactly it’s just the bones of it but I think yeah epilepsy management needs to come out of hospitals and come into the community.’

Ciara believes that GP’s are afraid of providing epilepsy care, however she would like to see more GP involvement in the management of the condition.
Ciara (CfPWE) - ‘It’s just that the GPs are very, very nervous of it. And I know the hospital write a letter explaining everything done but I’ve seen the letters - they are just gobbledygook. And you’d like your GP to have more management of it and be more involved.’

Ciara spoke of how she found hospital settings very clinical and would prefer to see aspects of care moved into the community.

Ciara (CfPWE) - ‘But I do think that going into a hospital it makes it very, its clinical, its illness, you know, whereas can we manage it in the community, can we have our bloods done in the community? Can the nurse specialist be based in the community?’

Freya believed that forging stronger links with Epilepsy Ireland could be a method of providing greater psychosocial care to PWE. She believes that if PWE had dedicated appointments with someone from Epilepsy Ireland to discuss psychosocial issues relating to their epilepsy, it could emphasise the importance of self-management activities and empower them to engage in these behaviours.

Freya (ANP) - ‘Forging that link much more with Epilepsy Ireland to making an Epilepsy Ireland visit as much more part of their yearly visit. So maybe they have an Epilepsy Ireland visit halfway through the year. And then an ANP visit the second-half of the year. Whether that’s virtual or face-to-face you know, it doesn’t really matter.’

6.3.8 Increased awareness of epilepsy among the general public and knowledge of the challenges faced in living with epilepsy

Almost all of the PWE and CfPWE who took part in the focus group spoke of their desire for greater awareness among the general public surrounding epilepsy and the challenges faced by individuals living with the condition. Andrew described how he feels greater awareness is needed.

Andrew (CfPWE) - ‘I think in general there needs to be greater awareness, public awareness and not just in the management of epilepsy itself. But greater public awareness in relation to what epilepsy is, how it affects people, how it can impact on people’s lives, not just their lives but the lives of the people around them and that it can be actually as challenging as any other medical condition.’
Lisa thinks that an awareness campaign would convey to the public how complex epilepsy is.

Lisa (Patient) - 'I think a really strong public information campaign on epilepsy, you know like the knowledge needs to be out there, I don't think it's out there enough you know. It's just seen as like a catch-all term when it's a very complex condition.'

Andrew believes that Epilepsy Ireland and the HSE have a role in educating the general public about epilepsy.

Andrew (CfPWE) - 'I still think that even Epilepsy Ireland, the HSE in general could do a lot more to help public awareness and I think by doing that, they could actually, you know, help in general. I think even little things, like for example if you come across somebody who is having a seizure. I think at some stage in our lives we are going to, even if a member of your family doesn't have, you don't know anybody who has epilepsy, you're going to witness somebody at some stage in your life who is having a seizure, you know. I think it would be nice to know that if something happens, that somebody, a member of the public would be able to come in and help that person, you know.'

An informed general public would be in a better position to support PWE when seizures occur and prevent prejudice according to Beverley.

Beverley (CfPWE) - 'One of the most difficult things and Gary has said it from time to time here, for anybody living with epilepsy is the uncertainty because you don't know when it's going to happen. And what you need around you in that situation is people who will be able to support you, not people who may judge you.'

Harriet spoke of how greater public awareness would help normalise different arrangements in employment for PWE.

Harriet (Patient) - 'So number one, making the knowledge and understanding of the general public improved. So making it possible or rather common practice for people with epilepsy, people with children, people with caring duties, anyone with responsibilities like that in any form to be able to work part-time, just make that normal, oh yeah well he or she is one of them. Ah yeah they work part-time, yeah that's what, you know 25%, 50% of the workforce does, you know.'
Lisa said that she would like to see a greater understanding from employers about the challenges faced by people living with epilepsy and for PWE not to have to hide their condition in the workplace.

*Lisa (Patient)* - ‘Yeah and like with employers, you know should have to, I don’t know what way you can do it but they have all these diverse and inclusion things, but is it happening? I don’t know. But now that there’s more opportunities to work from home, like I don’t know what way you can ramp it up but I’d like to see that happen. Obviously I’d love to be able to go back to work or you know without having to like be cloak and dagger about it and it just being normal and accepted and being able to be me without like hoping nobody finds out (laugh), who the real me is kind of thing.’

Jane would like to feel more confident about working and not to feel perceived as being lazy for not working.

*Jane (Patient)* - ‘I’d like to feel more confident about working, ok. I feel like I’m taking advantage of this situation or that people just think I’m lazy.’

Lisa feels that a focus on employment for PWE would be very beneficial for PWE.

*Lisa (Patient)* - ‘And like a focus on employment for people with epilepsy because you know obviously with myself and Jane (Patient) and then you know Harriet being limited in her employment, obviously more capable than what she’s achieving. Like and that in turn leads to depression and all these things. You know three intelligent women here, it’s ridiculous you know.’

Monica felt that teaching seizure first aid in secondary schools would be beneficial in reducing harm and injuries to herself and those around her.

*Monica (Patient)* - ‘I am kind of going from when I started, to now, on which they still don’t do - in secondary schools, like do first aid, health and safety. Because they didn’t do that through any of our years in secondary school.’

Beverley feels that seizure first aid and epilepsy education is something which should be built into the school curriculum.
Beverley (CfPWE) - ‘I think it’s something that could be built into the school curriculum in the SPHE that the kids do when they’re young, in junior school. They learn about lots of different things in junior school and I don’t see why they shouldn’t be taught simple first-aid and to be taught how to look after somebody who is having an asthma attack, or somebody who is having a seizure etc.’

A return to driving was mentioned by Jane as something which should she would like to be prioritised.

Jane (Patient) - ‘I don’t want to live like this or it would kill me to think that I’d have to live like this forever. Now independence is gone. Sorry I’ve marked out a few key words here, yeah. Feel like if I could drive again everything would be ok but that wouldn’t mean essentially that we found a medication that would work for me, but it all ties in to each other.’

Jane (Patient) - ‘Neither of you have mentioned driving, but I feel like if I could drive again I’d gain back some of my independence because that’s a huge thing.’

Lisa said that she would like to see funding provided to PWE which would enable them to pay subscription costs associated with eHealth tools.

Lisa (Patient) - ‘I’d like to see funding for, you know, so you set about the Epihunter and things like that, I’d love to see things, these initiatives being able to be funded for a person who is unable to work because it is, like €40 a month, that’s very expensive to someone who is not working, but could actually make a huge difference.’

Lisa felt that more funding was needed across the board for neurology services.

Lisa (Patient) - ‘If charities could allocate funding for new technologies and innovations like that. That will actually make a difference in someone’s life. And also we need more funding in general for neurology services in Ireland. It’s like obscenely underfunded, its ridiculous. The worst in Europe as I understand it. We’ve no epilepsy centre, nothing.’

6.3.9 Establishing reliable eHealth resources to direct PWE towards

Monica suggested that HCPs should provide more information to PWE and their family members about apps and other eHealth resources.
Monica (Patient) - ‘They could give more information on technology on apps like, you know “here is an Epilepsy Ireland app you can track your seizures and it automatically saves it so just in case your phone fell in a river just log in on a new phone and all your information is there”.’

A number of HCPs mentioned that they would like to establish which eHealth resources for PWE are reliable and they could then direct PWE or their families to these. Kate said that she would like to consolidate what websites and apps are useful to PWE so she can direct them to them.

Kate (NCHD) - ‘Reliable online advice that they can go to. You can give them a website that is reliable and has good information... I tell them that there are loads of apps and loads of ways to record seizures, they can write it down, or they can use any apps. But I don’t recommend specific apps or anything...But yeah, if we do have one to recommend for the service that would be great if everyone would use the same one.’

Mary agreed that it was important to establish what online resources were trustworthy before recommending them to PWE and their families.

Mary (NCHD) - ‘I suppose like Lucy says, give them options for online resources, different options for seizure diary to be kept. And all those things that they should know and trustworthy online resources. Because there are all sorts of apps there and I’m sure some of them are less good than the others. So just give them a few options.’

Kate said that the experience of PWE and families’ needs to be tapped into to establish which tools they believe are useful and patients would benefit from.

Kate (NCHD) - ‘Actually I don’t know any that are reliable. And then is that something, if you actually spoke, if you took a group of patients, well as a collective group are they using something. It’s you know, can they tell us what they’re using and then what we should be recommending.’

Freya said that it would be great to be able to direct PWE to podcasts or videos to aid them with self-management.

Freya (ANP) - ‘Things like facilitating a website that might have some of the social prescribing stuff on it. I mean that doesn’t have to be just a
James’s one. It could be a clinical care programme kind of approach for patients. To have them with their eLearning and maybe podcasts on topics...But a small little video on pregnancy, or VNS, or things like that. That you could refer patients along the pathway, just to say there’s a little bit of information up there that you might find valuable. We mightn’t have time to talk about it today, but there’s something there about how to remember to take your medication all the time. So like podcasts so that’s maybe something we could think about.’

6.3.10 Take a more holistic approach to epilepsy care

Fiona said that she would like to see more information provided about self-care activities PWE can do to help them manage their condition.

Fiona (Patient) - ‘They are great at telling you about alcohol and they are great at telling you about alcohol and smoking but they are not so good at kind of saying what about a little bit of exercise, maybe a walk every day or it’s more the other bit of the self-care.’

Lisa acknowledged that while there is lots of areas that PWE need help with, it is important that services that are created link in with each other and are integrated,

Lisa (Patient) - ‘Holistic services, we need wrap around services like everything plays in, dietary, like ketogenic services and so many people with epilepsy suffer from depression, anxiety, the memory problems. And I know there’s a lot there but (laugh) there’s a lot to do.’

Andrew believed that technology had a large role to play in allowing people who are not doctors to play a role in the management of epilepsy.

Andrew (CfPWE) - ‘I think for years and years and years, doctors have been managing the condition, managing the symptoms but I think a more holistic approach is needed in managing epilepsy because there is a much broader thing that needs to be looked at there insofar as the whys, the hows, the whens, and I think there’s still a long way to go. But I am very hopeful. I think technology is going to help. It’s not the panacea, but it’s going to help.’
### 6.3.11 COM-B Analysis of Data

<table>
<thead>
<tr>
<th>Reflective Motivation</th>
<th>eHealth that could aid in emergency situations.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>PWE and families having a choice between virtual and face-to-face interactions.</td>
</tr>
<tr>
<td></td>
<td>eHealth that could be perceived as easy to use.</td>
</tr>
<tr>
<td></td>
<td>eHealth where data generated would integrate across multiple platforms.</td>
</tr>
<tr>
<td></td>
<td>Establishing which existing eHealth resources are reliable and informing which eHealth tools HCPs could recommend.</td>
</tr>
<tr>
<td>Psychological Capability</td>
<td>Providing comprehensive education to PWE and their families surrounding ASMs.</td>
</tr>
<tr>
<td></td>
<td>eHealth that could alleviate memory difficulties experienced by PWE.</td>
</tr>
<tr>
<td></td>
<td>Informational videos and podcasts being provided to PWE and families to educate about psychosocial aspects of living with epilepsy.</td>
</tr>
<tr>
<td></td>
<td>Providing support to PWE to help manage relationships within their family which are under stress as a result of epilepsy.</td>
</tr>
<tr>
<td>Social Opportunity</td>
<td>Involving family members to a greater degree in epilepsy care.</td>
</tr>
<tr>
<td></td>
<td>Involving GPs to a greater degree in epilepsy care.</td>
</tr>
<tr>
<td></td>
<td>Forging stronger links between the DML Epilepsy Service and Epilepsy Ireland.</td>
</tr>
<tr>
<td></td>
<td>Involving PWE in multi-disciplinary team discussions.</td>
</tr>
<tr>
<td></td>
<td>Creating new ‘Care Co-Ordinator’ roles.</td>
</tr>
<tr>
<td>Physical Opportunity</td>
<td>Providing PWE and their carers with a platform where they could choose between virtual or face-to-face care.</td>
</tr>
<tr>
<td></td>
<td>Providing HCPs with appropriate hardware and software to deliver eHealth mediated care.</td>
</tr>
<tr>
<td>Physical Capability</td>
<td>eHealth that could time seizures for PWE.</td>
</tr>
<tr>
<td>Automatic Motivation</td>
<td>N/A.</td>
</tr>
</tbody>
</table>

Table 25 - Ideas generated by participants mapped onto the COM-B framework

In addition to grouping the ideas generated by participants into themes, they were each mapped onto their associated COM-B constructs. This mapping would facilitate the identification of an appropriate behavioural intervention function to facilitate the implementation of these ideas. The ideas located within their associated COM-B
Within the context of COM-B, the results indicate that participants feel future interventions targeting increased eHealth usage and self-management enablement could target a number of different constructs. In terms of social opportunity, PWE, carers and HCPs all suggested new links or relationships are formed with family members of PWE, General Practice and Epilepsy Ireland. There were also suggestions of creating new 'Care Co-Ordinator' roles and involving PWE and carers to a greater degree in MDT discussions and utilising their lived experience to a greater extent.

At the level of psychological capability to engage with eHealth and self-management, a number of the ideas suggested by participants surrounded enhancing knowledge surrounding epilepsy and management tasks. It was ideated that more comprehensive education and informational videos and podcasts could be provided to PWE and families surrounding issues ranging from ASMs to managing relationships within their families.

In terms of reflective motivation, PWE, their carers and HCPs all suggested various ways they feel eHealth could help manage aspects of epilepsy and receive greater engagement from PWE and their carers. These ideas included eHealth that could help in emergency situations, where data generated could be shared across multiple platforms and is perceived as easy to use by PWE. It suggested that providing PWE and carers with the choice to receive care virtually or face-to-face would improve engagement with remote tools. Establishing a list of currently existing eHealth resources which are reliable was deemed important for HCPs to promote eHealth usage to PWE and their carers.

From a physical opportunity perspective, HCPs felt that upgrading their existing hardware would facilitate a greater deal of eHealth enabled care to PWE. It was also said that creating a platform to allow PWE to choose whether they are cared for virtually or face-to-face would improve engagement with eHealth and self-
Ideas that would aid an individual’s physical capability to engage with eHealth and self-management were rare. A participant did suggest that if an eHealth solution could time their seizures, something they physically cannot do themselves, it would strongly encourage them to engage with such a tool. There were no ideas generated from participants which would target the automatic motivation of individuals to engage with eHealth.

6.4 Discussion

This was the final study associated with this PhD project exploring attitudes and behaviours towards eHealth and self-management among PWE, their carers and HCPs.

The three studies conducted prior to this primarily looked the challenges that PWE, their carers and HCPs perceived as existing with aspects of epilepsy self-management and eHealth usage. This particular study wished to provide participants with an opportunity to ideate and express their opinions about how epilepsy self-management and eHealth usage could be enhanced in the future.

