Care pathway for suspected seizures at the emergency department: an in-depth exploration

Thesis submitted in accordance with the requirements of the University
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Abstract

Background

Seizures due to epilepsy, or other conditions, result in ~60,000 emergency department (ED) attendances in England each year. Most are made by people with established epilepsy who represent a particularly vulnerable part of the epilepsy population. The UK's National Audit for Seizure Management in Hospitals (NASH) identified wide geographical variation in the standard of care people receive for seizures in ED. Seizure care in the ED and through to tertiary services is complex. In Mersey and Cheshire, a seizure care pathway was developed to improve the management of seizure patients. To date, little is known about the views of patients' experiencing the care pathway, those delivering its care, and the best way to audit this. This thesis aims to explore patients' and professionals' perspectives of the seizure care pathway and develop a patient-reported experience measure (PREM) to audit the pathway.

Methods

This qualitative evaluation project consisted of three inter-related studies. A systematic review was conducted to identify and evaluate currently available patient-reported experience measures (PREMs), as audit tools, for use specifically within the ED. Subsequently, two qualitative studies, using semi-structured interviews, were conducted to explore the experiences of people with seizures receiving care in the ED (n=27) and professionals delivering it (n=6). Participants were purposively sampled from three NHS hospital sites who were delivering the seizure care pathway. Interviews were recorded, transcribed verbatim and transcripts analysed thematically.

Findings

The systematic review revealed four previously designed PREMs for use within the ED population, but were not disease-specific to epilepsy. There was significant variation in the psychometric development of these PREMs. Scoping literature review identified few studies that assessed the experience of patients with epilepsy when presenting at the ED and in neurology services. The subsequent qualitative study with seizure patients sought to address this knowledge gap. Discontinuity in care, waiting and poor communication were elicited as some of the most important findings. A lack of memory of ED experience was explored and became a key finding of many interviews. This led to a reconsideration around the validity of developing a PREM for this population and from this point the scope of the thesis altered. Professionals' perspectives were explored and led to similar findings to patients, particularly in the lack of care continuity from ED onto neurology services.

Conclusion

This study provides a unique contribution to the literature on health care experiences of patients presenting to the ED following a seizure. Patient data identified potential gaps in ED care and subsequent follow-up services. Heath care professional data highlighted various operational barriers resulting in lack of consistency in the care. Clinical recommendations and future research suggestions have been made to develop and improve the care pathway, as well as the clinical environment and management of seizure patients along the seizure care pathway continuum.

Aim & Objectives

The overall aim of this study was to explore patients' and professionals' perspectives of the seizure care pathway as a service intervention through process evaluation and development of a Patient Reported Experience Measure (PREM). Study objectives are outlined below:

1. Conduct a literature review of evidence to explore current service provision in emergency seizure care, and to identify the theoretical underpinning behind quality improvement and service evaluation approaches.
2. Conduct a systematic review (study part one) of evaluative methods for measuring patient experience and their development.
3. Conduct qualitative interviews (study part two) to examine patients' experience of the seizure care pathway.
4. Conduct qualitative interviews (study part three) to examine staff perceptions of using the seizure care pathway in practice; barriers and facilitators to its use and suggestions for improvement.
5. Develop a Patient Reported Experience Measure (PREM) for use with seizure patients who have experienced the seizure care pathway.
6. Synthesise findings from patient and staff interviews and present recommendations to revise the pathway and plans for disseminating this across hospital sites.

Declaration

This thesis is the result of my own work and the material contained therein has not been presented either wholly, or in part, for any other degree or qualification. Where information has been derived from other sources, I confirm that this has been indicated within the thesis.

The work for this thesis was carried out at the Department of Molecular and Clinical Pharmacology, University of Liverpool, UK, and The Walton Centre for Neurology and Neurosurgery, Liverpool, UK.

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Publications related to work presented in this thesis

Journal Papers

Male L, Noble A, Atkinson J, Marson T. 2017**.** Measuring patient experience: A systematic review to evaluate psychometric properties of patient reported experience measures (PREMs) for emergency care service provision International Journal for Quality in Health Care, 29:314-326

Male LR, Noble A, Snape DA, Dixon P, Marson T. 2018**.** Perceptions of emergency care using a seizure care pathway for patients presenting to emergency departments in the North West of England following a seizure: a qualitative study, BMJ Open, 8

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Abbreviations

A&E	Accident and Emergency
ABN	Association of British Neurologists
ACTAD	Assertive Community Treatment for Alcohol Dependence
AED	Anti-Epileptic Drug
AEDQ	Accident and Emergency Department Questionnaire
BNF	British National Formulary
CAPS	Care After Presenting with Seizures
CCG	Clinical Commissioning Group
CHD	Chronic Heart Disease
CHF	Congestive Heart Failure
CLAHRC	Collaboration for Leadership in Applied Health Research and Care
COPD	Chronic Obstructive Pulmonary Disease
CPD	Continued Professional Development
CQI-A&E	Consumer Quality Index of the Accident and Emergency department
CSAG	Clinical Standards Advisory Group
CT	Computerised Tomography
CQC	Care Quality Commission
DGH	District General Hospital
DH	Department of Health
ED	Emergency Department
EDACP	Emergency Department Asthma Care Pathway
EEG	Electroencephalogram
EFQM	European Foundation for Quality Management
ESN	Epilepsy Specialist Nurse
GDPR	General Data Protection Regulations
GMC	General Medical Council
GP	General Practitioner
GPwSIe	General Practitioner with Specialist Interest epilepsy
GT	Grounded Theory
HaHP	Have a Heart Paisley
HES	Hospital Episode Statistics
HRQOL	Health-Related Quality of Life
ICP	Integrated Care Pathway
ILAE	International League Against Epilepsy
IMD	Index of Multiple Deprivation
IOM	Institute of Medicine
IPA	Interpretative Phenomenological Analysis
ISO	International Organisation of Standardisation

LCP	Liverpool Care Pathway
LSOA	Lower Super Output Area
MDT	Multidisciplinary Team
MIS	Minor Injuries Stream
MRC	Medical Research Council
MRI	Magnetic Resonance Imaging
NASH	National Audit for Seizure Management in Hospitals
NCHI	National Conversation on Health Inequalities
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research
NMC	Nursing and Midwifery Council
NWC	North West Coast
PPED	Patient Participation in the Emergency Department
PREM	Patient Reported Experience Measure
PROM	Patient Reported Outcome Measure
PWE	People with Epilepsy
QOF	Quality Outcome Framework
QOL	Quality of Life
RAC	Rapid Access Clinic
RCN	Royal College of Nursing
RCT	Randomised Controlled Trial
SCN	Strategic Clinical Network
SIGN	Scottish Intercollegiate Guidelines Network
SOP	Standard Operating Procedure
TA	Thematic Analysis
UCSQ	Urgent Care System Questionnaire
UEC	Urgent Epilepsy Clinic
UK	United Kingdom
VNS	Vagal Nerve Stimulator

Chapter One: Introduction

1.1 Thesis Scope

Within this thesis I present an investigation into the experience of an integrated seizure care pathway service from the perspectives of patients who were supported by it and professionals working to deliver it. In addition to this, I explore the possibility of an ongoing evaluation of the service through the development of a patient-reported experience measure (PREM) and make recommendations for future service improvement based on qualitative findings. In this chapter I provide background to the project and outline the scope and structure of the thesis.

1.2 Aim and objectives of thesis

The overall aim of this study was to explore patients' and professionals' perspectives of the seizure care pathway as a service intervention and to develop a patient-reported experience measure (PREM) to audit the pathway. The study objectives were:

1. To conduct a literature review of evidence to explore current service provision in emergency seizure care, and to identify the theoretical underpinning behind quality improvement and service evaluation approaches.
2. To conduct a systematic review (study part one) of evaluative methods for measuring patient experience and their development.
3. Conduct qualitative interviews (study part two) to examine patients' perspectives and experiences of the seizure care pathway.
4. Conduct qualitative interviews (study part three) to explore professional staffs' perspectives of using the seizure care pathway in practice.
5. Develop a patient-reported experience measure (PREM) for use with seizure patients who have experienced the seizure care pathway.

6. Synthesise findings from patient and staff interviews and present recommendations to revise the pathway and plans for disseminating this across hospital sites.

1.3 Importance of this topic

Seizures place significant demands on urgent and emergency care services. In England alone, seizures are responsible for ~60,000 emergency department (ED) attendances each year, at a cost to the National Health Service (NHS) of at least £88.2 million (Dickson et al., 2018; Dickson et al., 2016; Dixon et al., 2015; Ridsdale et al., 2013). Epilepsy is a chronic neurological condition involving repeated interruptions of brain functioning. These interruptions can present in a variety of ways and are referred to as epileptic seizures. It is the second most common serious neurological condition in the United Kingdom (UK), with a prevalence of up to 1% (Deacon and Wigglesworth, 2011).

The cost of emergency care for seizures and epilepsy are particularly high because around 50% of ED visits result in hospital admission. Indeed, 85% of hospital admissions for epilepsy occur on an unplanned basis (Dixon et al., 2015). Re-admissions further drive costs up; (Booth and Thompson, 2010; Dickson et al., 2016) ≥60% of people with epilepsy (PWE) re-attend ED within 12 months (Dixon et al., 2015; National Collaborating Centre for Primary Care, 2004). This rate of return is higher than for other chronic relapsing conditions, such as asthma and diabetes (Coulter et al., 2013). Additional costs arise from ambulance usage since 90% of patients attending ED for a suspected seizure do so by emergency ambulance (Ryan et al., 1998).

Emergency care for seizures can be important, even life-saving in some situations. Examples include someone with new onset epilepsy who experiences a first seizure, status epilepticus, as well as someone with established epilepsy who sustains a serious injury following a seizure or who is pregnant and has a seizure. Evidence suggests though that most people attending the ED following a seizure do not present with these reasons and do not, from a clinical perspective, require the full facilities of a Type 1 ED (defined as an ED that is led by a consultant doctor, provides a 24-hour service and has full resuscitation facilities and designated accommodation for the reception of accident and emergency) (NHS England, 2019). This is because most people have known epilepsy, rather than new epilepsy and most have had self-limiting seizures (Dickson et al., 2017; Dickson et al., 2016; Dixon et al., 2015). Such seizures may be treatable through basic first aid at home; placing patient in the recovery position, ensuring they are in a safe area and cannot further harm themselves while seizing, and timing the seizure to ensure it does not last longer than five minutes (Bromfield et al., 2006). Most PWE will make a full recovery from their seizure without needing to attend an ED.

Some of the clearest evidence comes from Reuber et al. (2000) who retrospectively reviewed ED records from a hospital in the North of England and found that, of those presenting with epileptological emergencies to one ED, nearly three quarters already had an epilepsy diagnosis when attending the department. Some patients had experienced uncomplicated seizures in line with their usual presentation. Others had experienced self-limiting seizures, but which were different in nature or frequency to their usual pattern (Reuber et al., 2000). Reuber et al.'s (2000) study suggests that a significant proportion of ED attendances and hospital admissions may have been avoidable . Whilst acute episodes leading PWE to visit ED do not typically require care within the ED, many of the visits appear to indicate a need for a step-up in patients' subsequent ambulatory care; be it to address the change in the person's epilepsy or, as will now be shown, deficiencies in the care they had been receiving.

The UK National Audit for Seizure Management in Hospitals (NASH), conducted in 2011 and 2013, captured audit data from 132 NHS trusts/health boards on ED utilisation following seizures, focusing on treatment from a clinical viewpoint (Dixon et al., 2015). The audit aimed to assess prior care, management of the acute event and follow-up of these patients. Findings suggested that care was often suboptimal and that there existed considerable disparity in the treatment of PWE and those experiencing their first seizure (Dixon et al., 2015).

When compared to guidance provided by the National Institute for Health and Care Excellence (NICE), it was apparent that the care of patients often fell short of recommendations. For example, in the case of a possible first seizure, it is recommended that all adult patients presenting to the ED be seen within two weeks by a medical practitioner with training and expertise in epilepsy to ensure precise and early diagnosis and initiation of therapy appropriate to their clinical needs (National Institute for Health and Care Excellence, 2016b). To help promote safety, NICE also consider it essential that the patient and their significant others be given information on how to recognise a seizure, first aid, and the importance of reporting further seizures. NASH2 found that only 55% of patients presenting with a possible first seizure were being referred on to a health care professional (HCP) with training and/or expertise in neurology and epilepsy. Moreover, only 27% were being advised on further seizure management (Dixon et al., 2015).

In those with established epilepsy, if seizures are not controlled and/or there is diagnostic uncertainty or treatment failure, NICE recommend the person be referred to tertiary services and seen within four weeks for further assessment (National Institute for Health and Care Excellence, 2016b). Although NASH2 identified that the proportion of PWE who had seen an epilepsy specialist in the previous 12 months had risen since the first audit, there were still 63% who had not, despite over 50% having had seizure-related ED attendances in the previous year (Dixon et al., 2015).

NASH2 also highlighted areas where specialists might help attendees achieve improved seizure control and quality of life (QoL), thereby avoiding acute hospital attendance and admission (Dixon et al., 2015). Two-thirds of those diagnosed with epilepsy visiting ED were on no therapy or monotherapy indicating additional treatment possibilities. Also, despite focal epilepsy being one of the most common epilepsy type, most likely to be refractory and often not best treated with the medication sodium valproate (Hamandi, 2015), sodium valproate is commonly prescribed. This indicates some PWE are, via their usual care provider, receiving outdated care.

Onward referral is likely important from a self-management perspective. Coping with life in the context of having epilepsy requires acceptance of diagnoses and adoption of specific self-management behaviours to prevent seizures and manage consequences. Increasing evidence indicates that PWE attending ED often need greater support in this respect, such as through the training that epilepsy specialist nurses (ESN) often provide (Mills et al., 2002; Ridsdale et al., 2013). Unlike for other chronic conditions, there is no NHS provision of a routine course that PWE can attend to learn about epilepsy once diagnosed. Consequently, knowledge and self-management confidence can be low, particularly in PWE who are older and those with low levels of formal education (Noble et al., 2012; Ziso et al., 2017). Compared to the wider epilepsy population, PWE attending ED have been found to have lower knowledge of epilepsy and seizure management. A third of participants from one ED sample responded incorrectly stating that it was always necessary to call a doctor or ambulance if a person with epilepsy has a seizure, even if it occurred without complications (Noble et al., 2012)(Personal communication, Dr Adam Noble, University of Liverpool). Only 11% of the wider epilepsy population have been found to give this answer (Jarvie, 1993).

When interviewed about their visits to ED, PWE have often expressed a need for immediate access to urgent care when they have a seizure. They explained how they and their family (to whom care decisions are often delegated when the patient is unconscious or lacks capacity) are often fearful of seizures, including the possibility of death and brain damage, and are unsure about how to manage them (Noble et al., 2013). This, they say, can lead them to call for an ambulance when they are about to have, or have had, a seizure. For many, this is an established pattern of behaviour. Telling quotes from interviews (Noble et al., 2013; Ridsdale et al., 2012) with PWE include:

> *“Cancer, you’re awake. I know you can die, but you’re awake. I’d prefer something like that…Having epilepsy, you’re going into a fit. You don’t know if you’re going to wake up or die. That’s why I call [999]!” (Patient, number 23)*

> *"[I was] just worried because I don't know anything about epilepsy…I only know the bad things…I know you can die… I am so worried I decided just to ring an ambulance…better safe than sorry." (Carer, number 60)*

Ensuring those PWE in need of specialist care receive it has been a longstanding challenge in the UK. Potential reasons why these patients may not always be identified and supported include; i) primary care is not incentivised (as it is for other conditions) to identify PWE with uncontrolled seizures, where there is diagnostic uncertainty or treatment failure; ii) there are far fewer neurologists per head than in other developed nations (Gregory et al., 2017); and iii) there are fewer nurse specialists than recommended (Campbell et al., 2019). An indication of the challenge is that only ~50% of PWE in the UK are currently seizure-free (Moran et al., 2004). Trial evidence indicates this should be ~70% (World Health Organisation, 2017).

Importantly, it is those in socially deprived areas who fare worst. Ashworth et al. (2007) found the difference in the proportion of PWE in the least and most deprived quintiles who were seizure free was 12%. An ED attendance represents an important opportunity to begin to redress this and efficiently identify those in need, be it to ensure those with new presentations are identified, promptly diagnosed, and treated as needed, or for those with established epilepsy to ensure their treatment and support is optimised, in line with their holistic care needs.

Part of the solution might lie with comprehensive service change; specifically, the introduction of a clinical care pathway within acute hospitals for seizure patients that institutes a more proactive and better coordinated model of care. The use of integrated care pathways (ICPs) to translate evidence-based policy and national guidelines into clinical practice has been used for numerous other clinical conditions. Stroke (Abdul Aziz et al., 2017), heart failure (Cawley and Grantham, 2011), and orthopaedic patients (Gholve et al., 2005) have seen ICPs used with positive effect. While many of the originally designed ICPs focus primarily on hospital care (Gholve et al., 2005), ICPs designed more recently have focussed on transition across inpatient services and ambulatory care, an area which has previously been neglected (Abdul Aziz et al., 2017; Cawley and Grantham, 2011).

A report from the Nuffield Trust provided an overview of *integrated care* in the NHS, defining it broadly as;

> *"…a term that reflects a concern to improve patient experience and achieve greater efficiency and value from health service delivery systems. The aim is to address fragmentation in patient services, and enable better coordinated and more continuous care"* (Shaw et al., 2011)(pp.3)

ICPs themselves represent complex interventions with multiple interacting and interdependent intervention components and outcomes (Seys et al., 2019). A full evaluation of them requires consideration of issues in addition to effectiveness (Moore et al., 2015). Guidance on how to develop and evaluate complex interventions such as the seizure care pathway is provided by the Medical Research Council (MRC) (Craig et al., 2008). 'Complex interventions' are defined as "*interventions that contain several interacting components"* (Craig et al., 2008) (pp.7). Such evaluation supports an understanding of why an intervention may or may not work, what its 'active ingredients' are and how the treatment plan and management may need refining (Grant et al., 2013; Moore et al., 2015). The MRC recommends that such questions are addressed through a 'process evaluation', whereby interventions can be evaluated to *"assess fidelity and quality of implementation, clarify causal mechanisms and identify contextual factors associated with variations in outcomes"* (Craig et al., 2008)(pp.3).

Previous research around the development and implementation of ICPs has focussed primarily on their effectiveness in clinical practice, with little consideration given to the perspectives of those experiencing and delivering the service offered. To identify whether service change is required for those presenting to the ED following a seizure, we must identify those interventions that work and consider how well they work and in what context. In exploring the seizure care pathway as an intervention, this thesis will consider questions related to the processes of the seizure care pathway from a patient perspective and from the system-wide context of the NHS. This will enable an exploration of patients' perspectives of the current seizure care pathway, providing insight into the workings of the intervention and the development of a PREM to allow ongoing audit of care using the seizure care pathway as an intervention.

1.4 Gaps in current knowledge of seizure care in the ED

Peoples’ experiences of seizure care in the ED are currently understudied particularly through ‘in-depth’ methods, such as qualitative interviews. As attested to by the findings of Ridsdale et al. (2017a) few trials contain in-depth qualitative evaluations to explore participants’ perceptions and behaviours. To our knowledge the work conducted as part of this thesis is some of the only work to capture the views of patients and carers in emergency care for seizure patients using qualitative methods (Shankar et al., in press). Previous research, conducted in Ireland, has investigated the use of a seizure care pathway intervention to support the improvement of care for seizure patients (Iyer et al., 2012). The study however, focussed on a reduction in admissions rather than attendances following seizures. Whilst representing an important development in understanding how the target population might be supported, minimal qualitative work was conducted to ascertain the experiences of those receiving and delivering care via the pathway intervention.

1.5 Background to the current project

Nine acute hospital sites serve a population of approximately 2.5 million people across the Cheshire and Merseyside region in the North West of England. Seven of these hospitals have neurology services supplied from a single tertiary centre, The Walton Centre. Via a ‘hub and spoke’ model, it runs epilepsy clinics at its own site and its neurologists visit the seven hospitals to conduct ward visits and run clinics three to four times per week.

In part, because of the findings from the NASH audits (Dixon et al., 2015), the Cheshire and Merseyside Strategic Clinical Network (SCN) co-ordinated the development of a seizure care pathway for adults presenting to the ED in collaboration with stakeholders to include; emergency physicians, general practitioners (GPs), alcohol services, neurologists, patient and public representatives and service commissioners (a full copy of the pathway is presented in Appendix A).

The seizure care pathway forms a management plan for clinicians in the ED, providing a flowchart for the care of patients presenting with a suspected seizure. Informed by

National Institute for Health and Care Excellence (NICE) guidelines (National Institute for Health and Care Excellence, 2016b), it offers recommendations for tests to be completed to identify possible seizure causes, outlines criteria for admitting patients, and provides a reminder to clinicians to provide an attached seizure advice sheet to the patient on discharge from the ED. In addition, the seizure care pathway provides clinical guidance on the management of status epilepticus and information about patient referrals for follow-up care; including the NICE recommended two-week referral criteria for new seizure patients (National Institute for Health and Care Excellence, 2016b).

The seizure care pathway was not developed explicitly on a theory of change model (Breuer et al., 2016); rather, it arose as a practical response to problems identified in emergency care provision for seizure patients and as a mechanism for meeting performance targets for follow-up care in the context of organisational and policy barriers within the ED. This is not unusual practice for behaviour change interventions, particularly in the NHS (Davies et al., 2010; Painter et al., 2008). Previous studies have highlighted that their design is often ‘theory-lite’ and not informed by detailed modelling or with reference to behaviour change theory (Painter et al., 2008). Rather, such pathways are often designed according to the so-called ISLAGIATT principle (‘it seemed like a good idea at the time’), a term coined by M. Eccles, Emeritus Professor of Clinical Effectiveness (Michie et al., 2014).

The seizure care pathway has been utilised in seven hospital sites across the Cheshire and Merseyside since 2015. To drive the use of the pathway in practice, three hospital sites (those included in this study) employed a research nurse to augment the use of the pathway. The role of the nurse further embedding the pathway into practice, through staff education and patient identification, was hoped to increase referral rates and improve outcomes and patient experience.

Aintree University Hospital (Liverpool University Hospitals NHS Foundation Trust), Warrington Hospital (Warrington and Halton Hospitals NHS Trust) and Arrowe Park Hospital (Wirral University Teaching Hospital NHS Foundation Trust) were the three hospitals selected for the active-intervention (i.e. pathway in place plus research nurse in post to enhance the pathway) (see table 1-1 for catchment populations). These were selected to try to ensure a representation of the types of hospitals covered by the Walton Centre. Selection of hospital sites for the augmented pathway was also governed by pragmatics based on availability of staff and resources.

Table 1-1 CAPS hospital sites catchment populations

Trust	Adult catchment population
Aintree University Hospital	362,908
Warrington and Halton Hospitals	313,996
Wirral University Teaching Hospital	351,885

Referring back to the NASH2 data for Aintree University Hospital and Arrowe Park Hospital, we can see wide variation in the care provided by the two hospitals (Dixon et al., 2015). Warrington Hospital did not take part in the audit and therefore we do not have any data on their seizure management performance prior to implementing the pathway.

NASH2 showed that Arrowe Park Hospital demonstrated some aspects of good care. For example, 63.3% of patients received some neurology input during their ED attendance, or were referred to a neurologist as an outpatient compared to the national average of 55.5%. Aintree University Hospital, despite its proximity to the Walton Centre (it is on the same hospital site), only referred or had neurology input for 37.8% of its patients, well below the national average.

There were aspects of inadequacy with respects to information provision at both sites. For example, at Arrowe Park Hospital only 6.7% of patients were spoken to about the management of future seizures, compared to a national average of 27.5%. At Aintree Hospital, discussions around driving only took place in 9.7% of cases, compared to an average of 22.1% (Dixon et al., 2015).

These headline figures from NASH2 suggest room for improvement in the management of seizures at both hospital sites, exemplifying the need for the seizure care pathway to help support clinical management.

To gauge the impact of the pathway, with and without active-intervention (i.e. research nurse to augment the pathway) the Care After Presenting with Seizures (CAPS) project was established. Funded by the National Institute of Health Research Collaboration for Leadership in Applied Health Research and Care North West Coast (NIHR CLAHRC NWC), sponsored by the University of Liverpool, the overall aim of the CAPS evaluation project was to explore patients' and professionals' perspectives of the seizure care pathway.

The CAPS study hypothesised that by using the current integrated seizure care pathway and providing specific support to identify and facilitate patients with seizures into a specialist neurology review, and thus optimising their therapy, further hospitalisation and ED attendance rates could be reduced and patient wellbeing improved. In addition to these patient-specific benefits, it was theorised that a net cost saving to the NHS would be possible.

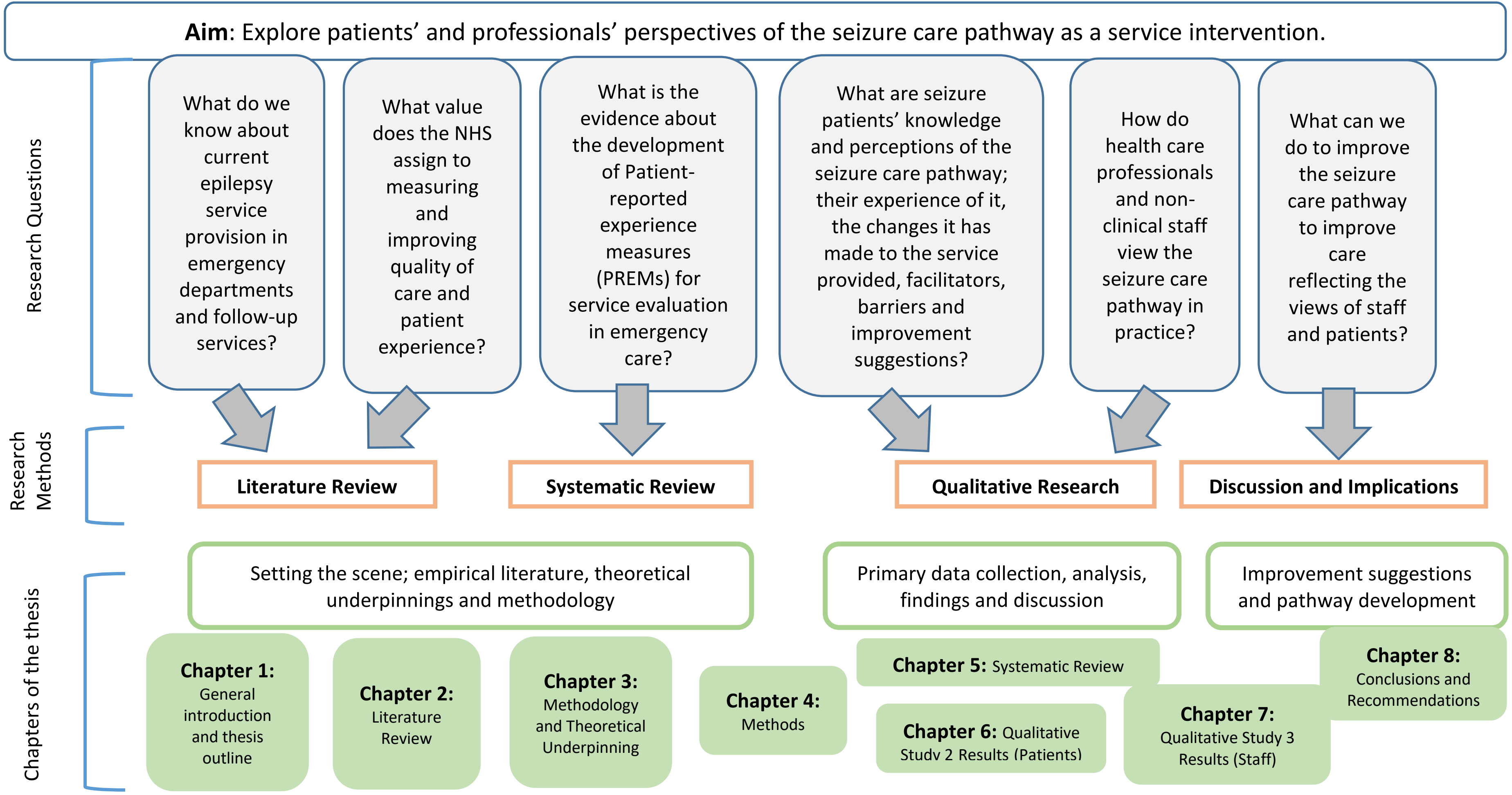
The objectives of the overall CAPs project were to;

1. Assess the impact and outcomes of a new care pathway for people presenting to ED with seizures.
2. Implement the care pathway + research nurse (active-intervention) across three hospitals in Merseyside and Cheshire that access neurology services from the Walton Centre.
3. Compare outcomes over twelve months in these three hospitals with other hospitals in Merseyside and Cheshire and the NWC.
4. Assess patient experience of and preferences for services.
5. Assess staff views of delivering care using the seizure care pathway.
6. Assess patient outcomes using Patient-Reported Outcome Measures (PROMs).
7. Assess service use and performance using routinely collected data and Patient-Reported Experience Measures (PREMs).

8. Estimate the cost effectiveness of the new pathway.
9. Identify recommendations for potential change in pathway content and operational processes.

This thesis aims to provide a unique contribution to knowledge in seizure research by using qualitative techniques to demonstrate how the seizure care pathway has impacted on patient experience and develop a PREM to audit the use of the pathway; addressing objectives four, five, seven and nine of the wider CAPs evaluation project. The aims and objectives presented in section 1.2, along with figure 1-1 provides an outline of the thesis plan and highlights the research questions to be addressed.

Figure 1-1 Diagrammatic outline of thesis plan



1.6 Thesis outline

This introductory chapter has provided background to the study and an overview of the current seizure care pathway. It serves also to evidence some previously highlighted disparities around seizure management in emergency care and identifies gaps in current knowledge.

Chapter two provides additional context; underpinning the work described throughout the thesis. The first section outlines key information regarding epilepsy and seizures (e.g. aetiology, treatment, management) and an overview of health care policy and guidance pertinent to seizure care and management in the ED. This is followed by a brief review of literature on patient experience of seizure care delivery and the role and experiences of the wider multidisciplinary team (MDT) including GPs and epilepsy specialist nurses (ESNs) in relation to care for PWE and seizures. ICPs are then described and evaluated. The review concludes with evidence on the importance of measuring patient experience and evaluation in health service delivery, to improve the experiences of those participating within it and those delivering it.

Chapter three describes the overall methodological approaches underpinning in this research, while chapter four identifies the working methods for this study and provides justification for the analytic tools and techniques chosen.

Chapter five presents the results from a systematic review conducted around current PREMs available for use in the ED, assessing their development and psychometric properties.

Chapters six explores patient perceptions of the seizure care pathway. Following on from this, chapter seven presents an analysis of the implementation of the seizure care pathway from the perspective of professional staff and clinicians tasked with delivering the intervention as part of standard care.

Chapter eight, the concluding part, draws together the various components of the thesis. Study findings are summarised and implications for ongoing service development and care for PWE identified. Study strengths and limitations are explored and recommendations for future research discussed.

Chapter Two: Epilepsy & Emergency Care *Literature Review*

2.1 Introduction

As described in chapter one, the ED seizure care pathway has been established for use in clinical practice. Despite this, the evidence base around its applicability remains limited. As a starting point to the evaluation of the pathway, this chapter takes a step back by surveying the literature in order to provide greater insight into epilepsy and seizures and consider the context of delivering seizure care. As well as exploring policy and guidelines around the treatment and management of epilepsy and seizures, the review will consider the current situation in relation to seizure care, exploring both retrospective audit data, and first-hand experiences from patients.

The chapter continues with a scoping review of literature on the experiences of health care professionals' (HCPs) responsible for delivering care, with a focus on primary and tertiary care services. Outcomes from a brief exploration of literature around the transition between ED and ambulatory care for seizure patients are discussed.

The role and utility of integrated care pathways (ICPs) in health care is conversed, with a consideration of acute care and augmented care pathways. Finally, the measurement of health care is addressed, with focus on how health care is most commonly measured, and how new guidelines may help to support a shift towards a more pragmatic, patient-friendly approach to measuring care quality and experience.

2.2 Epilepsy and seizures

According to the International League Against Epilepsy (ILAE) epilepsy is a disease of the brain. It is diagnosed when a person experiences either at least two unprovoked seizures occurring more than 24 hours apart or one unprovoked seizure, but has a 60% or above probability of a further seizure in the following ten years (Fisher et al., 2014). Epilepsy is considered to be resolved for individuals who either had an age-dependent epilepsy syndrome but are now past the applicable age or who have remained seizure-free for the last ten years and off anti-seizure medicines for at least the last five years (Fisher et al., 2014).

Characteristics of seizures include loss of consciousness, uncontrollable muscle spasms, and the biting of the tongue. However, these constitute only a small number of the symptoms that may arise prior to, during, and following a seizure episode. Different types of epilepsies manifest in different ways, producing different symptomatology and seizure presentations; ranging from subtle to severe and life-threatening (Baumgartner et al., 2001).

There are numerous causes of epilepsy, ranging from structural abnormalities and genetic disorders, through to insults to the brain, caused by injury or infection. In up to 60% of cases, aetiology remains undefined (Bell and Sander, 2001).

2.2.1 Epidemiology and presentation

Epilepsy is a chronic disease experienced by millions of people worldwide and a cause of substantial morbidity and mortality (Banerjee et al., 2009). It is estimated that approximately 50 million people worldwide have epilepsy, making it one of the most common neurological conditions globally (World Health Organisation, 2017). A recent systematic review identified a point prevalence of active epilepsy as 6.38 per 1000 persons, with a lifetime prevalence of 7.60 per 1000 persons (Fiest et al., 2017). Prevalence and incidence rates of epilepsy are higher in low to middle income countries (Fiest et al., 2017). In the UK, 402,000 individuals were registered with general practitioner (GP) practices as having epilepsy in 2008/09, representing an incidence rate of 6.2 per 1000 population (Booth and Thompson, 2010).