Twenty-three participants took part in eight separate groups from November 2020 to April 2021. This was one of many qualitative research studies which were conducted remotely during the CoVID-19 pandemic. The remote nature of this research was viewed as an advantage because it broke down barriers which typically prevent participants taking part in-person. An important positive impact that CoVID-19 has had on research methodology is the increased use of and confidence with video-conferencing. Research has indicated that newly found confidence with video conferencing among the general public due to CoVID-19 is a key reason why previously thought limitations of online focus groups, such as, lack of depth due to difficulties in probing and facilitating discussion online, have been mitigated in studies using such technologies [324].
A unique aspect of this work was the use of the Miro whiteboarding platform to visually engage participants. These platforms are not reported upon much in academic research studies and literature however they appear to be popular in market and user experience research. In this study, the Miro platform successfully served as a stimulus for discussion. The whiteboard allowed the moderator to direct the flow of each focus group in a more subtle manner than the conventional questioning of participants. This supported the methodological goal of this study to allow participants to collaborate and share ideas with each other about how they would like to see eHealth and epilepsy self-management improved going forward.

There were many ideas generated by participants about how they would like epilepsy care to improve going forward. The ideas generated did not solely surround how participants feel there could be a more proactive self-management component of epilepsy care or how eHealth could become more prominent in epilepsy management, but about how the health authorities and society could be more attentive and inclusive to the needs of people with epilepsy, their families and healthcare providers.

Many ideas surrounded adding new or more diverse roles to the Epilepsy Service. There were also suggestions of enhancing and engaging relationships between the Epilepsy Service and long established institutions such as General Practice and Epilepsy Ireland. It was also evident from the suggestions of participants that if we are to move to a model of care in which PWE manage their condition with a greater degree of independence, support and expertise will be required from a multitude of different sources apart from the nurses and neurologists in the DML Service.

Providing a choice to PWE about whether their care is predominantly virtual or face-to-face was seen as important for epilepsy care going forward. Chapter III indicated a large number of PWE are open to the idea of keeping at least some aspect of their care virtual going forward in a post-CoVID world. If the DML Service was to have some kind of platform which facilitated PWE to indicate how they would like to receive care it
would be a big step forward.

Staff had the idea of conducting virtual care from an 'eHub' equipped with appropriate hardware and software to deliver care via eHealth to PWE. The staff had confidence in their track record when it came to using digital innovation within the service so felt they would be in line for funding for grants in this area should they apply. Hardware, particularly that with cameras, would facilitate consultations via video conferencing software. It was mentioned by many participants that being able to see the face of the PWE or HCP would be a welcome addition to remote appointments or consultation.

All three populations in this study mentioned directions they would like to see eHealth take in the future and what they would like digital tools to do for them to help with epilepsy self-management. These included help in ICE situations, being perceived as easy to use, ordering medication automatically, timing seizures and data integrating across multiple platforms. The ability to access a PWE’s record in different hospitals or jurisdictions was also mentioned by participants as being a perceived advantage of having digital records. As outlined in Chapter I, the potential for eHealth, in particular wearable devices, in managing risk in epilepsy is significant, but the technologies that are currently available are varied, frequently complex, inconsistently validated and potentially confusing not only for PWE but also their friends, families and HCPs [170].

In Rugg-Gunn’s 2019 review ‘The role of devices in managing risk’, it is said that the ideal device for seizure disorders should detect and abort pre-ictal or ictal epileptic activity, summon assistance if required and store biometric data for later interrogation and integration. To date, all of these characteristics do not exist in a single mobile app, portal or wearable device, however it is very likely that reliable and validated devices incorporating many, if not all, of the above elements will emerge over the next ten years. The openness of PWE and carers in this study towards using eHealth and including features that will help their specific situation align with studies conducted in the area, indicating people currently experiencing epileptic seizures may be very willing to use eHealth tools to supplement health management [173,174]. From a
behaviour perspective however, literature indicates that maintaining engagement with eHealth tools is an enormous challenge [174]. A deep understanding of patient motivation to engage with such technology is integral to developing any eHealth tool intended for such use among patient or carer populations. It is imperative that PWE, family members and HCPs are involved in every step along the development process of eHealth tools to understand their concerns better and the practical steps that can be taken to improve acceptability and engagement.

6.5 Limitations

Four of the HCP participants who took part in the first phase of this research study were unable to take part in this second phase. While four additional staff were recruited, because they did not take part in a semi-structured interview they might not have felt as comfortable taking part in a qualitative research study as other participants or discussing matters relating to epilepsy self-management or eHealth.

The size of the focus groups conducted were generally small, with a minimum of two and a maximum of four participants across the eight groups which were held. It is possible that hosting fewer, larger sized groups could have possibly exposed participants to more ideas surrounding eHealth and epilepsy self-management and facilitated more innovative collaboration. However, in hosting numerous, smaller sized focus groups, it allowed more flexibility for participants to join a group at a time and date that was more convenient to them. The smaller group sizes allowed for more intimate discussions to take place and rapport to build more easily among participants and the facilitator.

6.6 Conclusions

The findings in this study combined with the findings of the studies presented earlier (Chapter II ; III ; V)) highlight the challenges and opportunities PWE, their carers and HCPs perceive as existing for eHealth to aid with self-management of epilepsy. The collective findings of these research studies suggest that stakeholders wish for
eHealth to play a role in facilitating some aspects of epilepsy management going forward. It is also evident that some environmental restructuring is required within Epilepsy Services in terms of staffing, equipment and overall culture if the approach is to promote a model of care in which PWE live more independently with self-management being a more prominent aspect of epilepsy care.

The ultimate chapter of this thesis (Chapter VII) will contextualise the findings of the research within the parameters of existing eHealth and self-management practices surrounding epilepsy. Moving epilepsy care in Ireland towards a model with less face-to-face interaction and a greater degree of self-management and eHealth usage will require a number of transformational changes to be made. Within Chapter VII, opportunities where eHealth can be utilised most effectively to enable epilepsy self-management will be recommended. The normalisation of processes being ‘tech-first’ means that eHealth will become increasingly prominent across many aspects of medical care. Irrespective of the approach adopted by policy-makers on a national level and clinical leaders at a local level, the information gathered from participants in this study provide insights into where stakeholders feel technology could benefit epilepsy management most.
Chapter VII: General Discussion and Recommendations

7.0 Introduction

Throughout the world there is a drive to improve the quality, safety and efficiency of chronic disease management. This body of research sought to assess how individuals currently approach self-management and eHealth tools in order to understand where future interventions could be successful. It was proposed that lessons learned in this project would inform how epilepsy services incorporated self-management and eHealth effectively into the delivery of epilepsy care moving forward. It was believed that adopting this research approach and facilitating discussion amongst PWE, carers and HCPs would optimally inform how to design and deliver service improvements.

7.1 Scope Of Thesis and Research Outcomes

The aims of this body of work were to examine the perspectives of PWE, carers and HCPs towards self-management and eHealth supports and to conceptualise the lived experience of living with epilepsy to understand mechanisms through which eHealth usage can be promoted.

There were four primary objectives outlined in order to meet these aims; establish baseline data surrounding medication adherence behaviour and perception of medication error across a cohort of PWE, understand perceptions of chronic epilepsy management via telemedicine from a patient and HCP perspective, understand challenges faced by PWE, carers and HCPs in relation to epilepsy self-management and using digital tools to facilitate this, and provide participants with an opportunity to ideate solutions to overcome perceived barriers and challenges identified in previous studies.

The understanding of the challenges faced by PWE, carers and HCPs was generated through an ethnographic research methodology. The emphasis of this research was to identify the barriers and facilitators of digital health that have the potential to improve the quality, consistency and reliability of clinical epilepsy services.
This PhD thesis did not include implementation and post-implementation research evaluation of any specific eHealth tools. It was not an objective of this thesis to design a new eHealth tool but rather to understand when and where eHealth tools could enable a greater degree of self-management in epilepsy care.

7.2 General Discussion

7.2.1 Perception of Medication Adherence And Medication Error Among PWE Attending the Epilepsy Service at SJH

Medicine taking behaviour is dynamic and variable across individual patients and non-adherence to ASMs can be intentional or non-intentional. The clinical audit described in Chapter II indicated that approximately 40% of respondents to a self-administered questionnaire fail to adhere optimally to their ASM regimens, which falls within the range of 29-66% indicated by O’Rourke and O’Brien’s systematic review [185]. Work by Ferrari et al has indicated that factors such as comorbidities, number of medications, duration of therapy, age, gender and educational status have been associated with medication adherence [332]. In this clinical audit, none of the above factors were significantly associated with non-adherent behaviour, however, PWE who perceived that they were exposed to medication errors were significantly more likely to be non-adherent to their medication. Research by Niriayo et al and Chapman et al indicates that medication beliefs and perceptions are an important predictor of medication adherence in PWE [333,334]. Both of these studies found that non-adherent patients are significantly more likely to have negative perceptions of ASM, with stronger doubts about the personal need for ASMs and stronger concerns about potential harm. It was also indicated in these works that PWE with negative perceptions of pharmaceuticals as a class of treatment and those who perceived themselves to be more sensitive to the effects of medicines had significantly stronger concerns about ASMs and were significantly more likely to be non-adherent. The perception of exposure to medication error and its significant association with non-adherent behaviour reported in this clinical audit ties confound with the findings of these bodies of work indicating medication beliefs are an integral influence on medication adherence.
While delving further into the area of medication error was beyond the scope of this doctoral thesis, the results of this clinical audit early in the PhD process indicated that concerns existed at a patient level regarding an aspect of epilepsy treatment. This highlighted the need to develop a more fundamental understanding of patient attitudes and beliefs regarding epilepsy management, which informed the design of the clinical audits and studies which followed this body of work during the course of the PhD. These results highlighted the need for further exploratory research into patient attitudes, beliefs and perceptions regarding not only ASMs, but all aspects of epilepsy care.

Undoubtedly, more effort needs to be devoted to improve the awareness of patients about the importance of ASM in order to improve adherence. However, as the results in this audit indicate, medicine taking is a highly dynamic, personalised and complex behaviour where a ‘one-size fits all’ solution is not appropriate. An intervention that forms part of an educational programme seeking to address patient doubts or concerns not just about ASM treatment, but wider epilepsy management, would prove more beneficial in this author’s opinion. Targeting adherence in isolation through an intervention will likely yield unsuccessful results given the highly dynamic and individualised nature of the behaviour. A future intervention seeking to improve medication adherence among PWE needs to address perceptual factors, such as their beliefs about necessity of medication or concerns they may have, and practical barriers, such as the individual’s capacity and capability to adhere. Developing an understanding of how an individual conceptualises epilepsy within their own lives and where they feel changes need to be made can allow PWE to view adherence to ASMs as a tool within their epilepsy self-management toolbox, not merely a paternalistic behaviour which they are ordered to do be clinicians who are prone to making errors.

7.2.2 Experience Receiving and Delivering Epilepsy Care via Telemedicine.

The results of the first clinical audit indicated that there would be huge value in understanding patient attitudes and beliefs towards all aspects of epilepsy care, not
just medication adherence and medication error. With the onset of CoVID-19 and health administrators and clinicians forced to adopt and implement remote models of care in a short space of time, an opportunity arose to assess patient and clinician perceptions of using telemedicine, a form of eHealth, for receiving and delivering epilepsy care.

A study in China following the onset of the pandemic indicated that PWE showed higher psychological distress scores than otherwise healthy individuals [227]. Epilepsy also tends to be more severe in those with intellectual disability whose daily routines have been disrupted by the pandemic. Quantitative data garnered from the National EEPR showed that two large urban centres - SJH and BH - managed to avoid any backlog, seeing almost the same number of cases in the three months up to the end of March 2020 compared to the three months after. The agility of the services undoubtedly was underpinned by the presence of the EEPR. Throughout the CoVID-19 pandemic, research has consistently displayed the benefits of electronic medical record systems for quick adaptation to delivering continuity of care to patients [335]. The functionality within the EEPR which allowed clinicians to securely access patient information such as their clinical notes, list of medications, investigations and contact details enabled staff to continue to provide care while working from home, protecting them from exposure to CoVID-19 by not having to come on-site to their typical hospital setting.

Survey data collected in this clinical audit, both pre-and post-CoVID, displayed high levels of satisfaction with telemedicine from both a clinician and patient perspective. Literature dating before March 2020 comparing the experiences and outcomes of telemedicine versus face-to-face visits for neurological conditions consistently displayed positive results for telemedicine [229,336,337]. Since the onset of the pandemic, numerous works have continued to indicate the suitability of caring for PWE using telemedicine [338–341]. Work published across from other disciplines of medicine including radiology [342], palliative care [343] and dermatology [344] have
also displayed positive experiences from the perspectives of patients and clinicians receiving and delivering care remotely or highlighted the efficacy of telemedicine. In this clinical audit, patients were carefully selected for these types of appointments based on the impression clinicians had of their condition from previous appointment history. Post-CoVID, all patients, not just pre-selected ones, were subject to telemedicine care - which raised concerns about the suitability of unselected cohorts, however the high satisfaction levels from clinicians and patients indicate that telemedicine can largely be a viable process for all, not just a select few who clinicians believe are suitable for it. It is likely that CoVID-19 acted as a catalyst for an overdue standardisation of telemedicine as a mode of care not just in chronic epilepsy or neurological disease management, but a wide variety of medical disciplines. A number of publication and policy documents have stated the opportunities and benefits of maintaining remote models of care for patients with chronic conditions in a post-CoVID world [218,220,226,230,231]. Undoubtedly, challenges surrounding the establishment of national guidelines, funding frameworks, clinical guidelines and defining context, training of clinicians, secure data sharing mechanisms and research to evaluate impact must be addressed before telemedicine exists on an equal footing with the traditional, gold-standard face-to-face consultation [345]. Nonetheless, results from this clinical audit and other work carried out both before and after the onset of CoVID-19 indicate an appetite on behalf of patients and clinicians to see telemedicine become a standard mode of care for chronic disease management.

7.2.3 Challenges and Opportunities Associated with Self-Management and eHealth Usage for Epilepsy Care.

The results of the clinical audits highlighted the need for further exploratory work to understand the attitudes and perceptions of PWE, their family members and HCPs towards the current system of epilepsy care, self-managing the condition and digital health tools.
While previous studies have used similar qualitative methodologies in capturing the lived experience and attitudes of PWE [101,132,240,241,292], this study uniquely included the participation of carers for PWE, HCPs delivering specialist epilepsy care and a behavioural framework to identify future intervention functions to address the challenges identified.