As the general population ages and average life expectancy increases, there has been a shift in the epidemiology of epilepsy (Beghi and Giussani, 2018). Epilepsy and seizures can develop in any person at any age; however, prevalence does increase with age; it is around 3 per 1000 in under 16s and 12 per 1000 in over 65s (Booth and Thompson, 2010). Incidence of epilepsy in young people is reducing, with most now diagnosed in adulthood (Beghi and Giussani, 2018). This exemplifies the need for the focus of this study to be on seizure health care experiences within the adult population.

Epilepsy is also more prevalent in areas of greater socioeconomic deprivation. People with epilepsy (PWE) are more likely to live in socially and economically deprived areas of the country and to be educationally disadvantaged (Kokkonen et al., 1997; Steer et al., 2014). Ashworth et al. (2007) found the difference in the proportion of PWE in the least and most deprived quintiles who were seizure free to be 12%. Strongest correlations between epilepsy prevalence and deprivation occur in education, employment and health and disability (Steer et al., 2014). The link is yet to be explained, however, Pickrell et al. (2015) suggest that social causation, whereby features associated with increased deprivation, result in an increased incidence of epilepsy. These include factors such as perinatal hypoxic injury, cerebral vascular disease, and head injuries that result in epilepsy and are directly associated with increased deprivation (Pickrell et al., 2015).

Those living with epilepsy in socially disadvantaged areas are also more likely to use emergency care services (Kossarova et al., 2017). Social inequality is associated with more than 158,000 preventable emergency hospitalisations in England (Cookson et al., 2016). Various reasons for increased ED attendance in disadvantaged neighbourhoods have been cited, including low levels of social support, loneliness, housing problems, and transport and access to primary care (Giebel et al., 2019).

Despite those living in the most deprived areas, and the elderly population, having a greater prevalence of epilepsy, they were within the groups of individuals identified in Grainger et al.’s (2016) study to be least likely to be referred on from ED. For example, 34% of those over 60 years of age were referred onto a neurologist on discharge following a suspected first seizure, compared to 68% of patients under the age of 60. This referral rate further declines with age; 52% of 60-69 year olds with a suspected first seizure were referred to neurology, compared to only 25% of those aged 80-89 (Ziso et al., 2017). Although we do not know exactly why this occurs, low referral rates may be due to some clinicians holding a nihilistic view that intractability is inevitable if seizure control is not obtained within a few years of therapy onset

(Luciano and Shorvon, 2007). Similarly, assumptions may be made about the willingness of certain patient groups to attend clinic appointments (Blank et al., 2013; Ziso et al., 2017).

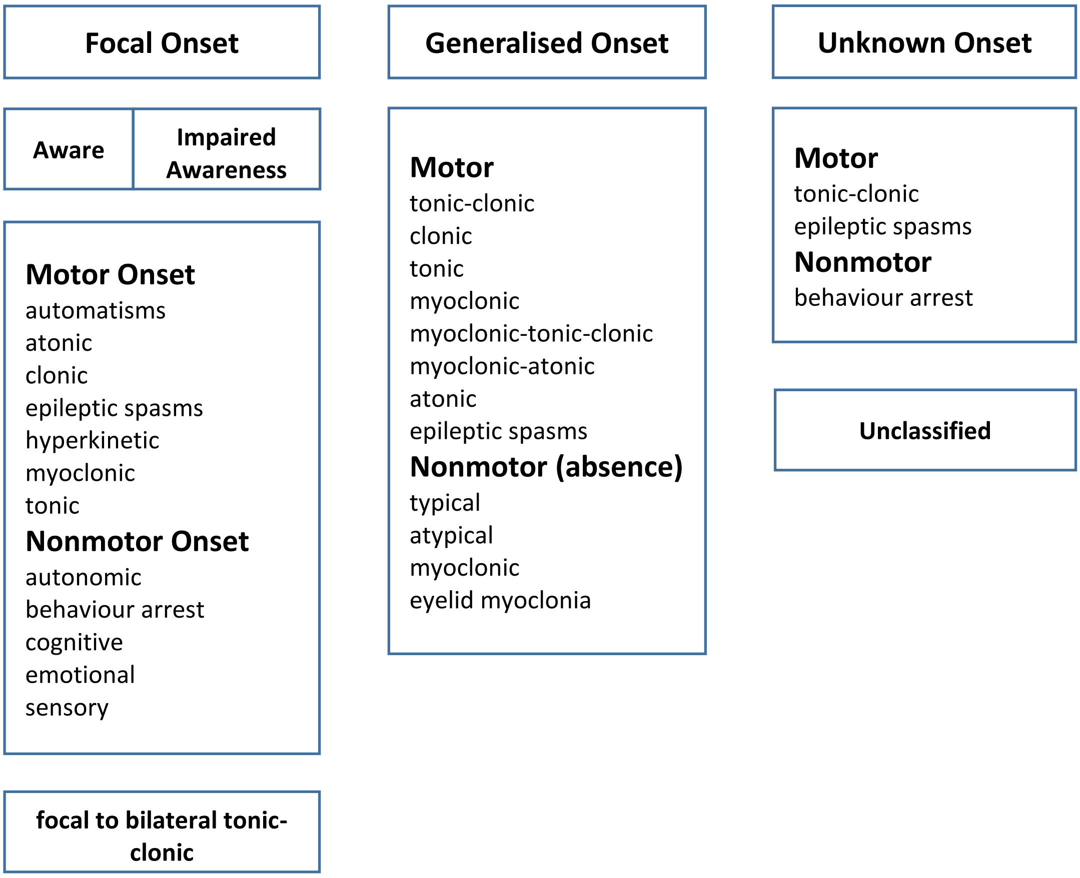
2.2.2 Diagnosis and disease classification

Timely diagnosis of epilepsy is important in ensuring appropriate treatment and support. National Institute for Health and Care Excellence (NICE) clinical guidelines (CG137) state that "*diagnosis of epilepsy in adults should be established by a specialist medical practitioner with training and expertise in epilepsy*" (NICE guidance CG137; 1:5.1) (National Institute for Health and Care Excellence, 2016b). This is important for individuals presenting to the ED following a suspected first seizure, who require timely onward referral to an epilepsy specialist who can then provide clinical diagnosis, if warranted. Tools that can assist in arriving at a diagnosis include investigations such as computerised tomography (CT) and magnetic resonance imaging (MRI) scans, electroencephalogram (EEG), blood tests, and developmental, behavioural, and neurological testing. Accurate history of the seizure event is fundamental to diagnosis; symptoms, duration of the seizure, past medical history, as well as any family history of seizures, are all important in formulating a diagnosis. Where the patient cannot remember events surrounding the seizure episode, caregiver or other eye-witness accounts of the seizure event are key.

The words 'seizure' and 'epilepsy' are sometimes used interchangeably, and while epilepsy is characterised by the presence of seizures, seizures can occur in patients without a diagnosis of epilepsy. Seizures can be provoked by factors that do not result in an epilepsy diagnosis, including drug overdose or withdrawal, cardiovascular disorders, metabolic disorders or some psychological disorders (Stafstrom and Carmant, 2015). Due to the non-pathognomonic nature of seizures and that there are conditions that can lead to symptoms that mimic epilepsy (e.g. non-epileptic attack disorder (NEAD)), misdiagnosis of epilepsies occurs in approximately 20% of cases (Oto, 2017).

Following a definitive epilepsy diagnosis, seizures are classified as having an onset that is focal, generalised and or unknown; this is then further categorised by epilepsy type (Fisher et al., 2017). Figure 2-1 demonstrates the ILAE classification of epilepsies.

Figure 2-1 Framework for classification of the epilepsies as defined by ILAE 2017 (Fisher et al., 2017)



Focal seizures can also be described as partial seizures and can be characterised by whether awareness is retained or impaired (Fisher et al., 2017). If awareness remains intact during the seizure, even where the person is unable to talk or respond, the seizure is called a focal aware seizure, replacing the more commonly used term ‘simple partial’ seizure. Impaired awareness at any point during a seizure renders it a focal impaired awareness seizure, replacing the term ‘complex partial’ seizure (Fisher et al., 2017).

Generalised seizures arise in both cerebral hemispheres simultaneously. Seizure types include tonic-clonic, atonic, tonic, clonic, myoclonic and absence seizures. Some seizure types can be ambiguous and difficult to classify, particularly where individuals have co-existing seizure types. There remains an ‘unknown’ category for when classification remains problematic.

The third level of possible classification relates to the epilepsy syndrome. Epilepsy syndrome refers to a cluster of features incorporating seizure types, EEG, and imaging features that tend to occur together. It may also include age-dependent factors, as well as co-morbidities. There is an extensive list of epilepsy syndromes as defined by ILAE (Fisher et al., 2014; Fisher et al., 2017).

2.2.3 Symptom management

Symptom management, namely seizure freedom, is key to the long-term management of people living with epilepsy and seizures. NICE guidelines state that once a diagnosis and seizure control has been established, primary care management is likely appropriate if care is straightforward and anti-epileptic drug (AED) therapy can be prescribed in primary care; where local circumstances allow (National Institute for Health and Care Excellence, 2016b). Primary care acts as a gateway to health care services, accounting for 90% of all patient contact in the NHS (Hobbs et al., 2016).

PWE and seizures are eligible for access to specialist neurology services and are commonly registered with a neurologist and epilepsy specialist nurse (ESN). NICE guidelines state that all patients’ experiencing their first seizure should be seen urgently, within two weeks, by a specialist in the management of epilepsies (National Institute for Health and Care Excellence, 2016b). Management of seizures may involve contact with primary, secondary and tertiary care services, but will also involve an element self-management (National Institute for Health and Care Excellence, 2016b). Coping with life in the context of epilepsy requires many significant life changes. PWE must become confident in managing their own condition, as well as learning to identify and manage seizure triggers, remembering to take AEDs, implementing precautions to minimise risks due to seizures, educating others what to do when a seizure occurs and learning what to do during recovery from seizures (Kralj-Hans et al., 2014). Strategies PWE reported for managing symptoms within the current study are presented in the findings in chapter six.

2.2.4 Treatment

Anti-epileptic drugs (AEDs) are the mainstay of treatment for those with known epilepsy, and are effective in controlling seizures in approximately 60% of all epilepsy patients (Kwan and Brodie 2000).

Taken from the British National Formulary (BNF), NICE list over 20 AEDs currently licenced for prescription in the UK (National Institute for Health and Care Excellence, 2017). When prescribing AEDs, clinicians take into consideration a wide range of factors when selecting the AED/s to use – including seizure type and frequency, lifestyle and age, drug side effects and interactions, co-morbidities, and, for women, whether they are of childbearing age (National Institute for Health and Care Excellence, 2017). It can take several attempts to find the AED/s and dosage/s that are best suited to an individual patient. Most seizures can be controlled with one drug (monotherapy) although in cases where epilepsy remains intractable, the addition of multiple AEDs (polytherapy) may be necessary (Kwan and Brodie 2000).

One concern with medical therapy is non-adherence. A recent study demonstrated almost 40% of people, are, to varying extents, non-adherent to AEDs prescribed for their seizures (Getnet et al., 2016). Several studies have explored reasons for non-adherence to medication. These studies commonly cite patient beliefs about taking medication, uncertainty about clinician recommendations, side effects, memory problems and complex drug regimens as reasons for non-adherence (Buck et al., 1997; Eatock and Baker, 2007; Jones et al., 2006).

One of the major medication-related factors to non-adherence is adverse effects caused by AEDs (Zafar et al., 2019). Carpay et al.'s (2005) study found 60% of patients reported adverse effects from their AED therapy, while moderate-to-severe subjective complaints of adverse effects, caused by AEDs, were found to be 67% among epileptic patients whose disease was assumed to be controlled. Patients on polytherapy AED treatment reported more adverse effects than those on monotherapy treatment regimens (Carpay et al., 2005; Uijl et al., 2006) . Uijl et al. (2006) found most common complaints to be cognitive, including memory problems, fatigue and dizziness, a finding attested by Carpay et al.'s (2005) cross-sectional evaluation study. The ultimate goal of AED therapy is to prevent further seizures, avoid adverse effects, and enable patients to lead active lives (Uijl et al., 2006); achieving this balance can take time and be personal.

An important contribution to present day treatment of epilepsy is that of surgical resection of the brain (Rugg-Gunn and Sander, 2012; Spencer et al., 2007). Evaluation of individuals for their appropriateness for surgical intervention is generally recommended after a) focal seizures persist despite the person having tried at least two AEDs or b) there is an identifiable brain lesion believed to be the cause of seizures (National Institute of Neurological Disorders and Stroke, 2015). In terms of success, around 70% of patients who undergo temporal lobe epilepsy surgery are rendered seizure-free in the short-term (Tanriverdi et al., 2008), with a significant reduction in AED dose also noted at long-term follow up. Previous studies have identified that alongside seizure freedom, epilepsy surgery can improve quality of life (Spencer et al., 2007; Tanriverdi et al., 2008). Despite this, numbers of patients' undergoing epilepsy surgery has remained stable in recent years, potentially due to the increasingly detailed information on chances and risks given to patients over time (Cloppenborg et al., 2016).

There are other, less commonly used treatments for epilepsy, including devices such as vagal nerve stimulation (VNS) (National Institute of Neurological Disorders and Stroke, 2015) and ketogenic diet (high-fat, low-carbohydrate) therapies (Kinsman et al., 1992; Nordli and De Vivo, 1997). The latter has been proven effective for children with some forms of medication-resistant epilepsy (Kinsman et al., 1992). The requirement for strict adherence to a ketogenic diet makes it difficult to follow in adult life. However, current research is exploring modified versions of the diet, which may prove more tolerable to adults (Martin-McGill et al., 2017).

2.3 UK guidelines and the wider evidence base for patient focussed emergency seizure care and management

As the variety and availability of services will likely facilitate or prohibit the frequency with which PWE and seizures contact primary, secondary and tertiary care services, this section will discuss aspects of NHS policy and service delivery as they relate to people experiencing seizures.

2.3.1 UK guidelines for epilepsy care

UK based audits of epilepsy care have shown significant deficiencies in acute care for seizures when benchmarked against clinical guidelines (Dixon et al., 2015). Evidence-based guidelines provide recommendations for the efficient and cost-effective management of epilepsy. NICE make recommendations on most clinical aspects of epilepsy management and are considered the 'gold standard' for epilepsy care in England. The clinical guidelines for epilepsy, *Epilepsies: diagnosis and management [CG137]* (National Institute for Health and Care Excellence, 2016b)*,* last updated in 2014, are used alongside *Epilepsy in adults Quality Standard [QS26]* (National Institute for Health and Care Excellence, 2013) by clinicians, care providers, commissioners, patients and their families/carers.

NICE provide advice around guideline use; they are not to be construed or used as a standard of care. Their remit is only advisory and, as such, should not replace clinical judgement or the HCPs responsibility for clinical decision-making. This sentiment is exemplified by the now well-known quote from David Haslam, Chair of NICE, that guidelines are just that -- *"they're guidelines and not tramlines"* (National Institute for Health and Care Excellence, 2016a). The prescriptive nature of their recommendations has prompted criticism about their practicality in the real-world context of NHS service provision. For example, it could be argued the specified waiting times and investigations are, to some extent, too ambitious. In addition, detailed descriptions of which HCPs should be involved in specific aspects of care may not be able to be matched within certain localities.

Some hospitals have developed their own trust-specific integrated care pathways (ICPs) for seizures based on evidence from guidelines, in conjunction with other support networks, such as the ILAE and College of Emergency Medicine (Codling, 2005; Iyer et al., 2012). Some research has previously been conducted around pre-hospital care and management of seizure patients (Dickson et al., 2017; Dickson et al., 2016), however, limited research has been conducted around seizure care pathway use in the ED. This thesis seeks to address this gap.

2.3.2 National audit of services

As discussed in chapter one, the National Audit of Seizure Management in Hospitals (NASH) has been conducted twice in the UK (2011 and 2013) to assess management of the acute seizure presentation to the ED and patient follow-up (Dixon et al., 2015). One hundred and fifty-four sites participated in the 2013 audit, representing 132 NHS trusts (80% of those who were approached), with data collected for a total of 4544 patients. Sites were asked to identify up to 30 consecutive adult patients who presented at the ED from 1st January 2013 with an episode thought to be a seizure and where the seizure was the primary reason for their attendance/admission. Sites were subsequently asked to complete two proformas per patient; a clinical proforma to capture the clinical care pathway for the patient and an organisational proforma, assessing the facilities and staffing available at the time of presentation (Dixon et al., 2015). These were predominantly completed by clinicians (82%) although nurses (11%) and audit staff or other HCPs (7%) also completed the proformas in some sites.

NASH identified wide variability among hospital sites, predominantly in the initial management of the acute event in the ED. The ordering of tests and investigations, as outlined in NICE guidance, was variable, as was the level of advice regarding follow-up care offered to patients. For example, evidence highlights that discussions around driving were only had with 35% of patients, despite NICE guidelines stating all patients should receive this information (Dixon et al., 2015; National Institute for Health and Care Excellence, 2016b). Similarly, investigations such as electrocardiogram (ECG), recommended in all patients, was only documented in 86.8% of patients.

NASH2 also found that a significant proportion of those presenting to the ED, particularly those with known epilepsy, receive tests that may be deemed unnecessary and, in some cases, might be associated with iatrogenic harm. For example, 21.6% of PWE were offered a CT scan. Often clinically unnecessary, such testing suggests inefficient use of resources and the possibility of overexposure to X-ray for repeat attendees (Dixon et al., 2015; Salinsky et al., 2018). There may be an argument that lack of clinical knowledge with regard to applying guidelines across clinical practice for seizure patients is problematic. This thesis aims to explore this potential area of concern in more detail through staff interviews (chapter seven).

A comparison of the findings from the first and second round of NASH revealed a small, but statistically significant, shift towards better care across the country (Dixon et al., 2015). However, it also highlighted that epilepsy care remained sub-optimal in many respects. While informative, NASH is limited by its methodology; it contains only retrospective data collected by HCPs and audit staff. It does not explore seizure patients' experiences of the care they received. Arguably, the use of a more detailed qualitative approach to data collection, which focusses on health care experience, to include *what* aspects of care are important to people experiencing seizures and *why,* would provide a broader, more in-depth understanding of how to best support this patient group. By focussing specifically on patient experience of the seizure care pathway in practice, this thesis seeks to address this current gap in understanding.

2.3.3 Patient and public involvement in the NHS

International health care policy leaders place importance on people's experiences of health care delivery, and invest significant resources in monitoring it and efforts to improve it (Ryan et al., 2014). Emphasis has been placed on patient-centred care since the 1980's; when the importance of patient experience and preferences began to be recognised and explored within mainstream health care policies (Lipkin et al., 1984).

In line with the NHS Constitution, patients and public are at the heart of what the NHS does. NHS England believe that:

> *"by listening to people who use and care about services, it can understand their diverse health needs better, and focus and respond to what matters to them" (NHS England, 2017)*(pp.6)

The NHS has a legal duty under the Health and Social Care Act (2012) to involve the public in its commissioning processes and decisions. Utilising various engagement opportunities, including HealthWatch, health and wellbeing boards, clinical commissioning groups (CCGs), local authorities and direct engagement with patient and public community groups and advocacy organisations, the NHS should be able to access a diverse range of patient views and experiences of its services (NHS England, 2017). HealthWatch England was established by the Health and Social Care Act (2012) to understand the needs, experiences and concerns of service users and to speak out on their behalf.

This reflects the NHS's increasing focus on patient and public involvement in service design and demonstrates that at a policy level, the experiences of patients are important in shaping the NHS of the future (NHS England, 2017). This suggests an increased importance for research investigating patient experience of service provision and knowing how to best capture this information, to ensure that relevant issues are addressed at local level, as well as at policy level. This thesis will endeavour to answer questions about how best to measure patient experience of seizure care, but first, will explore current literature around the health care practices previously experienced by seizure patients and those delivering seizure care.

2.4 Health care experiences of seizure care

Early studies investigating health care experiences of people experiencing seizures and/or living with epilepsy predominantly utilised quantitative design methods such as structured questionnaires to elicit data (Chappell and Smithson, 1998; Goldstein et al., 1997; Jain et al., 1993). Jain et al. (1993) surveyed seizure patients after their neurology clinic attendance and found that over 90% wanted more information and over 60% wanted to talk to someone other than their consultant about their diagnosis, namely an epilepsy specialist nurse (ESN). Chappell and Smithson (1999) conducted a questionnaire containing both quantitative and qualitative questions, to explore patient experiences of primary care services. Similarly, to Jain et al. (1993), 58% of respondents felt that they 'rarely' or 'never' received enough information about their condition in general practice. Patients reported qualitatively that they would value more information and time to discuss the effects of their epilepsy (Chappell and Smithson, 1998).

Weibe et al. (2014) completed a systematic review of studies that had investigated patient satisfaction with epilepsy care. The review identified that patients were least satisfied with communication, and the skills and knowledge they perceived various care providers to have; including GPs and neurology specialists. The review focussed on satisfaction with care from the perspective of individuals with established epilepsy diagnoses and did not include those presenting with new-onset seizures.

Several studies have been conducted using various qualitative methods to explore care experiences of PWE in different settings and in different patient groups. For example, qualitative studies have been conducted exploring women's views of epilepsy services using patient and ESN focus groups (Wallace and Solomon, 1999), the cultural diversity in care provision through exploration of epilepsy experiences of South Asian communities in the north of England using in-depth interviews (Ismail et al., 2005), and patient experiences of epilepsy surgery using open-ended survey questions (Ozanne et al., 2016). Similarities were found in results, with Wallace and Solomon (1999) and Ismail (2005) identifying a perceived lack of information and advice provision, and communication barriers as negative experiences of care. Ismail (2005) offered the highest praise to ESNs. Although this demonstrates how various qualitative methods have been used to explore experiences of PWE in different settings, there remains little report of evidence of experience of seizures in the ED environment.

More recently, a study conducted in Ireland, utilised a cross-sectional descriptive survey design to explore epilepsy services (Bennett et al., 2015). The survey was designed to ascertain satisfaction of PWE in the current service delivery, identify actual and preferred sources of epilepsy care, assess levels of information provision for PWE and explore views around how health care services in Ireland could be improved for PWE, utilising both quantitative and qualitative items within the survey. Results demonstrated high levels of perceived satisfaction in care, but participants offered several suggestions for service improvement, including better communication, less delay in accessing specialist care and easier access to investigatory services (Bennett et al., 2015). Where we may be able to draw on these findings to support improvement in care in the NHS, Ireland's service provision for

PWE and seizures differs from that in England. Furthermore, these findings relate to the wider epilepsy service provision and, as with much of the previous research around care experiences of PWE, little focuses directly on ED care services, particularly from a qualitative standpoint.

Ridsdale et al. (2012) interviewed PWE in-depth about their reasons for attending ED. Experiencing a seizure in an unfamiliar environment and being in the presence of people who lacked confidence and skills in the management of seizures were key reasons cited for emergency medical services being sought. Fear and concerns relating to the consequences of seizures were also mentioned. This study did not though ask patients about their experience of care whilst in the ED and the support offered thereafter (Ridsdale et al., 2012). Moreover, it focused solely on patients with diagnosed and established epilepsy (i.e., 1 year or more since diagnosis) despite evidence to suggest that 40% of people presenting to ED are experiencing their first seizure (Dixon et al., 2015).

A study more recently published in Australia explored the experiences of PWE attending the ED following an epileptic seizure using a survey that allowed respondents to provide free-text responses (Peterson et al., 2019). The Australian Longitudinal Survey 2016-17 collected sociodemographic data alongside respondents’ perspectives on living with epilepsy and the evaluation of health care services they had recently accessed. Main themes identified using basic content analysis included a loss of autonomy, frustration with poor understanding of epilepsy management, and stigmatisation in the ED (Peterson et al, 2019). Although the survey was open-ended, the reductionist nature of quantitative methods likely limited the detail respondents were able to provide (Choy, 2014; Creswell, 2014). As such, it may not have been possible for individuals to fully expand on their experiences and its significance.

Previously conducted research has failed to clarify what patients want from their emergency epilepsy care. While themes such as communication, information provision and time are highlighted as important across several studies, there are no current studies which bring together a pathway of care (the transition from ED services through to ambulatory care) and ask patients about their experiences of this. Previous research around transition between services in epilepsy has focussed primarily on adolescent transition from paediatric to adult services (Camfield et al., 2019; Rajendran and Iyer, 2016). It is well-known, and has been for many years, that UK epilepsy services can be fragmented, particularly between primary, secondary and tertiary care. During transitions of care, the lack of integration between facilities and inadequate communication among providers cause delays in delivering timely and appropriate health care to vulnerable patients and their caregivers. To address this issue, we need to ascertain what is important to patients. This will be explored through in-depth qualitative interviews with patient participants in chapter six.

2.5 Experience of professionals delivering seizure care

Access to acute neurology provision varies markedly across the country. This was illustrated by the 2017 survey of hospital neurologists conducted by the Association of British Neurologists (ABN). Of the 140 district general hospitals (DGHs) that took part in the survey, only 26% provided neurology ward consultations on three days or fewer per week, with 4% providing no neurology access at all (Gregory et al., 2017). Where DGH's lack a clinical neurologist on site, the responsibility of care falls to ED clinicians and ward doctors and this may not necessarily provide optimal care to patients with epilepsy or those presenting with seizures.

Alongside neurologists, numerous other HCPs may be responsible for/involved in the care of PWE and often a multi-disciplinary approach is necessary to provide optimal patient care. Bradley et al.'s (2016) Cochrane Review explored care delivery and self-management strategies for adults with epilepsy. The review included 18 different studies of 16 separate interventions, including those delivered in the hospital, in the community, in general practice and elsewhere, such as within the voluntary sector. The review considered outcomes including seizure frequency, AEDs, participant reported knowledge and information provision, reports of health and QoL, objective measures of general health status and social/psychological functioning, and costs of care and treatment (Bradley et al., 2016). The review identified the plausibility that innovative service models have potential to improve identified problems in epilepsy care such as knowledge and awareness of epilepsy in both clinicians and patients; timeliness and appropriateness of clinical care, follow-up and investigations; and poor communication among clinicians and between clinicians and patients (Bradley et al., 2016).

The role and experience of GPs and epilepsy specialist nurses (ESNs) will be discussed in the following two sections. These professional groups constitute only some of the professionals involved in the overall care of patients experiencing seizures. Within this study, paramedics, ED clinicians, administration staff, and seizure research nurses were all involved in managing the continuity of patient care throughout the seizure care pathway. However, there is no previous qualitative research conducted around the role and experiences of these professionals in the delivery of seizure care. My thesis addresses this gap in knowledge in chapter seven.

2.5.1 General Practitioners (GPs) role and experiences of seizure care

As in many chronic conditions, there has been a recent drive towards primary care management of epilepsy; increasing responsibility placed on GPs.

The Quality and Outcomes Framework (QOF), first introduced in 2004, is a voluntary reward and incentive programme, specifically for use in primary care (Roland and Guthrie, 2016). It rewards for quality of care provided to patients and helps to standardise improvements in care delivery (Roland and Guthrie, 2016). When QOF was initiated, epilepsy had four indicators which required GPs to hold a register of patients, record seizure frequency, review medication, and calculate the proportion of patients on their register who were seizure-free in the past year (Minshall and Neligan, 2014). However, since the initial development of QOF, all but one has been retired - namely, that the practice can produce a register of patients receiving drug treatment for epilepsy.

The evidence for the benefits of incentivising care is scarce and contradictory. Some practitioners may have seen QOF as a failure in the epilepsy population, in that it failed to improve primary care management of people with epilepsy (Minshall and

Neligan, 2014). Harrison et al. (2014) found evidence to suggest that QOF led to improvements in the management of long-term conditions; to be associated with a 10% decrease in emergency admissions compared to conditions that were not incentivised. However, as the evidence in this study is longitudinal and not controlled for variables there may be other attributable factors to this improvement, including the introduction of the 4-hour wait target, which led to those presenting to the ED with non-incentivised conditions being more likely to be admitted to avoid ED breaches (Harrison et al., 2014).

Research around GP provision of epilepsy care in the UK has been somewhat scarce in recent years, with much research in this area being more than 15 years old (Averis, 1997). Minshall and Neligan (2014) conducted a retrospective audit of GP epilepsy care following the introduction of the new GP contract in 2004 and previous NICE guidelines to assess whether these changes had brought about any improvements in care (Minshall and Neligan, 2014). Case notes of 540 patients with epilepsy were reviewed and revealed that 49% of patients with poorly controlled epilepsy were not under shared care, demonstrating a significant unmet need for PWE in primary care. Another study, in the North-East of England, also involved a retrospective case note review and found that 24% of patients with epilepsy did not have their epilepsy type logged and one-third did not have any seizure classification recorded (Smithson and Hukins, 2008). Epilepsy registers were inaccurate and one fifth of patients had not been reviewed in the previous year, despite NICE guidelines specifying this as ‘gold standard’ of care and registers being included as a QOF outcome (National Institute for Health and Care Excellence, 2016b).

Some research has been conducted around the role of the GP with specialist interest in epilepsy (GPwSIe) and the potential that the GPwSIe role has in improving clinical outcomes (Minshall and Neligan, 2019). Minshall and Neligan’s (2019) audit aimed to evaluate the effectiveness of a primary care GPwSIe-led service by determining the clinical outcomes of people newly referred to the service by other primary care practitioners or from consultant-led services. Principal findings suggested that 94% of people referred to the service were judged to have a positive clinical outcome as a result of interaction. Most significantly of the 85 PWE referred to the service with poor seizure control at the time of referral, many of whom had been previously under the care of general neurology services, 75% achieved seizure remission as a result of AED change initiated by the service, two were re-diagnosed with NEAD and one had their diagnosis questioned and AEDs discontinued. The study suggests a service incorporating a GPwSIe may prove effective in improving patient outcomes, quality of care and potentially reduce costs (Minshall and Neligan, 2019). Despite this preliminary evidence suggesting benefits, GPwSIe is not currently standard GP practice. According to the ILAE British Chapter records, there are currently only 30 GPwSIe across the UK. With over 7000 GP practices in England alone (Bostock and Oluwunmi, 2018), this demonstrates the constrained resource that this service offers.

Qualitative research conducted with PWE suggests that there exists ‘room for improvement’ in the care offered by GPs, particularly with regard to information provision and time to discuss implications of diagnosis (Chappell and Smithson, 1998; Thapar, 1996). Elwyn et al. (2003), for example, conducted focus groups to explore epilepsy patients’ experiences across five Welsh GP practices, and found that patients often expressed a dissatisfaction with services. A need for improved information provision, better local access to expertise and improved communication between clinicians were highlighted as main themes. Participants reported that GPs would often silence their concerns and demonstrate a lack of interest in their views, resulting in feelings of marginalisation (Elwyn et al., 2003).

Arguably, despite this study, and previous work, being conducted more than 15 years ago, there appears little progress in epilepsy primary care services and there is an argument for improved co-ordination of services and development of integrated service models between primary and secondary/tertiary care (Minshall and Neligan, 2019).

2.5.2 Epilepsy Specialist Nurses (ESNs) role and experiences of seizure care

ESNs are registered nurses with additional skills and expertise to manage and support PWE. A study by Goodwin et al. (2004) suggests that the ESN role is diverse (Goodwin et al., 2004). Often ESNs will have multiple roles requiring expertise in epilepsy knowledge and treatment, self-management education, psychosocial care, and clinical research (Prevos-Morgant et al., 2019). According to Epilepsy Action's recent mapping review, there are only 448 ESNs in the UK. These ESNs cover 600,000 PWE in the UK, including adults, children and people with learning disabilities (Campbell et al., 2019), demonstrating the scarcity in resource.

Ridsdale et al. (2013) conducted a non-randomised trial assessing an ESN intervention for people with newly diagnosed epilepsy using a mixed-methods approach. The study explored the effectiveness of an ESN-led self-management intervention plus treatment as usual (TAU) compared to TAU alone in reducing ED use and promoting patient wellbeing (Ridsdale et al., 2013). Although when using intention-to-treat analyses there was no significant effect of the intervention found on ED use at 6-month or 12-month follow-up, most participants reported that they valued receiving the intervention. Participants perceived the intervention to provide the opportunity for additional support in their abilities to make sense of symptoms, being given more information on epilepsy and an opportunity to talk about their feelings (Ridsdale et al., 2013). Those attending ED more frequently at baseline were found to be more likely to report that the ESN-led intervention helped them.

More recently, a study conducted in Ireland explored patient experiences of care to determine the differences between services with and without ESN input (Higgins et al., 2018). The study findings add to the body of evidence that reports the role of the ESN as having benefit to PWE, with evidence suggesting that PWE who attend a service with an ESN perceive they receive more support and information, and feel more involved in their care (Bradley et al., 2016; Higgins et al., 2018).

Hopkins and Irvine (2012) qualitatively investigated the perceived role of the ESN through focus groups with 19 ESNs working in England and providing care within adult services. Four core values were identified; holistic care, time for patients, continuity of care and proactive/responsive care provision (Hopkins and Irvine, 2012). ESN's view their role as inclusive within the MDT, as opposed to previous research which suggested that they were seen as an "add-on" (Goodwin et al., 2004).

They have also been proven to give rise in the improvement in knowledge of newly diagnosed patients (Bradley et al., 2016).

ESNs have been shown to provide empathetic levels of communication with patients and their families/carers. Previous research has shown that time spent educating and counselling patients can be associated with a reduction in trips to the ED, an increase in cost-saving, and promotion of self-esteem and social functioning (Ridsdale et al., 2013; Royal College of Nursing, 2010). Räty et al. (2009) explored the importance of the ESN role and suggests that nurses can help support patients' self-reflections around their illness and help them to cope better with their diagnosis. Nurses are perceived to have more time to discuss emotions with patients that other clinicians do (Prinjha et al., 2005), and showing empathy through listening and encouraging patients too talk can have positive outcomes on experiences (Räty et al., 2009). Whilst these findings are a useful starting point to inform research, there remains a gap in the knowledge of ESN care and the role, as delivered using the specific seizure care pathway and this will be explored qualitatively, from the patient and research nurse perspective, in chapters six and seven.