Broadly speaking, sentiment existed that PWE, carers and HCPs are open to the idea of eHealth and technology playing a greater role in their day-to-day lives to aid the management of epilepsy. Through the COM-B framework analysis, behavioural barriers to self-managing epilepsy and using digital tools to do so were identified and the ideas generated by participants in focus groups were also mapped onto this framework.

To date, a number of empirical studies have used the COM-B and TDF to generate behavioural targets for change implementation in different clinical areas [346], including low back pain [347–349], hand hygiene [350,351], blood transfusion [352], medication prescribing [353] and schizophrenia [354]. In recent years, studies have employed COM-B and TDF to identify barriers and facilitators towards adherence to evidence-based indicators in GP [355], adoption of a diet associated with cognitive function [356] and adherence to evidence-based practice within midwifery [357]. This PhD study demonstrated the utility of the COM-B framework for the identification of barriers and facilitators towards self-managing epilepsy using eHealth tools, offering insights into where future eHealth developments can optimally engage users and integrate within the current ecosystem of epilepsy care in Ireland.

Based on the COM-B analysis, psychological capability appeared to be a significant barrier towards self-managing epilepsy and using eHealth tools to do so. Many PWE expressed that they experienced memory difficulties as a result of their condition which limited their ability to self-manage optimally. Some HCPs believed that they did not have the required expertise to provide comprehensive self-management information to patients. Within the TDF, education is the primary intervention function recommended to increase knowledge and skills to improve an individual’s capability
of carrying out a behaviour. The need for increased education regarding epilepsy self-management and digital tools was also expressed by many participants in focus groups. To date, a handful of epilepsy self-management programmes delivered through an eHealth platform have been well validated and critically assessed. The WebEase platform includes three educational modules surrounding medication adherence, sleep and stress that can be completed online [153]. The original clinical trial successfully demonstrated improvements in self-efficacy, self-reported adherence, self-management and stress levels in an intervention group compared with a wait-list control group [153]. The Managing Epilepsy Well (MEW) network is another online resource hub which contains digital self-management programmes for PWE, each with a slightly different clinical focus. The PEARLS and UPLIFT programmes focus on improving depression and quality of life, while the HOBSCOTCH programme aims to assist with memory difficulties [155]. The MINDSET programme within the MEW suite is a digital clinical-decision support system that aims to identify a patient’s specific self-management challenges and subsequently craft an individualised education programme. Currently, each of these programmes is only available for patients receiving their care at dedicated epilepsy centres in the U.S. Given the need for a greater level of education surrounding self-management based on the COM-B analysis and the desire expressed by participants to learn more about these activities, this author feels that an educational eHealth intervention with similar aspects to WebEase or MEW would function well in addressing many of the behavioural barriers which exist among Irish PWE.

COM-B analysis also indicated that barriers to epilepsy self-management and eHealth usage lie at the level of reflective motivation. HCPs doubt the capability of eHealth to reduce their workload and many don’t believe that currently available eHealth tools enable PWE to self-manage their condition in a significantly superior manner than using non-digital tools. PWE felt that currently available eHealth tools often did not suit their individual self-management needs or they were unsure how eHealth tools could improve their self-management situation. These challenges felt by participants
in this study align with those previously identified by Shegog et al which indicated that eHealth tools which require daily maintenance and engagement may actually confer unnecessary added complexity to how patients manage their epilepsy [154].

The sentiment expressed by participants in this study that data inputted or generated by patients or carers through mobile seizure diaries or wearable seizure detection devices does not integrate into the EEPR is a source of frustration aligns with Page et al’s findings which attributed a lack of uptake of eHealth in the world of epilepsy care to the lack of integration of digital tools with current clinical care pathways [17]. These findings indicate that if an eHealth intervention were to be created which enabled patients to log data pertinent to their condition, manually or automatically, that was integrated with the EEPR and viewable to HCPs, it would likely increase the perceived utility of patient-facing eHealth platforms from the perspectives of PWE, carers and HCPs compared to products which currently are commercially available.

7.3 Recommendations

Based on the data generated across the clinical audits and qualitative research studies conducted as part of this PhD project, this author recommends the following actions to be taken in order for self-management and eHealth usage to be optimally utilised in the ecosystem of epilepsy care.

7.3.1 Recommendation 1: Restructuring Epilepsy Services with enhanced communication with Primary Care and Non-Governmental Organisations.

Data generated in the qualitative portion of this PhD study, as outlined in Chapters V and VI, indicated that PWE, their carers and HCPs found the lack of GP involvement in epilepsy care to be a source of frustration and participants in each of these three populations ideated that GPs would play a greater role in the provision of self-management support to PWE going forward. Epilepsy Ireland were also seen by many of the participants in this study as needing to play a more significant role in the self-management support of PWE and their families in this country.

The National Care Programme for Epilepsy (NCPE) was developed after many years of
engagement across a number of different stakeholders. The NCPE sought to implement a vision for the future of epilepsy care in Ireland involving integrated, holistic person-centred care (PCC). Research conducted since the launch of the NCPE has indicated however that pressures exist against advancing PCC aspirations. Boundaries within and between professions, disciplines, organisations and sectors are resulting in missed opportunities for collaborative practice and consequently this limits the optimal co-ordination of patient care. It has been found that service innovations and technological advancements often result in increased dependencies on HCPs rather than the intended clinician-to-clinician shared decision care and the clinician-patient shared decision making paradigm [29]. In theory, igniting intersectoral collaboration across primary care, tertiary care and non-governmental organisations will reap rewards for all parties involved in terms of optimising patient care, however in practice it is difficult to achieve. Nonetheless, there are steps which can be taken to strengthen the alliances between these institutions.

The HSE Framework for Self-Management Support was released in 2018, with an overview provided of self-management support options and recommendations offered for the implementation of self-management support, specifically in the provision of services for chronic obstructive pulmonary disease (COPD), asthma, diabetes and cardiovascular disease [358]. A number of the recommendations within this framework would also be applicable to the provision of self-management support in epilepsy care, based on the data generated within the studies as part of this PhD.

Within this HSE framework, a key recommendation is that existing and future ICT systems are used to support the implementation of self-management support including information sharing and continuity across services and care settings. Enhanced communication and collaboration between Epilepsy Services and primary care was suggested by many participants in this study. This author feels that if the National Epilepsy Electronic Patient Record (EEPR) was accessible to GPs and functionality existed to monitor self-management supports by HCPs working in
primary and tertiary care this would represent a step forward in the care of PWE. This approach would provide a platform for systemic care in the areas of social support, education, psychological strategies, practical support for physical care and action plans for use in the deterioration of a patient’s condition. If the ergonomic and interoperability issues perceived as existing by HCPs are overcome, it would represent a major step forward in allowing expertise from specialist epilepsy services and primary care to be utilised optimally to support self-management.

Epilepsy Ireland, the national patient representative organisation in Ireland, have a number of self-management resources available for PWE and their families to access. These resources include a ‘Living with Epilepsy Toolkit’, one-to-one support with community resource officers, regional support groups and the ‘STEPS’ self-management programme [359]. These resources would likely prove beneficial to PWE and their carers in building self-management skills and support, however there appears to be little knowledge among PWE, carers and HCPs of the existence of these resources based on the results generated in this research. If HCPs working in specialist epilepsy care and primary care were more familiar with these resources, their content and how PWE and their family members could benefit from them, they could become an important element within of self-management support for PWE across primary care, tertiary care and Epilepsy Ireland.

7.3.2 Recommendation 2: Standardising the use of behavioural theory in the design of eHealth tools for epilepsy self-management and integrating data generated by such tools. Research indicates that often individuals use apps in isolation [360]. The lack of integration of data generated by PWE and carers to the EEPR utilised by HCPs was cited as a barrier to stakeholders using eHealth for epilepsy self-management. Many study participants ideated that the integration of patient health data from different sources would be a major improvement to the current manner in which information is siloed. The potential for data integration is enormous. Integrative platforms might aggregate multiple distinct sources of data collected in real time, apply algorithms to
inform participant feedback, make predictions about future health outcomes, send feedback data to providers or other clinicians, link contextual data to provide real-time guidance to participants in context, and store these data for future use [360].

A flaw which exists in current eHealth platforms for self-management is that they are unlikely to promote long-term engagement or behaviour change [360]. With behavioural science excelling at devising effective feedback mechanisms, data from users could be leveraged to create feedback algorithms that consider a range of psychosocial, emotional, behavioural and/or contextual circumstances [360]. The COM-B analysis indicates that ‘reflective motivation’ is a major obstacle for PWE, their carers and HCPs choosing to engage with eHealth tools to aid with condition self-management. All three populations state that they are unsure exactly how current eHealth tools can significantly aid with self-management tasks and improve outcomes. The findings of this work align with previous studies which have indicated that eHealth systems for PWE need to be tailored to the individual needs of users through customisations, with engaging, motivating and accessible interfaces for users with varying levels of learning and cognitive needs [361]. It has also been stated that PWE would like wearable devices to be inconspicuous with a similar appearance to mainstream activity trackers and smartwatches, which aligns with sentiments expressed by participants in this study. These are important design elements that need to be addressed because they impact adoption, adherence and continuous use of eHealth tools.

Few mobile apps have been evaluated in a well-designed clinical trial [360]. This is a major scientific limitation and will impede the use of such tools being introduced clinical care, reducing their impact. The use of evidence based behavioural strategies in apps is also low relative to strategies typically employed in traditionally delivered interventions [360]. In light of this the National Institute for Health and Care Excellence (NICE) in the United Kingdom released guidelines for incorporating behaviour change techniques into digital and mobile health interventions [362].
the exemplars of diet and physical activity, smoking, alcohol and unsafe sexual behaviour, these guidelines highlight how future digital and mobile health interventions could incorporate behaviour change to reduce harm associated with these behaviours. Within the guidelines, it is highlighted that many developers of these digital interventions do not have a background in healthcare or behavioural science and this limits the incorporation of behaviour change techniques into intervention design. The committee which created these guidelines agreed that people are more likely to change their behaviour using interventions that allow them to tailor goals to their needs [362]. The committee also agreed that it was also important for interventions to be designed so that they can be scaled up and can be customised for local needs based on the preferences of users [362]. It is integral that eHealth development is guided by evidence based behavioural strategies and user-centred principles. In this author’s opinion, if the HSE, through their Digital Transformation Unit or otherwise, created or modified NICE’s guidelines so they were specific to the local context in Ireland, it would be a huge step towards the standardisation of using behavioural theory when developing eHealth tools for use within healthcare in this country.

The heterogenous nature of epilepsy means that each individual living with the condition is affected differently. Current eHealth tools that are available to PWE and their carers to aid with self-management offer limited functionality. Future eHealth developments need to offer personalisation to a greater degree than is offered currently. Behavioural science theory also needs to be utilised to a greater degree in order to provide users with personalised feedback that will engage them with eHealth tools in a manner that is most appropriate to them. In addressing these challenges relating to PWE’s beliefs about the capabilities and consequences of using eHealth, future interventions could centre around educating, persuading and modelling digital health solutions.

Patient engagement has been called ‘the blockbuster drug of the century’ [363].
Patient engagement remains a challenge for the progress and widespread use of eHealth. In this author’s opinion, with directed attention to behavioural science theory and principles, use of more advanced feedback strategies and engagement strategy interfaces, eHealth tools which are developed for epilepsy self-management going forward are more likely to be successful in terms of continued engagement and clinical outcomes.

7.3.3 Recommendation 3: Creation of a platform that would allow PWE and carers to choose how they receive care

The results of Chapters III and VI indicate that the majority of PWE, their carers and HCPs are open to the idea of many aspects of chronic outpatient epilepsy care being conducted via telemedicine. Both PWE and HCPs indicated high levels of satisfaction with the quality of care received via telephone call. While the widespread implementation of telemedicine was triggered by the onset of CoVID-19, the demand for telemedicine to remain in place as the pandemic wanes must be acknowledged. It needs to be decided how best to balance virtual and face-to-face care going forward.

There are PWE and carers who will not have the capability nor willingness to engage with eHealth. The WHO advises that particular care is needed to ensure the widespread use of telemedicine does not further disadvantage underserved and hard to reach groups [364]. Research has indicated that disparities exist in access to and the use of telemedicine. A study conducted in the U.S. indicated that insured patients, those who are employed, and have post high-school education had higher uptake of telemedicine services [365]. Special care is necessary to ensure services do not overlook ‘people with low literacy or few digital literacy skills, people with limited control over or access to mobile devices, people speaking minority languages, migrant populations in new settings, and people with disabilities such as sight or hearing impairment.’ [364].

If functionality is created which allows PWE and carers to select how they wish to engage with epilepsy services i.e. virtual, face-to-face or a combination of both, this can satisfy all parties involved and improve efficiencies. This would involve
collaboration across administrative and clinical staff, and if successful it would potentially allow a significant number of PWE to receive chronic outpatient epilepsy care via telemedicine. This author feels that this functionality would optimally exist within a patient portal linked to the EEPR, such as PiSCES. In providing patients, or their carers and family members, with a choice about the appointment type which they feel suits them best, it would prove to be hugely empowering. The author also feels that if video teleconferencing, such as Attend Anywhere, a telehealth solution endorsed by the HSE [366], was utilised in addition to telephone calls when providing telemedicine to PWE, it would increase the suite of telemedicine options available to PWE and carers and increase uptake and satisfaction with the care received.

It is important however, that in creating a new system where patients submit their preference for virtual or face-to-face care, the workflow and processes of HCPs are accounted for and an additional workload is not created for them. Another concept which must be considered in contributing to clinical resistance to increased use of telemedicine, is the new phenomenon researchers and journalists have begun calling ‘Zoom fatigue’ - tiredness, anxiety or worry from overusing virtual videoconferencing platforms [330,367]. If the implementation of new care pathways involving telemedicine are viewed as a quality improvement challenge and not a mere technical one, resistance on the part of HCPs can be reduced. In the WHO guidelines surrounding the use of telemedicine, it recommends that 'client to provider telemedicine: under the condition that it complements, rather than replaces, face-to-face delivery of health services; and in settings where patient safety, privacy, traceability, accountability and security can be monitored' [364]. If pathways are created and optimised to allow PWE to receive care via telemedicine or face-to-face interaction whenever is most appropriate and of preference to the patient or family, undoubtedly this would streamline care pathways and progress eHealth enabled epilepsy care.
7.3.4 Recommendation 4: Acknowledging the role of family members and carers in epilepsy care more formally and including them to a greater degree in treatment management

A finding from this body of work is that family members and carers play a significant role in helping PWE carry out self-management tasks and getting by in their day-to-day lives. These management tasks range from reminding PWE to take their medication, recording seizures when they occur, monitoring symptoms, researching alternative treatments and research studies for the person with epilepsy to enrol in and providing emotional and practical support to the person with epilepsy as they navigate their day-to-day lives living with the condition.