2.6 Integrated Care Pathways (ICPs): role and value within the care process

A range of labels have been utilised to describe care pathways in health care, including, but not limited to, ‘collaborative care pathways’, ‘patient focused pathways’, ‘clinical pathways’, and ‘care streets’ (Schrijvers et al., 2012; Whittle and Hewison, 2007). The term ‘integrated care pathway’ (ICP) is most commonly used to describe the standardised level of care that such interventions have been designed to deliver, based on national guidelines for clinical care (Campbell et al., 1998). Initially used in clinical practice in America, numerous ICPs have now been developed for various conditions and procedures worldwide. The UK’s National Pathways Association defined them as follows;

> *"An Integrated Care Pathway determines locally agreed, multidisciplinary practice based on guidelines and evidence, where available, for a specific patient/client group. It forms all or part of the clinical record, documents the care given and facilitates the evaluation of outcomes for continuous quality improvement."* (Overill, 1998)(pp.93)

Designed as a way of translating evidence-based national policy and guidelines into clinical practice, ICPs offer structure to clinical care, detailing essential steps in the care of patients with specific clinical presentations (Campbell et al., 1998). Vanhaecht (2007) suggested defining characteristics of a care pathway as outlined in Table 2-1, which is endorsed by the European Pathway Association (EPA) (Vanhaecht, 2007).

Table 2-1 Defining characteristics of a care pathway (Reproduced from Vanhaecht, 2007)

Characteristics of *care pathway*
• an explicit statement of the goals and key elements of care based on evidence, best practice, and patients' expectations and their characteristics; • the facilitation of the communication among the team members and with patients and families; • the coordination of the care process by coordinating the roles and sequencing the activities of the multidisciplinary care team, the patients and their relatives; • the documentation, monitoring, and evaluation of variances and outcomes, and • the identification of appropriate resources.

Table 2-1 demonstrates that a care process following a pathway style protocol cannot be fragmented and is by description, integrated in nature (Schrijvers et al., 2012). Integration is the term often used to encompass the complex nature of the care pathway; encompassing a lengthier period of care than, for example, a single clinic visit. A true care pathway follows a continuum of care and can include OPD activities, discharge from hospital and any further follow-up care, as illustrated in the seizure care pathway of this thesis (Appendix A). This level of integration of services across boundaries and organisations gives meaning to the term ‘integrated care’ (Overill, 1998). A report from the Nuffield Trust provided an overview of integrated care in the NHS, defining it broadly as;

> *“…a term that reflects a concern to improve patient experience and achieve greater efficiency and value from health service delivery systems. The aim is to address fragmentation in patient services, and enable better coordinated and more continuous care.”* (Shaw et al., 2011)(pp.3)

Used in the same context as NICE guidelines around patient experience (National Institute for Health and Care Excellence, 2012), integrated care and patient-centred care are often used interchangeably with similar end goals in mind. With the focus on the patient as the ‘organising principle of service delivery’ (Lloyd and Wait, 2005), the primary aim of ICPs is to provide a vehicle for seamless care and health management, by reducing duplication and driving efficiency without compromising care quality (Curry et al., 2013; Overill, 1998). ICPs aim to improve and facilitate multidisciplinary communication and care planning, reduce variation in clinical practice, improve patient-clinician communication, and support ongoing research and development in practice (Campbell et al., 1998). Furthermore, pathways can support staff education in specific conditions, particularly where staff are required to learn quickly about new interventions. By mapping out the patient’s journey ICPs aim to have; “*the right people, doing the right things, in the right order, at the right time, in the right place, with the right outcome”* (Allen et al., 2009)(pp.61).

2.6.1 Using ICPs: the evidence

ICPs have been utilised for many years with numerous clinical and organisational benefits. Several systematic reviews have been published in different areas, identifying ICPs and highlighting their value within clinical care (Allen et al., 2009; Baxter et al., 2018; Deneckere et al., 2012; Kul et al., 2012).

Allen et al. (2009) conducted a systematic review to identify circumstances where ICPs were effective, for whom and in what context, using a realist evaluative approach. The interventions in the review had similar aims; to improve service coordination and efficiency, and support adherence to best practice guidelines and protocols. The review reported on seven RCTs, identifying that ICPs supported proactive care management, timely interventions, and improved documentation and patient communication. The review also found however, that where patient trajectories were less predictable, for example in stroke and asthma presentations at the ED, the effectiveness of the pathway was not as profound (Allen et al., 2009). Allen et al.’s (2009) review suggested that the introduction and use of ICPs is most effective where there is a recognised need for service improvement, rather than in settings where best practice and clinical guidelines are already being adhered to and MDTs are well established.

A further systematic review conducted in 2012 by Deneckere et al. focused more specifically on the relationship between ICPs and the promotion of teamwork in clinical practice. The review identified 26 relevant studies. Within these studies, 20 team indicators were identified and it was found that ICPs positively affected 17 of these indicators (Deneckere et al., 2012). Most frequently positive effects from use of the care pathway were found on staff knowledge, team communication, documentation between professionals, and team relations, with a multidisciplinary approach and educational training sessions highlighted as ways to help ensure success of pathway implementation (Deneckere et al., 2012).

Most recently, a systematic review conducted by Baxter et al. (2018) explored the overall effects of integrated care, both in the UK and internationally. It included 167 studies and identified an extensive range of outcomes, which were subsequently grouped into three main areas; usage of health care resources, quality of care received by patients and outcomes for staff working experiences. Analysis indicated evidence of perceived improvement in quality of care, increased patient satisfaction and evidence of improved access to care. However, evidence was rated as inconsistent or limited for all other outcomes, including ED attendance, unscheduled admissions, and the system-wide impact of integrated care. There were limited differences between outcomes reported in the UK and internationally, although most interestingly perhaps, UK-based evidence indicated that patient waiting time and outpatient appointments may be reduced (Baxter et al., 2018).

Despite some of the benefits of ICPs in the improvement of services and patient experience, there remain opponents. Some clinicians and managers may argue that they do not have time to stand back from clinical practice to develop an ICP (Campbell et al., 1998). An argument cited against the use of ICPs is their rigidity and prescriptiveness in practice (Bryan and Holmes, 2002). Some clinicians have argued ICPs hinder flexibility in care and prevent forward thinking and individualised patient care.

Overall, although there are some concerns around the use of ICPs, there remains a number of potential benefits that may be derived from their use. Indeed, perhaps testament to the enthusiasm for the use of the ICP is the ever-growing number of care pathways designed for use in various health care settings, conditions and procedures within the NHS. Baxter et al. (2018) suggest that new models of care may be best targeted to specific patient groups rather than being a panacea for all. To stimulate more in-depth knowledge about the benefits and barriers to ICP use in practice, qualitative methods such as interviews and focus groups, which involve speaking directly to patients and HCPs to elicit concepts around care experiences, may prove useful (Baxter et al., 2018).

In the following section, the review will focus on the development of various care pathways currently in use in practice. Given that there is a substantial number of pathways for various conditions and settings, particular attention will be drawn to pathways that span a continuum of care across boundaries, principally starting at the 'front door' of the hospital, the ED; similar in scope to the seizure care pathway examined in this thesis.

2.6.2 ICPs in acute care

ICPs have been used in various clinical settings over many years with both positive and negative effect. Within the acute care setting, there are numerous pathways for use with different clinical presentations. In New Zealand, Taylor et al. (2006) retrospectively audited the acute stroke pathway that is used for patients in the acute medical units of district general hospitals (DGH's). Using case notes from patients presenting within a 6-month period before and after the introduction of the pathway, various data and outcome sets were used to assess the utility of the pathway (Taylor et al., 2006). However, in this study, there were no significant differences identified between any of the outcomes or process of care variables measured (Taylor et al., 2006).

These findings are supported by a Cochrane Review in 2005 which included three randomised and twelve non-randomised studies (Kwan and Sandercock, 2005). The study found that patients managed using a stroke care pathway had no significant benefit on functional outcome. There was some evidence that patients on the pathway may be less likely to suffer particular complications (e.g. urinary infections), and more likely to receive certain tests (e.g. brain scans), but patient satisfaction and quality of life may actually be worse (Kwan and Sandercock, 2005). It is interesting to consider why stroke pathways have not been found to improve clinical outcomes. It may be the case that the complexity of acute stroke care makes it difficult to adhere to a specific pathway and that stroke care needs to be more flexible in its nature. The reasons for the adverse effects are also unclear. One possibility is that if the aim of the care pathways identified in these studies was in part to shorten the length of stay in hospital, then there may be pressure on the staff to discharge the patients as soon as possible, which could be before they were ready for discharge. Evidently, this review took place almost 15 years ago, and as it has not been updated since, it is important that we remain mindful that clinical practice may have evolved in the time since.

Kul et al. (2012) conducted a review around the effects of ICPs in the treatment of heart failure patients, with a focus on the benefits to patient care. The review identified seven studies from the USA and Italy and highlighted that the use of care pathways in this patient population reduced hospital mortality and length of stay (Kul et al., 2012). There was no statistically significant difference observed in re-admission rates or hospitalisation costs of these patients and although the review demonstrates some positive effects on patient outcomes, it remains difficult to learn about patient experiences of ICPs from such data.

A Canadian study of the use of an acute Emergency Department Asthma Care Pathway (EDACP), demonstrated some positive outcomes when comparing management, admissions, repeat attendances and length of stay between five intervention sites and five control sites (Lougheed et al., 2009). There were statistically significant and positive differences in the management of the acute exacerbation of the disease, referral rates, and documentation and patient recollection of information provision. The EDACP was though only utilised by the intervention sites for 26.4% of the eligible attendances they received. Health care providers at the intervention sites, including clinicians, nurses, respiratory therapists and administrators, were interviewed about perceived barriers to implementation of the EDACP (Olajos-Clow et al., 2009). Around 60% of respondents valued the pathway as a useful tool in clinical practice, particularly in the promotion of best practice and the reduction in variation in clinical care offered to patients. Most barriers identified related to time constraints, including access to relevant documentation, training and equipment needed.

In addition to the acute management of long-term conditions, ICPs have also been used successfully in long-term follow-up care of people with chronic illness. For example, faecal incontinence can be a long-term and debilitating condition. Studies suggest that patients with faecal incontinence often experience disjointed care across fragmented systems, with limited access to the social, psychosocial and specialist support needed to address their needs (Norton et al., 2010; Rimmer et al., 2015); similar to that experienced by epilepsy patients. A qualitative study by Rimmer et al. (2015), interviewed patients to ascertain their views on their illness and the new integrated care pathway. Historical experiences of care were explored through interviews, with participants asked to make comparison to how current care may (or may not) have differed to care received prior to the pathway. Within this patient cohort, it was identified that many patients, historically, had difficulty accessing services in a timely manner (Rimmer et al., 2015). Since the development of the new ICP, patients viewed their ability to access services more positively and thought its introduction was noticeable and had led to a positive change that supported their care (Rimmer et al., 2015). The focus group of individuals living with faecal incontinence were part of a local community continence user group. These participants may be particularly active in their involvement in care and living with a long-term condition, which may indicate some sampling bias towards a more positive opinion. Bias can also arise as a result of not wanting to offend the provider. The interviewer was a clinician, and although it was made clear to participants that the interviewer had no vested interest in the service and was working to provide an honest evaluation, this knowledge may have caused patients to only discuss positive aspects of the service, making this a limitation of the study design (Rimmer et al., 2015).

2.6.3 Augmented ICPs

Finally, consideration will be given to augmented care pathways in relation to how they have been implemented and their subsequent effectiveness. Augmentation of a pathway occurs where one named HCP working as part of the MDT is tasked with not only delivering part of the pathway, but also explicitly has a responsibility of helping to ensure that all patients are cared for using the pathway and they remain the point of contact for patients throughout their care journey.

An example of a care pathway in practice which utilised an augmented care approach is the Assertive Community Treatment for Alcohol Dependence (ACTAD) trial, whereby each participant was assigned a key worker who undertook part of the intervention with the participant and became their point of contact (Gilburt et al., 2012). A qualitative study of participants was undertaken following the intervention, to assess their experiences of the pathway (Gilburt et al., 2015). The feedback from service users regarding the facilitation of the pathway by the key worker was generally positive. Service users highlighted the usefulness of the key worker, particularly in maintaining their motivation and drive to continue their recovery along the pathway. However, it is also demonstrated that there still remains some difficulty in negotiating different services and service boundaries, even with the support of a key worker, rendering services fragmented and unaccommodating to some service users (Gilburt et al., 2015). This appears to be a common feature of health care services, whether predominantly community- or hospital-based;

dependent on the findings in this thesis, bridging this gap may need to be a consideration in the future development of the seizure care pathway.

2.7 Measuring health care

Clinical governance ensures that NHS organisations are accountable for continuously improving the quality of the services they deliver, promoting high standards through benchmarking and comparison (Scally and Donaldson, 1998). A number of external agencies have taken responsibility for monitoring and evaluating the quality of services offered within the NHS including government departments, such as the Department of Health (DH), and independent agencies and regulators, such as the Care Quality Commission (CQC), NICE and the King's Fund (Ham, 2009). Examples of the wide range of methodologies that are currently utilised to measure health care are outlined in Table 2-2.

Measuring patients' perceptions of their experience of receiving health care is important, not only from an organisational standpoint, but equally for patient outcomes. From an organisational perspective, measuring patient experience provides opportunity to improve care based on raw data and knowledge about what patients need from services. Patient experience data is not synonymous with satisfaction. The former is intended to provide specific actionable results (e.g. objectively measurable survey data), whereas satisfaction is more difficult to respond to due to its subjective nature (Wolf et al., 2014). Boulding et al. (2011) recognised that measuring experience allows informed decisions to be made more readily around improving processes and utilisation of resources (Boulding et al., 2011; Manary et al., 2013).

Table 2-2 Methods of measuring quality of health care in 389 European hospitals (Lombarts et al., 2009)

Quality Improvement Measurement	Example of tool/methodology
Organisational quality management programmes	International Organisation of Standardisation (ISO) 9000, European Foundation for Quality Management (EFQM)
Systems for obtaining patients' views	Patient surveys, participation in development of protocols/standards of care, patient participation in quality committees
Patient safety systems	Adverse event reporting, drug safety management, patient identification systems
Clinical guidelines	Standard Operating Procedures (SOPs), hospital wide guidelines, area/disease-specific guidelines
Performance indicators or measures	Collection and use of hospital specific performance data
Internal audit, assessment of clinical standards	Performance reviews of staff, peer review, site visits, internal audit
External assessment	Assessment by external body, accreditation or certification institute, patient organisation and/or government inspection body

The demand on the health service to meet patient expectations is high. Organisations want patients to refer their friends and family, and to provide positive word-of-mouth feedback about their experiences. Trusts can reap the benefits of financial reward if this is achieved, allowing them to reach government driven targets and potentially gain associated financial incentives (Klinkenberg et al., 2011; Marshall and Smith, 2003). Lord Darzi's *High Quality Care for All* (Department of Health, 2008) paper emphasised the need to improve quality of care based on patients' own detailed experiences of their care, alongside more objective outcome data (Coombes, 2008).

In addition to financial gain, measurement of experience is important in terms of patient safety and outcomes. A systematic review by Doyle et al. (2013) demonstrated positive associations between patient experience and both self-reported and objectively measured health outcomes; including medication adherence, preventive treatment, and utilisation of health care resources. Although the review includes a large number of international studies, primarily from the USA, there is evidence to suggest that the findings of a positive correlation are consistent across a range of disease areas and health care settings (Doyle et al., 2013). Conversely, Chesaniuk et al. (2014) recognises that in disease-specific populations such as PWE, compounding factors which influence patients' willingness to adhere to treatment regimens and other aspects of their clinical care exist. Lack of support and information, the associated stigma of epilepsy as an illness and expectations not being met by health care providers, are all influencing factors (Chesaniuk et al., 2014). Poor adherence caused by a perceived poor level of patient experience can be detrimental to patient outcomes. It is important therefore, to continue to seek the best approaches to measure patient experience in specific disease populations, to demonstrate high quality care, driven by patient needs.

2.7.1 Evaluating impact of health service interventions

Health care interventions, such as the seizure care pathway, are an example of service re-design, with an overall aim to improve patient care, safety, outcomes, and experience. Such re-design can be complex, due to factors including, but not limited to, clinical, professional and organisational barriers, all of which can impact on service delivery. Interventions must operate in a real-world situation, where external variables may be difficult, impractical or even impossible to control (Mackenzie et al., 2010).

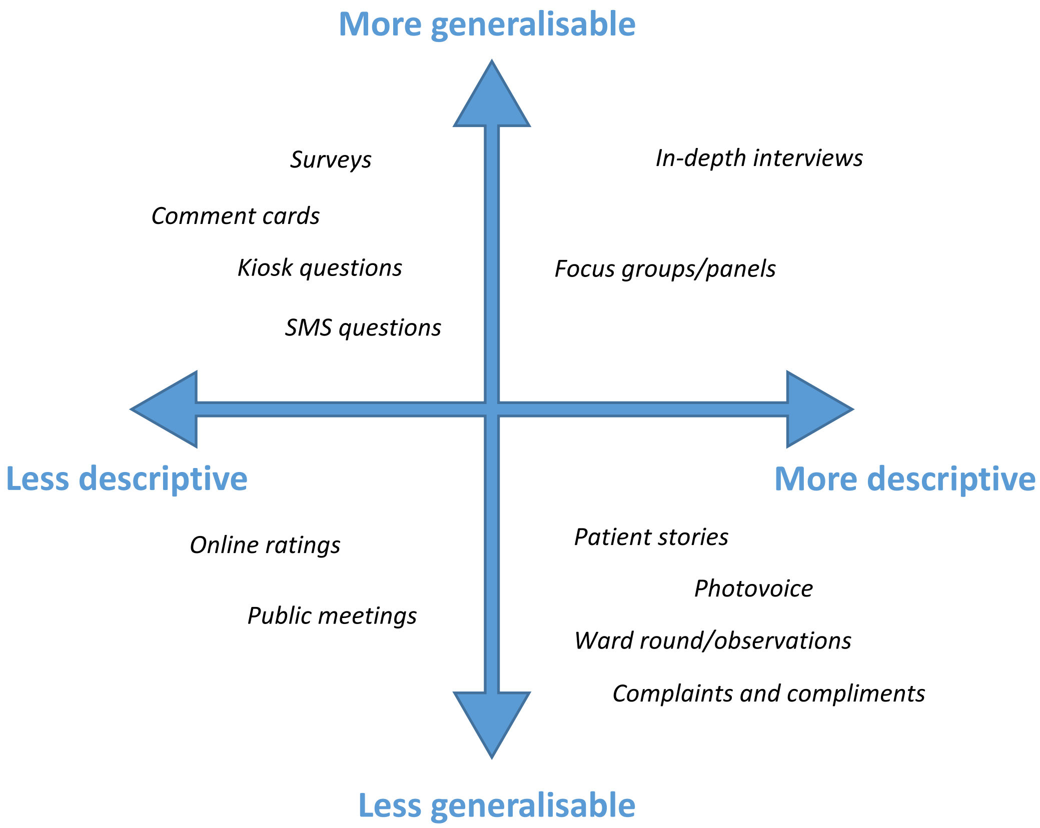
Early research to explore patient experience of such interventions predominantly focused on measuring their impact on numerous patient outcomes (e.g. clinical outcomes and admissions). Largely quantitative in nature, studies captured outcomes through randomised controlled trials (RCT), cluster-randomised studies, and other variations of randomised and non-randomised comparative studies

(Martiniuk et al., 2007; Salinsky, 1995). Alone, these studies use robust methods to help identify causal relationships, however, measurement and evaluation of patient experience of service delivery is complex. RCTs only allow us to understand the quantifiable benefits of interventions to patients and often fall short of explaining how or why interventions do or do not work (Salisbury et al., 2016; Sibbald and Roland, 1998). Additional methods of evaluation should ideally be written into trial protocols to help understand the process of what is happening and resulting effect (Figure 2-2).

According to Patton (1982), evaluation involves the systematic collection of information about the activities, characteristics and outcomes of a programme. Descriptive in nature, evaluation can be useful in the analysis of particular areas of practice to provide information to assist organisations to improve their policies and practices (Weiss, 1999).

Interventions may already be in place before an evaluation is proposed, as is the case in this study. In such cases, evaluation should focus on how well the intervention is implemented, how the components interact, and what leads to successful (or unintended) outcomes, not merely whether they work or not in terms of outcomes (Salisbury et al., 2016). The organisational and contextual background behind an intervention is often complex, particularly in the health care setting, where resources, changing demographics, patient health needs, organisational changes and policy are just a few of the issues likely to impact upon implementation (Mosadeghrad, 2014). It is important to adopt a pragmatic approach to this research, to not only highlight these issues, but to draw on potential areas for service improvement to meet the needs of the patients, where possible, in the context of the current health service remit and capacity.

Figure 2-2 Examples of methods used to measure patient and carer experiences of health services (Reproduced from Health Foundation report (2013) (pp.7)



2.7.1.1 Qualitative versus quantitative evaluation

Due to the complex and real-world nature of most health care programmes there can be ethical and practical limitations when planning and conducting service evaluations (Sibbald and Roland, 1998). Consequently, various methods to evaluate service delivery have been adopted in order to address the complexities that arise within the phenomenon of the patient experience of a service intervention. A study by Wolf et al. (2014) calls for a move away from focusing on surveys developed without patient input as a measure of patient experience. Such surveys may not be conducive to service development, as they lack consideration of patient experiences in their development.

Qualitative techniques for the evaluation of health care interventions have emerged with the aim to offer a different and more enlightened view of health service delivery; not just in relation to what happened and the causes, but also to ascertain why certain outcomes occurred and to generate potential explanations for such outcomes (Patton, 2002) Qualitative methodologies used in evaluative research include, for example; phenomenology to identify lived experience of an intervention (what role does the health care professional's experience play in their treatment of patients?) (Pickard, 2017); participatory action research to assess implementation solutions for improvement in a service (Taylor et al., 2015); and, ethnography to explain the complexities of an intervention (for example, how is the ED environment conducive to treating seizure patients?) (Bunce et al., 2014).

Quantitative and qualitative methods do not have to be used exclusively. Where appropriate, a mix of methods and methodologies can be used to yield an evaluation and produce convergent findings. Bunce et al. (2014) demonstrates this using ethnography, embedded within a larger mixed method translational study. Here, utilising both qualitative and quantitative data sets resulted in a rich, nuanced picture of the implementation process (Bunce et al., 2014).

Rigorously designed surveys, developed following qualitative work about what matters most to patients, are more likely to provide quality data that will support service change and pathway development (Beattie et al., 2015). For example, the proposal of this thesis is to develop a patient-reported experience measure (PREM) after conducting qualitative interviews with patients to engage them and explore what is important to them. A survey will then be designed to ask about these elements and test that the care delivered is appropriate to patient needs.

2.7.1.2 Medical Research Council (MRC) guidance on process evaluation

The MRC published guidelines around the development of complex interventions in 2000, with revisions made to incorporate a robust evaluative process within intervention development (Craig et al., 2008). Complex interventions are described as those "*built up from a number of components, which may act both independently and interdependently*" (Campbell et al., 2000)(pp.455). The original guidelines focussed on the development and evaluation of complex interventions by way of a randomised controlled trial (RCT). Subsequent guidance has moved away from this to recognise the role of nested qualitative studies, such as the one described in this study, and complex interventions outside of the health service (Moore et al., 2015).

Since the development of the initial guidance on the delivery of complex interventions, the MRC has also developed specific guidance around process evaluation (Moore et al., 2015). So-called process evaluations move the focus away from outcome-driven approaches to explore the implementation of an intervention, providing insights into its success or failings, based on causal mechanisms, contextual factors and external influences (Oakley et al., 2006). Process evaluation can help researchers to distinguish between intervention failure (where the intervention concept is flawed) and implementation failure (where the intervention is poorly delivered/developed) (Rychetnik et al., 2002). The effectiveness of an intervention in everyday practice may not be as pronounced as anticipated and this lack of effect may reflect implementation failure (or teething problems) rather than genuine ineffectiveness; a thorough process evaluation is required to identify such issues (Moore et al., 2015).

Process evaluations are particularly necessary in multisite, pragmatic trials, where there is likely to be variation in the way the ‘same’ intervention is implemented, making it an appropriate framework to adopt within this study (Oakley et al., 2006). When nested within a trial, as this process evaluation has been in the Care After Presenting with Seizures (CAPS) project, it can be used alongside evaluation of outcomes, to aid the assessment of the fidelity and quality of an intervention (Moore et al., 2015). Evaluation takes place in a wide range of settings that can constrain the researcher’s evaluation approach and methods adopted (Craig et al., 2008). Complex interventions emerge from various sources, which may greatly affect how much leeway the researcher has to modify the intervention, to influence the way it is implemented, or to adopt an ideal evaluation design (Belsky et al., 2006). For example, within this project, the seizure care pathway had already been implemented in practice prior to commencement of the evaluation process; thus, evaluation will be undertaken alongside implementation, rather than prior to implementation.

The MRC process evaluation framework (Moore et al., 2015) offers a non-prescriptive, pragmatic approach to evaluation, making it open to various methods and methodological choices.

2.7.1.3 Patient-Reported Experience Measures (PREMs)

A patient-reported experience measure, also known as a PREM, is a measurement of a patient's perception of their personal experience of the health care they receive during an episode of care. A PREM asks patients specific questions about their recent health care experience. Compared with a traditional patient satisfaction survey, a PREM allows for a more objective assessment of care by explicitly identifying aspects of service delivery that are achieved and those requiring improvement (Maini et al., 2018).

To date, there appears to be limited application of PREMs in clinical practice in the ED and little research considering their validity and reliability. The Picker Institute UK have come closest, with a number of questions within the UK-based national NHS patient survey and the Accident and Emergency Department survey that explores generic patient experiences using survey methods (The Co-ordination Centre, 2016). Communication with HCPs, information provision, involvement in decision-making, physical comfort, emotional support, and care transitions are all aspects of care that feature in these surveys and have previously featured in other PREMs (Coulter, 2017; Teale and Young, 2015; Triemstra et al., 2010).

Teale and Young (2015) reported on a PREM to assess users' experience of intermediate care, either at home or in community hospitals. Questions for this were derived from the 2008 Picker Institute Adult Inpatient Survey and items covered staff involvement, decision-making, emotional support and care transitions. Triemstra et al. (2010) also developed three experience measures to assess long-term care of patients in the Netherlands. The PREMs were developed for use in somatic care wards (residential care, 81 items), psychogeriatric care (residential, 72 items) and home-based care (117 items) and included domains such as shared decision-making, communication and information, participation and autonomy and care continuity (Triemstra et al., 2010).

All of the PREMs discussed were developed utilising patient and/or staff input to develop the concepts and themes based on specific needs and contexts. The PREMs discussed above used consensus meetings with stakeholders and previously developed questionnaires to develop the new measures (Teale and Young, 2015; Triemstra et al., 2010). The PREM designed for use by older people in community services was developed using a Delphi consensus process and included representation by a patient and public group, indicating appropriate feasibility work conducted when developing the new measure (Teale and Young, 2015). The Consumer Quality Index Long-Term Care measure was also developed with adequate background work, including a nationwide consensus of all parties and stakeholders involved in the sector, including patient participants (Triemstra et al., 2010). These are both well designed PREMs with evidence of in-depth background work supporting their construction.

While generic PREMs can be valuable in auditing patient experience of services, they risk losing disease-specific elements. A disease-specific health care experience may involve different facets of care that reflect different aspects of a patient pathway or journey. Taking epilepsy as an example, it may be difficult to use the same PREM to compare a hospital admission following a seizure episode to a routine annual review in an outpatient setting, as appropriate questions, along with patient’s expectations and feelings might be different in both situations. This may be similar for other complex and long-term conditions.

At the time of writing, there are no epilepsy-specific PREMs for use in the adult population. One PREM has been designed specifically to evaluate NHS epilepsy services for the paediatric population developed as part of the National Epilepsy 12 Audit; the *Epilepsy12 PREM* (Maini et al., 2018). The questionnaire was developed through an extensive literature review focussing on previous surveys of patient experience and satisfaction, as well as consulting HCPs, young PWE, and parents/carers of young PWE through surveys and interviews (Maini et al., 2018). Potentially a more extensive development process could have been utilised, possibly through a Delphi consensus and engagement with a broader stakeholder group. The paper describes the psychometric analysis of the development process indicating good face validity and internal reliability for the parent/carer dataset; it was less favourable for the children/young people version (Maini et al., 2018). Construct validity was indecisive, with confirmatory factor analysis of hypothesised constructs being weak. However, convenience sampling and a low response rate (between 24%-49%) compounds weak sampling which may have influenced the results. Using the PREM in a more representative sample of the population treated for epilepsy may improve the validity of the questionnaire (Maini et al., 2018).

At the time of writing no epilepsy specific PREMs for use in adult service delivery have, to the best of my knowledge, been designed, and no research has been conducted around the utility of such measures within this specific patient population. Reliance is currently being placed on generic measures such as the NHS Survey and Accident and Emergency Department survey to capture the experiences of seizure patients when presenting to the ED (The Co-ordination Centre, 2016). I question whether it would be feasible to develop a PREM for the specific epilepsy population, and whether there are any PREMs currently available that could be adapted to suit the needs of the specific population and to assess patient experience of the seizure care pathway.

2.8 Summary

PWE and seizures can struggle to access co-ordinated health care services in a timely and effective manner. This is relevant in both primary, secondary and specialist care services. While there is a large body of literature on the unmet needs of seizure patients in various health care settings, there is little evidence on the experience of ED care and ongoing transition to ambulatory care by PWE and those experiencing seizures, particularly with a focus on qualitative methodologies.

There is also little evidence on the experiences of care delivery for these patients from the perspective of HCPs. Although there is some evidence of experiences of care by GPs and ESNs, it is important to consider the views of all professionals involved in the care pathway. This includes the experiences of emergency care clinicians, administration and booking staff, and epilepsy research nurses, all of whom play an equally important role in the functioning of the care pathway and service delivery.

In addition, little is known about the most effective way to evaluate health care interventions despite the measurement of patient experience now being common practice in the NHS. Measurement tools should be proven to be valid and reliable, with input about patients' specific needs, in order to produce an appropriate and meaningful evaluation (Beattie et al., 2015). Without ensuring this validity, studies may continue to produce results that have limited application in evaluating and/or improving care and services offered within the NHS.

This current project is concerned with patients' perspectives of the seizure care pathway. Given the prevalence of seizures and the demand they place on urgent and emergency care services, the value of the seizure care pathway in improving patient experiences requires exploration. Development of a robust method to measure patient experience of the seizure care pathway will likely prove useful to clinicians and organisational managers in providing recommendations for further development and improvement of the pathway. A pragmatic qualitative design study was considered appropriate for this thesis. The following chapter will discuss the methodological choices made to address study aims and objectives.

Chapter Three: Methodology

The Philosophical Approach

3.1 Introduction

The previous chapter presented background to the topic and identified the rationale for undertaking the current study. The scoping literature review explored methods for evaluation of patient experience. There are many ways that patient experience can be measured; one being specific patient-reported experience measures (PREMs). Studies highlighted in chapter two explore their value and suggest their potential usefulness for exploring seizure patients' experiences in the ED, however, to date this has not been investigated. This lack of knowledge base prompted the need for the first research objective, namely, to;

- Conduct a systematic review of evaluative methods (study part one) for measuring patient experience and their development.

In addition, findings from the review of relevant bodies of literature identified health care experiences for those experiencing seizures as highly variable and, in some instances, comprised un-coordinated care which lacks person-centredness. As there is only a limited body of literature around the specific topic of seizure care in the emergency department (ED) in the United Kingdom (UK), there is an explicit need to research peoples' experiences of such health care services. Therefore, the second objective of this research was to;

- Conduct qualitative interviews (study part two) to examine patients' experience of the seizure care pathway.

Finally, there is a dearth of literature on health care professional's (HCPs) experiences of delivering care to patients' presenting to the ED during/following seizures. Existing evidence focuses primarily on clinical management, rather than the holistic, on-going care that people with epilepsy (PWE) and seizures require according to previous research. In responding to this need, a third objective of this research was to;

- Conduct qualitative interviews (study part three) to examine HCPs perceptions of delivering care using the seizure care pathway in practice; barriers and facilitators to its use and suggestions for improvement.

In order to address the research objectives posed, a realistic evaluative study design has been adopted, underpinned by the Medical Research Council's (MRC) framework for process evaluation, discussed in chapter two, section 2.7.1.2 (Moore et al., 2015).

The purpose of this chapter is to discuss the development of the methodological approach used for the empirical stages of this study. Firstly, the chapter will address questions of ontology and epistemology in relation to research methods (discussed in chapter four) chosen for this study and will explore the application of critical realism (CR) as a theoretical stance. The limitations of adopting an exclusively quantitative approach when developing a complex intervention, such as an integrated care pathway (ICP), will be discussed and justification for the incorporation of nested qualitative evaluation techniques provided. In concluding, the chapter presents a discussion of the theoretical underpinning and rationale for the choice of evaluative measures used within this study; namely the conduct of a two-part qualitative study involving both service users and HCPs and justification for conducting a systematic review exploring previously designed evaluative tools for patient experience in the ED.

3.2 Ontology and epistemology

During the design of a study the researcher must be aware of their 'ontological' and 'epistemological' stance. This is important because it supports the development of the philosophical basis of a research project. Understanding that different research paradigms exist is imperative to enable one's own perspective and approach to be situated and understood within the context of the research study (Guba and Lincoln, 1994). As such, early questions need be considered around research beliefs; unless the right questions are asked to explore and explain, then our knowledge of reality could be flawed.

Ontology deals with the fundamental nature of existence. It is related to the nature of social reality; what can be known and how. When conducting research, different ontological perspectives give rise to different strategies (Crotty, 1989; Mason, 2006) What some choose to explore depends on the researchers' ontological position. Others may disagree and choose something else. There is no right or wrong answer to these questions as different people view topics differently depending on, for example, their role, value set or background.