Since the early 1980’s, it has been acknowledged that comprehensive epilepsy care needs to systematically include an understanding of individual dynamics, family systems and psychosocial milieu [368]. While HCPs in this study acknowledge that family members are an important resource in helping PWE to manage their condition, there is little formal recognition to their role in self-management support beyond including them in clinic discussions.

Given the significant role that carers and family members play in epilepsy self-management based on the results of this study, if their role was leveraged so that they could enable positive behaviour changes among the people they care for, there is large potential for improving self-management support to PWE.

However, merely including family members in patient-oriented disease education sessions has shown little impact on patient outcomes [369]. Just as patient self-management interventions are more successful when they focus on the patient’s role in illness management and are based on behavioural theory, a new model for family involvement in epilepsy management should focus on the unique roles that family members take and be based on an appropriate theoretical model of enabling behaviour change [370].

Previous interventions designed for carers have primarily been with carers of people
with special needs in mind, for example patients with dementia or terminal cancer, and have focused on managing caregiver stress or on teaching family members how to directly manage tasks such as giving medications, helping with activities of daily living and communicating with HCPs as the patients’ proxy [371–373]. These interventions are likely to be inappropriate for carers and family members seeking to support self-management of more functionally independent patients such as many of the PWE and carers who took part in this study.

With the rise in chronic disease prevalence among younger, more functionally independent individuals, new family support models will need to address this group’s needs. Family roles that are likely to be more common in supporting functionally independent adults include: facilitating and motivating behaviour change; partnering in information gathering, assisting problem solving and decision making; helping patients maintain their work and social roles and supporting the patient-HCP relationship [128].

Managing relationships within the families of PWE was cited as an area where PWE and carers would like to see further support. Because patients often want to be as independent as possible in their disease self-management, family members may inadvertently overstep boundaries or offer unwanted help [374,375]. Family members may be perceived as nagging or criticising when trying to help, or may even cause patients to be less confident in their ability to care for their own disease [376,377].

This author feels that involving family directly in clinical care processes will contribute to carers providing chronic epilepsy management in a more integrated fashion than what exists currently. An example which could be followed is that of the CarePartner programme, an intervention conducted across the U.S. which began more than a decade ago. The CarePartner programme gave family members specific roles in monitoring patient symptoms, self-testing and medications [378]. At the beginning of the programme, a selected family member was given written and online information.
about illness management. During the programme, patients were called weekly by an automated telephone service to report information about their symptoms, nutritional intake, medication adherence and availability of their medication supply. A report summarising the patient’s responses to the assessment were automatically emailed to the family member. The report highlighted any concerning patient responses and suggested actions the family member could take, as well as a time frame for following up. A twelve week pilot study involving heart failure patients found that over 70% of patient participants reported that their participating family member helped them to solve self-management problems [378]. If this were to be modified to an Irish epilepsy care setting, it is possible that the automated telephone service could be replaced via a questionnaire delivered via a patient portal linked to the EEPR. This information could then be stored securely and made easily available to HCPs providing epilepsy care, as well as carers and patients themselves. Programmes that help family members define specific roles in clinical care can make use of their presence at clinic visits and family members’ frequent desire to be kept informed of clinical information [128]. The incorporation of a model such as that used in the CarePartner intervention has potential for supporting family relationships, patient autonomy and appropriate designation of tasks and boundaries for epilepsy self-management in this author’s opinion.

7.3.5 Recommendation 5: Understanding the priorities of each individual person living with epilepsy and making treatment and management decisions based on this understanding

Within the system of chronic disease management, HCPs typically define control of the condition from the perspective of disease processes: avoiding mortality and morbidity and reducing pain, distress and suffering [379]. HCPs typically work one to one and focus on response to ASM treatment. This does not help PWE to overcome important aspects of day to day life such as social isolation, improve their self-confidence and learn about self-management [102].

As the results of the research conducted for this PhD thesis show, PWE, their carers
and HCPs all feel that epilepsy treatment needs to focus less on ASM treatment and more on psychosocial and holistic aspects of living with epilepsy. The COM-B analysis conducted as part of Chapters V and VI demonstrated that a number of cognitions, motivations and environmental factors influence whether or not an individual chooses to engage in an epilepsy self-management behaviour. The heterogenous nature of the epilepsies means that the manner in which the condition physically manifests and emotionally impacts each individual is unique. Undoubtedly, the health intuitions held by each person with epilepsy are different, and each individual has their own priorities within their own lives that they would like to see minimally impacted by their epilepsy.

The outpatient appointment remains a cherished setting for patients living with chronic disease and HCPs to talk about health, illness, diagnosis and treatment. Despite time constraints and economic pressures, this time needs to be focussed on addressing the intuitions, goals that arise from them and how to identify treatments that meet these goals.

This author feels that eHealth may improve the efficiencies of translating intuitions into context-specific values and ultimately treatment plans.

The importance of honouring the patient experience is now a widely appreciated construct and a common measure of healthcare quality with an evidence base. Patients having control over healthcare decisions is useful only when transparency exists in all aspects of care; evidence, costs, processes, outcomes and errors. Claims that patients should have control and a transparent understanding of all aspects of care have largely been ignored due to institutional inertia, a lack of financial incentives and the primacy of HCPs. There are few incentives to change this orientation and HCPs too often perceive confrontation and frustration rather than partnership.

If a new paradigm was to be employed where HCPs worked with a patient’s own intuitions about their epilepsy and overall health to align patient preferences with HCP recommendations, it would represent a significant step forward in providing
independence to PWE and making epilepsy care more patient-centred. In routine care, patient goals and care preferences are infrequently and haphazardly written and communicated, often conflicting, and typically focus on end of life care or chronic disease biomarkers [380–383].

Patient priorities (PP) are a combination of the specific and realistic outcomes and activities (health outcome goals) that individuals want based on what matters to them and the healthcare activities, including medications, self-care, tests and visits that they’re willing and able to perform (healthcare preferences) to achieve their outcome goal [384]. Naik et al. have shown that when older adults set goals that are specific to their individual lives, they typically fall into one of four health-related values categories: social and spiritual connections, functioning and independence, life enjoyment and pleasurable activities and balancing quality and quantity of life (managing health) [379,385]. Studies have shown that many patients with diabetes and hypertension choose not to change their dietary habits or take certain prescribed medications because these treatments conflict with their social relationships or age related identities [379]. The results of this research also indicated that often PWE or their carers are reluctant to engage with ASM treatment or recommended lifestyle adjustments as they are perceived as negatively impacting the social relationships and other aspects of life that PWE deem more important than maintaining seizure freedom.

Naik et al. have developed an intervention called Patient Priorities Care (PPC) that aims to help HCPs provide healthcare to older patients with multiple chronic conditions that aligns with their priorities, which include their individual values (what matters most), desired outcomes and healthcare preferences [386]. In the PPC process, a trained facilitator works with each patient to identify the patient’s healthcare priorities: their values, outcome goals and healthcare preferences. The patient priorities are then documented in the patient’s electronic health record. The clinician then uses the documented patient priorities to make treatment decisions that align with these priorities [387]. Studies investigating outcomes resulting from PPC indicate
that it reduces polypharmacy and patient reported treatment burden while increasing
care that aligns with patient goals [388,389].

If clinicians began consultations by asking patients 'What matters to you?' rather than
'What is the matter with you?', it would represent a positive change towards a more
patient-centred service delivery. Asking questions about what matters to patients is a
great opportunity to improve quality in service delivery and tries to get to the essence
of patient-centred care, which the Institute of Medicine has listed as one of the
priorities for quality improvement [390]. If clinicians received training to identify
specific and realistic goals based on what matters most to patients by initiating
conversations around these health categories, rather than response to treatment or an
update from the patient’s last visit, it would be an enormous step forward in making
epilepsy care more patient centred. While PPC was developed with the purpose of
treating older patients with multiple chronic conditions, if the same principles were
applied to developing treatment plans for PWE there is enormous potential for
broadening the scope of discussions in clinical appointments beyond ASMs and
systematically including aspects of self-management support into epilepsy treatment.

In this author’s opinion, it is time for the NCPE to be revisited and revised. The findings
of this PhD research, alongside Byrne et al, Varley et al and Power et al [29,44,391]
conducted in recent years have shown that the NCPE’s focus of ‘putting the patient
and family at the heart of every decision and empowering them to be genuine partners
in their care’ is not being achieved in reality. Undoubtedly, the reality of working in a
strained healthcare system with institutional pressure to provide care to as many
patients as possible often conflicts with the ethos of PFCC which the NCPE wished to
underpin the vision for epilepsy care in Ireland. If the NCPE was to re-designed so that
an intervention such as PPC, in which an individual’s priorities and goals were
systematically identified, documented and treatment modified to facilitate the
reaching of these goals, it would represent an enormous step forward towards
achieving a more holistic, patient-centred form of epilepsy care that patients, their
family members and HCPs yearn for.

Effective management of chronic diseases requires active, ongoing participation by patients and carers outside of healthcare settings. The self-management priorities of each PWE certainly need to be considered to a greater extent than they are currently. The heterogenous nature of the epilepsies means everyone is affected in uniquely. There is no 'one size fits all' solution however a system which allows individuals to manage their condition to alleviate the challenges which are most important to them will go a long way.
Bibliography


Royal College of Physicians of Ireland, National Clinical Programme for Epilepsy (NCPE). The National Clinical Programme for Epilepsy MODEL OF CARE Clinical Strategy and Programmes Division 2016.


[43] Cavalleri GL, Petrovski S, Fitzsimons M, Delanty N. eHealth as a Facilitator of


[57] Robb JF, Hyland MH, Goodman AD. Comparison of telemedicine versus in-person visits for persons with multiple sclerosis: A randomized crossover study of


[72] Bautista RED, Shoraka AR, Shapovalov D. Factors associated with superior self-management skills among individuals with epilepsy. Epilepsy Behav


Y/TABLES/3.


[134] Lua PL, Neni WS. Awareness, knowledge, and attitudes with respect to epilepsy:


https://doi.org/10.1016/j.yebeh.2018.05.044.


https://doi.org/10.1002/pds.1012.


https://doi.org/10.1177/0011000006287390.


[243] Higginbottom GMA. Sampling issues in qualitative research n.d.


[263] COREQ (COnsolidated criteria for REporting Qualitative research) Checklist. n.d.


[281] McDonagh LK, Harwood H, Saunders JM, Cassell JA, Rait G. How to increase


Kitzinger J. The methodology of Focus Groups: the importance of interaction between research participants. Sociol Health Illn 1994;16:103–21. https://doi.org/10.1111/1467-9566.ep11347023.


Merton RK, Kendall PL, Fiske M. Focused Interview: A Manual of Problems and


[350] Boscart VM, Fernie GR, Lee JH, Jaglal SB. Using psychological theory to inform


[363] Kish L. PATIENT ENGAGEMENT IS A STRATEGY, NOT A TOOL. How healthcare organizations can build true patient relationships that last a lifetime n.d.


[374] Martire LM, Stephens MAP, Druley JA, Wojno WC. Negative reactions to received


[382] Brown VA, Bartholomew LK, Naik AD. Management of Chronic Hypertension in


Feasibility of Clinicians Aligning Health Care with Patient Priorities in Geriatrics


Appendices

Appendix 1: Copyright Permission

Dear Jack Banks,

Thank you for your query.

Please note that, as one of the authors of this article, you retain the right to reuse it in your thesis/dissertation. You do not require formal permission to do so. You are permitted to post this Elsevier article online if it is embedded within your thesis. You are also permitted to post your Author Accepted Manuscript online.

However, posting of the final published article is prohibited.

"As per our Sharing Policy, authors are permitted to post the Accepted version of their article on their institutional repository – as long as it is for Internal Institutional use only.

It can only be shared publicly on that site once the journal-specific embargo period has lapsed. For a list of embargo periods please see: Embargo List.

You are not permitted to post the Published Journal Article (PJA) on the repository."

Please feel free to contact me if you have any queries.

Kind regards,

Anita Mercy Velthakkan
Senior Copyrights Coordinator

Elsevier | HCM - Health Content Management
Appendix 2: ‘Harriet’s’ testimonial as a participant in this research project.

I agreed to take part in the study for a number of reasons. The main one was the hope that I could give a voice to people with active epilepsy, that I could accurately represent other patients by sharing my own personal experiences and opinions. Hopefully I could provide correct feedback on the healthcare that I had received in the past, and valuably suggest how technology could be used to improve healthcare and epilepsy management in the future.

In early 2020 I was interviewed by the researcher Jack in a one-to-one meeting. I was a little nervous beforehand, but I was looking forward to it as well and all nerves vanished once I met Jack who was very easy to talk to. I answered his simple questions about my epilepsy, about the ways that I try to manage it through paper and screen, and how I thought technology might be used to manage it in the future. Sitting on campus in Trinity College, Dublin, it felt like a light-hearted conversation, and it was a pleasant experience.

Later that year I took part in a focus group on Zoom with Jack and two other patients. That meeting I found more distressing. What disturbed me was hearing how having uncontrolled seizures had such a damning effect on the other patients’ lives, on their careers – both had been required to stop working – and personally, such as a lack of support from family. It was also slightly disappointing to learn that neither patient was really using technology to manage their epilepsy. I had hoped that I might be able to get some tips about a useful device or app.

In the meetings, the ideas that I had for how technology could be used for epilepsy management and healthcare included: a diary app that would remind a patient when to take their medication and that a patient could use to keep a record of when they had different types of seizures and perhaps discover links between what triggered them; the ability to use the same app as a portal to share this information with
healthcare professionals, to improve general communication between patients and healthcare professionals, and to give patients access to their medical records; a tool that could be used to help any patients suffering from poor memory; and self-driving cars. I agreed that I would be interested in using a seizure-detecting device, if such a thing could be worn.

To participate in the study felt very rewarding, to think that I might be contributing towards the improvement of healthcare and the creation of worthy technology. It was also extremely interesting to find out what topics are being researched and to interact with other epilepsy patients and discover their suggestions. It was reassuring to hear confirmation that I’m not the only one struggling to keep epilepsy management under control, and that there might be hope for all of us with technology in the near future.
Appendix 3: Perceived Medication Adherence and Medication Error Questionnaire.

Medication Adherence Questionnaire

A study is being carried out within the Neurology department of St. James’s Hospital investigating medication adherence and medication errors in patients. We would be very grateful if you would take part.

Personal Details (If you are a friend/relative/partner/carer please provide the patient’s details below)

Name: _____________________  Gender: _____________________

Age: _____________________

If you have attended the Epilepsy Clinic more than once and are happy to participate in the study, please answer the following questions (Circle your choice unless prompted to do otherwise)

1. How many epilepsy medications are you currently taking? _______________

Please list all epilepsy medications you are currently taking in the box below.
2. How often do you forget to take your medication or miss a dose? (Place a tick beside the most appropriate answer)

- Never
- Occasionally (Once every 2-4 weeks)
- Regularly (More than once every 2 weeks)
- Frequently (More than once every week)

3. Have you ever intentionally not taken your medication as prescribed?  Yes  No

If yes, why so? ____________________________________________________________

4. How effective do you believe your current medication is at controlling seizures?

Very effective  Somewhat effective  Not effective

5. Have you at any stage felt your medication has been ineffective at controlling seizures?  Yes  No

6. Has your medication ever yielded unwanted side effects?  Yes  No

7. Do you feel that a ‘stigma’ is attached to the epileptic condition or have you ever felt embarrassed about being epileptic?  Yes  No

8. Do you have any mental health or neurological condition other than epilepsy?  Yes  No

If yes, please state: ____________________________________________________________

A ‘medication error’ is defined as any error occurring in the medication use process from prescribing to dispensing to administration.
9. As far as you are aware, have you ever been subject to any of the following medication errors?

(i) Prescribing Error (Incorrect selection of drug/dose/strength/route by prescribing doctor) - Yes, No
(ii) Dispensing Error (Incorrect drug dispensed by pharmacist) - Yes, No
(iii) Administration Error (Drug taken incorrectly by patient or administered improperly to patient) - Yes, No

Do you have any additional comments relating to any aspect of your epileptic medication you wish to make? If so, please leave them below.

Thank you for your help.
Appendix 4: Letter from SJH-TUH JREC confirming ethical approval.

Mr Jack Banks,  
St James’s Hospital,  
James’ Street,  
Dublin 8  

29th August 2019  

REF: From the Outside in - Designing tools to promote independence and wellbeing in epilepsy care  

REC: 2019-08 List 31 (08)  
(Please quote reference on all correspondence)  

Date of Valid Submission to REC: 06.08.2019  
Date of Ethical Review: 26.08.2019  
R&I Application Number: N/A  

Dear Mr Banks,  

Thank you for your correspondence in which you sent in a response to the Committee’s letter which detailed the Committee’s queries and concerns in relation to the initial submission for the above referenced research study.  

The Chairman, Prof. Richard Dean, on behalf of the Research Ethics Committee, has reviewed your correspondence and has given full Ethical approval for the study to proceed.  

The following documents were reviewed:  

- Email, dated 06.08.2019

Applicants must submit an annual report for ongoing projects and an end of project report upon completion of the study. It is the responsibility of the researcher/research team to ensure all aspects of the study are executed in compliance with the General Data Protection regulation (GDPR), Health Research Regulations and the Data Protection Act 2018. Additionally, please note for documents submitted for GDPR purposes that the REC and the Chair are not confirming that you’re documents are GDPR compliant, they are approving the document from an ethical perspective.

Yours sincerely,

REC Officer – Dr Sadhbh O’Neill  
SJH/TUH Research Ethics Committee  

The SJH/TUH Joint Research and Ethics Committee operates in compliance with and is constituted in accordance with the European Communities (Clinical Trials on Medicinal Products for Human Use) Regulations 2004 & ICH GCP guidelines.
Appendix 5: Letter from SJH-TUH confirming approval to conduct focus groups remotely.

SJH/TUH Research Ethics Committee Secretariat
email: researchethics@tuh.ie

Mr Jack Banks,
St James’s Hospital,
James’ Street,
Dublin 8

09th September 2020

REF: From the Outside-In: Co-Designing Tools to Promote Independence and Wellbeing in Epilepsy

REC: 2020-08 List 31 – Amendment (14)
(Please quote reference on all correspondence)

Date of Valid Submission to REC: 17.08.2020
Date of Ethical Review: 31.08.2020

Dear Mr Banks,

The Chairman, Prof. Richard Deane, on behalf of the Research Ethics Committee, has reviewed the amendment you submitted to the SJH/TUH JREC for the above named study and has given FULL approval for this amendment.

The following documents were reviewed:

- Letter to Chair

Please note that ethical approval for this study is only active under the following conditions:
1. Applicants must submit an annual report for ongoing projects.
2. Applicants must submit an end of study declaration/end of study report upon completion of the study.
3. All adverse events must be reported to the JREC.
4. All changes (minor and substantial) to documentation/study must be submitted to the JREC using the amendment request form and the changes must be tracked/highlighted clearly. Approval from the JREC is required before implementation of the changes.

It is the responsibility of the researcher/research team to ensure all aspects of the study are executed in compliance with the General Data Protection regulation (GDPR), Health Research Regulations and the Data Protection Act 2018.

Yours sincerely,

REC Officer – Dr Sadhbh O’Neill
SJH/TUH Research Ethics Committee

The SJH/TUH Joint Research and Ethics Committee operates in compliance with and is constituted in accordance with the European Communities (Clinical Trials on Medicinal Products for Human Use) Regulations 2004 & ICH GCP guidelines.
PARTICIPANT INFORMATION LEAFLET - PATIENT

Study Title: ‘From the Outside In’ – Co-Designing Tools to Promote Independence and Wellbeing in Epilepsy Care

Principal investigator's name: Dr Colin Doherty
Principal Investigator's title: Consultant Neurologist
Telephone number of principal investigator: 01-4103688

Co-investigator's name: Mary Fitzsimons
Co-investigator's title: Epilepsy eHealth Programme Director, RCSI

Co-investigator's name: Jack Banks
Co-investigator's title: PhD Researcher

You are being invited to take part in a research study to be carried out at epilepsy centres across Ireland, including at St. James's Hospital.

Before you decide whether or not you wish to take part, you should read the information provided below carefully and, if you wish, discuss it with your family, friends or GP (doctor). Take time to ask questions – don't feel rushed and don't feel under pressure to make a quick decision.
PART 1 – THE STUDY

Why is this study being done?
This study is looking to gain an understanding of the role that technology can play in the care of people with epilepsy and to make patients with epilepsy active stakeholders in the design of eHealth technologies for condition management.

‘eHealth’ is the term used to describe the use of IT and mobile technologies in the delivery of healthcare. Examples of eHealth include electronic patient portals, mobile applications, telehealthcare, online referrals and electronic prescribing.

The National Epilepsy Care Programme and the Sláintecare vision both strongly advocate for shifting care where possible from expensive hospital based settings to the community. Undoubtedly, this will involve the use of eHealth and technological solutions. However, the facilitators and barriers associated with eHealth adoption for epilepsy care remain largely explored. A clear need exists to understand attitudes towards epilepsy, current approaches to condition management, illness management and technology use prior to the design and implementation of eHealth solutions.

The overall aims of this study are to establish a blueprint for realising the health and wellbeing benefits of eHealth mediated services and to describe the conditions for optimum adoption of technological support.

Why am I being asked to take part?
You are being asked to take part in this project because you have epilepsy and / or you are under the care of Dr Colin Doherty’s epilepsy service which is delivered from St. James’s Hospital, Dublin.

Do I have to take part? What happens if I say no? Can I withdraw?
You don’t have to take part in this study. If you decide not to take part it won’t affect your future medical care. You can change your mind about taking part in the study any time you like. Even if the study has started, you can still opt out. You don’t have to give us a reason. If you do opt out, rest assured it won’t affect the quality of treatment you get in the future. If you wish to opt out, please contact Jack Banks who will be able to organize this for you.
How will the study be carried out?

This study will be carried out over 18 months, commencing in Autumn 2019.

There will be approximately 20 patients with epilepsy recruited as participants in the study.

There are two components to this study and you are free to participate in as many or as few of these as you wish.

The first component involves one to one interviews with people with epilepsy. Interviews will allow participants to tell their stories uninterrupted with a researcher. Questions will surround participants’ lived experience with epilepsy, current approaches to epilepsy management and the role participants would like to see eHealth to play in their epilepsy care.

The second component will involve focus groups with epilepsy patients. It is expected that three focus groups will take place.

In the first focus group, study participants will do some ‘thinking’ about what eHealth is, what extent eHealth currently plays a role in the care and management of epilepsy and what are the facilitators or inhibitors to development of new eHealth innovations for epilepsy care and management. During focus groups participants will be able to share ideas and generate discussion about eHealth and technology usage for epilepsy care. Interviews and focus groups will be held on site at St.James’s Hospital or the FutureNeuro offices in the RCSI.

Based on the interviews and focus groups, mock ups of eHealth devices and technologies will be presented to study participants in the second and third focus groups. Feedback from participants would inform improvements in design, utility and reach of potential technology. This process of ‘patient co-design’ will allow people with epilepsy participating in the study to become active stakeholders in the design and management of their care. These focus groups will be held on site at St.James’s Hospital or the FutureNeuro offices in the RCSI.

What will happen to me if I agree to take part?

When you attend the epilepsy clinic a researcher will meet with you to provide you with information about the project. You will be given this information leaflet and the researcher will go through it with you to answer any questions you may have. You can take the information away and discuss it with friends/family or your doctor before you make a decision about taking part. If you decide to take part in the project the researcher will ask you to sign a consent form. The researcher will give you a copy of the consent from for your records.
Are there any benefits to me or others if I take part in the study?

Your participation will help inform the conditions for optimum adoption of eHealth supports for epilepsy managements. This research will identify practical, material and organisational barriers to smooth introduction and continued support of assistive technologies. The ‘co-design’ methodology used in this study allows the attitudes and opinions of patients who partake in the study to design their own care – the success of this project could change approaches to epilepsy and chronic disease research.

Are there any risks to me or others if I take part in the study?

Sometimes when people talk about their experience (e.g. in a focus group setting or interview) it can cause them to feel a bit emotional or nervous. Be assured that the researcher conducting the interview and/or facilitating the focus group is experienced and trained at putting people at ease in such situations. If for any reason you feel upset following your participation, we will arrange for you to discuss this with an appropriate professional.

Will I be told the outcome of the study? Will I be told the results of any tests or investigations performed as part of this study that relate to me?

The results from this study may be included in publication in peer-reviewed journals and as poster and oral presentations at national and international conferences. Other methods for disseminating this research will include: publication in Epilepsy Ireland Newsletter; Reports to relevant National Committees (e.g. Department of Health & HSE; National Patient Safety Advisory Group; eHealth Ireland; Clinical Effectiveness Group); Applications to Healthcare Innovation Awards; via Patient Education Initiative (e.g. Epilepsy Ireland STEPS Programme); via Healthcare provider education (e.g. postgraduate seminars for nurses, doctors and allied health professionals etc.).

PART 2 – DATA PROTECTION

What information about me (personal data) will be used as part of this study? Will my medical records be accessed?

We will be using your personal information in our research to help us learn how your epilepsy influences your attitudes and approaches to eHealth. The researcher will ask you for some small information about your epilepsy such as how long you have the condition, current seizure control and current number of anti-epilepsy medications as this may have a bearing on how you engage with eHealth. Other than this, the researcher does not need to review clinical content for the purposes of the research.

What will happen my personal data?

Your personal information that will be used for this research will only be accessible to the research team (PhD researcher and PI) of this project. The researchers will keep some
identifiable information such as name, address, date of birth, contact details so that they can contact you over the course of the project. You will be given an individual project code number such as “SJHP0010”. This code would indicate that the researchers met you at St. James’s Hospital (SJH) and that you were the 10th patient (0010) to join the project. The code will be used by researchers when they are storing information collected from you for the research study (e.g. interview data, focus group data). This means your information will not have an identifier attached to it.

Data collected for this project will be stored for the duration of the project. On completion of the project in December 2020, the data will be retained for a further duration (between 5-7 years) while the project reports and articles for publication are being prepared. Once this project reports and articles are written and accepted for publication, the data will be ready for destruction.

We will not transfer your personal data outside of Ireland.

<table>
<thead>
<tr>
<th>Who will access and use my personal data as part of this study?</th>
</tr>
</thead>
<tbody>
<tr>
<td>For the purposes of analysis, input will be required from some other research co-applicants and co-investigators (see part 5 of this document for names and roles of these collaborators). This may involve sharing data with the researchers for analysis and interpretation. In this regard only coded data (with no personal identifiers) as described above will be shared. This will result in minimising the data shared about participants between the research collaborators.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Will my personal data be kept confidential? How will my data be kept safe?</th>
</tr>
</thead>
<tbody>
<tr>
<td>All data generated from this study will be kept strictly confidential. All information handled in the course of this project is strictly confidential and will not be made available by us to anyone other than those directly involved in this research project. Any clinical details coming to the notice of the researcher about you or your treatment will be managed in strictest confidence by members of the research team. Any publications from this research will be presented in a way that does not allow you, or anyone else who takes part in this study, to be individually identified.</td>
</tr>
</tbody>
</table>

Coded project data will be stored on a secure central computer server based at Trinity College Dublin. The security of this server is arranged so that it is partitioned for different projects. For example, a secure partition set up for this project will only be accessible to the authorised researchers (PhD researcher and PI) working on this project. No other personnel will have permission to access this secure partition/folder on the server.

<table>
<thead>
<tr>
<th>What is the lawful basis to use my personal data?</th>
</tr>
</thead>
<tbody>
<tr>
<td>We will only use your personal data for our research with your explicit consent. This in accordance with articles 6 and 9 of the General Data Protection Regulations (GDPR 2016).</td>
</tr>
</tbody>
</table>
PART 3 – COSTS, FUNDING & APPROVAL

Will it cost me anything if I agree to take part?
No. Interviews and focus group will take place at a location convenient to participants. Where necessary, you will be reimbursed for the cost of travel to these locations as will the cost of refreshments during these events.

Who is funding this study? Will the results study be used for commercial purposes?
The PhD researcher, Jack Banks, is fully funded by FutureNeuro, a neurological disease research centre based in the RCSI under the jurisdiction of Science Foundation Ireland. Ancillary research costs associated with this study are being covered by FutureNeuro. This project is being led by Dr Colin Doherty at St.James's Hospital with collaboration from Mary Fitzsimons, the Epilepsy eHealth Programme Co-Ordinator at RCSI.

Has this study been approved by a research ethics committee?
Full ethical approval for this study was granted by St. James's Hospital / Tallaght University Hospital Joint Research Ethics Committee (SJH-TUH JREC) on August 29th 2019. The SJH-TUH JREC can be contacted at researchethics@tuh.ie. There are no links between any of the researchers involved in this study and the committee who granted ethical approval. The researchers on this project must submit an annual report to SJH-TUH JREC and an end of project report on completion of the study.

PART 4 – FUTURE RESEARCH

Will my personal data and/or biological material be used in future studies?
We will only process the data you provide for the purposes of this research project. It is not intended to use your data that you provided for this study for any further study. However, should this change, we will not use your data in any further study without your prior consent.

PART 5 – FURTHER INFORMATION
Where can I get further information?