Epistemology is theory of knowledge and how this knowledge can be generated and understood (Crotty, 1989; Mason, 2006). It is the exploration of the relationship between the individual who has potential to hold the knowledge (i.e. the researcher) and what can be known to that individual (Creswell, 2007). Therefore, where ontology refers to what exists, epistemology contemplates how we can come to know about that which exists (Wainwright, 1997).

The perception that qualitative and quantitative research is distinct is based on different philosophical principles. Each approach belongs to a different 'paradigm' where pure quantitative researchers take a positivist stance and qualitative researchers adopt a more interpretivist approach (Brannen, 2015; Tariq and Woodman, 2013). Research paradigms can be characterised through their ontology, epistemology, and methodology (Guba and Lincoln, 1994). Justification for using realism as a paradigm for evaluative research and how it relates to both positivist and interpretivist approaches will be discussed in the following section.

3.2.1 Philosophy of critical realism

Critical realism (CR) is a school of philosophy which sits between positivism (the world is comprised of discrete elements and events that interact in an observable, determined and regular manner (Collins, 2010)) and subjectivism (the world is socially constructed, with all observations and viewpoints simply another way of approaching 'reality' (Ratner, 2002)). CR mixes differing ontological and epistemological views to identify the structures that generate the social world in order to challenge inequalities and injustices (Bhaskar, 1978; Bhaskar, 1989).

3.2.2 Positivism and it's relation to realism

Positivists (or objectivists) believe in causality, that is, *"there are independent causes that lead to the observed effects"* (Remenyi, 1998) (p.32). With such beliefs, results are generalised, and hypotheses are either verified or refuted by these observed effects. Positivists contend that there is a single reality, concentrating research on objective measurements and quantifiable data analyses. For example, a study by Luoni et al. (2011) explored health-related quality of life (HRQOL) in patients with pharmacoresistant epilepsy using validated quantitative assessments. The study looked specifically at 'independent causes' such as demographics, disease, and treatment-related variables that could potentially influence HRQOL. Realists may argue that positivist research is somewhat superficial, in that it only measures health status and does not tap into the intended aspects of patients' values and experiences that are important to them on an individual basis (Gill and Feinstein, 1994). Positivists aim to remove the bias of humans, but in doing so may fail to take human experience into consideration and the context of which they are a part of; something that is important in the context of realist research.

As the author of this thesis, I concur with this argument and believe that quantitative analysis alone cannot capture the true the context of patient perspectives. Quantitative work appears detached from the true meaning of patient experience and the question of '*how*' and '*why*' certain processes and events occur (Abhyankar et al., 2013; Choy, 2014; Kelley et al., 2003). However, some quantitative data, collected and analysed through the wider CAPS project, may be used through the discussion sections of the qualitative chapters, to support the findings and help provide some wider context. We know that the questions posed in this investigation cannot be answered solely through outcome-focused approaches and therefore qualitative evaluation is necessary to help explain the complexity of the seizure care pathway as an intervention (Rossi et al., 2004). Table 3-1 demonstrates the advantages and limitations of both qualitative and quantitative research approaches.

Table 3-1 Qualitative versus quantitative research (Creswell, 2014)(pp.5)

Qualitative Research	
Advantages	**Disadvantages**
• Provides detailed perspectives of a few people • Captures the voice of participants • Allows participants' experiences to be understood in context • Is based on the views of the participants not of the researcher • Appeals to people's enjoyment of stories	• Has limited generalisability • Provides only soft data (not hard data such as numbers) • Studies few people • Is highly subjective • Minimise use of researcher's expertise due to reliance on participants
Quantitative Research	
Advantages	**Disadvantages**
• Draws conclusions from large numbers of people • Analyse data efficiently • Investigates relationships within data • Examines probable causes and effects • Controls bias • Appeals to people's preference for numbers	• It is impersonal, dry • Does not record the words of participants • Provides limited understanding of the context of the participants • Is largely researcher driven

3.2.3 Subjectivism and its relation to realism

Subjectivism is one example of an anti-positivist perspective. The goal of subjectivists is to understand and explain a problem in its contextual setting; they do not perceive that it is a question of causality but rather a question of the meanings that individuals attach to certain situations (Holden and Lynch, 2004). That is, rather than testing pre-existing hypotheses, the hypothesis results from data analysis. Anti-positivism asserts that objective knowledge of the world around us is not fully accessible and that it is imperfect. Seeking to establish the most likely truth, it is believed that we can only understand the world through perceived knowledge.

Subjectivism appears to be a more appropriate stance to take for social science research due to the complex nature of human beings and their social, philosophical, biological and cultural behaviours. Subjectivists seek to draw out depth and detail to illuminate the reality of experiences people may have in health care settings (Appleton and King, 2002). A deeper understanding can be achieved by focusing on fewer participants and asking open-ended questions to elicit more meaningful answers. Such approaches have been increasingly used to ascertain patient experiences, perceptions, needs and values within specific health care settings and during specific episodes of care (Karasouli et al., 2016; Wen and Tucker, 2015; Wiman et al., 2007).

Despite being an excellent tool for the development of concepts and ideas, a purely subjectivist position also has limitations. Such research is highly subjective in nature and there is potential for researcher bias (Kaptchuk, 2003; Mehra, 2002; Ratner, 2002). On a practical level there are ways to reduce such bias which are discussed in more detail in chapter four. A further disadvantage of a single paradigmatic choice of subjectivism is that it is not generalisable. In health care research, generalisable data is often deemed more suitable as it can be used on a wider scale to inform practice and facilitate change. However, the goal of qualitative research is not generalisability but rather the generation of a rich contextualised understanding of human experience through the intensive study of smaller datasets. There is an international abundance of generalisable quantitative data around epilepsy outcomes and quality of life (QoL) (Guekht et al., 2006; Kellett et al., 1997; Mahrer-Imhof et al., 2013; Ridsdale et al., 2017) but the literature explored within chapter two suggests that there is only a limited amount of empirical qualitative work conducted to combine this with the fundamental understanding of what emergency care means to PWE and seizures and how this relates to their needs and expectations.

3.3 Critical realism as a theoretical position in this study

Critical realism is not a research method but a methodological orientation; an approach to constructing and selecting research methods (Pawson and Tilley, 1997). This section provides discussion in relation to the researcher's theoretical stance of CR, and how this position 'fits' as a means to providing answers to the research questions posed in this study.

Critical realism, as a theory, seeks to identify the need for change (McEvoy and Richards, 2006). The aim of this study relates directly to services that exist within the world of health care; the services offered along the seizure care pathway. This world however remains uncertain, in that patients and HCPs construct their own social understanding of this 'reality', through discourse, interactions and context development (Barker, 2002). By exploring the underlying question of *'What works, for whom and in what circumstances?'* I seek to uncover the said 'reality', explore the patients' perspectives of the seizure care pathway in practice, and how changes may be made to improve the services offered to seizure patients (Allen et al., 2009).

Presentation to an ED is a reality for many individuals at some point their lives. How this reality is interpreted by an individual however, is mediated by the individuals' understanding and experience of it, influenced by their expectations and values. Two separate individuals who experience a similar clinical presentation at the ED may have differing reactions to the experience due to context, resources and reasoning. Likewise, an individuals' reaction to the ED experience following a simple fall, may vary significantly to that if they experience a more life-threatening presentation, such as that of status epilepticus or an acute traumatic brain injury. Therefore, a theory of participants' experiences of attending the ED will generate understanding of the topic, but will never prove definitive, as all knowledge is circumstantial and somewhat partial.

Realism offers a high level of explanatory power when dealing with complex interventions. Wong et al. (2012) add that complex interventions do not act in a linear fashion, are reliant on the people delivering the intervention, and are highly dependent on the context in which they take place. Literature around integrated care pathway (ICP) evaluation in faecal incontinence services, for example, highlights the positive changes in accessibility and streamlining the patient pathway that the ICP has had (Rimmer et al., 2015). However, this does not mean that the same pathway for faecal incontinence implemented in another locality would achieve the same outcomes. The findings may be altered due to differing values and perspectives on behalf of both those implementing (staff) and those receiving (patients) the service. This highlights the importance of considering both professional and patient experiences of such pathway interventions.

Critical realism has been increasingly recognised as an appropriate methodological approach to evaluation within health care (McEvoy and Richards, 2003; Walsh and Evans, 2014). Research has been conducted using this methodological paradigm in both cardiology (Clark et al., 2007) and maternity service (Abhyankar et al., 2013) programme development. Clark et al. (2007) made use of a critical realist approach when evaluating 'The Patient Pathway' (PP), introduced as part of the Scottish National Demonstration Project 'Have a Heart Paisley' (HaHP), a regional project addressing the primary and secondary prevention and treatment of chronic heart disease (CHD). The HaHP study recognised the value of CR in giving scope for the explanation of complex social and psychosocial issues which may have influence over the effectiveness of the programme. Qualitative analysis identified that the effectiveness of the programme was less determined by content, than by social and physical experiences of attending the programme and long-term health opportunities (Clark et al., 2007; Clark et al., 2005). Such an approach offers a theoretical framework for action that may bring about meaningful change that is not tokenistic in nature (Stickley, 2006).

McConnell et al. (2015) utilised a realistic evaluation method to assess factors affecting the successful implementation of the Liverpool Care Pathway for dying patients (LCP). Participants included a range of staff who had experience or involvement in the implementation and management of the LCP in practice. McConnell et al. (2015) recognised the importance of context within which programmes are delivered, and the influence that social mechanisms may have on implementation. A limitation to this study may be that it focuses solely on staff experiences and does not evaluate patient and family experiences of end-of-life care. To provide a more robust evidence-base, both staff and patient experiences should be explored and findings used in parallel to guide the refinement and implementation of such complex ICP interventions.

Previous studies highlight how a CR stance can be used as a suitable theoretical lens for the exploration, development and implementation of an ICP. Within this study the theoretical position of CR will be used to bring together findings from both patient and staff interviews to explore underlying mechanisms within the ED and ambulatory care service which influence the care experienced by PWE and seizures. CR is also recognised as pertinent in the study of health inequalities (Angus, 2006). Social patterns and health inequalities are underlying mechanisms that need to be recognised and addressed to enable interventions to be equitable and to support patients to overcome such barriers (Clark et al., 2007).

Table 3-2 provides justification for why a CR theory was considered most appropriate for this current work. The table provides a transparent overview of the decision-making process; drawing together a summary of the research objectives and how these objectives ‘fit’ within the theoretical position of CR. The table also identifies the research methods adopted in each phase of the study.

Table 3-2 Justification of critical realism as a theoretical perspective in the study and research methods adopted

Research Question (s)	Critical realist focus	Critical realist rationale	Substantive Focus	Methods
1) Conduct a literature review of evidence to explore current service provision in emergency seizure care, and to identify the theoretical underpinning behind quality improvement and service evaluation approaches.	To understand the phenomenon based on description as well as underlying explanation	Critical realist approach attempts to distinguish between the core theoretical concepts underlying apparently unrelated empirical investigations to synthesis diverse yet commensurable primary studies (Okoli, 2012)	Discovery of knowledge about what the service currently delivers nationally, in comparison to guidelines and patient need. Identification of literature around quality improvement and staff involvement in improving patient care.	Broad scoping review of literature around current epilepsy and seizure services with a focus on ED and ambulatory care services. Exploration of literature on measuring experience of health care from both the patient and professional perspective.
2) Conduct a systematic review (study one) of evaluative methods for measuring patient experience and their development.	Outcomes- past standardised measures versus ideas for new condition-specific PREM	Critical realist ontology is not antagonistic to the measurement of experience and outcomes (Pawson and Tilley, 1997; Pratschke, 2003)	Identification of existing measures and justification for development of new disease specific PREM	Systematic review looking specifically at ED PREMs that are currently in use and their development, with a focus on their development and psychometric testing
3) Conduct qualitative interviews (study two) to examine patients' experience of the seizure care pathway.	Mechanisms/contexts and their link to experience	Qualitative methods are indispensable in researching generative social causality and explaining different aspects of social reality (Iosifides, 2011) Use of comparisons by outcome to understand	Patient experience of the seizure care pathway (from ED through to outpatient appointment) Identification of patient demographics which may influence patient experience (e.g. gender, IMD, age, seizure status)	Qualitative interviews with patients regarding their experience of attending ED following a seizure and their experience of follow-up service after ED attendance (qualitative study part one)

		underlying mechanisms (Lawson, 2003)		
4) Conduct qualitative interviews (study three) to examine staff perceptions of using the seizure care pathway in practice; barriers and facilitators to its use and suggestions for improvement.	Mechanisms/contexts and their link to experience	Qualitative methods are indispensable in researching generative social causality and explaining different aspects of social reality (Iosifides, 2011)	Staff experience of using the pathway in practice either directly (clinical) or indirectly (non-clinical)	Qualitative interviews with staff, both clinical and non-clinical exploring their experiences around implementation of the seizure care pathway (qualitative study- part two)
5) Develop an appropriate Patient Reported Experience Measure (PREM) for use with seizure patients who have experienced the seizure care pathway.	Implementation context (Clark et al., 2005)	To bring together the qualitative methods/findings and provide context to the measure delivered based on outcomes	Audit/assess patient experience of the seizure care pathway.	Develop PREM using results from qualitative study, cognitive interview techniques and methods of psychometric development.
6) Identify areas for development within the seizure care pathway that would potentially improve its use in the care of seizure patients transitioning between services.	Implementation context (Clark et al., 2005)	The context in which the measure is delivered and implemented will influence individual outcomes (Ackroyd, 2000)	Improvement suggestions based on concepts from qualitative work.	Develop ideas and suggestions that may be useful in future implementation of the seizure care pathway in clinical practice and suggestions for future research

3.4 Qualitative inquiry as an evaluative research methodology

Pragmatism in evaluation studies is widely accepted and can include either qualitative and quantitative methods, or a combination of both (Office of Data, 2016). Consideration of the research aim and objectives, as explored in section 3.1, and the selection of the most suitable approach to answer the questions at hand is critical (Patton, 2002). A review by Rapport et al. (2015) highlighted the usefulness of qualitative techniques in epilepsy research. Much of the current qualitative epilepsy research focuses on the impact on patient's lives more generally, rather than on their specific experiences of health care service delivery and episodes of care (Bishop and Allen, 2003; Räty et al., 2009).

For this study, a qualitative line of inquiry was believed to be the most appropriate methodology to elicit themes and concepts through data analysis that could not be hypothesized *a priori* and were unique to the seizure pathway. Table 3-3 outlines the different roles of evaluation within intervention development and, where applicable, relates these directly to their use within this thesis, demonstrating the important role qualitative research plays in the evaluative process of this study.

Table 3-3 Qualitative evaluation of interventions

Role in Evaluation of Interventions (Office of Data, 2016)(pp.6)	Applicability to study
Theory of Change/Logic Model Development • Logic model development: Generating *detailed information* about programme inputs, activities, and outcomes • Theory of change: Explaining *how* and *why* a programme exerts its effects	N/A- these specific models were not used within this study as the intervention had already been past the initial design process and was already being used in practice.
When Established Measures are Inappropriate or Do Not Exist • In early stages of research when unclear what measures are best • With populations for whom valid standardised measures do not exist • With populations who may be more comfortable with storytelling and narrative	Systematic review prior to qualitative work demonstrated that valid measures within this specific population did not exist (see chapter five). Memory recall problems and post-ictal states make answering specific time-measurable questions difficult in this population (Farrell et al., 2016; Fisher et al., 2000).
Studying Programme Implementation • How well-defined practices and programmes are • Level of buy-in/readiness for the programme among community members/stakeholders • Programme providers' staff hiring, training, coaching, and evaluation practices	These issues were of key importance to the evaluation process in this thesis and were addressed through the qualitative components of this study through the analysis of both patient (chapter six) and professional (chapter seven) interviews. It was important to be selective in determining which professionals to interview. It was recognised only certain members of staff (based on their knowledge and experience) would be able to answer specific questions

• Efforts made re: organisational change necessary to implement the programme	related to care pathway implementation; including for example, organisational change and training need.
Opening the 'Black Box' of Programme Effects Unpacking why the programme had the effect it did by exploring: • Experiences of clients and staff • Contextual changes that might affect outcomes • What outcomes mean to programme participants • Unintended programmatic side effects • How well/faithfully the programme was implemented	Intervention effects were comprehensively explored within this study through qualitative interviews with both patients and professionals. It was important to interview both first seizure patients as well as those patients with known epilepsy (and often experiences of previous ED attendances) to ascertain what impact(s) implementation of the pathway had on varied care experience (Pope et al., 2002).
Making Research Reports More Accessible • Present some findings in a non-technical format (i.e. quotes, not statistics) • Stories and narratives about participants' experiences resonate with policymakers and other stakeholders • Quotes and stories enliven technically dense reports and make them more readable	Dissemination of research findings via presentations and peer reviewed publications will be an ongoing endeavour throughout the process of this research study to raise awareness of the issues identified and to promote debate regarding solutions and/ or recommendations to address problems raised. Participant quotes have been used, as appropriate, in the presentation of findings as a means to validating the trustworthiness of findings, and to promote the relevance and understandability of the research, particularly among lay members of the epilepsy community who may be interested in this work (Riesmann, 1993).

3.5 Credibility of qualitative inquiry

The credibility of research data, and the conclusions derived from their analysis, begins with the implementation of sound, consistent methods for collecting and considering data (Miles and Huberman, 1994; Patton, 2002). Words such as validity, credibility, trustworthiness, and reliability are often used broadly and interchangeably when describing data and conclusions drawn from studies. This section will discuss mechanisms for ensuring quality within the research design including credibility in terms of rigour in qualitative methods and validity within the study results presented.

3.5.1 Rigour

Quality assessment in qualitative research is related to credibility and transferability beyond the study participants. Measuring and assessing such aspects of qualitative research is widely debated, with researchers arguing the potential difficulties in measuring quality using the same methods as those used in quantitative research (Noble and Smith, 2015). Other qualitative researchers argue it is possible to measure quality using the same broad concepts of validity and relevance used for quantitative research, but that these concepts need to be *"operationalised differently to take into account the distinctive goals of qualitative research."* (Mays and Pope, 2000) (pp.50). An extensive dialogue, over recent decades, concerning the value of qualitative research has occurred, which highlights alternative ways of determining the quality of knowledge generated within the interpretive paradigm (Bailey, 1996). As Jerome Bruner (1986) notes:

> *"Human science can no longer only seek mathematical and logical certainty. Instead, it should also aim at producing results that are believable and verisimilar".* (Bruner, 1986) (pp.11)

Within this literature, it is proposed that qualitative research findings should be evaluated for trustworthiness, credibility, and authenticity (Bailey, 1996b). As the researcher I believe that a study of this nature is credible when it presents faithful descriptions and can demonstrate how interpretations have been arrived at.

Riessman offers a set of four criterion which have been used to attempt to demonstrate credibility of the qualitative work conducted in this thesis (Riessman, 1993). Table 3-4 outlines these criteria and demonstrates how they were applied within qualitative study part two and three of this thesis.

3.5.2 Validity

Validity in qualitative research refers to the ‘appropriateness’ of the tools, processes and data (Leung, 2015). Validity asks the questions;

- Are the research questions valid for the desired outcome?
- Is the choice of methodology appropriate for answering the research questions?
- Is the design valid for the methodology?
- Is the sampling and data analysis process appropriate?
- Are the results and conclusions valid for the sample and context?

The above questions are addressed in various sections throughout this chapter and in chapter four.

‘Internal’ validity refers to how well the data supports the conclusions drawn from the research, and how well alternative conclusions can be ruled out (Office of Data, 2016). Qualitative researchers can adopt strategies to ensure that their conclusions present as full and accurate picture of what is being studied as possible. All conclusions must be supported by the data, and the interpretative process must be rigorous, as described in Table 3-4.

Table 3-4 Approach to ensuring rigour in qualitative research

Riessman's Criteria (Riessman, 1993)(pp.65-69)	How criterions were addressed through this study?
***Persuasiveness**:* This refers to the comprehensiveness, plausibility and style of evidence that is provided to enable the reader to make an informed judgment on the evidence and its interpretation.	This relates to the researcher strengthening her own theoretical claims with evidence from participants' accounts and analysis of diverse cases. This has been done by considering negative and deviant cases within the study and recognizing them, in context, within the analysis process.
Coherence: This is the means by which the narrative researcher demonstrates that an interpretation is more than ad hoc and is used to gain differing perspectives on the story	Coherence demonstrates that there are common themes within the analysis. Such themes were discussed within the research team and with supervisors throughout their development. Memo writing helped the researcher to understand and justify these themes based on the participant responses.
Correspondence**:** This relates to the process of taking the analysis back to those studied for verification and/or discussion	This relates to sharing of findings with participants or 'member-checking'. It is concluded that research credibility is more likely if participants concur with the researcher's interpretation of their story. Within this research, this process of participant validation was not written into the ethics submission. Through discussion with academics and supervisors the researcher realized the importance of validating findings with participants. The researcher has decided to do this by sending a summary of findings to each participant, allowing the participant chance to respond and

	validate the findings. This makes the research visible and allows a degree of systematic scrutiny within the work.
Pragmatic Use*:* This refers to the extent that a study will become the basis for further research by other investigators and in contrast to other validation criteria is future orientated	This relates to further research that might be undertaken as a result of the initial research in this study. Riessman goes on to say: *'we can provide information that will make it possible for others to determine the trustworthiness of our work by (a) describing how the interpretations were produced, (b) making visible what we did, (c) specifying how we accomplished successive transformations and (d) making primary data available to other researchers.' (p.69)* (Riessman, 1993). Each aspect of the study has been discussed in detail and a clear plan of the whole study is outlined in table 3-2 within this chapter. The development of interview findings was discussed with peers during research team meetings and supervisors at regular intervals during the analysis process. Finally, the ability to transfer concepts from this study could be helpful in applying to other ED patients with varying conditions where the evidence for use of a specific care pathway is under researched.

'External' validity refers to the degree to which conclusions may apply to settings other than the one studied (Office of Data, 2016). It is important in qualitative research, just as much as it is in quantitative analysis, to consider which aspects of the results can be extrapolated beyond the specific settings of the original study. Patton (2002) calls extrapolations "*modest speculations on the likely applicability of findings to other situations under similar, but not identical, conditions*" (pp.548). There is great debate over 'generalisability' of data, particularly within qualitative research. Some qualitative researchers are somewhat dismissive of the fact that qualitative data can be generalised (Miles and Huberman, 1994). Others however, are realistic in their views that the question over whether or not their findings have any applicability beyond their own specific study, is one of importance (Miles and Huberman, 1994). When it comes to evaluative research, those who fund and use these studies quite reasonably want to know if the work yielded any knowledge or lessons that can be useful in future programmes (Patton, 2002). When the study includes findings based on qualitative data, the questions then are what, exactly, can be generalised from those findings and what determines the confidence we can have in those claims. These are questions which I have considered in the process of this project and in the writing of the thesis and are addressed in context with the overall findings, discussion and recommendations made in chapter eight.

3.6 Systematic review as a research methodology

As a research methodology in its own right, a systematic review "*attempts to collate all empirical evidence that fits pre-specified eligibility criteria to answer a specific research question.*" (Liberati et al., 2009)(pp.2). This may involve the use of statistical methods (i.e. meta-analyses) dependent on the types of empirical research studies included within the review. Systematic reviews are often referred to as 'original empirical research' as they review primary data and provide synthesis of the findings (Aveyard and Sharp, 2011; Boland et al., 2008).

In terms of the evidential hierarchy, systematic reviews of RCTs are considered of upmost superiority, while expert opinion occupies the lowest rung of the hierarchical ladder (Evans, 2003). In health care research, they are regarded as a critical component of the development of evidence-based clinical practice and can be used to support practice development (Sackett et al., 2000). A shift towards using systematic reviews in high quality research is imperative when looking to inform education, research and practice as a result of the study (ten Ham-Baloyi and Jordan, 2016).

3.6.1 Stages of a systematic review

Researchers differ on the number of steps taken when conducting a systematic review (ten Ham-Baloyi and Jordan, 2016). Khan et al. (2003) outline five steps in a systematic review which are presented below (Figure 3-1).

3.6.2 Justification for utilising a systematic review

Systematic reviews have previously been used with effect in evaluative research of service interventions (Blakemore et al., 2015; Glazier et al., 2006; McElwaine et al., 2016). The systematic review that was proposed within this study aimed to assess the quality and acceptability of previously designed evaluative tools used to measure patient experience and quality of services, rather than the quality of the actual intervention. This was conducted with a view to assess previously developed PREMs for use in emergency medicine and explore PREMs as a method for service evaluation. Previous systematic reviews have also been conducted to assess evaluation measures (Dambi et al., 2016; Wakefield et al., 2017). Wakefield et al. (2017) conducted a review looking at psychometric properties of eHealth technology evaluation measures. The review aimed to identify previously developed measures, characterise the components and assess psychometrics. Of the measures discovered through the review, none included a complete psychometric evaluation and conclusions highlighted the need to develop psychometrically sound measures focusing more specifically on concepts important for use in eHealth innovations (Wakefield et al., 2017).

Based on previous research and evidence, a systematic review methodology was chosen as the most appropriate way to answer the research question, 'what is the evidence about the development of patient-reported experience measures (PREMs) for service evaluation in emergency care?' The conduct of a systematic review, utilising an explicit, rigorous and transparent methodology to synthesise literature and help inform subsequent parts of the evaluation process, was the most appropriate methodology to answer this research question and to provide a novel contribution to the findings.

Figure 3-1 Stages of a systematic review (Khan et al., 2003)

Step 1: Framing questions for a review
The problems to be addressed by the review should be specified in the form of clear, unambiguous and structured questions before beginning the review work. Once the review questions have been set, modifications to the protocol should be allowed only if alternative ways of defining the populations, interventions, outcomes or study designs become apparent.

Step 2: Identifying relevant work
The search for studies should be extensive. Multiple resources (both computerized and printed) should be searched without language restrictions. The study selection criteria should flow directly from the review questions and be specified a priori. Reasons for inclusion and exclusion should be recorded.

Step 3: Assessing the quality of studies
Study quality assessment is relevant to every step of a review. Question formulation (Step 1) and study selection criteria (Step 2) should describe the minimum acceptable level of design. Selected studies should be subjected to a more refined quality assessment by use of general critical appraisal guides and design-based quality checklists (Step 3). These detailed quality assessments will be used for exploring heterogeneity and informing decisions regarding suitability of meta-analysis (Step 4). In addition, they help in assessing the strength of inferences and making recommendations for future research (Step 5)

Step 4: Summarizing the evidence
Data synthesis consists of tabulation of study characteristics, quality and effects as well as use of statistical methods for exploring differences between studies and combining their effects (meta-analysis). Exploration of heterogeneity and its sources should be planned (Step 3). If an overall meta-analysis cannot be done, subgroup meta-analysis may be feasible.

Step 5: Interpreting the findings

The issues highlighted in each of the four steps above should be met. The risk of publication bias and related biases should be explored. Exploration for heterogeneity should help determine whether the overall summary can be trusted, and, if not, the effects observed in high-quality studies should be used for generating inferences.

3.7 Summary

This chapter sought to ground the research aim; namely, to conduct a nested process evaluation to explore the patients' perspectives of the seizure care pathway as a service intervention, within a philosophical, theoretical and methodological framework.

The exploration and application of CR as a theory has been used to underpin a pragmatic approach to the conduct of this study. The objective in doing so is to guide the research process in a way that is both responsive to the research aim and objectives and to ensure that data capture is appropriate for addressing the research questions under investigation (see Figure 1-1). Justification for the chosen methods utilised in the conduct of both qualitative parts two and three in this study are discussed in detail in the following chapter.

Chapter Four: Working Methods

4.1 Introduction

The aim of this evaluation project was to explore patients' perspectives of the seizure care pathway as a service intervention. Chapter three argued for the use of a critical realist stance to achieve this, utilising a systematic review, qualitative data, and secondary quantitative data derived from the wider CAPS project, to support the findings. The suitability of this pragmatic approach in evaluation research and the usefulness of qualitative techniques in epilepsy research (Rapport et al., 2015) was also highlighted in the previous chapter.

The utility of the systematic review within the study was outlined in chapter three and specific details of the systematic review are further explored in chapter five. This chapter sets out the working methods used during qualitative data collection. The chapter will begin with features of the research method applicable across both qualitative studies within this thesis (patient and staff) to include; study set-up, ethical considerations, data management and analysis. Respective differences in method, across the two studies; namely recruitment and sampling procedures will then be discussed. The rationale for the choice of methods lies within the chosen methodology and is responsive to the research questions under exploration (see figure 1-1).

4.2 Study design

Qualitative inquiry has gained popularity in health care research since the mid-1980's (Mays and Pope, 1995). Qualitative inquiry explores the beliefs and understandings of behaviours and experiences and can help to explain why certain interventions are often not implemented successfully in clinical practice (Al-Busaidi, 2008). In relation to the seizure care pathway, quantitative researchers may want to highlight the effects of the pathway on service use and patient outcomes. This could likely be achieved using routinely collected data, outcome data, and using quality of life (QoL) questionnaires. Such data has been collected as part of the wider Care After Presenting with Seizures (CAPS) project. Aspects of this will be utilised in chapters six and seven and within the discussion to provide context for this nested qualitative evaluation. Such data, alongside the qualitative findings from this thesis, may lead to recommendations, specifically designed for the seizure patient population, to streamline resources and improve clinical outcomes and experiences.

There are numerous qualitative data collection techniques used within health service research (Gill et al., 2008; Onwuegbuzie, 2010; Tracy, 2012). The choice of technique can give starkly different findings; careful consideration of the study aims, and research questions is therefore essential before a choice is made. This chapter sets out my methodological thinking, as the researcher, and discusses the relevance of the selected methods for this study.

4.3 Study set-up

4.3.1 Ethics and regulatory body approvals

Approvals were obtained from the research sponsor (University of Liverpool - protocol number: UoL001140) and from Wales Research Ethics Committee 7, (reference number: 15/WA/0207) (see Appendix B). Approvals from Health Research Authority (HRA) and the Research and Development department of each participating National Health Service (NHS) hospital trust (IRAS ID 173222) were also obtained prior to commencing the study.

4.3.2 Lone worker policy

In line with University of Liverpool guidelines a lone worker policy was implemented to alert members of the research team to the potential risks of lone working, to identify the responsibilities each person has in this situation, and to describe procedures to minimise such risk.

4.3.3 Interviewer

All interviews were conducted by me; the author of this study. As a researcher, I recognised that particular skills are necessary to undertake semi-structured interviews and made sure I was informed on the research skills required. Literature suggests that several characteristics make a good interviewer. These are listed in Table 4-1 below.

Table 4-1 Characteristics of a good interviewer (Liamputtong, 2011)

- Good listening skills
- Have adequate knowledge of the project
- Non-judgemental
- Sensitive to the needs of the participants
- Patience and flexibility
- Ability to withhold own assumptions and opinions
- Respect towards participants

I recognised many of the above characteristics in myself, which I had developed and practiced in my previous role as a staff nurse. I also reflected on the importance and influence of previous experiences, both personal and professional on my research stance. These considerations in relation to my positionality within the research are outlined in appendix O.

My research and communication skills were further developed through participation in qualitative research courses, as well as visiting and observing care in ED and epilepsy outpatient clinics. In addition, two pilot interviews were conducted and feedback on technique sought from members of the supervisory team. This helped to enhance my confidence in the conduct of qualitative interviews. The process related to conducting the pilot interviews is discussed in section 4.7.6.1.

4.4 Ethical considerations

It is recognised that qualitative research may involve an element of risk to those participating. For this study due consideration was therefore given in the research design to issues surrounding informed consent, maintenance of anonymity and confidentiality, potential to cause psychological distress, and power relations and deception. The following section will discuss these risks and the strategies used throughout the research process to reduce their occurrence and protect participants.

4.4.1 Confidentiality, anonymity and data management

Qualitative data may contain multiple clues to an individual's identity (Richards and Schwartz, 2002). It is important to protect participants by using an explicit process of informed consent and the maintenance of confidentiality and anonymity.

Access to the patient sample was provided by the research nurse who acted as gatekeeper to information (Lee, 2005). Access to the HCP sample was facilitated by the ED CAPS study lead clinician. All potentially confidential information was transferred securely through encrypted email. A password protected Excel database was set up to store all participant contact details and personal study numbers were used for anonymity according to the Data Protection Act (1998) and Freedom of Information Act (2000).

Confidentiality was assured before each interview commenced. This included the secure storage of the digital recorder (Olympus DM-650 device) used to record interviews in a cabinet in a locked office. Transcripts and recordings were stored on computer in a password protected folder and were used only for the purposes of the research study, in line with the University of Liverpool's data protection policies and standard operating procedures.

Participants were informed that pseudonyms would be used in transcripts and other identifying details would also be altered. Care was taken to ensure that any subsequent reports and publications would not identify individuals by name or inference in order to protect anonymity.

In addition, due consideration was given to confidentiality of participants within the location where interviews were taking place. In the participants home setting, interviews were paused if there was any interruption from anybody who had not consented to take part in the interview or any other distractions (i.e. telephone, doorbell). It was ensured that participants were happy with the location of the interview before the recording commenced and participants were made aware that should this change, they were able to stop the interview at any point. Where interviews were taking place away from the participants home, on the hospital site, a ‘do not disturb’ sign was placed on the office door and any other interruptions were dealt with in a similar manner (i.e. interview was paused until participant was happy to re-commence).

4.4.2 Study-related documents

To enable potential participants to provide informed consent, oral and written details relating to the purpose, extent and implications of their involvement in the study was provided. In line with HRA NHS recommendations (Health Research Authority, 2018), a comprehensive participant information sheet was devised which outlined the study in detail, together with researcher contact details, to enable those with an interest to seek further information should they wish to do so. The consent form was developed using the same recommendations.