Principal investigator's name: Dr Colin Doherty
Principal Investigator's title: Consultant Neurologist
Telephone number of principal investigator: 01-4103688

Co-investigator's name: Mary Fitzsimons
Co-investigator's title: Epilepsy eHealth Programme Director, RCSI

Co-investigator's name: Jack Banks
Co-investigator's title: PhD Researcher

Data Controller’s/joint Controller’s Identity: St James’s Hospital and Trinity College Dublin

Data Controller’s/joint Controller’s Contact Details: St. James Hospital
James St., Dublin 8
Phone: 01-410 3000

Trinity College Dublin
College Green
Dublin 2
Phone: 01-896 2153
Data Protection Officer: Data Protection Officer,
Secretary's Office, Trinity College Dublin,
Dublin 2, Ireland.

What happens if I wish to make a complaint?
If you have any concerns about the management of yours or other people’s personal data during the course of this research, you have the right to lodge a complaint with the Data Protection Commissioner (see www.dataprotection.ie)

Will I be contacted again?
If we were to contact you in the future, it would only be in relation to future studies that may be of interest.
Appendix 7: HCP Participant Information Leaflet

PARTICIPANT INFORMATION LEAFLET – HEALTHCARE PROVIDER

Study Title: ‘From the Outside In’ – Co-Designing Tools to Promote Independence and Wellbeing in Epilepsy Care

Principal investigator’s name: Dr Colin Doherty
Principal Investigator’s title: Consultant Neurologist
Telephone number of principal investigator: 01-4103688

Co-investigator’s name: Mary Fitzsimons
Co-investigator’s title: Epilepsy eHealth Programme Director, RCSI

Co-investigator’s name: Jack Banks
Co-investigator’s title: PhD Researcher

You are being invited to take part in a research study to be carried out at epilepsy centres across Ireland, including at St. James’s Hospital.

Before you decide whether or not you wish to take part, you should read the information provided below carefully and, if you wish, discuss it with your family,
friends or GP (doctor). Take time to ask questions – don’t feel rushed and don’t feel under pressure to make a quick decision.

You should clearly understand the risks and benefits of taking part in this study so that you can make a decision that is right for you. This process is known as ‘Informed Consent’.

**PART 1 – THE STUDY**

**Why is this study being done?**

This study is looking to gain an understanding of the role that technology can play in the care of people with epilepsy and to make patients with epilepsy active stakeholders in the design of eHealth technologies for condition management.

‘eHealth’ is the term used to describe the use of IT and mobile technologies in the delivery of healthcare. Examples of eHealth include electronic patient portals, mobile applications, telehealthcare, online referrals and electronic prescribing.

The National Epilepsy Care Programme and the Sláintecare vision both strongly advocate for shifting care where possible from expensive hospital based settings to the community. Undoubtedly, this will involve the use of eHealth and technological solutions. However, the facilitators and barriers associated with eHealth adoption for epilepsy care remain largely explored. A clear need exists to understand attitudes towards epilepsy, current approaches to condition management, illness management and technology use prior to the design and implementation of eHealth solutions.

The overall aims of this study are to establish a blueprint for realising the health and wellbeing benefits of eHealth mediated services and to describe the conditions for optimum adoption of technological support.

**Why am I being asked to take part?**

You are being asked to take part in this project because you are involved in the delivery of health services for people with epilepsy who receive healthcare services from St. James’s Hospital. You therefore know about how health services (e.g. out-patient clinics, telephone advice line, rapid-access seizure clinic, primary care, community care, outreach services etc.) are provided for people with epilepsy. For this reason, you can be very helpful to informing researchers about how eHealth is currently being used for epilepsy care and where developments and improvements
are needed.

**Do I have to take part? What happens if I say no? Can I withdraw?**

You do not have to take part in this study. If you decide not to take part it won’t affect your role or working relationship with the epilepsy services delivered by St. James’s Hospital.

You can change your mind about taking part in the study any time you like. Even if the study has started, you can still opt out. You do not have to give us a reason. If you do opt out, rest assured it will not affect your working relationship with the epilepsy service at St. James’s Hospital.

If you wish to opt out, please contact the PhD researcher Jack Banks who will be able to organize this for you.

**How will the study be carried out?**

This study will be carried out over two years, commencing in September 2019.

There will be approximately 20 patients with epilepsy recruited as participants in the study, as well as 10 relatives/carers/friends of patients with epilepsy and 10 healthcare providers (HCP).

There are two components to this study and you are free to participate in as many or as few of these as you wish.

The first component will involve one to one interviews and focus groups with epilepsy patients. Interviews and focus groups will allow study participants to do some ‘thinking’ about what eHealth is, to what extent eHealth currently plays a role in the care and management of epilepsy and what are the facilitators or inhibitors to development of new eHealth innovations for epilepsy care and management. During interviews, participants will be allowed to tell their stories uninterrupted to the researcher. During focus groups participants will be able to share ideas and generate discussion about eHealth and technology usage for epilepsy care. Interviews and focus groups will be held on site at St.James’s Hospital or the FutureNeuro offices in the RCSI.

The second component will involve further workshops to promote continuous improvement and implementation of eHealth through co-design. Based on the feedback from participants collected through ethnography, interviews and the initial workshops. mock ups of eHealth devices and technologies will be presented in workshop format to study participants. Feedback would inform improvements in design, utility and reach of potential technology. This process of ‘patient co-design’ will allow people with epilepsy participating in the study to become active
stakeholders in the design and management of their care. These focus groups will be held on site at StJames’s Hospital or the FutureNeuro offices in the RSCI.

**What will happen to me if I agree to take part?**

When you attend the epilepsy clinic a researcher will meet with you to provide you with information about the project. You will be given this information leaflet and the researcher will go through it with you to answer any questions you may have. You can take the information away and discuss it with friends/family or your doctor before you make a decision about taking part.

If you decide to take part in the project the researcher will ask you to sign a consent form. The researcher will give you a copy of the consent form for your records.

**Are there any benefits to me or others if I take part in the study?**

Your participation will help inform the conditions for optimum adoption of eHealth supports for epilepsy managements. This research will identify practical, material and organisational barriers to smooth introduction and continued support of assistive technologies. The ‘co-design’ methodology involving HCP and patients used in this study allows the attitudes and opinions of HCP and patients who partake in the study to design the care they provide and receive – the success of this project could change approaches to epilepsy and chronic disease research.

**Are there any risks to me or others if I take part in the study?**

Sometimes when people talk about their experience (e.g. in a focus group setting or interview) it can cause them to feel a bit emotional or nervous. Be assured that the researcher conducting the interview and/or facilitating the focus group is experienced and trained at putting people at ease in such situations. If for any reason you feel upset following your participation, we will arrange for you to discuss this with an appropriate professional.

**Will I be told the outcome of the study? Will I be told the results of any tests or investigations performed as part of this study that relate to me?**

The results from this study may be included in publication in peer-reviewed journals and as poster and oral presentations at national and international conferences. Other methods for disseminating this research will include: publication in Epilepsy Ireland
PART 2 – DATA PROTECTION

What information about me (personal data) will be used as part of this study? Will my medical records be accessed?

The only personal data that will be kept from HCP are name, address, date of birth and contact details so that they can contact you over the course of the project.

What will happen my personal data?

Your personal information that will be used for this research will only be accessible to the research team (PhD researcher and PI) of this project. The researchers will keep some identifiable information such as name, address, date of birth, contact details so that they can contact you over the course of the project. You will be given an individual project code number such as “SJHP0010”. This code would indicate that the researchers met you at St. James’s Hospital (SJH) and that you were the 10th clinician (0010) to join the project. The code will be used by researchers when they are storing information collected from you for the research study (e.g. interview data, focus group data). This means your information will not have an identifier attached to it.

Data collected for this project will be stored for the duration of the project. On completion of the project in December 2020, the data will be retained for a further duration (between 5-7 years) while the project reports and articles for publication are being prepared. Once this project reports and articles are written and accepted for publication, the data will be ready for destruction.

We will not transfer your personal data outside of Ireland.

Who will access and use my personal data as part of this study?

For the purposes of analysis, input will be required from some other research co-applicants and co-investigators (see part 5 of this document for names and roles of these collaborators). This may involve sharing data with the researchers for analysis and interpretation. In this regard only coded data (with no personal identifiers) as described above will be shared. This will result in minimising the data shared about participants between the research collaborators.
Will my personal data be kept confidential? How will my data be kept safe?

All data generated from this study will be kept strictly confidential. All information handled in the course of this project is strictly confidential and will not be made available by us to anyone other than those directly involved in this research project. Any publications from this research will be presented in a way that does not allow you, or anyone else who takes part in this study, to be individually identified.

Coded project data will be stored on a secure central computer server based at Trinity College Dublin. The security of this server is arranged so that it is partitioned for different projects. For example, a secure partition set up for this project will only be accessible to the authorised researchers (PhD researcher and PI) working on this project. No other personnel will have permission to access this secure partition/folder on the server.

What is the lawful basis to use my personal data?

We will only use your personal data for our research with your explicit consent. This in accordance with articles 6 and 9 of the General Data Protection Regulations (GDPR 2016).

PART 3 – COSTS, FUNDING & APPROVAL

Will it cost me anything if I agree to take part?

No. Interviews and focus group will take place at a location convenient to participants. Where necessary, you will be reimbursed for the cost of travel to these locations as will the cost of refreshments during these events.

Who is funding this study? Will the results study be used for commercial purposes?

The PhD researcher, Jack Banks, is fully funded by FutureNeuro, a neurological disease research centre based in the RCSI under the jurisdiction of Science Foundation Ireland. Ancillary research costs associated with this study are being covered by FutureNeuro. This project is being led by Dr Colin Doherty at St James's Hospital with collaboration from Mary Fitzsimons, the Epilepsy eHealth Programme Co-Ordinator at RCSI.

Has this study been approved by a research ethics committee?

Full ethical approval for this study was granted by St. James’s Hospital / Tallaght University Hospital Joint Research Ethics Committee (SJH-TUH JREC) on August 29th.
2019. The SJH-TUH JREC can be contacted at researchethics@tuh.ie. There are no links between any of the researchers involved in this study and the committee who granted ethical approval. The researchers on this project must submit an annual report to SJH-TUH JREC and an end of project report on completion of the study.

PART 4 – FUTURE RESEARCH

Will my personal data and/or biological material be used in future studies?
We will only process the data you provide for the purposes of this research project. It is not intended to use your data that you provided for this study for any further study. However, should this change, we will not use your data in any further study without your prior consent.

PART 5 – FURTHER INFORMATION

Where can I get further information?

Principal investigator's name: Dr Colin Doherty
Principal Investigator’s title: Consultant
Neurologist
Telephone number of principal investigator: 01-4103688

Co-investigator's name: Mary Fitzsimons
Co-investigator’s title: Epilepsy eHealth Programme Director, RCSI

Co-investigator's name: Jack Banks
Co-investigator’s title: PhD Researcher

Data Controller's/joint Controller's Identity: St James's Hospital and Trinity College
Dublin

**Data Controller’s/joint Controller’s Contact Details:**

**St. James Hospital**

James St., Dublin 8

Phone: 01-410 3000

**Trinity College Dublin**

College Green

Dublin 2

Phone: 01-896 2153

- **Data Protection Officer:**
  Data Protection Officer,
  Secretary’s Office, Trinity College Dublin,
  Dublin 2, Ireland.

**What happens if I wish to make a complaint?**

If you have any concerns about the management of yours or other people’s personal data during the course of this research, you have the right to lodge a complaint with the Data Protection Commissioner (see www.dataprotection.ie)

**Will I be contacted again?**

If we were to contact you in the future, it would only be in relation to future studies that may be of interest.
## Appendix 8: Participant Consent Form

### PATIENT CONSENT FORM

**STUDY TITLE:** ‘From the Outside In’ – Co-Designing Tools to promote Independence and Wellbeing in Epilepsy Care

To be completed by the **PARTICIPANT**:

<table>
<thead>
<tr>
<th>I have read and understood the Patient Information Leaflet describing this research project. The information has been fully explained to me and I have been able to ask questions, all of which have been answered to my satisfaction.</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>I understand that I don’t have to take part in this study and that I can opt out at any time. I understand that I am free to withdraw from the study at any time without giving a reason and this will not affect my future medical care.</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>I agree to allow the researchers use my information (personal data) as part of this study as outlined in the information leaflet.</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>I consent to participate in the following aspects of the research study having been fully informed of the risks, benefits and alternatives (note: it is okay to say ‘no’ to any component):</td>
<td></td>
<td></td>
</tr>
<tr>
<td>a) One to One Interview</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>b) Focus Group Meetings</td>
<td>YES</td>
<td>NO</td>
</tr>
<tr>
<td>I give informed explicit consent to have my data processed as part of this research study.</td>
<td>YES</td>
<td>NO</td>
</tr>
</tbody>
</table>
I consent to a nominated family member/care giver providing information/details of my epilepsy care to researchers for the purpose of this project. | YES | NO
---|---

I have been given a copy of the Patient Information Leaflet and this completed consent form for my records. | YES | NO
---|---

I consent to be contacted (phone/email) by suitably qualified members of the team as part of this research study. | YES | NO
---|---

I consent to be re-contacted by researchers about possible future research unrelated to the current study for which I may be eligible. | YES | NO
---|---

| Participant’s Name (Block Capitals): | |
| Participant’s Signature: | |
| Date: | |

To be completed by the **RESEARCHER**: 

| I have fully explained the purpose and nature (including benefits and risks) of this study to the participant in a way that he/she could understand. I have invited him/her to ask questions on any aspect of the study. | YES | NO
---|---

| I confirm that I have given a copy of the information leaflet and consent form to the participant. | YES | NO
---|---

| Researcher’s Name (Block Capitals): | |
| Researcher’s Title & Qualifications: | |
| Researcher’s Signature: | |
| Date: | |
Appendix 9: PWE semi-structured interview topic guide

Qualitative Interview Objectives:

- Explore patients’ experience of epilepsy, how they view their epilepsy and the impact seizures and epilepsy diagnosis has on their life.
- Understand the current challenges that PWE experience, both within the healthcare system and outside it, and what factors affect those challenges.
- Establish a need for additional supports related to eHealth, identify what supports these might be.
- Identify what barriers and facilitators exist to successful eHealth adoption by PWE and their carers for remote monitoring of the condition.

A) Introduction

Aim – To build rapport with and settle interviewees

1. Please tell me about yourself

   Explore who they live with, their school year, hobbies, interests.

B) Experience and Impact of Living with Epilepsy

Aim – Understand patients’ experience of diagnosis, the functional impact of condition on their lives and their emotions, feelings and behaviors.

2. Can you tell me about your first seizure experience?

   Who was around? What did they do? How did you feel afterwards? What caused the seizure? Was there anything that could have been done to prevent it? How did the people around you react?