Initial drafts of these documents, together with the participant interview appointment letter and the study-specific interview topic guides were subsequently circulated to the supervisory team, the wider CAPS study management group and to a lay member of the research team for review. The recruitment details were checked by a patient representative for language, with consideration taken to ensure that materials did not seem to be blaming or labelling ED attendances as clinically ‘inappropriate’. Careful attention to such details were essential to maximise recruitment in a potentially challenging population group, as discussed in more detail below (section 4.7.2). Consideration was paid to the content and layout of the documents and the clarity and relevance of interview questions. Language and formatting were edited in response to reviewers’ feedback prior to submission of the documents to sponsorship and ethics committee (see appendices C, D, E and F).

4.4.3 Informed consent

All participants were provided with a participant information sheet (Appendices C and D) prior to the interview and were given opportunity to ask questions. Patient participant consent included the confirmation that their participation in the study was voluntary and that they were eligible to withdraw at any time without giving reason and without any effect on the care they receive.

Both verbal and written consent was obtained before each interview commenced, including written consent for the interview to be digitally recorded. During patient interviews, if a patient chose for a carer to be present during the interview, a separate carer consent form was also completed. Both consent forms were duplicated; one was retained by the participant and one kept in the site file. Appendices E, F and G detail patient, carer, and staff participant consent forms used respectively.

4.4.4 Promoting trust in the research relationship

A recent study suggests that there is benefit of a health care professional (HCP) as the interviewer in qualitative research within the health care discipline, as they are in a position to have greater understanding and provide empathy with the situation (Sivell et al., 2015). It is equally important for researchers to be explicit about their background and to recognise the influence this could have on the participant-researcher relationship (Sivell et al., 2015). The research relationship may naturally incur development of a power imbalance. Evidence suggests that when the researcher has a HCP background, this power imbalance may be exaggerated (Etherington, 2001; Sivell et al., 2015).

It is important to develop a good rapport with participants; to enable them to feel comfortable and promote willingness to participate fully in the interview process (Karnieli-Miller et al., 2009). However, it is also possible that interviewee's may seek to provide information that is expected or desirable to the researcher (Ryan and Dundon, 2008). Morse et al. (1989) recognise that this is more of a problem where trust is not gained with the participant. For this reason, it was important, as the researcher, to develop a professional level of rapport, while maintaining a certain level of objectivity to help to prevent researcher bias.

While it was important to be open with participants about my role and the boundaries that this ensues, Richards and Emslie (2000) recognise that full disclosure of the researcher's professional role and the participant's perceptions of that role have the capacity to influence the level of data shared. Although my background is that of a HCP, the role and experience that I have does not allow me the expertise to provide information about epilepsy care and management that some participants may expect. It was important that this was made explicit at the beginning of each interview. Nevertheless it was equally important to be able to provide some support to participants if required (Richards and Schwartz, 2002). In the context of the current study, epilepsy information booklets were offered to participants following interviews for additional support and advice. Participants were given opportunity to ask any further questions or voice any other concerns that they may have after completion of their interview.

Although it is often assumed that a qualitative interview, which allows the participant to speak in their own terms, can be therapeutic (Small, 1998), this characteristic can potentially lead to exploitation and harm if participants are encouraged, through insensitive questioning, to divulge more information than they had anticipated. The probing nature of qualitative interviews can sometimes induce stress and anxiety to participants (Richards and Schwartz, 2002). It was important as a researcher, to reduce the risk of participant exploitation and coercion. All participants were fully informed that they were able to stop the interview at any point or refuse to answer any questions that they may feel uncomfortable answering, without this affecting any further care that they would receive.

4.4.5 Strategies to avoid participant misrepresentation

Within qualitative research, data analysis is influenced by various factors including the theoretical framework adopted and the characteristics and preconceptions of the researcher (Richards and Schwartz, 2002). It was important to be mindful of this throughout the data interpretation phase in order to avoid misrepresenting participants by taking their views out of context.

To reduce the level of misrepresentation, the researcher planned to send out a summary of the research findings, allowing participants the opportunity to respond with feedback before any findings are published. This was discussed with the participants at the end of each interview, to ensure that they were informed of this process and were happy to receive and make comments where necessary. Furthermore, discussion with supervisors and other researchers about the data can help to minimise the risk of misinterpretation. Also, the recognition of my position within the research and the potential influence this may have on the interpretation of the dataset can help to reduce this risk (Appendix O).

4.4.6 Potential benefits to participants

Whilst the participant information sheet did not imply direct benefit to those participating, it did suggest that participants might appreciate being given the opportunity to tell their side of the story and that the findings from this study might benefit others in the long-term.

4.5 Data management

Data were managed in line with Data Protection Act requirements (1998). The data collection and analysis of this study was conducted prior to the new General Data Protection Regulations (GDPR) requirements being released. All participant information sheets provided detailed description of the study to allow informed consent, along with the participant's role in the study and how their data would be stored and protected. Interview data were anonymised before being sent to an external body at the university for transcription. A confidentiality agreement was also signed between the researcher and the transcriber to support maintenance of participant confidentiality. Electronic data were removed from the audio recorder and stored on the University of Liverpool secure network. All transcripts were stored within password protected files. Hard copies of consent forms and participant information were stored in a locked cabinet within a locked office. Participant transcripts were printed, and hard copies also stored within a locked cabinet in a locked office. In compliance with the University of Liverpool's policy on the retention of data records, data will be retained in an appropriate storage facility for 10 years. When the time comes to delete/destroy the data this will be done in line with legal, ethical and research funder requirements with sensitivity to confidentiality and security.

4.6 Data analysis

The data were analysed using thematic template analysis (Crabtree and Miller, 1999; King, 2012). Thematic analysis (TA) is a widely used qualitative analytic method (Braun and Clarke, 2006). Described as having ‘theoretical freedom’, TA provides a flexible and useful research tool in identifying, analysing and reporting patterns (themes) within a dataset, allowing data to be analysed and described in rich detail (Braun and Clarke, 2006). Unlike other methodological frameworks such as grounded theory (GT) and Interpretative Phenomenological Analysis (IPA) which were also considered for use in this study, TA is often considered a method rather than a methodology. It was the most suitable approach to use in this study, as its flexibility and pragmatism meant that it could be adjusted to fit best and to address the wide range of research questions that the author sought to answer. Unlike GT and IPA, TA can be used across the epistemological and ontological spectrum, and can be underpinned by any number of theories (Braun and Clarke, 2006). It is important to remember my epistemological stance throughout the analysis process, which has been discussed in depth within chapter three (Holloway and Todres, 2003).

As a more pragmatic approach, thematic analysis moves away from more structured approaches of GT and IPA. One method, described by Crabtree and Miller (1999), is that of template analysis, whereby;

> *“…researchers can develop codes only after some initial exploration of the data has taken place, using an immersion/ crystallisation or editing organising style. A common intermediate approach is when some initial codes are refined and modified during the analysis process.”* (Crabtree and Miller, 1999)(p.167).

4.6.1 Developing the template

All transcripts were initially read and coded independently into initial codes, subsequent sub-themes and overarching themes. *A priori* codes, as well as codes developed deductively from the data were used to develop a coding framework. The coding framework developed iteratively as transcripts were analysed. Further analysis was conducted with the support of a colleague - a senior qualitative researcher (DS), who independently analysed the transcripts to confirm emerging concepts, themes and sub-themes (Noble and Smith, 2015; Sandelowski, 1993).

4.6.2 ‘A priori’ themes and preliminary coding

Before data analysis commenced it was important to read through the transcripts for familiarisation. I also listened to the audio recordings while completing this process to check for any transcription errors.

As previously discussed, template analysis typically begins with some pre-defined codes which help guide initial analysis. I made use of the topic guide when generating the initial coding frame. The topic guide itself was drawn from empirical literature review, my own personal knowledge and previous exploratory research, making it a good starting point for the development of a coding frame. I also utilised data from the first three interview transcripts, as well as the two pilot interviews, to help with the development of a preliminary coding template.

4.6.3 Revising the template

Once the initial coding template was constructed, I worked systematically through the transcripts to analyse the text. This involved detailed, systematic, line-by-line coding, with consideration given to how the codes might be meaningfully clustered to develop categories and concepts, and the subsequent development of themes. This enabled a bottom-up approach to the identification of concepts and categories generated by the data.

Typically, this process involved working through three transcripts using the same coding framework, before reflecting on themes generated through analysis and any changing scope within the data. After each three-interview analysis, I amended the template on reflection of the findings. The process of template amendment was recorded to provide transparency of the analytic process and as a means to promoting confidence in the trustworthiness, credibility, and authenticity of researcher findings and interpretations (Bailey, 1996a). A final iteration of the coding template is appended (Appendix J).

4.6.4 The ‘final’ analytic template

Researchers often find it difficult to decide when to stop the process of development when constructing an analytical template (King, 2004). Within this study, it was decided that the template was final following several iterations. To support this decision, familiarity with the data had been developed through slow, careful and repeated reading. Audio-recordings were repeatedly listened to and notes taken on what seemed significant. This decision was taken in collaboration with the supervisory team. Appendix J shows the final analytic template used in this study.

4.6.5 Theoretical framework of candidacy

After analysis of the first three interviews with participants, and discussion with the supervisory team, it was decided that the theoretical concept of ‘candidacy’ could provide an interpretative framework for the findings. The framework, originally applied to access to services for people from under-served groups, describes candidacy as the outcome of the ways in which *“people’s eligibility for medical attention and intervention is jointly negotiated between individuals and health services*” (Dixon-Woods et al., 2006).

Spheres of experience influence the behaviour of patients, HCPs, and the systems of health care at all points on the access route to services. The candidacy framework offers an integrative framework exploring how services and service-users interact (Mackenzie et al., 2013). It suggests that barriers to optimal service use are to be found at material, structural, organisational, professional, social, culture and individual levels, and brings these together in its theory of patient journeys through the NHS. Such journeys are augmented over time by patients’ personal, social, and cultural circumstances, which also must be taken into consideration.

Health service research traditionally examines access from the point of entrance into the care system (Kovandžić et al., 2011). This maybe where the journey starts for some individuals, but for others, particularly those with long-term chronic conditions, their beliefs and motivations may influence their decision-making when accessing and utilising services. For example, illness beliefs of PWE suggest that some individuals may view their condition as one which they have very little control over (Hosseini et al., 2016). This could potentially have impact on service use, whereby individuals with epilepsy feel that accessing some services is futile due to the inability to make change to their condition. Alternatively, such beliefs may result in increased service use where it is felt that self-management is not possible due to the low perceived control of seizures. Current research around illness beliefs in PWE have focused on psychosocial needs (Dilorio et al., 2003; Hosseini et al., 2016; Jones et al., 2006) without necessarily addressing how this translates into presentation at health care services.

Dixon-Woods (2006) framework of candidacy resulted from a critical interpretative synthesis of the available literature around access to health care. The original framework of candidacy incorporates seven sections. However, as an emerging and still relatively new concept, iterations and developments have since ensued, with refinements made by Mackenzie et al. (2013), who has worked to develop a more practicable model that is applicable within research methodology. Mackenzie considered candidacy through six dimensions, outlined below in Table 4-2.

Koehn argues that the candidacy model "*accounts most fully and systematically for the phenomenon of access and the way in which vulnerabilities arise in relation to it*" (Koehn, 2009)(pp.587). This makes it a suitable framework for the investigation of health care service access, namely through the seizure care pathway. A qualitative study conducted by Hunter et al. (2013) explored the choices made by patients' with long-term conditions when accessing emergency health care using a framework of candidacy. The concepts help to understand health care decision-making during vulnerable crises and how previous experiences shape perceptions of candidacy.

Table 4-2 Adapted description of the stages of the Candidacy Framework (Dixon-Woods et al., 2006; Mackenzie et al., 2013)

Stages	Description
Identification	The process by which an individual recognises their need for a service, identifying themselves as a suitable 'candidate' for care within health services.
Navigation	Knowledge of services available and appraisal of the practicalities of accessing such services. Includes barriers to access of services.
Permeability	The ease of which individuals can use/access a service. Includes the complexities of its referral process and the 'cultural alignment' of the service with individual needs and values.
Presentation	The ability to self-present, communicate and articulate their 'need' for the service. This also relates to the ability to voice concerns if needs are not met or standards are not appropriate.
Professional adjudication	Professional perceptions/actions that may or may not disadvantage individuals. Such behaviours that influence a person's progression through services and access to ongoing care.
Operating conditions	Incorporates factors at societal and macro levels, such as the availability of local resources for addressing candidacy. This can be dependent on the political, economic and environmental context at the time of presentation.

Candidacy has also been used to research physical symptoms, for example, exploring perceptions, views and experiences of diabetes education (Ockleford et al., 2008). Qualitative interviews were conducted with participants following their involvement in a structured programme of group education sessions aimed at enabling self-management of type 2 diabetes. Candidacy was explored through semi-structured interviews with 36 people with diabetes; 19 of whom had attended the additional education sessions and 17 who had been randomised to receive standard care. Their illness perception affected their candidacy; if they did not perceive themselves as ill, they did not see the reasoning for their need to take part in the intervention (Ockleford et al., 2008). This highlights the value of investigating patients' perceptions where they may seek help or use services inappropriately. Utilising the candidacy framework as an interpretative framework for the seizure care pathway will be useful to assess both access to care at the start of the patient's journey, but also access along the continuum of care and how this is affected by different factors, either positively or negatively.

It became clear from a very early stage of data analysis that people experiencing seizures and presenting to the ED made very different decisions regarding their need for health care intervention and the choice to attend the ED. I therefore decided to utilise the framework of candidacy within the discussion to explore patient perspectives and beliefs of their care experiences which may incorporate social factors. I conducted the remaining interviews, with both patient and staff participants, with this framework in mind.

4.7 Qualitative patient interviews

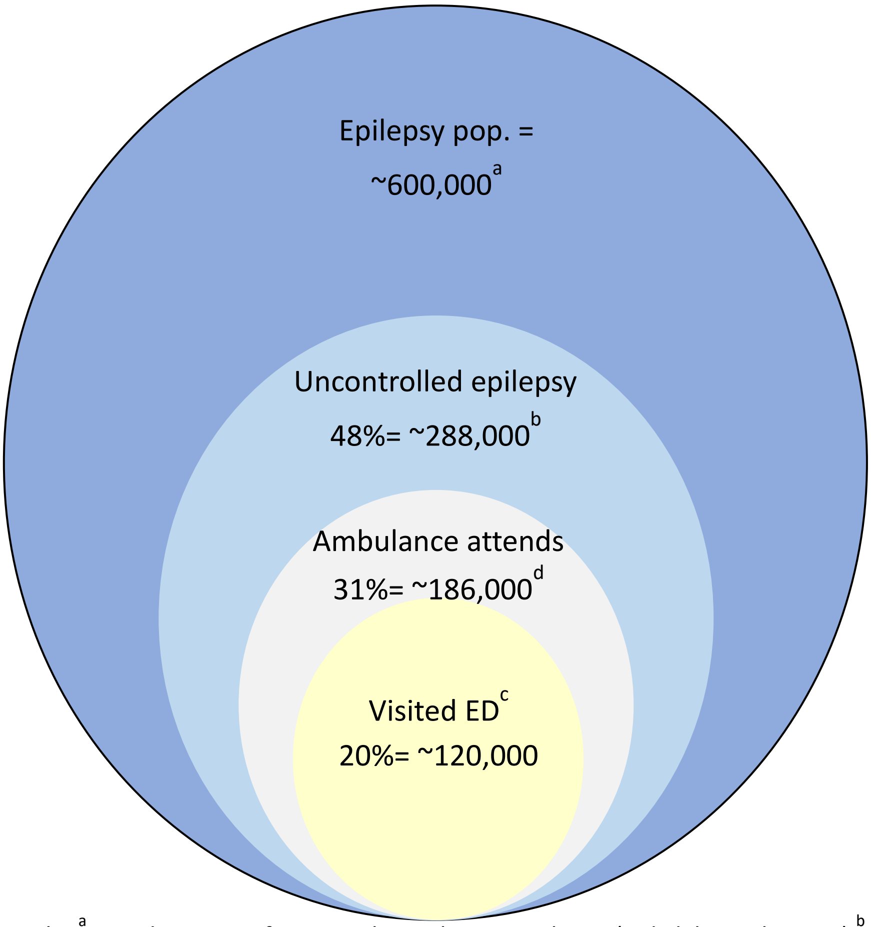
4.7.1 Introduction

The above section describes the common features of both study two (patient interviews) and three (HCP interviews) of this thesis. This section describes the population of interest, study setting, sampling and recruitment of patients and carers into study two.

4.7.2 Population

Participants were recruited via the CAPS study, described in chapter one, after presenting to one of three participating ED sites in the North West of England, following a seizure. Access to this particular patient population was negotiated via the CAPS research nurse at each hospital site, acting as gatekeeper during the initial phase of recruitment. People with established epilepsy, at least who visit ED, have a unique profile. Compared to other parts of the epilepsy population ED attendees report more seizures, anxiety and stigma, and are more likely to live in socially deprived areas (Allard et al., 2017; Noble et al., 2012). They also cannot be assumed to be synonymous with the part of the epilepsy population that has uncontrolled epilepsy. Indicators of this are that whilst ~48% of PWE in the UK have, according to some data, experienced a seizure in the past year, only ~20% attend ED. This may be because some people do not seek emergency care in the first instance, whilst others decline to visit ED even after an ambulance has attended. This is represented in Figure 4-1.

Figure 4-1 Approximation of ambulance service use and ED attendance by PWE in the UK



Notes: Not to scale; [a] Based on ~1% of UK population having epilepsy;(Ridsdale et al., 2011) [b] Moran et al. indicate 48% of people with epilepsy will have had a seizure in prior 12 months;(Moran et al., 2004) [c] Hart and Shorvon found that ~20% of PWE had attended an ED in the prior 12 months;(Hart and Shorvon, 1995) [d] When a call is received by ambulance service described as relating to a 'convulsion', 'fit', 'seizure', the call handler implements endeavours to ask standardised questions to gauge, such things as severity and potential aetiology. For those using Advanced Medical Priority Dispatch System, according to Protocol 12, one question is "Is s/he an epileptic?". Most callers should be able to answer question as most (~70%) seizure calls made by relative, friend or carer. Audit data from two regional ambulance services (North-West Ambulance Service; Yorkshire Ambulance Service) indicates that in 2018 of those attended to ~70% of those who indicate a history of epilepsy are conveyed to ED, and 30% are not.

Recruitment of people with uncontrolled epilepsy into evaluative studies has previously been reported to be challenging. For example, in the HTA-funded SMILE (UK) trial, PWE living in the London area who had experienced at least two seizures in the prior year were invited into a trial of self-management that had a 12-month follow-up; 37% of those invited took part (Kralj-Hans et al., 2014).

Challenges can arise within this population due to the nature of the condition itself (e.g. unpredictable but frequent seizures) and its consequences (e.g. anxiety about travelling alone, inability to drive, memory impairment etc). A range of evidence-based strategies were therefore deployed to try to maximise recruitment. These included 1st class postage of invitations for interview, reminder phone calls 24 hours prior to interview taking place, flexibility regarding when and where research appointments took place, the use of an "opt-out" approach to contacting patients about the study, multiple contact attempts and all patient-facing documents being developed collaboratively with a patient and public representative group (Ellard-Gray et al., 2015).

4.7.2.1 Eligibility criteria

The lower age limit for eligibility to take part in this study was 16 years. This age was deemed appropriate as at the age of 16 years, adolescents with known epilepsy typically transition from paediatric to adult neurology services.

Eligible patients were those presenting to the ED following a seizure who met the following criteria;

- Established diagnosis of epilepsy and presented following an **unprovoked** seizure
- No current clinical epilepsy diagnosis but have presented to ED following a suspected **unprovoked** seizure

4.7.2.2 Exclusion criteria

Individuals excluded from the study were those who;

- Presented following a **provoked** seizure

- Resided outside the Walton Centre NHS Foundation Trust catchment area (Cheshire and Merseyside area ~2.5 million people). This is because patients from outside this catchment area are not offered a follow-up appointment through the pathway. In such circumstances, the CAPS research nurse will still write to their general practitioner (GP) advising them of their attendance at the ED, with a recommendation that the patient should be referred on for an appointment at their local hospital or neurology service.
- Individuals with a learning disability or those not fluent in spoken or written English. These exclusions were applied on the grounds of study limitations and the potential for communication difficulties in relation to obtaining informed, signed consent and interview participation.

4.7.2.3 Definition of seizure criteria

Unprovoked seizures are those occurring in the absence of any precipitating factors. **Provoked** seizures are those precipitated by a number of factors including hypoglycaemia, fever, alcohol withdrawal and head injury (Stafstrom and Carmant, 2015). It is part of the clinical decision-making process in the ED to establish whether the patient has had a provoked or unprovoked seizure and subsequently requires treatment and follow-up through the seizure care pathway. This should be clearly documented in a patient’s case notes by the ED clinician managing the patient.

4.7.3 Data collection method

In this study I chose to use semi-structured interviews with participants on a one-to-one or one-to-two basis, with a carer present. Interviews are commonly used to gain an insight into people’s direct experiences as described by themselves, making it an appropriate choice of method to meet the aim of this research (Gill et al., 2008). The interview approach provided a powerful medium of exploration through which to enhance understanding of participants’ experience of the seizure care pathway. The presence of a carer within these interviews also proved useful during the data collection process; providing further insight into experience(s) when participants could not always recall events, as outlined in more detail in chapter six.

Previous qualitative studies around patient experience have utilised one-to-one interviews in various settings, exploring a variety of topics (Gellerstedt et al., 2013; Kamphuis et al., 2004; Stirling et al., 2016). For example, Hipwell et al. (2014) conducted semi-structured interviews with staff and patients about their experiences of diabetic retinopathy screening. Hipwell et al. (2014) recognises the importance of such interviews in identifying important insights and sociocultural meanings of health and illness experiences that will inform future practice and further research. Such interviews allow time to discuss sensitive topics. As Jones (1985) succinctly states;

> *"In order to understand the other persons' constructions of reality we would do well to ask them…and to ask them in such a way that they can tell us in their terms . . . and in a depth which addresses the rich context that is the substance of their meanings"* (Jones, 1985) (pp.46)

One-to-one interviews are an effective data collection tool for addressing sensitive topics. For this study this approach was considered more appropriate than conducting focus group discussions for a number of reasons, not least because participants may feel uncomfortable discussing such potentially sensitive topics within a group setting (Smithson, 2000). Previous research indicates that people with epilepsy (PWE) may find the ability to concentrate challenging and, as such, may find the focus group environment difficult to cope with (Ponds and Hendriks, 2006). Furthermore, as a consequence of 'felt' stigma and a level of embarrassment (Jacoby, 1994; Scambler and Hopkins, 1986), PWE are fearful of having a seizure in a public place; this may influence their decision to take part in a focus group with unfamiliar individuals in an unfamiliar environment (England et al., 2012; Goldstein et al., 1990). By utilising one-to-one interviews and allowing participants to select a person who they are familiar with to be present during the interview, I hoped that this would minimise the risk of anxiety for the participant and encourage them to be more likely to agree to take part.

4.7.4 Study settings and venues

The evaluation study was conducted at three ED hospital sites across the North West of England, all of which fell within the Walton Centre NHS Foundation Trust's catchment area; Aintree University Hospital (Liverpool University Hospitals NHS Foundation Trust), Warrington Hospital (Warrington and Halton Hospitals NHS Trust) and Arrowe Park Hospital (Wirral University Teaching Hospital NHS Foundation Trust).

Attending an interview in a hospital or community setting, may prove difficult for this population. People with uncontrolled seizure are typically prohibited from driving. Using public transport to attend the interview may also be an issue due to fears around having a seizure in public (Bishop and Allen, 2003; England et al., 2012; Fisher et al., 2000; Goldstein et al., 1990). For these reasons, a decision was made to conduct individual patient/carer interviews at a venue and time most convenient to the patient, in order to minimise participant inconvenience. It remained important to offer choice to ensure individuals were not excluded from participating in the study due to location. If participants were not comfortable with being interviewed in their home or this was inconvenient, alternative arrangements were sought, namely the use of an office away from the main hospital building. To promote recruitment, travel expenses were offered to participants should they wish to attend a location away from their home to be interviewed.

4.7.5 Recruitment

4.7.5.1 Screening

Screening for eligible patients to the current study was supported by three CAPS research nurses who were in post at the three recruiting NHS hospital sites. Patients from each of the research sites who met the CAPS study inclusion criteria were invited to participate by one of the research nurses, who acted as gatekeepers.

The recruitment process to CAPS required participants to sign a consent form which included consent to be contacted about participation in qualitative interviews within the current study. Before obtaining consent for this aspect of the study, a brief was given to each research nurse about the aim and objectives of the qualitative study to enable informed consent to be obtained. Once consent to the CAPS study had been sought, telephone contact with potential participants was made; as detailed in Figure 4-2.

4.7.5.2 Consent

Following consent to the CAPS study, patient information including name, address, date of birth and telephone number were provided by the gatekeeper. At this point telephone contact was made with potential participants to determine their interest in taking part in the qualitative aspect of the research. Some participants provided verbal consent over the phone, in which case, an interview date and time was confirmed and a patient information sheet (appendix C) and letter confirming details of the interview (appendix H) was posted to them. Where patients were unsure about participating or a request for further information was made prior to consenting, a patient information sheet was posted out to their home address.

In circumstances where contact could not be made a telephone message was left. If there was no response, two subsequent attempts were made to contact the patient in order to facilitate recruitment from a patient population who frequently report memory problems and whose lives can be disrupted by episodic relapses of their condition (Farrell et al., 2016; Helmstaedter et al., 1994). Research ethics approval to send out recruitment letters directly to potential participants had not been sought; consequently, the only initial point of contact was via telephone only.

4.7.5.3 Sampling strategy

Selecting a sample in qualitative research requires consideration of the study aim and objectives, alongside the characteristics of the study population. Developing a well-defined sampling strategy is as important in qualitative research as in quantitative research in the generation of robust and unbiased results (Luborsky and Rubinstein, 1995). As such, a number of techniques can be used to select a qualitative participant sample (Luborsky and Rubinstein, 1995).

In this study a purposive ‘quota’ sampling technique was used (Luborsky and Rubinstein, 1995). This was considered appropriate to achieve range and diversity within and across the study sample; an important aspect of the study was to include participants from a wide range of backgrounds, in order to ascertain whether their background influenced their experience and expectations of the service provided. Purposive ‘quota’ sampling is also helpful in identifying the most information rich cases in order to learn about issues fundamental to the purpose of the research (Suri, 2011). The sample matrix (Appendix K) outlines the demographic characteristics against which ‘quota’ sampling took place in order obtain the sample in study two. The sample comprised of adult patients who had attended the ED following a seizure. Further details of inclusion and exclusion criteria are specified in section 4.7.2.1.

In qualitative research, sample size is driven by the aim, sampling strategy and iterative analysis of findings of the study. The ultimate size of the sample can be difficult to predefine. Often sample size is related to the achievement of data saturation; that is, no new themes or concepts are generated (Mason, 2010). Data saturation can be achieved at different times in different studies, often driven by the aim of the study. For example, Charmaz suggests that a smaller study with *“modest claims”* (p.114) might achieve saturation with lower participant numbers than a study that aims to describe a process spanning disciplines (Charmaz, 2006). For example, a study that describes addiction in a specific group may achieve saturation quicker than one exploring a description of addiction in general (Mason, 2010). It is important to ensure the collection of sufficient data in order to reflect depth and diversity of the phenomenon whilst not having so much data as to render the study unmanageable (Kvale, 1996).

Though it would have been possible to extend the sample size if necessary, data saturation was achieved after around twenty interviews; a decision facilitated by ongoing data analysis. In this study, saturation was achieved when the selection of participants sufficiently represented the population of PWE, and later interviews were no longer generating new topics. Once no new themes were identified by the researcher in the data across five subsequent interviews, saturation was considered to have been reached and interview recruitment ceased (Mason, 2010).

4.7.6 Data Collection

4.7.6.1 Pilot interviews

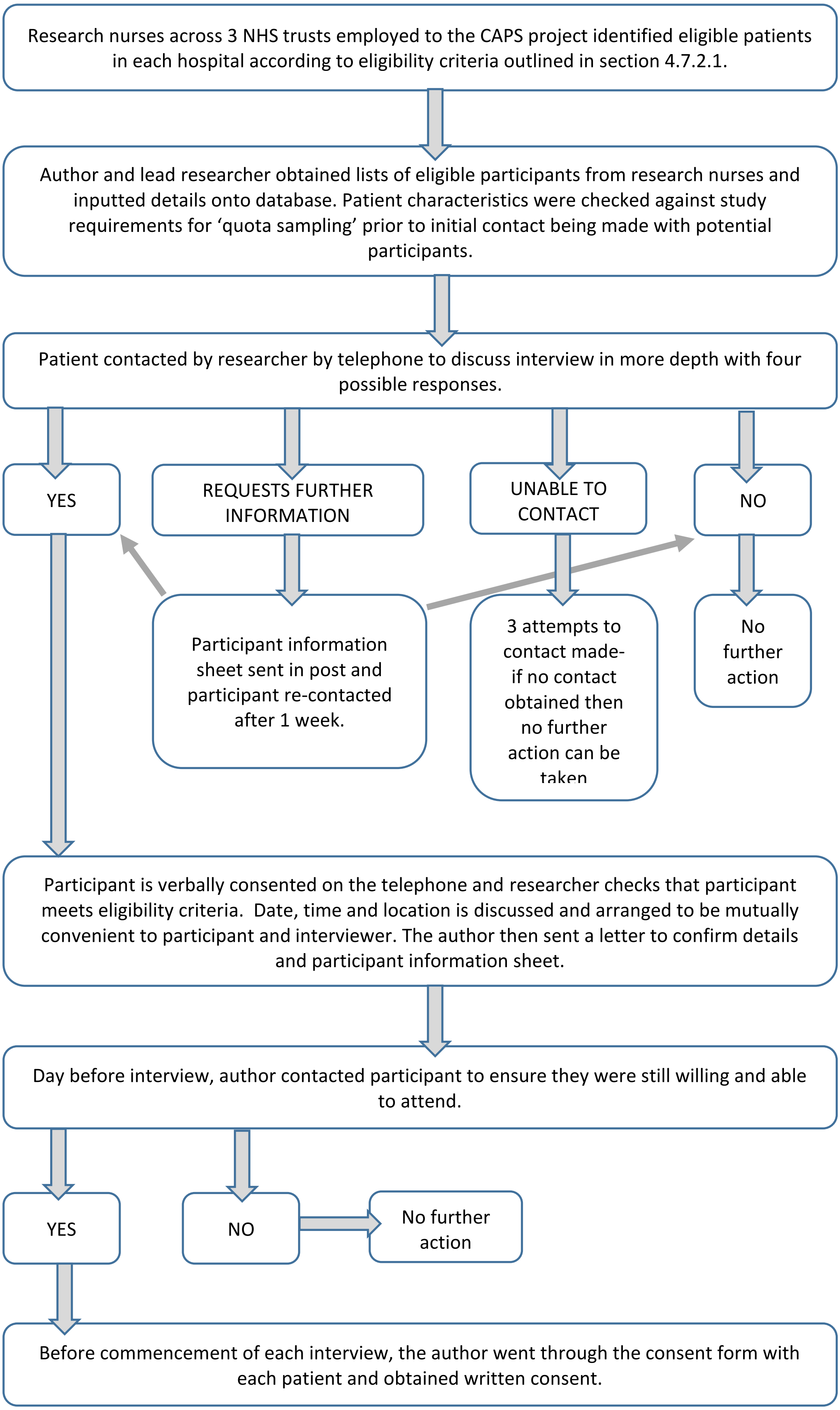
As with all research, qualitative and quantitative, it is important to first pilot the study to test methods to be employed (Creswell, 2007). It was therefore essential to pilot the interview schedule with participants who had similar inclusion criteria to those I proposed to recruit to the study (Cormack, 2000; Gill et al., 2008). This process not only enabled me to gain confidence in interviewing skills but helped to ensure that the topic guide was appropriate and facilitated responses from participants that would provide data to answer the research questions.

A local neurological charity supported the identification of participants to take part in the pilot phase of this study. Consent was sought as per consent procedure for the main study interviews (see section 4.5.7.2). Two pilot interviews took place in November 2015 prior to the main study opening to recruitment. Following completion of the pilot interviews, time was set aside to meet with the supervisory team to discuss any concerns regarding interview technique and the topic guide. This promoted self-reflection and learning and enabled topic guide iteration prior to commencement of further interviews. The most significant learning point for the pilot phase was the need to ask for clarification or expansion of a response where detailed offered by participants was limited.

4.7.6.2 Conduct of interviews

Participant interviews were conducted across a 14-month period from March 2016-May 2017. No financial or other incentive was offered to participants. Discussions were semi-structured using a pre-defined topic guide (see section 4.7.7.2) and were digitally recorded (Figure 4-2). Each interview was scheduled to last between 30mins-one hour. Inevitably, the length of semi-structured interviews varies, dependent on the topic to be explored, the researcher and the participants' willingness to partake. Gill et al. recognise that often health care interviews tend to last between 20-60 minutes (Gill et al., 2008).

Figure 4-2 Patient participant recruitment process



Time spent building a rapport with the participant was also required. This was important in allowing them to feel comfortable in answering questions that they could possibly find sensitive or upsetting, dependent on their experiences (DiCicco-Bloom and Crabtree, 2006).

It is important to keep participants engaged and to ensure that they do not find the interview process arduous. PWE often have difficulty concentrating and remembering (Eddy et al., 2011). Acknowledgement of this at the beginning of the interview was vital. It was made clear to participants that if they wished to take a break then this would be perfectly acceptable. This was key to try to make the participant feel as comfortable as possible in order to elicit the most detail possible out of the interview process (DiCicco-Bloom and Crabtree, 2006).

4.7.7 Interview format

4.7.7.1 Overview of the research project

The interview began with completion of the informed consent process. This involved an explanation of the wider CAPS research project to assist participant understanding of how the evaluation would fit within the study. In addition, the introduction would serve to promote the participants' sense of competence in participating in the interview and assure them that what they had to say was of interest.