3. Can you describe your experience of receiving a diagnosis of epilepsy?

   When was the diagnosis confirmed? Who provided it? What tests were carried out? What were your thoughts / feelings / behaviors at the time? Have your feelings changed over time since the diagnosis?

4. What impact has having an epilepsy diagnosis had on your life?

   What do you do day to day to prevent or manage seizures? What feelings do you experience? Has your behavior changed? Does epilepsy influence places you go? Your relationships? Your career / personal aspirations?

C) Experience of Epilepsy Treatment and Care
Aim – To understand what participants perceive about their treatment and care. Explore what logistical, physical, and emotional supports they receive in their lives.

5. How is your epilepsy treated?

Do you take prescribed medication to control seizures? Has your medication changed – if so why? How often do you attend appointments? Where do you attend appointments? Who are your appointments with?

6. What supports do you receive to help you with your epilepsy?

Do you seek out support? What influences the support you receive? Do different people have different roles in helping you? Does support meet your expectations?

D) Epilepsy Self-Management

Aim – Understand what activities patients engage in to manage their epilepsy when away from their clinicians.

7. Are there any challenges you face managing your epilepsy?

Tell me how you manage your medication? Is this how your HCP told you to manage your medication? Do you have any challenges managing your medication?

8. What activities do you undertake to manage your epilepsy?

What factors impact how you manage your epilepsy? Be open here – don’t lead

E) The role of eHealth in Epilepsy Self-Management

Aim – Establish current levels of knowledge and usage of eHealth by PWE. Explore what would support and stop PWE from using technology to manage their condition.

9. Are you currently using any technologies to help with epilepsy management?

Would you consider yourself a tech-savvy person? Are you aware of any technologies? Has your HCP ever spoken to you about any? Have you used any? Would you be open to using technology to manage your epilepsy?

10. Having earlier discussed some of the challenges you face living with epilepsy (bring up participant’s discussed challenges here), is there a way that you feel technology could help you with the management of your condition?

Can you identify a challenge you face in managing epilepsy that technology could solve for you?
11. If you did have a technology to help you manage your epilepsy, what would get in the way of you using it?

What is stopping you accessing technology to manage your condition? Patient’s own beliefs and attitudes to technology?

12. What would encourage you to use continually use technology to manage your epilepsy?

What encourages you to use technology to manage your condition?

13. Is there anything that you would like to add that you have not had the opportunity to share during this interview?

(Thank interviewee for participation and end the interview).
Appendix 10: HCP semi-structured interview topic guide

Qualitative Interview Objectives:

- Explore HCPs experience of delivering epilepsy care.
- Understand how HCPs view epilepsy self-management and what activities PWE need to do when away from hospital settings.
- Establish what is and isn’t working for clinicians at the moment with the way in which they provide care.
- Identify what eHealth HCPs currently use, where they feel tech could help them/PWE manage epilepsy care and what they feel the future holds for epilepsy care.

A) Introduction

**Aim** – To build rapport with, settle interviewees and provide context to their career as an epilepsy HCP.

1. **Tell me about yourself.**

   Explore who they live with, hobbies, interests.

2. **Based on the info you provided in the screening questionnaire, you have been working in epilepsy care for ________ years. Why did you begin to work in the epilepsy sphere?**

   What attracted you to work in epilepsy care?

B) Epilepsy Care Process

**Aim** – To gain an understanding of how HCPs provide care for PWE. Build a picture of what information clinicians need to do to provide adequate care.

3. **When you begin to treat a person for their epilepsy, what are the first steps you take?**

   Do you read their medical records? Who do you have to contact to get their medical records? Do you meet the patient face to face? Do you call the patient? Is first contact different if the patient has ID? Is first contact different if the patient is homeless? What patient factors would require a different first contact?

4. **Once the patient begins treatment, how do you manage them?**

   Do patients see you face to face? How often? Do you contact patients via telephone or email? Do you contact any other HCPs when managing a patient’s care? HCPs on your own team? HCPs in other hospitals? HCPs in Primary Care? Pharmacists? Outreach Services?
5. When PWE and their carers are not with you, what activities must they do to manage their epilepsy?

What are your thoughts on PWE self-managing their condition? Do you think there are self-management practices PWE perform more than others? What are the most important self-management practices?

C) Epilepsy Care – Facilitators and Barriers to Optimal Care

6. Within the current epilepsy care system, what facilitates you to provide the best care you can for patients?

What allows you to do your job well? Having accurate information about the patients? Having an accurate history about the patient? What supports exist for you as an epilepsy care provider?

7. Within the current epilepsy care system, what barriers exist that stop you providing the best care you can for patients?

What are the main challenges you encounter trying to do your job? Getting an accurate impression of the patient’s condition? Selecting appropriate treatment for PWE? High volume of PWE to deal with? Communication with other HCPs? Utilizing multiple EHR’s?

D) eHealth

Aim – To establish what role eHealth currently plays in the care of PWE, the preferences of HCPs with regard to eHealth and how they believe eHealth fits into the future of care.

8. Are you currently using any technology when delivering epilepsy care?

Are you aware of any technologies that exist to provide epilepsy care?

9. Having earlier discussed the challenges you face delivering epilepsy care, is there a way you feel technology could help you?

Are there any existing innovations you know about that would improve care? Can you think of a problem that technology could solve for you?

10. Where do you think technology could be best utilized in epilepsy care?

Could it help in clinical appointments? Could it help organize patient data more efficiently? Could it help with patient communication? Could it stratify patients on urgency of care?

11. Do you think there would be issues implementing new technology to deliver
epilepsy care?

Has there been previous poor experiences with tech implementation in your work?

12. Do you think it’s possible for the barriers to tech implementation to be overcome?

13. From your experience with patients, do you think they are interested in using technology to manage their epilepsy?

Do patients ever ask about apps / wearables / tech for any aspect of epilepsy? Are there any specific populations of PWE you think tech is more suitable to?

14. What direction do you see the future of epilepsy care taking?

Is this a good or a bad thing? Do you have any hopes or fears with regard to epilepsy care?

15. Is there anything with regard to epilepsy self-management, epilepsy care or eHealth you would like to discuss that we have not mentioned?

(Thank interviewee for participation and end the interview).
Appendix 11: Initial Codes and Descriptive Themes from Semi-Structured Interviews with PWE, Carers and HCPs.

Initial Descriptive Theme 1: Emotional Impact of Epilepsy

<table>
<thead>
<tr>
<th>Code:</th>
<th>Files</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acceptance of Condition</td>
<td>11</td>
<td>57</td>
</tr>
<tr>
<td>Anger</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Anxiety</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>Bullying</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Burden</td>
<td>5</td>
<td>17</td>
</tr>
<tr>
<td>Childhood</td>
<td>8</td>
<td>29</td>
</tr>
<tr>
<td>Depression</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>Disease Confrontation</td>
<td>10</td>
<td>28</td>
</tr>
<tr>
<td>Embarrassment</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>Family Support</td>
<td>15</td>
<td>135</td>
</tr>
<tr>
<td>Fear</td>
<td>11</td>
<td>43</td>
</tr>
<tr>
<td>Hopelessness</td>
<td>3</td>
<td>16</td>
</tr>
<tr>
<td>Independence</td>
<td>13</td>
<td>127</td>
</tr>
<tr>
<td>Positives of Epilepsy</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Psychology and Counselling</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Resilience</td>
<td>8</td>
<td>29</td>
</tr>
<tr>
<td>Stress</td>
<td>6</td>
<td>23</td>
</tr>
<tr>
<td>Trauma</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Individual Personality Types</td>
<td>5</td>
<td>28</td>
</tr>
</tbody>
</table>

Initial Descriptive Theme 2: Day to Day Functional Impact of Epilepsy

<table>
<thead>
<tr>
<th>Code:</th>
<th>Files</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alcohol</td>
<td>5</td>
<td>12</td>
</tr>
<tr>
<td>Driving</td>
<td>10</td>
<td>31</td>
</tr>
<tr>
<td>Education</td>
<td>13</td>
<td>70</td>
</tr>
</tbody>
</table>
**Initial Descriptive Theme 3: Physical Manifestations of Epilepsy**

<table>
<thead>
<tr>
<th>Code:</th>
<th>Files</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment</td>
<td>15</td>
<td>64</td>
</tr>
<tr>
<td>Family Interference</td>
<td>12</td>
<td>45</td>
</tr>
<tr>
<td>Family Planning</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Fertility and Pregnancy</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Finances</td>
<td>6</td>
<td>11</td>
</tr>
<tr>
<td>Hobbies</td>
<td>8</td>
<td>13</td>
</tr>
<tr>
<td>Intellectual Disability</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Memory</td>
<td>12</td>
<td>47</td>
</tr>
<tr>
<td>Preventive Actions</td>
<td>6</td>
<td>22</td>
</tr>
<tr>
<td>Public Perception of Seizures</td>
<td>13</td>
<td>88</td>
</tr>
<tr>
<td>Seizures in Public</td>
<td>7</td>
<td>22</td>
</tr>
<tr>
<td>Spelling</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Stigma</td>
<td>11</td>
<td>48</td>
</tr>
<tr>
<td>Volunteering</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Patient's Own Perception of Seizures</td>
<td>5</td>
<td>25</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Name</th>
<th>Files</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Auras</td>
<td>12</td>
<td>23</td>
</tr>
<tr>
<td>Co-Morbidities</td>
<td>6</td>
<td>18</td>
</tr>
<tr>
<td>Exercise</td>
<td>6</td>
<td>16</td>
</tr>
<tr>
<td>Fatigue</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Physical Injury</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Seizure Frequency</td>
<td>11</td>
<td>43</td>
</tr>
<tr>
<td>Seizure Types</td>
<td>12</td>
<td>96</td>
</tr>
<tr>
<td>Side Effects</td>
<td>13</td>
<td>58</td>
</tr>
<tr>
<td>Sleep</td>
<td>10</td>
<td>29</td>
</tr>
<tr>
<td>SUDEP</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
Initial Descriptive Theme 4: Receiving Epilepsy Care

<table>
<thead>
<tr>
<th>Name</th>
<th>Files</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ability of Patients to Self-Manage</td>
<td>8</td>
<td>91</td>
</tr>
<tr>
<td>Accessing Care</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Ageing Population</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Being Familiar with Return Patients</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Benefit of Accurate Patient History</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>CBD</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Change in Epilepsy Care</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>Clinical Leadership</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Clinician Interference</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Clinicians Sharing the Same Vision</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Cognitive or Memory Issues in Patients</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Communication within Epilepsy Team</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Community Based Epilepsy Care</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Consultant Culture</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Creating Treatment Plans</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Defining Self-Management</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>8</td>
<td>20</td>
</tr>
<tr>
<td>Diet</td>
<td>6</td>
<td>13</td>
</tr>
<tr>
<td>Difficulty of Keto Diet</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Discharging Patients</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Discrimination of Nurses</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Dogs</td>
<td>5</td>
<td>11</td>
</tr>
<tr>
<td>Educating GP's</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Educating Patients</td>
<td>8</td>
<td>43</td>
</tr>
<tr>
<td>Emergencies</td>
<td>4</td>
<td>10</td>
</tr>
<tr>
<td>Emergency Dept Referrals</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Empowering Patients</td>
<td>6</td>
<td>11</td>
</tr>
<tr>
<td>Name</td>
<td>Files</td>
<td>References</td>
</tr>
<tr>
<td>---------------------------------------------------</td>
<td>-------</td>
<td>------------</td>
</tr>
<tr>
<td>Epilepsy Care in the Past</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Epilepsy Ireland</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Epilepsy Specialist Nurses</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Epilepsy Surgery</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>EPR</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Face to Face Appointments</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Failed Medication</td>
<td>9</td>
<td>20</td>
</tr>
<tr>
<td>Fear of Change</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>First Seizure</td>
<td>14</td>
<td>29</td>
</tr>
<tr>
<td>Fitting Patients in Outpatient Clinics</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Frustration with New Contract GP</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>General Practice</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>General Practice</td>
<td>8</td>
<td>36</td>
</tr>
<tr>
<td>Genetics</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Geographic Issues</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Getting into Epilepsy Care</td>
<td>7</td>
<td>16</td>
</tr>
<tr>
<td>Hiring New Non-Clinical Staff</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Historical Context for Dietary Treatment</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Holistic Epilepsy Care</td>
<td>6</td>
<td>16</td>
</tr>
<tr>
<td>HSE vs Rest of World</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Inpatient Consults</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Integrated Care Pathways</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Investigations for Diagnosis</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td>Keto Diet Management</td>
<td>1</td>
<td>19</td>
</tr>
<tr>
<td>Lack of Patient Engagement</td>
<td>6</td>
<td>31</td>
</tr>
<tr>
<td>Lack of Physical Resources</td>
<td>8</td>
<td>35</td>
</tr>
<tr>
<td>Lack of Recognition of Good Work of Service</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Legislation</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Lifestyle Advice</td>
<td>6</td>
<td>34</td>
</tr>
<tr>
<td>Listening to Patients</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>Name</td>
<td>Files</td>
<td>References</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>-------</td>
<td>------------</td>
</tr>
<tr>
<td>MDT</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Medical Culture Change</td>
<td>5</td>
<td>7</td>
</tr>
<tr>
<td>Medical vs Psychosocial Care</td>
<td>5</td>
<td>30</td>
</tr>
<tr>
<td>Medication Adherence</td>
<td>13</td>
<td>80</td>
</tr>
<tr>
<td>Medication Adherence</td>
<td>5</td>
<td>22</td>
</tr>
<tr>
<td>Medication as Primary Treatment</td>
<td>5</td>
<td>14</td>
</tr>
<tr>
<td>Mental Health Issues in Epilepsy</td>
<td>3</td>
<td>20</td>
</tr>
<tr>
<td>Morality and Ethics</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>National Service</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Negative Clinician Experience</td>
<td>8</td>
<td>22</td>
</tr>
<tr>
<td>Non-Epileptic Seizures</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Non-Seizure Related Advice</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Number of Hours Per Week</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Number of Staff</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Patients Over-Using Services</td>
<td>4</td>
<td>10</td>
</tr>
<tr>
<td>Physical Aspect of Medication</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Previous Experience in Other Sector</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>Private Practice</td>
<td>6</td>
<td>24</td>
</tr>
<tr>
<td>Providing Care in a Crisis</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Public Epilepsy Care</td>
<td>11</td>
<td>62</td>
</tr>
<tr>
<td>Referral Process for Diet</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Role of Consultant in Epilepsy Care</td>
<td>3</td>
<td>17</td>
</tr>
<tr>
<td>Role of Family in Supporting Self-Management</td>
<td>4</td>
<td>12</td>
</tr>
<tr>
<td>Role of Nurses</td>
<td>8</td>
<td>59</td>
</tr>
<tr>
<td>Sodium Valproate</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Speeding Up Appointments</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Strategies to Encourage</td>
<td>6</td>
<td>18</td>
</tr>
<tr>
<td>Name</td>
<td>Files</td>
<td>References</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>-------</td>
<td>------------</td>
</tr>
<tr>
<td>Self-Management</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Successful Medication</td>
<td>11</td>
<td>22</td>
</tr>
<tr>
<td>Surgery</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Terminology</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Transition to Adult Care</td>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>Trial and Error</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Using a Pager</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Video EEG Monitoring</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>VNS</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>Waiting Lists</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>
Appendix 12: Final Codes and Themes from Semi-Structured Interviews with PWE, Carers and HCPs.