4.7.7.2 Topics

A broad agenda of topics is necessary for qualitative data collection: a topic guide helps to provide this (Ritchie and Spencer, 1994). Participants were encouraged to discuss their views and experiences in relation to the following broad areas;

- Their individual experience of the ED (to include; decision to attend, care process(es), interactions with professionals, support and information sharing)
- Previous ED experiences (to include; similarities/differences to any previous seizure-related attendances, likes/dislikes)
- What is 'good' care? (to include; expectations in the ED, service provision, shortfalls- what is lacking? Improvement suggestions, barriers and facilitators)

- Transition experience (to include; follow-up time, communication, past and present experiences)
- Experience of follow-up/outpatient neurology services (to include; role of neurologist, benefits of follow-up, role of GP, communication improvement suggestions)

At the end of each area of discussion, I ensured the participant had no further comments to add prior to moving on to the next topic. This enabled the participant, in their own time, to voice any other views that were not covered in the topic guide and ensured that I was not being overly prescriptive with questioning.

Topics of interest were developed iteratively, dependent on participant responses in prior interviews. The development of the topic guide was discussed regularly with the supervisory team.

4.7.7.3 Interview summary and close

Each interview included a closing summary, inviting any additional comments or questions from participants. I then gave thanks to the participant for their time and willingness to take part before turning off the recording. Following each interview, post-interview field notes/ reflections were noted, as soon as possible, on return to the study office (DeMarrais, 2004; Roulston et al., 2003).

4.7.8 Data Analysis

Thematic template analysis (King, 2004) was used to analyse data in this study. Template analysis, a detailed and discrete form of thematic analysis, emerged initially in the 1990’s (Crabtree and Miller, 1999), with more recent work in health care template analysis being completed by Nigel King (Brooks et al., 2015). The data analysis process is detailed more thoroughly above in section 4.6.

4.8 Qualitative staff interviews

4.8.1 Introduction

The above section describes working methods specific to qualitative study two; patient and carer interviews. This section describes the population of interest, study setting, sampling and recruitment of HCPs, to qualitative study three.

4.8.2 Recruitment

Following ethical approval, I contacted gatekeepers (clinical leads already involved in the wider CAPS study), to support identification of appropriate staff and HCP participants (Lee, 2005). HCPs were eligible to take part if they had been directly or indirectly involved in the care of patients along the continuum of the seizure care pathway. In addition to HCPs, I recognised that other staff including administrative support staff were involved in the care pathway process and so it was decided that these should also be included in recruitment. All participants selected worked at either Walton Centre NHS Foundation Trust or Aintree University Hospital. The decision was taken to include only staff from one ED, Aintree University Hospital, where the care pathway and pathway nurse is in place and the Walton Centre NHS Foundation Trust. It was anticipated that the proximity of these two hospitals, whose facilities are on the same site, and the fact that a CAPS research nurse liaises directly with both hospitals, would promote the most effective use of the pathway.

I visited the ED on various occasions to introduce the study to eligible clinicians during their handover meetings and recruited clinicians in this way. An alternative method of recruitment included emailing eligible staff involved in seizure care within the ED or at the Walton Centre NHS Foundation Trust to introduce the study and recruit where possible. Those who responded affirmatively to the request to participate and provided their contact details, were emailed to schedule an interview at a time and place of their convenience and were provided with the relevant participant information sheet (Appendix G). Interviews were offered either face-to-face or via telephone dependant on participant choice. Face-to-face interviews were conducted in an office on the hospital site.

4.8.3 Interview process

HCP and administrative staff participant interviews were conducted over a five-month period from June 2017 - November 2017. Interviews were semi-structured in nature, with topic guides used dependent on participant background. Different questions were used to ensure the topic guide was responsive to the varied participant roles; including both clinicians and administrative staff. Interviews were scheduled to last up to 45 minutes.

In addition to specific role-based questions, staff participants were encouraged to discuss their views and experiences in relation to the following broad areas;

- Their role, professional experience, and understanding of the seizure care pathway for use in the ED.
- Practicalities of using the pathway in practice in their specific job role (to include; efficiency of the pathway, changes made to care based on pathway introduction, barriers and facilitators to its use)
- ED processes and priorities (to include; what impacts the use of the pathway on a day-to-day basis, priority of epilepsy in the ED, clinical/professional issues related to its use)
- Improvement suggestions (to include; ways to improve pathway, transition between services, clinical/organisational/systems level ways to improve transition)

At the end of each area of discussion, participants were asked to comment further, should they wish to do so, before proceeding to the next topic. Topics of interest were developed iteratively, through participant responses in prior interviews and discussion with team members at research supervision meetings.

4.8.4 Confidentiality

Due to the small sample size expected for this study it was important to be particularly rigorous in maintaining anonymity of participants to protect identity during participation and dissemination of findings. This was done using techniques addressed in section 4.4.1.

4.9 Summary

This chapter provides an in-depth discussion about the qualitative research methods utilised in the study, allowing the exploration of patient and staff experiences of the seizure care pathway. Methodological approaches were chosen in accordance with both the nature of the research and the epistemological stance taken within this thesis, as a critical realist researcher, as outlined in chapter three. An important consideration was the unique and challenging profile of the patient population and several evidence-based techniques have been deployed to maximise patient recruitment.

Utilising semi-structured interview techniques combined with iterative analysis allows for the development of themes and concepts to illuminate both patient and HCP experiences of help-seeking, service navigation, and service use and provision. Use of the theoretical framework of candidacy allowed for the exploration of both PWE and HCPs experiences and perceptions of the services available and how these services are accessed (Dixon-Woods et al., 2006; Mackenzie et al., 2013). Qualitative findings from patient and professional interviews are presented in chapters six and seven respectively.

Chapter Five: Systematic Review

Current patient-reported experience measures (PREMs) for evaluative use in emergency care medicine[1]

5.1 Introduction

The Medical Research Council (MRC) framework for evaluation of complex interventions suggests that systematic reviews prove useful to underpin process evaluation. As discussed in chapter two, there are a variety methods and techniques used in health care to measure patient experience, including, but not limited to, the use of patient-reported experience measures (PREMs). Although PREMs are commonly used in a variety of health care settings to evaluate patient experience, there are no clear guidelines to the development of validated PREMs for this purpose. Whilst undertaking the scoping literature review presented in chapter two, it became evident that no systematic reviews had previously been conducted to identify and assess current PREMs for use specifically within the emergency department (ED).

This chapter outlines a systematic review conducted to address this gap in knowledge by assessing the development and psychometric properties of PREMs for use within emergency care. Although we are focusing specifically on epilepsy within the ED in this thesis, there is no evidence of any PREMs having been specifically designed for this patient population and so we have decided to widen the review to ED-specific PREMs, with a view to exploring the development of disease-specific PREMs later in this thesis (chapter eight). The work in this chapter appears as a paper in the International Journal for Quality in Health Care (Male et al., 2017).

The chapter begins with an overview of the main aim of the systematic review; the general process of the review; the search strategy adopted; and the approach to data collection, and quality assessment. Next, it details eligible studies before going on to

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[1] Work presented in this chapter have previously appeared in "Leanne Male, Adam Noble, Jessica Atkinson, Tony Marson; Measuring patient experience: a systematic review to evaluate psychometric properties of patient reported experience measures (PREMs) for emergency care service provision, *International Journal for Quality in Health Care*, Volume 29, Issue 3, 1 June 2017, Pages 314–326, https://doi.org/10.1093/intqhc/mzx027"

summarise the methodological qualities of the studies describing PREMs. The chapter then concludes with a critical synthesis of the findings and consideration of the wider implications of this review within the context of the thesis.

5.2 Systematic review

5.2.1 Objectives

The objectives of the systematic review were to;

- Identify existing questionnaires available to measure patient experience in the ED
- Identify studies which examine the psychometric properties of current PREMs for use in ED
- Critically appraise the quality of the methods and results of the measurement properties using defined criteria for each instrument
- Summarise outcomes

Primarily these objectives will lead to a clearer understanding of the validity and reliability of currently available instruments.

5.2.2 The systematic review process

A systematic review *"attempts to collate all empirical evidence that fits pre-specified eligibility criteria to answer a specific research question."* (Liberati et al., 2009)(pp.2). Unlike traditional literature reviews which report studies at face value, the systematic review aims to delve deeper, using transparent and replicable methods to identify, critically appraise and summarise original research studies (Centre for Reviews and Dissemination., 2011). As well as being vital in the development of evidence-based health care, systematic reviews also help to identify gaps in knowledge (Petticrew and Roberts, 2006).

The review process is guided by a number of key stages (Higgins and Green, 2011):

- Developing a review protocol
- Comprehensive search of the literature using an *a priori* search strategy
- Application of inclusion and exclusion criteria
- Critical appraisal of evidence
- Data extraction
- Analysis

It is important to begin the process by determining whether a review is required to avoid unnecessary duplication of work (Centre for Reviews and Dissemination., 2011). A search of the Centre for Reviews and Dissemination database, PROSPERO, was actioned alongside a basic search of the main electronic databases including MEDLINE. Searches did not identify any current reviews of the specific topic area of ED PREM development.

5.3 Methods

5.3.1 Data sources and searches

An initial scoping search, comprising of key word searches (patient experience, patient satisfaction, emergency care, experience measure, questionnaire) in MEDLINE and CINAHL highlighted a range of study designs that could be used within the review. However, given that the focus of the review was on the reporting of the development of PREMs it was decided to select only studies which i) described the development and/or evaluation of a PREM for use specifically with ED patients; or ii) described instruments designed for self-completion by people who were or had recently received ED care (or a close significant other, i.e. relative or friend).

A comprehensive search strategy was adopted. Online database searches included MEDLINE, Scopus, CINAHL, PsycINFO, PubMed and Web of Science. The keywords used were ‘patient experience’ OR ‘patient reported experience’ OR ‘patient reported experience measure’; ‘emergency medical services’ (MeSH); ‘measure’ OR ‘tool’ OR ‘instrument’ OR ‘score’ OR ‘scale’ OR ‘survey’ OR ‘questionnaire’; and ‘psychometrics’ (MeSH) along with Boolean operators. Appendix L outlines an example of the specific MEDLINE search conducted. The Internet was also used as another source of data via Google using combinations of the identified search terms and searches of the Picker Institute website, National Health Service (NHS) surveys website and Care Quality Commission (CQC). Citations of studies identified, review articles and guidelines were also searched for any potential additional studies. The search was performed in March 2016 and updated in December 2016.

5.3.2 Study selection

Studies were included if they described the development and/or evaluation of a PREM for use with ED patients. The instrument needed to be designed for self-completion by the patient (or a close significant other, such as a relative or friend). Participants in the study needed to be aged 16 years or older and the study needed to be written in English. Studies focusing on Patient Reported Outcome Measures (defined as a patient’s self-assessment of some aspect of their health) or patient satisfaction (based on discussion of satisfaction measures), rather than PREMs were excluded, as were review articles and editorials. Studies were limited to those published in English. Finally, studies that recruited less than 50 patients were excluded.

Titles and abstracts were reviewed by myself to exclude duplicates and studies not meeting the inclusion criteria. Where a decision could not be made based on abstract and title, full text articles were retrieved, and in-depth evaluation was carried out with the support of a second reviewer. Full texts of the remaining articles were reviewed by two reviewers to assess against inclusion and exclusion criteria.

5.3.3 Data extraction

Data from the methods and results sections of each publication were reviewed by myself, extracted and tabulated using a standardised form (Appendix M). Author comments and opinions were not included in data extraction. The data extraction form covered four aspects:

- General information about the article: authors, article title, year and country.
- Study characteristics: aim, target population, recruitment and setting.
- Participants: sample size, participant eligibility criteria.
- Intervention: mode of administration, scoring scale, number of items/domains, subscales used.

5.3.4 Quality assessment

Several frameworks exist for evaluating the quality of patient-reported health questionnaires. These are used to determine if an instrument is adequate for the intended use in the target population.

Within this systematic review, the quality checklist of Pesudovs et al. (2007) was used to assess each included study as this checklist has been developed and used in the assessment of a diverse range of patient questionnaires, making it a validated and suitable framework to use within this review (Pesudovs et al., 2007; Salvilla et al., 2014; Worth et al., 2014).

Pesudovs et al.’s (2007) framework includes a robust set of quality criteria that assess instrument development and psychometric performance. The former includes describing the purpose of the instrument and its target population, the steps taken in defining the content of the instrument, and the steps involved in developing the rating scale and scoring system. The latter focuses on different types of validity and reliability, as well as responsiveness and interpretation of the results. Appendix N outlines the framework and the definitions used to assess how the measure performs against each criterion. For the present study, each PREM was given either a positive (✓✓), acceptable (✓) or negative rating (X) against each criterion.

Each PREM was independently rated by two reviewers against the Quality Assessment Criteria (Pesudovs et al., 2007) and any disagreements were resolved through discussion. The reviewers were myself and JA, a postdoctoral researcher with a background in research medical imaging. Instrument developers were not contacted to clarify anomalies and/or queries regarding reporting quality. Due to the heterogeneity of the studies included, it was decided that only a narrative analysis would be performed to generate a synthesis of findings of the included studies.

5.3.4.1 Quality assessment criteria: instrument development

Pesudovs et al.,'s (2007) quality assessment criterion are outlined in Appendix O. Instrument development was assessed against six criteria. The pre-study hypothesis and intended population was rated positively if there was a clear statement made of the aims and target population, as well as the intended population being studied in adequate depth (>50 participants). Face validity is measured as the extent to which the content meets the pre-study aims and hypothesis. Item identification is the selection of items relevant to the target population. Positive rating of item identification resulted from evidence of consultation with key stakeholders, including patients, staff and experts, through methods such as in-depth interviews, and a review of relevant literature. Following this, the determination of items for the final instrument, is measured by item selection. Rasch or factor analysis should be employed, with missing items and floor/ceiling effects taken into consideration. Statistical justification for the removal of items should be incorporated in the analysis for a positive rating to be achieved for item selection. Unidimensionality is achieved when all items fit within an underlying construct; Rasch or factor analysis for each construct with factor loading >0.4 for all items demonstrated a positive rating. If the study reports the use of Cronbach's alpha, rating would be deemed as acceptable. The final criterion measured was response scale. If the response scale was noted and justified a positive rating was given. If no justification was provided, then the rating would only be deemed as acceptable.

5.3.4.2 Quality assessment criteria: instrument performance

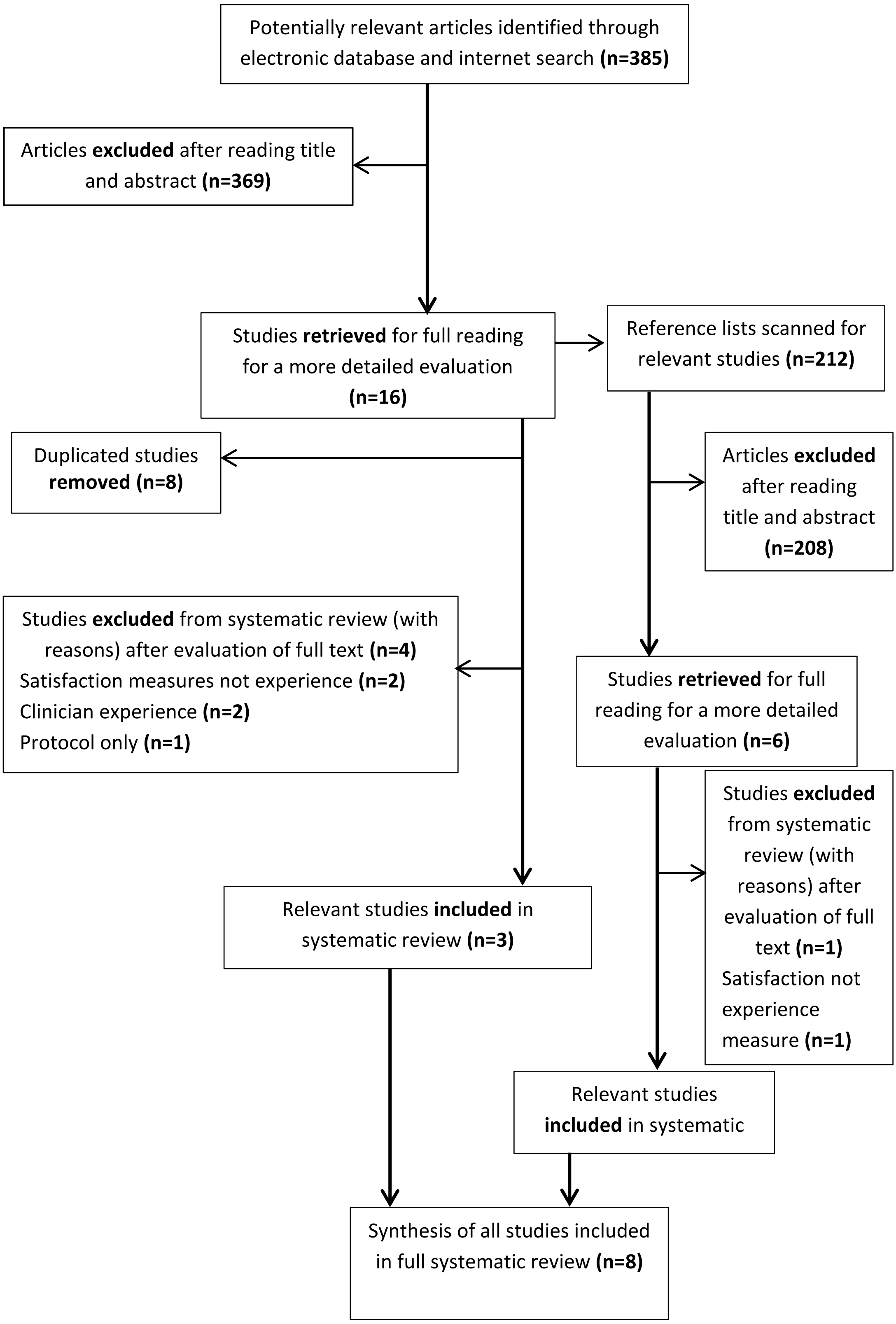
Instrument performance was assessed against five criteria of validity and reliability (Pesudovs et al., 2007). Convergent validity explores the degree of correlation with a new measure. A positive rating was offered if the instrument could be tested against an appropriate measure and a Pearson's correlation coefficient of between 0.3 and 0.9 is given. Predictive validity ascertains the instruments ability to predict a future event. If it had been tested against an appropriate measure and gives a coefficient value >0.3 then it was deemed positive. Test re-test reliability is a statistical technique used to estimate components of measurement error by testing comparability between two applications of the same measure at different time points. Measured using Pearson's *r* value or intraclass correlation coefficient (ICC), a value of >0.8 received a positive rating. If it was measured by Pearson's *r* value or ICC and had a value of <0.8 then the instrument performance was rated as acceptable. If it was not recorded as measured, the instrument received a negative rating. Finally, for performance, the extent to which an instrument can detect clinically important differences over time was assessed. Discussion of responsiveness of change over time, along with measurement of the minimally important difference (MID), would receive a positive rating. If no measurement was taken, but discussion of responsiveness was had within the paper, the instrument performance would be rated as acceptable. If no aspect of responsiveness was discussed, then the instrument would be rated negatively.

5.4 Results

5.4.1 Search results

A total of 597 articles were identified, of which 575 were excluded after reading title and abstract. Full text articles were assessed for the remaining 22 articles, after which a further 14 articles were excluded for the following reasons; duplication of same publication (n=8), patient satisfaction measure rather than experience (n=3), protocol only (n=1) and clinician experience measure rather than patient (n=2). A total of 8 papers met the inclusion criteria representing four different PREMs; the Accident and Emergency Department Questionnaire (AEDQ), Patient Participation in the Emergency Department (PPED), Urgent Care System Questionnaire (UCSQ), and Consumer Quality Index of the Accident and Emergency Department (CQI-A&E). A PRISMA flow diagram showing the number of references identified, retrieved and included in the review is presented in Figure 5-1.

Figure 5-1 PRISMA flow diagram



5.4.2 Characteristics of included studies

The characteristics of included studies is summarised in Table 5-1. All eight studies were conducted after 2008 and within Europe; with four conducted in the United Kingdom (UK), two in Sweden and two in the Netherlands. Three studies reported methods used to inform the design of the PREM, as detailed below. Five studies evaluated the psychometric development of PREMs. Four were original studies and one followed up with further development work, including details of psychometric testing of the original instrument (Bos et al., 2013b). Within the four studies, one was a large multi-centre study across 151 hospital trusts in the UK (Bos et al., 2013a), one was a smaller multi-centre study (Frank et al., 2011), one targeted a single specific hospital (Bos et al., 2012), and one recruited patients at random from general practice (O'Cathain et al., 2011).

In the five studies reporting on the psychometric development of PREMs, the mean age of patients ranged from 51-56, although not all measures reported specific age ranges, and one did not discuss participant demographics (O'Cathain et al., 2011). Two of the studies recruited using purposive sampling (Bos et al., 2012; Frank et al., 2011), one recruited through a systematic random sample (Bos et al., 2013a) and the final used a geographically stratified sample generated by random digit telephone dialling (O'Cathain et al., 2011).

All of the studies utilised postal self-completion questionnaires (n=4) (Bos et al., 2013a; Bos et al., 2012; Frank et al., 2011; O'Cathain et al., 2011), with the Urgent Care System Questionnaire (UCSQ) also incorporating telephone surveys as well as the self-completion option (O'Cathain et al., 2011). The length of the PREMs described within the studies varied from 17-84 items across 3-11 domains. Domain content and names varied, as detailed in Table 5-1. Some focused on the sequential stages of the hospital episode, from attendance to discharge (Bos et al., 2013a; Bos et al., 2012), whereas others focused on specific areas of hospital care quality, such as patient participation, which included patient involvement in their care (Frank et al., 2011) and convenience (O'Cathain et al., 2011). All instruments were administered following discharge from hospital but the permitted time from discharge to completion varied between measures; from one week to three months post-discharge.

5.4.3 Instrument development

A summary of the outcome of the evaluation of the properties of each of the four PREMs is presented in Table 5-2. All measures reported some aspects of psychometric testing, with validity being tested more frequently than reliability. Content validity was the aspect of validity most commonly reported.

All of the items used in the PREMs were developed following qualitative concept elicitation interviews or focus groups with patients (Bos et al., 2013a; Frank et al., 2009; Frank et al., 2011; O'Cathain et al., 2008; O'Cathain et al., 2011). In development of the Urgent Care System Questionnaire (UCSQ), focus groups were completed with 47 people and 13 individual interviews purposively selected from GP practices in one geographic area (O'Cathain et al., 2008). This was highlighted as a limitation to the development phase of this PREM, as the study author proposed to interview over 20 participants to achieve data saturation; this target was not reached and therefore it could be argued that the questionnaire may not be representative of patient needs and experiences.

The Patient Participation in Emergency Departments (PPED) questionnaire was developed following phenomenological analysis of nine depth interviews with patients who had previously been treated in an ED in Sweden who were used to elicit concepts for the questionnaire (Frank et al., 2009). For the Consumer Quality Index Accident and Emergency (CQI-A&E), focus groups were conducted with 17 participants who had recently been treated in ED. Following the focus group, the first draft questionnaire was developed and sent to ten patients. These patients were then called one week later and asked to completed cognitive interviews by telephone and were able to inform refinements to the items included (Bos et al., 2012).

Finally, for the development of the Accident and Emergency Department Questionnaire (AEDQ) the Department of Health and Healthcare Commission were consulted, and focus group interviews with patients who had attended ED in the previous six months, for various conditions, were completed with 35 participants over 4 focus groups. The development focused on the five ‘domains’ constructed by the Department of Health that are conceptually and thematically similar within the development of all patient experience surveys in the National Patient Survey Programme (Bos et al., 2013).

It is questionable whether these constructs should be similar, as the development paper for the CQI-A&E survey (Bos et al., 2012) argues for the development of several CQ-Indices for different conditions. Bos et al. (2012) recognises that different patient groups have different priorities and stressed the need for specific questionnaires for different services. For example, CQ-Indices have been developed for a variety of condition-specific patient groups such as the rheumatoid arthritis questionnaire (Zuidgeest et al., 2009) and the hip and knee questionnaire (Stubbe et al., 2007b), as well as others for different care settings (Stubbe et al., 2007a).

Table 5-1 Data extraction results

Reference	PREM developed	Research Aim(s)	Qualitative Method	Participants, sample selection & socioeconomic (SE) factors	Main Themes
Picker Institute Europe, (2008) (Picker Institute Europe, 2008)	Accident and Emergency Department Questionnaire (AEDQ) ₁ Bos et al., (2013) (Bos et al., 2013a)	Define the sampling framework and methodology that would be usable in all NHS acute trusts using emergency care. To identify issues salient to patients attending ED. Consult with project sponsors regarding scope of survey. Test the face validity of the questionnaire using cognitive interviews.	Focus groups (n=4)	35 participants- male (n= 17), female (n=18). Recruitment by specialist research recruitment agency- purposive recruitment based on age, sex and area of residence. Participants must have attended ED within the last 6 months. A selection was made regarding socioeconomic status (based on present or most recent occupation).	**1. Waiting** Length of time to be seen. Being told how long they would be waiting. Waiting time at different stages (i.e. waiting for tests, waiting for results) **2. Staff-interpersonal aspects of care** Having confidence and trust in staff. Being treated with dignity and respect. Being able to understand explanations given by nurses and doctors. Doctors and nurses listening carefully to patients. **3. Tests and Treatment** Assessing pain and providing pain relief (particularly while still waiting to see the doctor). Condition/injury dealt with to patient’s satisfaction. Not receiving conflicting advice from staff.

					Not having to return to ED following day due to visit being ‘out of hours’ for tests/treatment. **4. Environment** Level of privacy at reception when ‘booking in’. Cleanliness of ED. Not feeling disturbed or threatened by other patients. Overall comfort of waiting areas. **5. Discharge or admission to a bed** Being given information about their condition and/or treatment. Being admitted to a bed on a ward quickly and/or not having to wait too long to be transferred to another hospital. **6. Other Issues** Reason for attending ED as opposed to other services (e.g. minor injuries unit, NHS Direct, GP etc). Car parking.
Frank et al. (2009a) (Frank et al., 2009)	Patient Participation in the Emergency Department (PPED) Frank et al. (2011) (Frank et al., 2011)	Describe patients’ different conceptions of patient participation in their care in an ED.	Interviews (n=9)	9 participants- women (n=4), men (n=5). Purposive strategic sampling based on sex, age, and patients from different sections of the ED (i.e. medical, surgical, infectious	**1. Being acknowledged** **2. Having a clear space** **3. Struggling to become involved**

				diseases, orthopaedics, and ear, nose and throat).	
O’Cathain et al. (2008)	Urgent Care System Questionnaire (UCSQ) O’Cathain et al. (2011) (O'Cathain et al., 2011)	To explore patients views and experiences of the emergency and urgent care system to inform the development of a questionnaire for routine assessment of the systems performance from the patient’s perspective.	Focus groups (n=8) and interviews (n=13)	60 participants- 8 focus groups with 47 participants and 13 individual interviews. Purposive sampling of focus groups- covering a range of demographic and geographic groups. This included parents of young children, people with no children, a group socially deprived, an affluent group, another of black and ethnic minority people, a group living in a rural area and one living in an urban area. Approached face-to-face in the	**1. Seeing the System** **2. Accessing the System** Choice or confusion? Making choices. Ease of access. **3. Communication and Coordination** Coordination between services. Informational continuity- the importance of patient records. Communication between professionals and patients. The effect of waiting- a vacuum of information. **4. Progress through the system** Need for proactive behaviour. Seeking healthcare in the context of social responsibilities.

				street and invited if they had an urgent health problem in the past 4 weeks and attempted to contact any service within the emergency and urgent care system. For individual interviews, recruitment was done through a GP practice in one primary care trust. A purposive sample was selected by a GP or other member of practice staff based on inclusion criteria provided.	
[1] Accident and Emergency (A&E) used interchangeably with Emergency Department (ED)					

Reference	**Research Aim(s)**	**Mode of Administration**	**Participants, sample selection & socioeconomic (SE) factors**	**No. of items/domains in measure**	**Domains Measured**
Bos et al., (2013) (Bos et al., 2013a) Accident and Emergency Department Questionnaire (AEDQ)[1]	To determine which method of obtaining summary scores for the A&E department questionnaire optimally combined good interpretability with robust psychometric characteristics.	Self-completion postal questionnaire.	151 hospital trusts in England. For each eligible trust, a systematic sample of patients out of a 1-month sample of A&E attendees was selected (n=850). Patients not eligible is they were <16 years old, had attended minor injuries unit or walk-in centre, had been admitted directly to Medical or Surgical Admissions Units or had planned attendance at outpatient clinic run through the emergency department. Patients not eligible is they were <16 years old, had attended minor injuries unit or	51 items; 11 domains.	1. **Arrival at Emergency Department (5 items)** 2. **Waiting (4 items)** 3. **Doctors and Nurses (7 items)** 4. **Your care and treatment (6 items)** 5. **Tests (4 items)** 6. **Pain (4 items)** 7. **Hospital environment and facilities (3 items)** 8. **Leaving the emergency department (8 items)** 9. **Overall (2 items)** 10. **About you (8 items)** 11. **Any other comments**

			walk-in centre, had been admitted directly to Medical or Surgical Admissions Units or had planned attendance at outpatient clinic run through the emergency department. *Age Range:* 54 (mean) *Gender:* 45% male, 55% female *Ethnicity:* Not discussed		
Frank et al. (2011) (Frank et al., 2011) Patient Participation in the Emergency Department (PPED)	To develop and test the psychometric properties of a patient participation questionnaire in emergency departments.	Self- completion postal questionnaire	356 participants recruited after 4 reminders (46% uptake). E.D. patients over 3 days at three hospitals in central Sweden (28-30 Nov. 2008). Eligibility not specific; over 18 years. Exclusion criteria were those accompanied by an interpreter and those registered as deceased during the E.D. visit.	17 items; 4 domains.	**1. Fight for participation (5 items)** **2. Requirement for participation (5 items)** **3. Mutual participation (4 items)** **4. Participating in getting basic needs satisfied (3 items)**

			Age Range: 19-94 (56 mean) *Gender:* 51% male, 49% female *Ethnicity:* Not discussed		
O' Cathain et al. (2011) (O'Cathain et al., 2011) Urgent Care System Questionnaire (UCSQ)	To psychometrically test the Urgent Care System Questionnaire (UCSQ) for the routine measurement of the patient perspective of the emergency and urgent care system.	Self- completion postal questionnaire and telephone survey.	Response rate to postal survey (n= 457) (51% uptake). In telephone survey- 11604 calls made to obtain quota sample of 1014. The 2 surveys identified n=250 participants who had used system within previous 3 months. Postal survey of 900 of the general population and telephone survey of 1000 members. Selected randomly by geographical stratified sample and random digit dialling. Sent directly to patients over 16 years and to parents/guardians of	21 items; 3 domains.	**1. Progress (13 items)** **2. Entry (3 items)** **3. Patient Convenience (5 items)**

			those under 16 years of age. No specific eligibility criteria apart from patients must have used emergency or urgent care system within the previous 3 months. *Age Range:* Not discussed *Gender:* Not discussed *Ethnicity:* Not discussed Conducted in UK.		
Bos et al. (2012) (Bos et al., 2012) Consumer Quality index of the accident and emergency department (CQI-A&E) 1	Development of a patient reported experience measure for accident and emergency departments- Consumer Quality index of the accident and emergency department (CQI-A&E)1	Self- completion postal questionnaire	Discussion of content development within this study as there was no previous qualitative study conducted. Content Development: Focus groups with patients (n=17) treated in the A&E department at the University Medical Centre Utrecht, aged 18 and over, with known postal address and phone number were sent invitation by	84 items; 9 domains	1. **General** 2. **Before arriving in the A&E** 3. **Reception desk A&E** 4. **Health professionals in the A&E** 5. **Pain** 6. **Examination and treatment** 7. **Leaving the A&E** 8. **General A&E** 9. **About you**

			post to participate. (n=10) also took part in cognitive interviews- no eligibility/selection criteria noted. Psychometric Validation: Large urban hospital in central location in Netherlands. All patients who attended A&E during one week in January 2010 were included (n=653). Patients who attended with known postal address and no reported death were eligible. Participants n= 304 (47% uptake) *Age Range:* 51 (mean) *Gender:* 159 male, 145 female *Ethnicity:* Not recorded		
Bos et al. (2013) (Bos et al., 2013b) Consumer Quality index of the	To test internal consistency, the validity and discriminative	Self- completion postal questionnaire	N = 4883 of participants responded (40% uptake).	78 items; 9 domains	**1. General (3 items)** **2. Before arriving in the A&E (11 items)** **3. Reception desk A&E (4 items)**

accident and emergency department (CQI-A&E) [1]	capacity of CQI-A&E [1] in a multicentre study design, to confirm and validate preliminary results from Bos et al. 2012 (Bos et al., 2012).		Announcement made in online medical national newsletter in Netherlands. 21/100 EDs in Netherlands chose to participate. In the sample, 600-800 patients per ED were selected randomly out all ED attendances in the previous 3 weeks. Patients with a known postal address and no reported death were eligible. *Age Range:* 52.8 (mean) *Gender:* 49% male, 51% female *Ethnicity:* Not discussed		**4. Health professionals in the A&E (8 items)** **5. Pain (3 items)** **6. Examination and treatment (16 items)** **7. Leaving the A&E (11 items)** **8. General A&E (11 items)** **9. About you (11 items)**

[1] Accident and Emergency (A&E) used interchangeably with Emergency Department (ED)

The key patient-reported concepts that ultimately featured in the different PREMs through item selection included waiting time (e.g. length of time to be seen), interpersonal aspects of care (e.g. having confidence/trust in staff), tests and treatment (e.g. assessing pain and treating appropriately), and the environment (e.g. cleanliness of the ED, not feeling threatened by other patients). Item identification work revealed similar concepts that were most important to patients (Frank et al., 2009; O'Cathain et al., 2008). The team that developed the CQI-A&E also conducted what was labelled an ‘importance study’ as part of the instrument development to establish relative importance of different items within the questionnaire to patients visiting ED (Bos et al., 2012).

All instruments demonstrated the use of unidimensionality to determine the homogeneity among items. Results varied with CQI-A&E and UCSQ demonstrating positive results with Cronbach’s alpha >0.7 in all domains (Bos et al., 2012; Bos et al., 2013b; O'Cathain et al., 2011). Overall, PPED had a Cronbach’s alpha of 0.75 during first test and 0.72 from second test but two of the four domains had an α of <0.70 (Frank et al., 2011). Finally, the A&E department questionnaire had 13 domains, 6 of which had an α <0.70 demonstrating reduced unidimensionality (Bos et al., 2013a).

Item selection was generally well reported, with adequate discussion of floor/ceiling effects. Only Bos et al.’s (2012) study explicitly clarified how missing items were handled, with exclusion from the study if the questionnaire was returned with over 50% missing (Bos et al., 2012). Response scales were identified as Likert scales in all bar one study (Bos et al., 2013a), where response scale was not discussed.

5.4.4 Instrument performance

The performance of the four different PREMS was largely unsatisfactory, with the quality appraisal demonstrating that limited information is available on their respective construct validity, reliability and responsiveness to change.

Convergent validity was discussed only within the AEDQ (Bos et al., 2013a) but was discussed in terms of the overlap in concepts within the same measure rather than against a separate measure. Similarly, divergent validity was only discussed for the

CQI-A&E instrument (Bos et al., 2012), where discriminative capacity between different EDs at different hospital trusts was discussed in a follow-up paper on instrument performance (Bos et al., 2013b).

Also, only PPED addressed test-retest reliability with acceptable intra-class coefficients (ICC) between 0.59 and 0.93 (Frank et al., 2011). The other three studies did not measure test-retest reliability of the instrument; however, it was recognised as a limitation to the study in the performance of the UCSQ (O'Cathain et al., 2011). Of the four measures identified, not one had its level of responsiveness assessed.

An important limitation recognised by Bos et al. (2013) during the development of the AEDQ instrument was the potential of recall bias by participants due to patient symptoms. It was questioned whether symptoms such as a loss of consciousness in the ED may affect patient recall. Although cognitive interviews were conducted before the instrument was implemented and found the survey to work well, it was only cognitively tested on 15 patients, with only one of these being reported to be ‘semi-conscious’ during his time in the ED (Picker Institute Europe, 2008). This may be important in the development of a PREM specifically for the epilepsy population, due to recall issues associated with post-ictal memory impairment (Farrell et al., 2016).

Another consideration of the AEDQ instrument is that data reduction to provide a summary score caused loss of content and therefore the scores do not represent all aspects of a patient journey throughout ED (Bos et al., 2013). From a clinical viewpoint, it may be preferable to evaluate quality of care from arrival to departure from ED, and sometimes beyond, and so using individual items rather than reducing data may be more appropriate (Bos et al., 2013).

Table 5-2 Quality assessment of PREM development

✓✓- positive rating ✓- acceptable rating X- negative rating

Instrument Development

Measure	Pre-Study Hypothesis Intended Population	Actual content area (face validity)	Item Identification	Item Selection	Unidimensionality	Choice of Response Scale
CQI A&E (Bos et al., 2012) Consumer Quality Index Accident & Emergency	✓✓	✓✓	✓✓	✓✓	✓✓	✓
AEDQ (Bos et al., 2013a) Accident and Emergency (A&E) Department Questionnaire	✓✓	✓✓	✓✓	✓✓	✓	X
PPED (Frank et al., 2011) Patient Participation in Emergency Departments	✓✓	✓✓	✓✓	✓✓	✓✓	✓✓
UCSQ (O'Cathain et al., 2011) Urgent Care System Questionnaire	✓	✓	✓	✓	✓✓	✓✓

Table 5-3 Quality assessment of PREM performance

✓✓- positive rating ✓- acceptable rating X- negative rating

Instrument Performance

Measure	Measure	Convergent Validity	Discriminant Validity	Predictive Validity	Test re-test reliability	Responsiveness
CQI A&E (Bos et al., 2012) Consumer Quality Index Accident & Emergency	X	✓	X	X	X	X
AEDQ (Bos et al., 2013a) Accident and Emergency (A&E) Department Questionnaire	✓	X	X	X	X	✓
PPED (Frank et al., 2011) Patient Participation in Emergency Departments	X	X	X	✓	X	X
UCSQ (O'Cathain et al., 2011) Urgent Care System Questionnaire	X	X	X	X	X	X

5.5 Discussion

To the best of my knowledge, this systematic review is the first to identify PREMs for use in the ED and consider their psychometric properties. Four PREMs were identified and subjected to an appraisal of their quality. All instruments had some aspects of their psychometric development reported on. Whilst the developers of each of these measures stated that they considered them to be valid and reliable, the quality appraisals completed as part of the systematic review do not fully support this. Studies examining psychometric performance of PREMs are limited, suggesting an area in which future instrument development can be improved.

5.5.1 Summary of review findings

This review provides an overview of the literature relating to the development of PREMs for use in the ED. Content validity and theoretical development has been well reported across the four identified PREMs. Themes of importance included waiting time, interpersonal aspects of care, tests and treatment, and the clinical environment. Bos et al. (2012) recognised that different patient groups may have differing priorities during episodes of care, highlighting the importance of developing specific questionnaires to account for the needs and experiences of specific patient populations.

Some instruments appear to have limited positive psychometric properties and caution should be taken when using them. This is not to say that these instruments do not have their uses, but that these need to be considered carefully when selecting an instrument. For example, we could query how some questionnaires stand up to recall bias that may be an issue for patients with loss of consciousness and therefore may have a reduced level of validity in such populations (Bos et al., 2013).

Disappointingly, for none of the PREMs studied did we find evidence on responsiveness. Responsiveness refers to the ability of an instrument to detect change over time, and is a highly relevant factor if the PREM is to be used to assess how successful an intervention has been to enact change within a clinical service (Coombes, 2008).

Pesudovs et al.’s criteria for quality assessment (Pesudovs et al., 2007) offered a rigorous and standardised critique of validity and reliability. At times it appeared difficult to fit the reported psychometric results into the quality criteria used. For example, CQI-A&E used an importance study as part of content validity which did not fall agreeably into any quality criteria category. We used consensus discussion to reach agreement on anomalies within the data extracted. It may be difficult to create an assessment criterion that would definitively encompass all aspects of instrument development, as many different methods can be adopted. However, Pesudovs et al.’s (2007) tool is a good starting point for assessing psychometric properties of PREM development.

5.5.2 Interpretation of findings in relation to previously published work

There is little current evidence of other reviews that explore the psychometric properties of PREMs in emergency care. Findings regarding the inadequate reliability and validity testing of such measures within the general population are supported by outcomes of a broader evidence review conducted by The Health Foundation (Health Foundation, 2013). It highlighted that general hospital surveys often have limited information about their validity and reliability as there is no standardised or commonly used instrument or protocol for sampling and administration (Health Foundation, 2013).

5.5.3 Implications for practice and future research

The themes identified through content validity development of the PREMs present areas of great importance for the designing, commissioning and delivery of clinical care, as described by the general ED patient.

I question in this thesis whether seizure patients will have the same requirements, needs and expectations when attending the ED as the general population. The complex nature of epilepsy, combined with the circumstances under which many patient’s experiencing seizures present to the ED following a seizure event (i.e. not clinically requiring Type 1 ED care), may plausibly alter the needs and expectations of such patients.

This therefore leaves a considerable research gap, both in knowledge relating to the epilepsy population and the development of a seizure-specific PREM for use in ED. There is need to utilise high quality qualitative research to gain a more thorough understanding of the full seizure care pathway experience for people with seizures. This will help to ascertain whether a previously developed measure would be suitable to assess and monitor the ongoing use of the pathway or whether seizure patients will have specific needs which will require the generation of an ED seizure-specific PREM. This will be addressed in this PhD through chapters six and seven.

Future research should consider drawing on the most promising existing PREMs as a starting point for the development of new measures. Existing instruments which have not been psychometrically tested are not necessarily flawed, just untested. Such instruments may give useful information but should be used with caution and improved validation will allow them to provide more credible findings for use in service improvement by health care clinicians and managers.

It may well be that a new, seizure-specific measure, would be necessary to capture the unique experiences of patients using the seizure care pathway. If a new PREM was to be developed specifically for the monitoring and assessment of the use of the seizure care pathway in the ED from a patients' viewpoint, it would be important to complete a full psychometric testing of the instrument prior to its use using an adaptation of Pesudovs et al.'s criteria for quality assessment (Pesudovs et al., 2007).

5.5.4 Strengths and limitations of the review

Application of the search strategy identified four PREMs that fitted the inclusion criteria. Given the advances and importance given to patient experience in health care and the desire to measure these experiences, we possibly would have expected to see more than the four PREMs identified in this review. The time and investment required to develop a rigorous PREM and the specificity of this population may have had influence on the number of PREMs previously developed.

As noted earlier, instrument developers were not contacted to clarify anomalies and/or queries regarding reporting quality, which could be considered a limitation of this review. It is possible that not all PREMs were identified by the searches of traditional academic database, since some PREMs might have been locally developed (for example, by hospitals or government departments) and not been formally published. The additional searching of reference lists of included studies and targeted internet searches though attempted to address this issue of identifying PREMS within the grey literature.

5.6 Summary

Current PREMs for use within emergency care settings offer promise for use within clinical practice, with some further development work completed to support the credibility of findings drawn from their results. Further development and testing of these measures will make them more robust. Looking ahead in terms of future PREM development, it would be of benefit to have a standardised sampling and administration protocol to allow easier development of PREMs specific to various areas and disease populations.

Different patient groups have differing priorities and therefore there is a need for explicit questionnaires to address and measure whether EDs are meeting these priorities. This highlights the importance of understanding the specific needs of patients presenting to the ED with seizures if we are to measure their needs appropriately.

Considering these findings, the analytic chapters that follow will explore qualitative findings from patient and staff interviews. Eliciting this information will assist in determining what matters most to patients; ascertaining whether any measures are actually measuring what seizure patients perceive to be the more pertinent issues in their care. The topics explored during content development work for pre-existing PREMs will be used as a basis for the initial qualitative interview topic guide for patient interviews, with the iterative development of further questions as the interview process progressed (chapter six). Staff interviews will also explore their views on the use of the seizure care pathway, their involvement in quality improvement and how effective they feel the pathway is in practice at supporting their management and the ongoing care of seizure patients (chapter seven). Together, the results of the above systematic review and accompanying qualitative studies provide the foundation for this PhD research and the recommendations made for future practice and evaluation of services.

Chapter Six: Results

Qualitative Study One: Patient Interviews[2]

6.1 Introduction

This chapter presents findings from the analysis of 27 face-to-face in-depth interviews with patient participants. The themes, identified with the use of thematic template analysis (King, 2012), reflect participants' experiences of an integrated seizure care pathway service; comprising collective, meaningful accounts related to their seizure event, decision to seek care, navigation, engagement, empowerment and continuity of care.

To elicit data, interviews were conducted with the use of an interview schedule (Appendix I). The schedule comprised questions explored in pre-existing, patient-reported experience measures (PREMs) - identified through the systematic review (chapter five), and emergent issues and relevant concepts derived from the literature (chapter two). Details of the methods used, and the analytic process adopted are described in the working methods chapter (chapter four).

People with established epilepsy who visit ED have a unique profile as recognised in chapter four, section 4.7.2. To help evaluate the representativeness of the current study sample, this chapter therefore also presents an overview of selected quantitative statistics from the wider Care After Presenting with Seizures (CAPS) project. To provide context for this chapter within the wider CAPS project, the research aim and questions are also re-iterated in Table 6-1.

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[2] Work presented in this chapter have previously appeared in "Leanne Male, Adam Noble, Tony Marson; Perceptions of emergency care using a seizure care pathway for patients presenting to emergency departments in the North West of England following a seizure: a qualitative study, *BMJ Open,* 2018, **8**:e021246. doi:10.1136/bmjopen-2017-021246

Table 6-1 Research aim and questions

Research Aim
To conduct a process evaluation exploring the patients' and professionals' perspectives of the seizure care pathway as a service intervention.
Research questions to be answered by qualitative study (part 1)
1. What are patients telling us about current epilepsy service provision in emergency departments (EDs) and follow-up services? 2. What are seizure patients' knowledge and experiences of the seizure care pathway; their experience of, the changes it has made to the service provided, facilitators, barriers and improvement suggestions? 3. What can we do to modify the seizure care pathway to improve care reflecting the views of patients and staff?

Prior to presentation of findings, the chapter begins by describing the sample characteristics, demographics and recruitment factors.

6.2 Sample characteristics

6.2.1 Recruitment

Between October 2015 and April 2017, the Walton Centre received 361 referrals from the CAPS project for patients who had attended the ED of Aintree Hospital, Arrowe Park Hospital or Warrington Hospital. During the recruitment window of the qualitative study 181 potential participants were invited to take part. Of these potential participants, 124 could not be contacted due to the patient not answering telephone calls or not replying to messages left by the researcher (n=90) and incorrect patient details/ incorrect telephone number having been recorded within the hospital record (n=34). A further 17 patients declined to participate. Reasons offered by patients for refusal included anxiety about their diagnosis, poor memory, and time constraints. Strategies employed to increase uptake of participants are detailed in chapter four, section 4.7.2. Despite deploying a range of evidence-based methods to maximise recruitment, a low recruitment rate was experienced.

A total of 40 (22%) participants agreed to participate. However, five patients cancelled/ failed to attend their interview and a further eight patients who had initially agreed to take part could not be subsequently contacted to make further arrangements. A total of 27 patients therefore proceeded to interview. Therefore, the final acceptance rate was 14.9%.

6.2.2 Sample demographics

Table 6-2 outlines the socio-demographic characteristics of the sample. Twenty-seven participants were interviewed face-to-face including 12 females and 15 males, with participant ages ranging from 17-78 years. All the participants who consented to be interviewed were of White British ethnicity. Most were interviewed in their own homes; two opted to be interviewed within a meeting room at the neurology hospital. Eight participants had a carer or significant other present during the interview process; four of these were first seizure patients while four were patients with established epilepsy. All participants (patients and carers) were required to complete a consent form. Interviews were all recorded using an Olympus DM-650 digital recording device. Participants were happy that interviews would be paused should there be any interruptions from anybody who had not consented to take part in the interview. Only one interview was interrupted by a telephone call and this was dealt with appropriately – allowing the participant to have some privacy to answer the call before recommencing the interview.

Some of the participants had established epilepsy. Others were on the pathway because they had attended ED having experienced a suspected seizure. Via the pathway some of these participants had received a clinical diagnosis of epilepsy, others had either received an alternate diagnosis for the event that led to their ED attendance or were still undergoing treatment and were yet to receive a diagnosis. Participants are categorised using the diagnosis they received from specialist neurology services, as recorded within the neurology records (i.e., known epilepsy, unprovoked first epileptic seizure, and unprovoked non-epileptic seizure).

Table 6-2 Participant demographic characteristics

	Known Epilepsy (n=12)	Unprovoked First Epileptic Seizure (n= 9)	Unprovoked Non-Epileptic Seizure (n=6)
Age (years)			
Mean	50	37	32
Range	24-78	17-64	19-45
Gender			
Male	6 (46.2%)	5 (62.5%)	4 (66.7%)
Female	7 (53.8%)	3 (37.5%)	2 (33.3%)
Employment			
Full time work	3 (23.1%)	1 (12.5%)	2 (33.3%)
Part time work	2 (15.4%)	1 (12.5%)	0 (0%)
Not employed	8 (61.5%)	5 (62.5%)	3 (50%)
Education	0 (0%)	1 (12.5%)	1 (16.7%)
IMD Regional Decile			
1-3 (most deprived)	9 (69.2%)	4 (50%)	3 (50%)
4-6	2 (15.4%)	3 (37.5%)	2 (33.3%)
7-10 (least deprived)	2 (15.4%)	1 (12.5%)	1 (16.7%)

6.2.3 Sample representativeness

The sample of participants that took part in the qualitative evaluation of the CAPS project was broadly representative of the overall population that were referred to the pathway during the qualitative recruitment period from March 2016 - May 2017 (see Table 6-3 and Figures 6-1, 6-2 and 6-3). Specifically, of the patients that were referred onto the pathway, 52.4% were male versus 55.6% that took part in the qualitative interviews. Importantly, a comparison of the characteristics of the population that was referred to the CAPs pathway to data from the second round National Audit for Seizure Management in Hospitals (NASH) shows they were comparable to the population that attends ED for seizures, where 57% of patients were found to be male and the mean age was 45 years (Dixon et al., 2015). It is noteworthy though that the mean age of participants from Arrowe Park Hospital was lower than average (35.5 years) and the level of deprivation of participants interviewed in the Warrington area appears to be higher than would have been expected.

Table 6-3 Qualitative participant demographics compared to CAPS population

	Participants – N (%)		**Male – N (%)**		**Age (mean)**		**Deprivation**	
							Mean IMD rank (SD)	
Trust	CAPS	Interview	CAPS	Interview	CAPS	Interview	CAPS	Interview
All	361 (100%)	27 (7.5%)	189 (52.4%)	15 (55.6%)	44.3	42.1	10123 (9466)	9530 (9407)
Aintree	173 (47.9%)	15 (55.6%)	89 (51.4%)	9 (60%)	46.2	43.9	7115 (8147)	6625 (8420)
Arrowe Park	102 (28.3%)	8 (29.6%)	55 (53.9%)	4 (50%)	42.4	35.5	11910 (9510)	15157 (10818)
Warrington	86 (23.8%)	4 (14.8%)	45 (52.3%)	2 (50%)	42.8	48.3	14018 (9999)	9170 (6011)

Figure 6-1 Gender demographics of CAPS participants v. interview participants

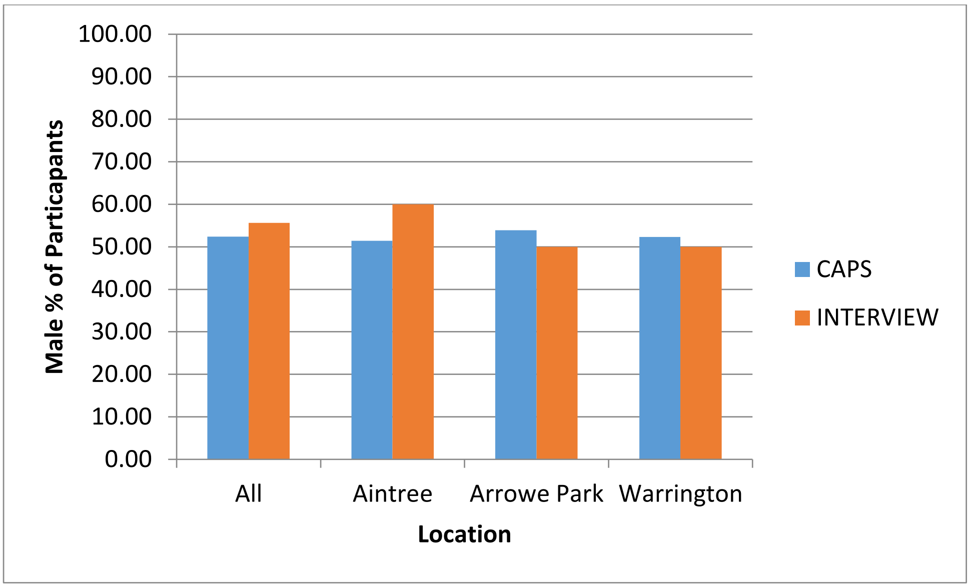


Figure 6-2 Age of CAPS participants v. interview participants

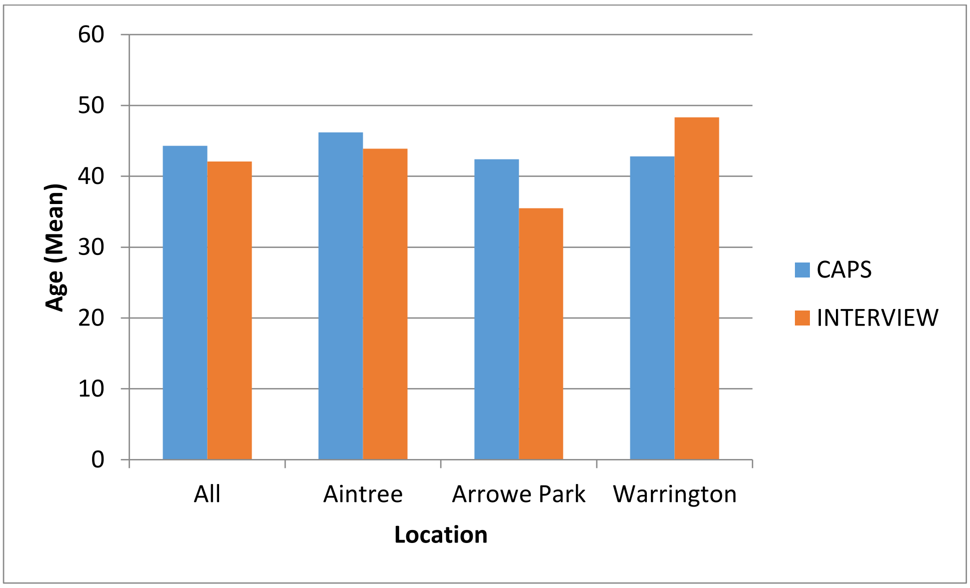
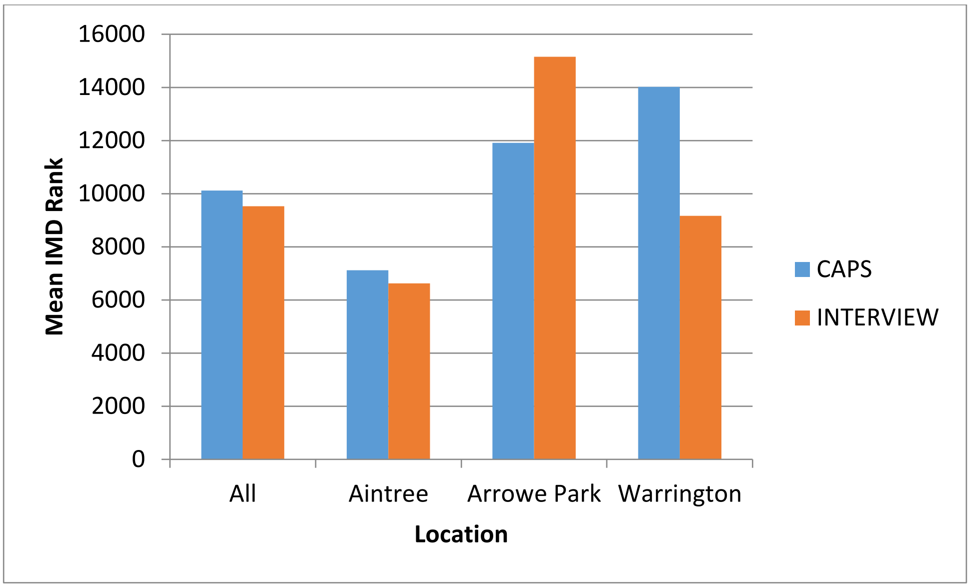


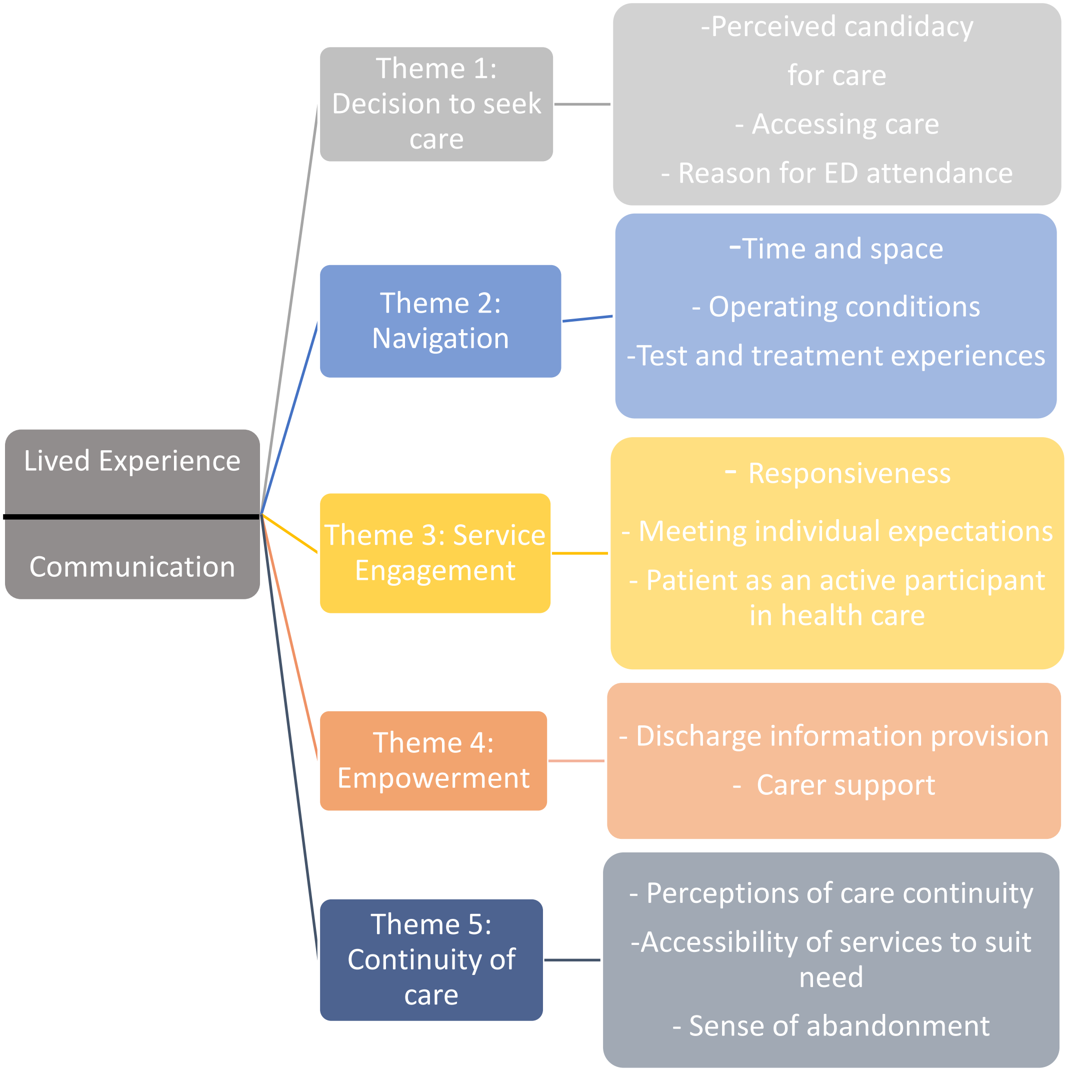
Figure 6-3 Deprivation demographics of CAPS participants v. interview participants



6.3 Results

Following analysis of patient interviews five main themes and 14 sub-themes, reflecting participant's experiences of the seizure care pathway, were identified (Figure 6-1). In addition, two overarching themes were generated through data analysis; lived experience and communication. These two overarching themes will be considered and exampled in relation to discussion around each of the main and connecting sub-themes as they permeated discourse whatever the foreground. The concepts of lived experience and communication, as perceived by participants, proved important throughout the analytic process as they enabled contextualisation of data and a holistic approach to data analysis.

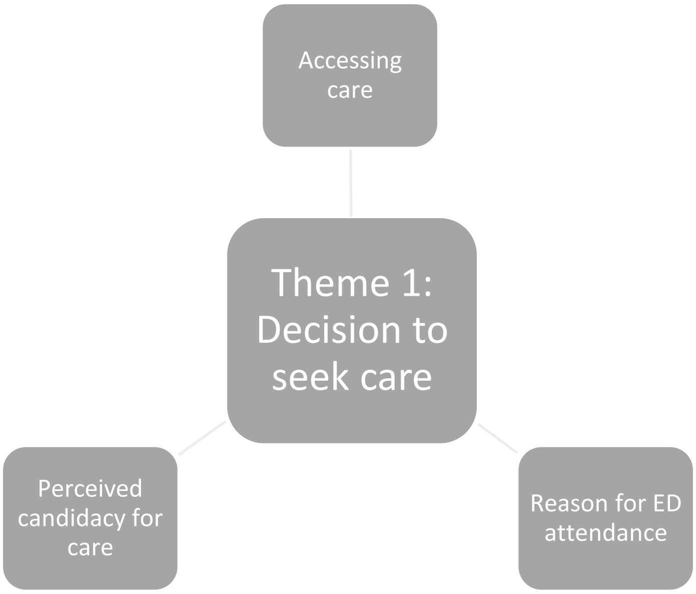
Figure 6-4 Main themes for patient participant interviews



6.4 Decision to seek care

Decision to seek care was the first main theme arising from discussion of the pathway. This theme centred on participants' accounts of the initial decision to seek medical care at the ED during their seizure episode. Three sub-themes were developed, underpinned by aspects of the decision-making process identified by the participants; (i) their perceived candidacy for care, (ii) their experience of accessing care, and (iii) participants' identification of possible causes of their seizure (Figure 6-2). These sub-themes are explored in detail below.

Figure 6-5 Theme 1: Decision to seek care



6.4.1 Perceived candidacy for care

Participants predominantly began their interview by providing justification for their need to attend the ED; their perceived candidacy for care (Dixon-Woods et al., 2006). Participants experiencing first seizures were less likely to give reason to a possible cause for their seizure episode, often because they did not know why, or in some cases, what had happened. One participant, a male who had experienced a diagnosis of non-epileptic seizure, described their episode as a collapse rather than a seizure, but did explain a possible cause for the event.

> *"I was on a train. I was at a friend's house overnight and I was stuffy and clammy and hadn't slept much the night and I collapsed due to the heat conditions."* (P17, Unprovoked Non-Epileptic Seizure, M, 19)

While participants experiencing their first seizure referred more commonly to their symptoms of memory loss, injury and seizure signs as perceived reasons for needing emergency care, participants with known epilepsy were more likely to identify potential causes for their seizure event which led to their ED attendance.

Participants with known epilepsy described episodes of stress, missed medications and tiredness as likely causes of their seizure episode, particularly where their seizures were normally well controlled.

> *"I was just absolutely exhausted and I didn't get to the chemist to get my repeat prescription so I had two days without any medication."* (P35, known epilepsy, F, 38)

> *"people are looking at me like I'm a lunatic and of course that causes stress and then stress will kick off another seizure."* (P05, known epilepsy, F, 43)

6.4.2 Accessing care

Many participants utilised the ambulance service in response to their seizure event. However due to their seizure or post-ictal state, often this decision was taken out of their hands. Decisions to call emergency services were frequently made and actioned by an observer such as a relative, a carer, or a bystander if the seizure had occurred in a public place.

> *"I was in work and I just woke up in the ambulance. The lady was working for [bus company] rang one [ambulance] so then I just woke up in that."* (P21, Unprovoked First Epileptic Seizure, F, 24)

Once the ambulance had been called, most participants, including those with established epilepsy, felt they had little choice in the decision for them to attend the ED. They believed their inability to influence this outcome was a consequence of their post-ictal state and as such, paramedics had made this decision on their behalf.

> *"I went in the early hours of the morning... ambulance took me in, obviously I went straight in... I wasn't really aware of what was going on because of what had happened to me…. when I woke up the paramedics were at the bottom of my bed and I said to them 'what are you doing here?''* (P08, Unprovoked First Epileptic Seizure, F, 64)

> *"I don't think there was much choice to be honest…it was the ambulance staff that made that decision."* (P17, Unprovoked Non-Epileptic Seizure, M, 19)

While decision-making around accessing care because of a seizure event was often in the hands of 'others', this did not mitigate how patient's felt about the decisions made of their behalf. For example, accounts of lived experience within this study tell us that despite there sometimes being a clinical reason for ED attendance, some patients with known epilepsy expressed feelings of guilt about attending the ED following a seizure. One male participant with known epilepsy, conveyed to the ED by paramedics following a seizure spoke of his personal sense of guilt. Having become more lucid and less post-ictal, he believed he did not require full ED services and treatment; an opinion informed by his perceived sense of burden toward paramedic staff. He explained:

> "*there was the guilt trip I suppose on the last one because I had, this was adding to the anxiety because I was stuck on a trolley with paramedics looking after me and I'm thinking they could be out saving someone else's life. So that added to the pressure if that makes sense. Erm and that's why I said look you can't wait any longer and so I signed a self-discharge form because I felt guilty*." (P32, known epilepsy, M, 41)

As participants, particularly with known epilepsy, have lived with their condition for many years, they described their ability to manage their condition without the need for additional health care services. This changed their perception of candidacy, even in situations where initially it was felt (by others) that they needed to access the health care system. Unfortunately, due to the nature of epilepsy, the decision to access care is not one that can often be made by the person experiencing the seizure. This makes it difficult for patients to express their views about how they would like to be treated.

6.4.3 Reason for ED attendance

Reasons for calling an ambulance predominantly centred on either a need to moderate a sense of fear in self or others, to seek assistance with what was considered to be '*an unusual seizure event*' or to obtain treatment for an injury resulting from a seizure.

> *"he was blue, he was rigid and he doesn't remember…there was a pool of blood around his head and I couldn't find out where it was coming from because at first I couldn't see he's damaged his head really…I phoned 999."* (P12, Unprovoked First Epileptic Seizure, M, 63, Carer)

Participant accounts of lived experience highlight how fear of the unknown, particularly in relatives, results in perceived need for emergency medical care, in both those with known epilepsy and those experiencing their first seizure.

> *"my husband gets the ambulance because he panics…but then it's safer isn't it with a seizure anyway."* (P01, known epilepsy, F, 78)

> *"my wife found me having a seizure in bed, didn't know what it was at all…my wife didn't know what was going on because it was the very first seizure I've had."* (P03, Unprovoked First Epileptic Seizure, M, 37)

Participants with known epilepsy were more likely to cite they attended the ED in response to an unusual seizure or as the result of an injury following a seizure.