Final Theme 1: HCPs express doubt about their resources and capability to deliver comprehensive psychosocial care to each PWE and how new eHealth will integrate into workflow packages.

<table>
<thead>
<tr>
<th>Code</th>
<th>Files</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education sessions</td>
<td>6</td>
<td>13</td>
</tr>
<tr>
<td>Email and TAL Services</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td>Lack of 'out of hours' care</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Lack of reporting in between appointments</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Lack of resources</td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td>Problems if a response is needed quickly</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Reluctance of GPs to become involved in epilepsy care</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Technology workflows changing</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

Final Theme 2: Epilepsy care needs to focus less on ASMs and more on psychosocial aspects of the condition.

<table>
<thead>
<tr>
<th>Code</th>
<th>Files</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Balance between seizure freedom and side effects</td>
<td>9</td>
<td>9</td>
</tr>
<tr>
<td>HCP desire for a more holistic service</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
Final Theme 3: Family members and carers are heavily relied upon by PWE and HCPs to perform important self-management tasks.

<table>
<thead>
<tr>
<th>Code</th>
<th>Files</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>HCPs talking about what they know</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Mechanisms for remembering to take medication</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>PWE noticing a culture change</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>PWE perceived importance of taking medication</td>
<td>6</td>
<td>8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Code</th>
<th>Files</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Affecting family relationships</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Appreciation of family</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Developing knowledge about self-management</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Distressed and upset family members</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>Independence</td>
<td>9</td>
<td>23</td>
</tr>
<tr>
<td>Medication adherence</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Misunderstanding of condition from family</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Seizure management</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Seizure tracking and information collecting</td>
<td>5</td>
<td>7</td>
</tr>
</tbody>
</table>
Final Theme 4: HCPs doubt the willingness and capability of many PWE to engage in self-management activities. PWE’s difficulties with memory and recall and a lack of belief regarding the necessity for self-management activities prove to be barriers.

<table>
<thead>
<tr>
<th>Code</th>
<th>Files</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Transport</td>
<td>8</td>
<td>10</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Code</th>
<th>Files</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acceptance of epilepsy</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Benefits of accepting diagnosis</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Empowered patients</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Having a negative outlook</td>
<td>3</td>
<td>11</td>
</tr>
<tr>
<td>Having a positive outlook</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Lack of patience</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Memory and recall issues</td>
<td>12</td>
<td>22</td>
</tr>
<tr>
<td>Misconceptions surrounding the condition</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Philosophy towards own epilepsy</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Previous adverse experiences</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Questioning why self-management is needed</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Unwillingness of PWE to engage</td>
<td>3</td>
<td>5</td>
</tr>
</tbody>
</table>

Final Theme 5: A lack of data integration across eHealth platforms, the perception of
digital interactions as being impersonal, privacy concerns and a lack of perceived utility are barriers perceived by PWE, their carers and HCPs as existing towards using eHealth tools.

<table>
<thead>
<tr>
<th>Code</th>
<th>Files</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advantages of face-to-face interaction</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Being familiar with technology</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Excessive technology use</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Financial barriers</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Linking of data with EEPR</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Motivation to use eHealth tools</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Privacy and consent issues</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Problems with EEPR</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Siloed information</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Subtlety of wearables</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Unconvinced by utility of apps and wearables</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Website</td>
<td>1</td>
<td>4</td>
</tr>
</tbody>
</table>
Appendix 13: PWE/ Carer Focus group topic guide

PWE/Carer Focus Group topic guide

1. Participants will join the meeting link on Zoom

2. Once all participants have joined, I will say the following

‘Thank you all very much for joining this morning. This group forms a part of the second phase of my qualitative research project. This body of work is looking to understand how people with epilepsy and their families currently self-manage their condition and how clinicians approach it when providing care. In developing this understanding, it is hoped that technological supports developed in the future are suitable for the real-world experience of individuals with epilepsy, their carers and clinicians who provide care.’

3. After that introduction, I will ask the following:

‘What does the term epilepsy self-management mean to you?’

The purpose of this question is to allow participants perception of self-management to initiate their involvement in discussion.

4. I will then move on with the following: 11:15-11:33am

‘Thanks very much for that folks. On my whiteboard here I have summarised the many ways you all told me during the interviews how you manage epilepsy.

- Medication was considered very important for epilepsy management. Many people living with epilepsy have a medication routine such as taking at the same time and same place each day, using medication boxes and alarms on their phones to remind them to take it. Family members are often the ones who manage medication.
- An often-cited challenge to taking medication was the trade-off between having less seizures and experience side effects such as difficulty concentrating, brain fog and side effects.'
• Keeping a healthy lifestyle was important. Sleep was cited by almost everyone as an important factor for limiting the impact of seizures. Having past-times such as playing sport, exercising, music, drama were seen as activities which could only positively impact a person’s health and lessen impact of epilepsy.

• Contacting the DML service if they are struggling, be it through email, telephone advice line or attending their appointments. You guys largely perceived these modes of communication to be adequate and were appreciative of the great work done in particular by the nurses.

• Between clinical appointments, many of you monitor the number of seizures you are having. Some like to use notebooks, pen and paper, and others use IT tools such as mobile apps or excel spreadsheets.

When I brought technology up in the interviews, there was an understanding that there are many tools which currently exist to help people learn about their conditions, seek advice and maintain healthy lifestyles or keep them safe.

• Many of you mentioned that you have researched various aspects of epilepsy online on google.

• Wearable devices such as Fitbits and Apple watches were familiar to many of you as being useful for tracking information about sleep. Some participants mentioned that if these devices could be used to detect seizures it would be great.

• My Fitness Pal was mentioned as a useful app for logging information about food.

• Apps with GPS tracking capabilities were mentioned as a potential option for family members or carers.

• There was some awareness of technologies already available to PWE and their families. Seizure detection watches were being used by some participants. Mobile diary applications were also used by some participants to log information relating to epilepsy.

'With all of this in mind, my next question for you is have you noticed any changes in how you manage epilepsy in the last 12 months?’

5. Thank the participants for their contribution in relation to the previous questions.

'Bearing all that has been said thus far; I would like you all to consider two questions here:

1. How might we balance face to face and virtual care going forward?

2. How might we do things differently to encourage more active self-management from patients and their carers?’
Allow 5 minutes for participants to write down ideas that they have.

6. Allow participants to broadcast their ideas and encourage discussion among participants.

7. Thank participants for attending the session.
Appendix 14: HCP Focus group topic guide

1. Participants will join the meeting link on Zoom -

2. Once all participants have joined, I will say the following -

‘Thank you all very much for joining this morning. This group forms a part of the second phase of my qualitative research project. This body of work is looking to understand how people with epilepsy and their families currently self-manage their condition and how clinicians approach it when providing care. In developing this understanding, it is hoped that technological supports developed in the future are suitable for the real-world experience of individuals with epilepsy, their carers and clinicians who provide care.’

3. After that introduction, I will ask the following:

‘What does the term epilepsy self-management mean to you?’

The purpose of this question is to allow participants perception of self-management to initiate their involvement in discussion.

4. I will then move on with the following:

‘Thanks very much for that folks. On my whiteboard here I have summarised the major themes which emerged from the interviews we carried out last year. In terms of what clinicians believed to be important self-management behaviours, the following came up consistently:

- Adherence to anti-seizure medications.
- Contacting the DML service if they are struggling, be it through email, telephone advice line or attending their appointments.
- Keeping a seizure diary. It did not appear to matter to you if this was kept on a pen and paper format or a spreadsheet / other digital format. The most important aspect mentioned by you guys was accuracy.
- Maintaining a healthy lifestyle, avoiding triggers or stressors which may cause seizures to occur.’

When I brought technology up in the interviews, there was a universal acknowledgement that there are various tools available currently to PWE and their carers, including the
portal, smartphone seizure diary applications, wearable devices and mindfulness apps.

While you showed awareness that these technologies are available, it was clear that you think there is a long way to go before anything currently available is largely taken up in widespread use. Some of the barriers you perceived to an increased emphasis on self-management and technology use included the following from clinician and patient perspectives.

- **Lack of personnel**: The shortage of staff numbers in the department and the number of patients being seen by the service means that it is difficult to provide comprehensive biomedical and psychosocial care to every individual who receives their care from the DML.

- **Appointments and medication**: A large portion of each clinical appointment centres around medication and finding the optimal regimen for each patient. Given the pressure on service and number of patients you have to see, often this medication discussion is the only one which takes place during consultations.

- **When patient or family members raise aspects about more holistic aspects of care or non-medication related issues of their epilepsy, clinicians often flag other services such as Epilepsy Ireland that patients can get in touch with.**

- **The physical capability of some epilepsy patients to self-manage their own condition was highlighted in many issues. Individuals with cognitive issues, be it as a result of epilepsy type, intellectual disability or side effects of medication can mean an individual will struggle to perform the tasks outlined above.**

- **In terms of psychological factors surrounding self-management, it was noted that many people with epilepsy are not willing to engage with the condition or perform the tasks to minimise impact of epilepsy. There were no factors such as age, gender, seizure types etc that you guys associated with being a better ‘self-manager’ in PWE.**

- **It was mentioned that health literacy is often an issue among PWE attending the DML service and this may influence engagement in self-management tasks.**

- **A barrier which you guys mentioned in relation to promoting the usage of wearable devices was the subscription cost associated with these devices. It was said that you did not want to place additional financial pressure on PWE and their families in return for a product which you were not entirely convinced about how effective they were.**

‘With all of this in mind, my next question for you is have these challenges changed over the last 12 months?’

5. Thank the participants for their contribution in relation to the previous questions.
‘Bearing all that has been said thus far; I have two questions that I’d like you to take 5 minutes to consider:

1. How might we balance face to face and virtual care going forward?

2. How might we do things differently to encourage more active self-management from patients and their carers?’

Allow 5 minutes for participants to write down ideas that they have.

6. Allow participants to broadcast their ideas and encourage discussion among participants.

7. Thank participants for attending the session.
Appendix 15: Initial Codes and Descriptive Themes from Focus Groups with PWE, carers and HCPs.

Initial Descriptive Theme 1: Everyday challenges

<table>
<thead>
<tr>
<th>Code</th>
<th>Files</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acknowledge how difficult self-management is</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Driving</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Employment</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Increased funding for epilepsy research</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>More education for the public</td>
<td>2</td>
<td>7</td>
</tr>
</tbody>
</table>

Initial Descriptive Theme 2: eHealth tools

<table>
<thead>
<tr>
<th>Code</th>
<th>Files</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data integration across eHealth platforms</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>eHealth tool which can manage a specific aspect of a person's epilepsy</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>Enhancing the EEPR</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>Existing online resources</td>
<td>4</td>
<td>8</td>
</tr>
</tbody>
</table>
### Initial Descriptive Theme 3: Telemedicine

<table>
<thead>
<tr>
<th>Code</th>
<th>Files</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allowing patients to choose whether they're seen face to face or virtually</td>
<td>4</td>
<td>13</td>
</tr>
<tr>
<td>Hardware improvements</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Service selects whether patient is seen virtually or face to face</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

### Initial Descriptive Theme 4: Epilepsy Service Organisation

<table>
<thead>
<tr>
<th>Code</th>
<th>Files</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication between PWE and HCPs</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Greater involvement of other HCPs</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>PWE becoming part of the MDT</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

### Initial Descriptive Theme 5: Patient-Level Factors

<table>
<thead>
<tr>
<th>Code</th>
<th>Files</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complete questionnaires after appointments</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Empowering patients</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Focusing on activities PWE can do</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Code</td>
<td>Files</td>
<td>References</td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>-------</td>
<td>------------</td>
</tr>
<tr>
<td>More education for PWE about the treatment of their condition</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Support for family members</td>
<td>3</td>
<td>6</td>
</tr>
</tbody>
</table>
Appendix 16: Final Codes and Themes from Focus Groups with PWE, carers and HCPs.

Final Theme 1: Using knowledge as a tool to empower PWE to self-manage

<table>
<thead>
<tr>
<th>Code</th>
<th>Files</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Empowering patients</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>More education for PWE about the treatment of their condition</td>
<td>3</td>
<td>7</td>
</tr>
</tbody>
</table>

Final Theme 2: Adopting a ‘whole family’ approach to care and providing support to family members and carers of PWE.

<table>
<thead>
<tr>
<th>Code</th>
<th>Files</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support for family members</td>
<td>3</td>
<td>6</td>
</tr>
</tbody>
</table>

Final Theme 3: Providing PWE with a choice as to whether they’re seen virtually or face to face.

<table>
<thead>
<tr>
<th>Code</th>
<th>Files</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Allowing patients to choose whether they’re seen face to face or virtually</td>
<td>4</td>
<td>13</td>
</tr>
</tbody>
</table>

Final Theme 4: Upgrading the technical infrastructure within epilepsy services and creating an ‘eHub’
Final Theme 5: Developing apps and wearables which integrate with current clinical systems and help navigate the challenges unique to each PWE.

<table>
<thead>
<tr>
<th>Code</th>
<th>Files</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hardware improvements</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Enhancing the EEPR</td>
<td>5</td>
<td>8</td>
</tr>
</tbody>
</table>

Final Theme 6: Utilising the lived experience of PWE, their carers and other HCPs to better effect

<table>
<thead>
<tr>
<th>Code</th>
<th>Files</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Data integration across eHealth platforms</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>eHealth tool which can manage a specific aspect of a person’s epilepsy</td>
<td>4</td>
<td>11</td>
</tr>
</tbody>
</table>

Final Theme 7: Increasing awareness of epilepsy among the general public and knowledge of the challenges faced in living with epilepsy

<table>
<thead>
<tr>
<th>Code</th>
<th>Files</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>More education for the public</td>
<td>2</td>
<td>7</td>
</tr>
</tbody>
</table>
Final Theme 8: Establishing reliable eHealth resources to direct PWE to

<table>
<thead>
<tr>
<th>Code</th>
<th>Files</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Existing online resources</td>
<td>4</td>
<td>8</td>
</tr>
</tbody>
</table>

Final Theme 9: Taking a more holistic approach to epilepsy care

<table>
<thead>
<tr>
<th>Code</th>
<th>Files</th>
<th>References</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication between PWE and HCPs</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>