> ''*I was having so many within a short space of time it was getting scary."* (P39, known epilepsy, F, 37)

> "*the second time when he had a second seizure I rang an ambulance as well because he banged his head and I was worried."* (P03, Unprovoked First Epileptic Seizure, Carer)

> *"So that's the only reason, the only, if I have a fit normally I don't bother going to A&E [accident and emergency] if I bite my tongue or whatever. But if I've injured myself like dislocated my shoulder or broken rib or something like than I go to hospital with it. So that's the only reason... I fell against the kitchen unit... or I should of said I landed and I broke my rib on the kitchen unit and couldn't breathe. So that's why I ended up back in there [ED]."* (P39, known epilepsy, F, 37)

Where reasons for attending the ED were discussed, lived experience of attendance, and in some instances, reluctance to attend, were also frequently communicated by participants. For example, one participant, who had experienced a first seizure, was particularly anxious about going to hospital because of a recent admission for another medical problem they had previously experienced and the perceived impact of this. Although not explicitly describing a negative experience of the ED, the event of being conveyed to hospital following a seizure was perceived negatively. This perception was informed by the participant's lived experience of the constancy and frequency of recent hospital admissions:

> *"I'd not long got out of hospital. I'd just been discharged I think two days earlier…I was a little bit apprehensive going back into hospital because I'd just come out and you know… nothing to do with the hospital itself… just the fact that I'm constantly in there."* (P02, Unprovoked First Epileptic Seizure, F, 40)

Despite initially identifying a perceived candidacy for care due to clinical reasons, there appears to be a tension between clinical need for ED and reluctance to attend; predominantly with patients with known epilepsy. This manifests as a perceived *'sense of burden'*.

In summary, participants perceive a seizure event, particularly a first seizure or an unusual seizure to be a medical emergency, for which they view themselves as requiring health care services, i.e. the ED. Their worry and fears resulting from the event contribute to this perceived candidacy for care.

6.5 Navigation

Navigation of services explores the concept that patients must be aware of the services available to them and how they can access such care (Dixon-Woods et al., 2006). Within this theme three sub-themes were generated through analysis of the dataset; test and treatment experience, time and space, and operating conditions.

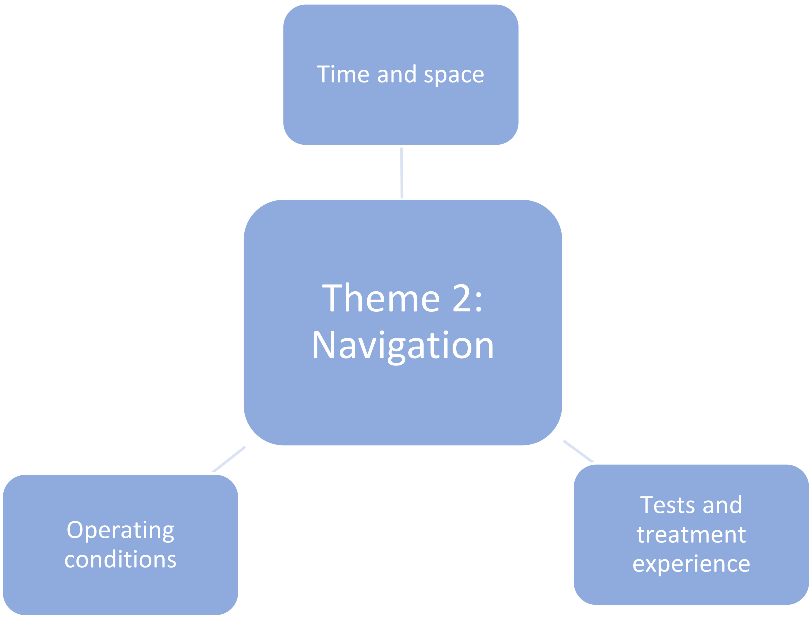
Interview data suggests that once patients access the emergency care service, the main focus is on tests and treatment they experience in their care process. Navigating the ED, including accessing areas of different tests and treatment, as well as the communication around this process is a predominant feature of most interviews.

Timeliness is one of the six important dimension of health care recognised by the Institute of Medicine (IOM) (Institute of Medicine, 2001). It is perhaps unsurprising therefore that time and waiting was viewed by most participants as factors influencing their health care experience. Regardless of whether the participant perceived their treatment as being fast or slow, time was continually referred to in participant accounts, highlighting its importance in relation to how participants experience health care processes. Perceived waiting times in relation to access to care is a collective theme throughout the interviews, with a longer wait-time frequently accompanied by negative impressions of overall experience.

Some participants gave mention to the resources and facilities available within the health care setting and how these affect ED waiting times and perceived efficiency of the service, demonstrating insight into potential reasons for delays in the ED. Participants then use these observations to provide some level of justification for why they may be made to wait for care i.e. other sicker patients, lack of staff, and time of ED attendance.

Operating conditions, as outlined in Dixon-Woods candidacy framework, explores the local influences such as resources and finance that can impact on health care experiences (Dixon-Woods et al., 2006). Operating conditions within the National Health Service (NHS), particularly of direct access services such as the ED, are under ongoing and significant scrutiny. With the prevalence of its discussions within the media, political field and the general public, it is unsurprising that many participants discussed such issues within their interviews (Blunt et al., 2015). Within each of these sub-themes, we describe and explore how the pathway as an intervention is perceived by participants.

Figure 6-6 Theme 2: Navigation



6.5.1 Tests and treatment experience

Tests and treatment became one of the main sub-themes of the interview discussions, with most participants providing descriptive accounts of the tests and treatment they had received, particularly within the ED. These experiences included not only a narrative explanation of the physical tests/treatment received throughout the care pathway but also how these were communicated by health care professionals (HCPs). However, the descriptions of these experiences were often somewhat vague. Many participants did not remember a great deal about the event or time spent in the ED; often recalling information they had been told by relatives' post-ictally. One participant had no recollection of events from the time of being conveyed to the ED until she was admitted to a ward.

> *"the only thing I can say really is that I can't actually remember it [being in ED]…I can't even remember getting into the ambulance and out of the ambulance…honest I can't even remember going into that A&E"* (P18, known epilepsy, F, 38)

Paramedics were often the first health care professional participants saw following their seizure. While the current seizure care pathway does not incorporate care provided by paramedic teams, participants often discussed their treatment experience of being conveyed to the ED; these accounts have therefore been included in the analysis. Where participants themselves could not remember the event, carers frequently reported their experience of paramedic care. Most commonly, participants perceived this aspect of their clinical care to be positive.

> "*a gentleman and a lady come in from the ambulance service and they were really really good…they calmed him [the patient]"* (P12, known epilepsy, Carer)

> "*they [ambulance staff] were really nice…I was dead confused and they said I'd had a seizure because I was like obviously I didn't know that… I've never had one before. But they were nice."* (P21, Unprovoked First Epileptic Seizure, F, 24)

> "*the paramedics were spot on….you could just tell they knew what they were doing I felt safe with them you know what I mean…made me feel like that I was in safe hands."* (P07, Unprovoked First Epileptic Seizure, M, 29)

Although the response from the ambulance service was seen positively by most participants, one carer of a participant with known epilepsy expressed concerns about the limited information ambulance staff have on patients. In this instance, the participant who had the seizure had little to no recollection of the event and after trying to start the interview on her own, had to ask for the support of her partner in order to be able to answer the interview questions. He said:

> "*She's not with it…..I can give her full medical history but they won't take that anyway because of the fact that I'm not…*
> *Respondent: they want to hear it from me"* (P06, known epilepsy, F, 26 and Carer)

Once in the ED, participants referred to various tests and treatments they received during their attendance/admission. Blood pressure monitoring and electrocardiogram (ECG) recording are tests that participants recalled most frequently during interview. It may be that other tests are not remembered so prominently or not recognised by participants and this is why they are not discussed, rather than the fact they did not take place. Other injury-specific tests and treatments occurred, which appeared to be more memorable to some participants. One participant who had experienced a head injury as a result of his seizure reported a negative experience of treatment.

> "*they [doctors] said you can go home… I still had blood everywhere and I think it was one of the girls, one of my daughters she said aren't you going to sort that out and they went oh yes so they cleared me up and sent me home.*" (P12, known epilepsy, M, 63)

Participants with known epilepsy appeared to be more aware of the tests and treatments they received and gave the impression of being more knowledgeable about the system and what should be done when making comparisons with what happened during previous experiences. Although not using the terms 'expert patient' directly, those with known epilepsy reported how their previous experiences and knowledge influenced their perceptions of the service. Participants recalled experiences where they perceived treatment to be lacking.

> "*one of the women [staff] forgot to put a line [cannula] in me, so she took about 2 hours before they realised there was no line [cannula] put in.*" (P06, known epilepsy, F, 26)

> "*it was a bit weird getting discharged because it was like they didn't know she'd been discharged as well. So she had a drip in her hand and we were just sitting there…who's taking this out exactly.*" (P06, known epilepsy, Carer)

Although many participants did not discuss details of specific tests received in the outpatient department (OPD), treatment was discussed in terms of communication with the neurologist and time spent explaining and answering questions; these interactions were reported generally as positive aspects of care and prompted a positive feeling in participants.

> *"his whole manner put you at ease… you know you can be a little scared sort of over-awed sometimes can't you with doctors and…depending on the way they speak and the way they handle things but it was so… relaxed the atmosphere so it was easy you know…and it makes you feel better because you tell them more."* (P01, known epilepsy, F, 78)

> *"[doctor] he's brilliant on the meds [medication] side of things because he knows everything back to front….he'll say give me time and I'll have a think and he'll give you like two or three different options."* (P06, known epilepsy, Carer)

> *"I came out well after the appointment [OPD] I felt reassured...I didn't come out wondering and questioning things if you know what I mean, I was satisfied when I came out."* (P21, Unprovoked First Epileptic Seizure, F, 24)

Miscommunication and resulting conflicting information regarding diagnosis and treatment was discussed by one participant who felt as though he was misinformed by the emergency care clinician about his diagnosis. After being told little information in the ED, the participant was subsequently told during his OPD appointment about some thickening and hardening of the arteries in the brain, known as cerebral arteriosclerosis, of which he had no previous knowledge.

> *"I didn't know nothing about the hardening of the arteries…we didn't know about this they never told us anything did they?"* (P12, known epilepsy, M, 63)

The participant reported the level of communication in the ED to be *"highly unprofessional"* and was *"unsatisfied"* but claimed that the neurologist at the OPD appointment *"gave me reassurance".*

> *"he was a really nice gentleman [neurologist]…he was pretty good…told me I couldn't drive so I wasn't happy about that... no the one in Walton was pretty good but were better than [ED hospital]…he explained more…he sort of gave me reassurance."* (P12, known epilepsy, M, 63)

There was a sense, that during their test and treatment experience at follow-up, participants prioritised the need for HCP's to ensure their feelings were being listened to over actual tests and treatment they received. This contrasted with the acute emergency, where focus lay primarily on the test and treatment experience.

6.5.2 Time and space

Many participants reported delays in access to services, starting on arrival at the ED, which impacted on the perceived permeability of the service (Dixon-Woods et al., 2006). Permeability refers to the ease of access to care. For example, highly permeable services require less work and fewer resources from patient's who access them – for example, EDs in the UK which have 24/7 access (Hunter et al., 2013).

Participants’ experience of waiting times in the ED varied at different points of access within their journey through the department. Reference was repeatedly made to (i) “*waiting for triage”*, (ii) “*waiting for tests*”, (iii) “*waiting to see a doctor*”, and (iv) “*waiting for follow-up”*. Each of these identified reference points highlight a potential obstacle to the provision of prompt health care access and service provision. Participants who perceived their wait time as “*quick”,* particularly in comparison to previous experience, reported positive feedback of the process.

> *“there was no question of she’s going to wait or whatever; come right through and I say I saw that doctor…they were absolutely brilliant I couldn’t fault them at all.”* (P08, Unprovoked First Epileptic Seizure, F, 64)

Conversely, where participants perceived waiting times to be “*long*”, there was an association with the reporting of a poor experience of care. This was reflected by increased distress and anxiety experienced by participants as a result of the wait.

> “*if you're waiting on one of them beds to see a doctor…it does make you feel a bit on edge…people just get upset sitting out there.”* (P29, known epilepsy, M, 59)

Upon arriving at the ED, before being seen by a clinician, participants described (i) being taken straight into the resuscitation area (ii) having to wait in a corridor, (iii) seeing the receptionist, or (iv)waiting in the main waiting room area, as environments of care. Where participants were conveyed via ambulance, they reported being more likely to be taken through to the resuscitation facilities or made to wait with ambulance staff on the corridor if the ED was particularly “*busy*”, a physical attribute of the department frequently described by participants. Where they were taken immediately through to the resuscitation area, participants generally reported their experience positively.

> “*I’ve never found any problems really…especially with the seizures because I’ve been taken in by ambulance so I’m seen pretty well straight away.”*
> (P01, known epilepsy, F, 78)

> *“I got taken straight through…and I think obviously I got my bloods took and everything… I think within half an hour that I was in A&E…within 45 minutes I’d seen a doctor…I think to be honest with you I think I was only in there about 3 hours and then I, I got discharged because I was seen that quick.”*
> (P02, unprovoked first epileptic seizure, F, 40)

Most participants reported their experience positively when being taken straight into the resuscitation department. However, one patient's relative expressed concerns and frustration about this aspect of their experience; they had not been able to accompany their relative into the resuscitation department and had to wait in a separate room. This situation was different to previous experiences and provoked concerns for the relative. The participant's dependence on their partner to relay information in this situation was evident.

> *"I'd rather have been in with him…with him not being able to remember anything I'd rather be with him as he gets taken in that room [resus] you know as soon as I've give my name at the front [reception] go in with him so if they ask questions he doesn't give the wrong answer, which he would do."* (P29, known epilepsy, Carer)

This level of reliance on family members became apparent in several interviews with participants with known epilepsy. Accounts of perceived responsibility were not only recognised by participant's relative/carer but directly by the participant themselves:

> "*do you know what might be better I might get my partner because half of it I can't remember because of the seizures…when your seizing you just can't remember everything."* (P06, known epilepsy, F, 26)
>
> *"for most of her care stuff I can do off the back of my hand like, we sat in the ambulance and I can list off everything that's wrong with her."* (P06, known epilepsy, Carer)

A commonly reported feature was lack of bed space within the department, resulting in participants being left on trollies in the ED corridor for significant periods of time. Thirteen of the twenty-seven participants (48%) recounted the experience of waiting on a trolley in a corridor as their initial experience of the ED.

> "*they were so backed up that we came in via ambulance and you know the way they have all the trolleys down the corridor backed up, they were that bad that the paramedics had to stay with me for 3 hours in a corridor."* (P05, known epilepsy, F, 43)
>
> *"I'm sat in the corridor on a trolley for 4 and a half hours. Just in a gown…there was loads it was just like a queue of trollies with people on it was like 4 and a half/5 hours just sat, lying around waiting."* (P26, Unprovoked First Epileptic Seizure, M, 38)

Further interviews revealed participants' observations about the environment (often described as "*busy*" and "*noisy*") which influenced their wait and contributed to the heightened fear and anxiety explored earlier. Drawing from their own retrospective observations, some participants made suggestions about how the space in the ED could be made more conducive to supporting those following a seizure. These suggestions included the use of side rooms, dimmed lighting, and a quieter area to enable patients to recover from their seizure in a calm and timely manner. One participant, who had been particularly distressed by the lack of facilities she perceived to be "*appropriate"* following a seizure, spoke at length about this:

> *"…they realised then they had to put me in a dark room to take my bloods and everything and then they said we'll try and put you somewhere quiet… they moved me up to the next waiting area… again there was the television on, flashing lights and we said you know you can't do that. If you put me in a dark room where it is nice and quiet my seizures will stop and calm down but they won't listen*." (P05, known epilepsy, F, 43)

As an overarching theme, several participants suggested that if communication about waiting times and the route through the facility was clearer, they would have been happier with the situation. Often, however, participants reported being left to wait without being informed of potential wait times. As described below, participants felt neglected when left in such circumstances.

> "*I've been at A&E in different hospitals where I've been sat there for 3 hours before you know anybody even says hello to me…I appreciate that they've got to sort of triage and then put them in order of priority haven't they but even just to give you some sort of idea of wait times … I think everybody sort of prepares themselves mentally they're in for a long wait and all that but I think there could be a lot done to alleviate that so people don't get stressed out about it."* (P23, Unprovoked Non-epileptic Seizure, M, 30)

Lack of communication around waiting times was not only associated with waiting for an initial clinical assessment but was reported by participants throughout their journey through the pathway and the ED. One participant highlighted the importance of communication in alleviating the experience of patient worry. She recognised that her previous experience of the health service, might have made her more observant regarding '*things going on'*, but acknowledged some interesting points around waiting and communication:

> *"So I think communication's a key for patient who don't, are a bit nervous or about being there [ED] and things like that and waiting times I think they just need to tell people and explain why they're waiting…what they're waiting for…what's coming up next…They kind of should explain what's going to be happening next… so when the nurse comes up to you and they say you know, I think they should say you'll probably go for an x-ray it could take this amount of time but it could be longer… I went for an x-ray; didn't know why I was going for an x-ray…I didn't actually know why I was having the chest x-ray in the first place. So things like that like that will upset people. It would worry people if they weren't aware of their surroundings, it would upset people."* (P15, Unprovoked Non-epileptic Seizure, F, 25)

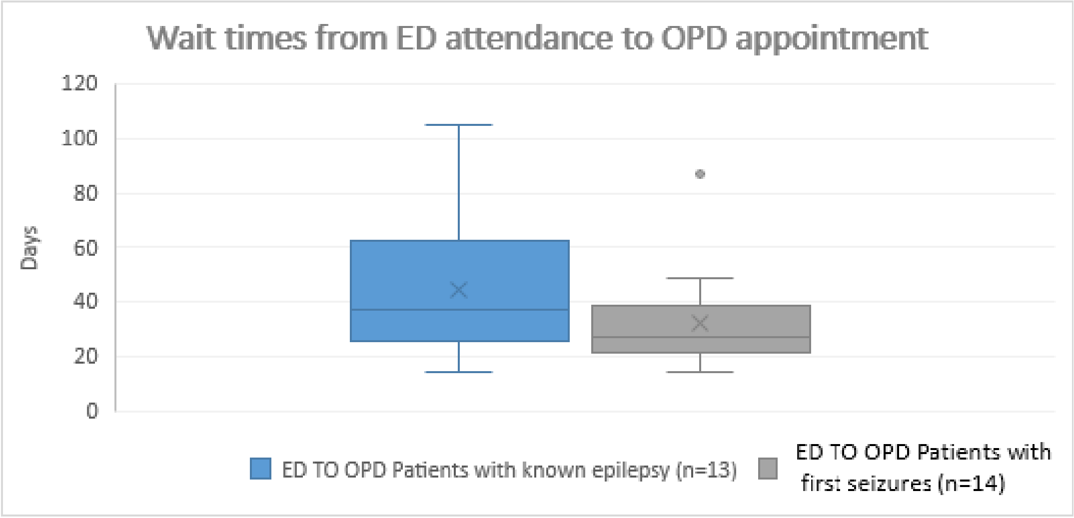
"*Waiting to see a doctor"* was also discussed by participants. While some participants were positive about their waiting time and recalled being seen quickly throughout the process, a few reported that they were unhappy with their wait experience, specifically regarding wait to see a clinician, describing the experience as *"frustrating"*.

> *"obviously it took a while doctors I mean there was loads of doctors walking around and sat down on the computer…it got me frustrated."* (P36, Unprovoked First Epileptic Seizure, F, 23)

> "*I would have been, liked to have been informed of how long…I didn't want my Dad hanging round there for nothing…I'm not saying it was annoying because I know they're busy but just frustrating when you're waiting round that long and you just want to get away and get home."* (P26, Unprovoked First Epileptic Seizure, M, 38)

Finally, *"waiting for follow-up"* was spoken about by most participants. Participants within this study waited on average 38 days (SD 23), ranging from 14-105 days, from ED attendance to OPD appointment (Figure 6-4). Participants with known epilepsy were on average seen slower (44 days) than those experiencing a first seizure (32 days).

Figure 6-7 Wait times from ED attendance to OPD appointment



Qualitative findings indicate participants' perceived wait to follow-up were variable. The majority reported satisfaction with their follow-up wait time, while others spoke of the negative experience of this. The variability of these views is captured below.

> *"absolutely fine…it was a couple of days for the letter and I got the appointment about a week later."* (P25, Unprovoked First Epileptic Seizure, M, 51)

> *"they [ED staff] told us that he'd been referred and it would be in about 2 weeks... I think it was nearly 3."* (P16, known epilepsy, Carer)

Although the above are reasonably positive perceptions of waiting times, one participant explained that the uncertainty of what was going to happen after leaving the ED and how long they were going to have to wait to be seen caused her worry, especially when the process did not run smoothly in terms of communication of appointments.

> *"It was frustrating not knowing what was going on and then the fact that I had to chase it up the appointment. If I hadn't of chased it up 3 times I'd have never got to see the neurologist."* (P14, Unprovoked Non-epileptic Seizure, F, 45)

A further three participants reported having to also chase up appointments after not receiving any communication from neurology OPD, despite being told in the ED what the follow-up process would entail.

> *"they [ED staff] said you'll go to outpatients, you'll get a letter through… the actual letter didn't come through so we rang, I rang up and they said a letter*

> *should of gone through but if it hasn't arrived this is your appointment. So they gave me the appointment over the phone and it arrive within a couple of days…but it was literally like a day or two before my appointment…so if I hadn't have rang up then I think if you had plans you might have missed it."* (P15, Unprovoked Non-epileptic Seizure, F, 25)

> *"well they [ED staff] said that they were going to send a referral to the neurologist and then I need to wait for a letter from them to confirm they've received it. They said it would only take about a week to get receiving it and it had been like 9 days and I hadn't heard anything so I gave the neurology, I gave them a call and they said they haven't received anything yet… so they reported me back to A&E so I rang A&E and they said they had sent it but they hadn't processed or whatever or God knows and they said they'd send it again."* (P23, Unprovoked Non-epileptic Seizure, M, 30)

> "*what had happened is erm A&E had done you know on the first seizure had done a referral to neuro and then somehow it had got lost in the system. So we had to go to our GP [general practitioner] and say we've not heard anything… so she [GP] done a referral to neuro and so then we got 2 appointments within the space of a week."* (P05, known epilepsy, F, 43)

As an improvement suggestion, one participant proposed that alternative methods of contact could be used to improve the issue with communication to better suit the needs of the population. In this suggestion he included the use of up-to-date technology, moving away from simple letters, to texting and emailing appointments and updates.

> *"I mean for my lifestyle and all that its, sometimes I don't pick up post for quite some time so it could be difficult to you know book appointments and things like that and you know understand that I've actually received these letters and what not. So if they could do something on an email or a text message or something like that to sort of maybe give you a heads up that you know we've erm or like if they've received my referral so I don't have to chase it up so you know just keeps you in the loop really that you know everything's getting taken care of rather than me having to actively go and chase things and what not."* (P23, Unprovoked Non-epileptic Seizure, M, 30)

Once they had received their appointment and attended the OPD, most participants reported being accepting of their waiting time in the department. One anomaly was noted from a participant who found waiting in the OPD to be a negative experience.

> *"rubbish, awful, we turned up on time. The waiting room was empty and we still had a 45-minute wait before we got called in…as we arrived there was another guy shouting and screaming at the receptionist because they hadn't been seen and they'd waited so long and he walked off in a huff... so we sat*

> *down and thought oh God it's empty… you know you kind of expect to wait 10 minutes, half an hour over your appointment time but it's like 45 minutes and we still hadn't been seen and there was nobody else in there. So I wasn't impressed with that."* (P05, known epilepsy, 43)

In summary, participants revealed feelings of worry and distress in relation to lack of communication around waiting times within the ED. As an important factor in this research, participants suggest ways in which communication could be improved to improve the delivery of the seizure care pathway and the service as a whole.

6.5.3 Operating conditions

Participants often conveyed a perceived understanding or reasoning as to why certain processes did not occur in line with their expectations. In relation to causes for waiting times, reasons articulated by participants can be differentiated as acceptable and non-acceptable (Mathews et al., 2015). Acceptable waiting is that which is described as justifiable and as such, is agreeable to participants. Use of the triage system and the need to prioritise care of "*other, sicker patients*", was recognised by participants as justifiable reason for delay in their own treatment. This sentiment is demonstrated in the below comments:

> "*there was a lot more people coming in with worse things than me so yes it was just quite frantic and rushed and lucky to see people when I did I suppose."* (P17, Unprovoked Non-epileptic Seizure, M, 19)

> "*waiting a long time can be a little bit frustrating but you know I could go in and I've just had a fit and there could be people in front of me like oh been in a car accident, so I do understand that you know priority and I mean sometimes you'll read up you know that you know you wait long and all the rest."* (P08, Unprovoked First Epileptic Seizure, F, 64)

Lack of staff and resources in the ED were highlighted as a potential cause of increased waiting times and influence on the operating conditions of the ED. This was recognised by many participants and articulated as being a 'normal' situation and one which they must accept as part of current NHS service provision.

> "*they [staff] were run off their feet like they were everywhere…I get that they're stretched and rushed off their feet."* (P33, known epilepsy, M, 44)

> *"it could have been, it should have been so much quicker, much quicker and more time with a doctor, but it depends on how many staff are on and how under pressure the staff are."* (P12, known epilepsy, Carer)

> *"I mean it's not A&E's fault because they are so backlogged and short staffed…"* (P05, known epilepsy, F, 43)

> *"you know I know they're busy because my [family members] both work in a hospital so I know erm I had a bit of feedback off them as to they're rushed off their feet."* (P08, Unprovoked First Epileptic Seizure, F, 64)

In tandem with staffing and resource constraints, participants identified 'time of day' in relation to ED attendance as a causal factor for increased wait. Participants' reflections on their experience enabled them to recognise that certain times of the day and certain days of the week were particularly busy. These times, for example, included evenings, with reference to Friday and Saturday nights. Here participants recognised that EDs are regularly frequented by intoxicated individuals or by those who have injuries caused by alcohol and/or drug use. Participants frequently expressed negative viewpoints about the use of EDs in relation to alcohol and drug use. The view that attendance under such circumstances was a misuse of the service and therefore a non-acceptable cause of waiting.

> *"I think they were just happy to have a call out on a Friday night that wasn't a drunk in town basically."* (P06, known epilepsy, F, 26)

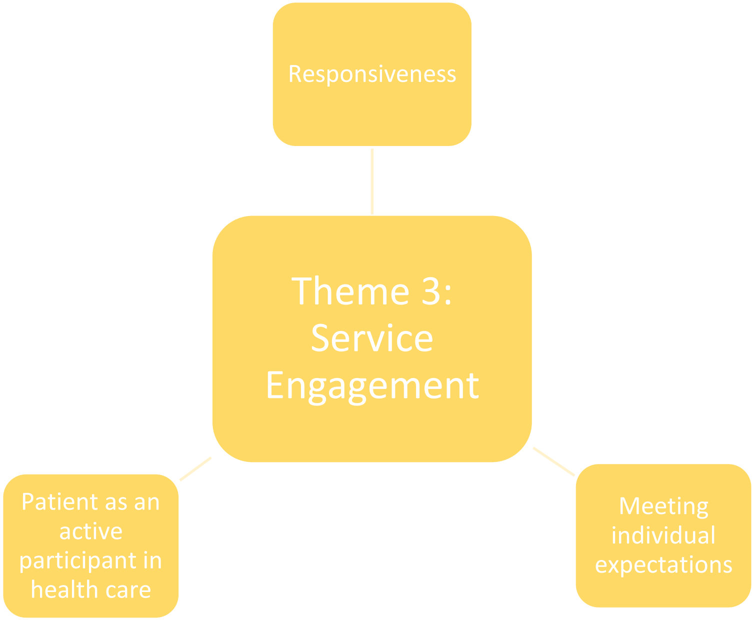
> *"if it was 10 o'clock on a Saturday night it would be totally different wouldn't it…"* (P08, Unprovoked First Epileptic Seizure, F, 64)

> *"if you go on a Friday night and it's an adult and you're going to A&E you are going to wait longer or early hours in the morning sometimes because there has been a lot of drunks brought in or fighting through drink or drug misuse and stuff like that really…and sometimes when they're in with that and you've got someone coming in…it's a bit annoying when you're waiting."* (P01, known epilepsy, Carer)

6.6 Service Engagement

Once access to the health service has been achieved, response, particularly by HCPs, to the attendance became one of the major themes discussed by participants. Participant descriptions in relation to tests and treatments received in the ED, symptom control and pain management were common features throughout each interview. This theme includes discussion of individuals' expectations, including service performance and how well clinical need is met. Participants' perceptions of the responsiveness of the service and the role played by HCPs in recognising the patient as an individual and an active participant in their own health care and supporting patient decision-making is also explored (Figure 6-5).

Figure 6-8 Theme 3: Service Engagement



6.6.1 Meeting individual expectations

NICE epilepsy guidelines state that first seizure patients should be reviewed by a neurologist within two weeks of their initial presentation following a seizure episode (National Institute for Health and Care Excellence, 2016b). Within our study only 7% (n=2) of participants were seen within this time frame:

> *"they said it would be [referral] about two weeks but I think it was about three or four"* (P22, Unprovoked Non-Epileptic Seizure, M, 28)

Unfortunately, miscommunication of information led participants, in some cases, to feel dissatisfied with the service they received:

> *"we we're told by A&E somebody will be in touch with you in the next 48 hours well that doesn't happen it doesn't happen at all."* (P05, known epilepsy, F, 43)

> *"it was just frustrating not knowing what was going on and the fact I had to chase it up the appointment…I even went to the doctors and the doctors left it up to me to chase them up and that is definitely wrong"* (P14, Unprovoked Non-Epileptic Seizure, F, 45)

Lived experience can influence individuals' expectations. Some participants, particularly those with known epilepsy, appeared to be calm about the event of going to ED, citing *"it is what it is"* (P06, known epilepsy, F, 26) and generally explaining their ability to manage the situation in a calm manner. Conversely, one participant who experienced non-epileptic attack disorder (NEAD) discussed the negative influence the experience had on her life; explaining that nobody, including HCPs, understood what it was really like to live with such a condition:

> *"yes because half of them [staff] have most probably not even heard of it [NEAD] anyway. Or they've heard the basics oh it's not it's in their head do you know what I mean so that's how you get treated oh it's in your head."* (P14, Unprovoked Non-Epileptic Seizure, F, 45)

> *"you don't realise you just become a burden I think to everyone and you don't get invited anywhere anymore…it's like everything has come to a complete standstill and it's a shock when you think you've got so many friends."* (P14, Unprovoked Non-Epileptic Seizure, F, 45)

6.6.2 Responsiveness

Participants discussed the interactions they had with HCPs at different time points in their care pathway, with a predominant focus on communication. Participants referred to the time that HCPs spent engaging with them and responding to their needs, referring to this contact time on three key levels; (i) time spent with HCPs, (ii) visibility of staff members, and (iii) communication. Many participants reported being satisfied with these levels of interaction and the subsequent positive affect they had on perceptions of care. As one participant noted:

> *"the doctor spent a bit of time with me and explained to me what had happened so I knew myself 'cause I couldn't really remember nothing, all I can remember was waking up and the paramedics were there you know what I mean…so getting that [explanation] 'cause that was important to me knowing what happened."* (P07, Unprovoked First Epileptic Seizure, M, 29)

In contrast, others spoke of negative experiences related to the perceived limited time spent specifically with HCPs. Participants reported that waiting for a doctor to arrive often induced fear and uncertainty; triggering worrying thoughts about what might be wrong and what might happen next. These negative feelings were articulated mainly by those participants who had experienced a first seizure, for whom the event and ED environment was largely unfamiliar. Overall, participants commonly held the view that doctors and nurses were "*in a rush*", describing them as "*run off their feet"* (P33, known epilepsy, M, 44). Such observations and experiences bore a sense of "*urgency*" for participants and a perceived inadequacy in the communication and support offered by HCPs. This distress is articulated below by one participant.

> *"I don't know how long the doctor was with me or the nurse but it didn't seem very long at all… yes I would have liked to have known more and the amount of time I spend in there, it seemed a very little time I spent with the doctor or the nurse."* (P12, known epilepsy, M, 63)

One participant with known epilepsy was more relaxed about the visibility of HCPs, not least because they expressed being more *"in control*" of the situation. This participant reported a more positive experience of visibility of HCPs. They felt happy with the amount of time spent in consultation with doctors and nurses; even if this time was minimal and contact related mainly to routine basic observations.

> *"we were pretty much left to our own devices really, they checked that she was ok and then off they went. They weren't really regular check-ups because its more just waiting for her to come back round and be lucid and waiting for a doctor to turn up."* (P06, known epilepsy, Carer)

An anomaly to this finding within our study was a participant who had attended the ED on several occasions in the previous year and reported ongoing issues with the delivery of care within the ED. On this occasion she stressed concerns about staffing levels in the ED which led to fears for safety and a sense of heightened insecurity about the level of care received. These fears occasioned a negative perception of the care pathway and general experience within the ED:

> *"there was no medical staff available because they were so busy… I felt in danger because nobody knew what they were doing…. I mean it's not*

> *necessarily A&E's fault because they are so backlogged and short staffed"* (P05, known epilepsy, F, 43)

Participant perceptions of responsiveness in the OPD were very different in comparison to the ED. OPD was perceived as being a more relaxed environment; the availability of more time, as a resource for delivering care was frequently acknowledged. Participants described feeling more satisfied with their outpatient care, reporting better communication with staff, having questions answered, and generally feeling happier about the care they received. Such positive interactions with health care services had positive impact on the participants' health and overall wellbeing. Offers of reassurance, being taken seriously and taking an interest in the participant were all characteristics of the health care experience that resulted in positive perceptions of care. As can be seen below, these feelings were analogous both for participants with known epilepsy and those visiting the OPD for the first time following their first seizure event.

> "*I came out well after the appointment [outpatients] I felt reassured and I wasn't I didn't come out wondering and question things if you know what I mean…I was satisfied when I came out."* (P21, Unprovoked First Epileptic Seizure, F, 24)

> "*the follow-up is good isn't it…his [doctor] whole manner put you at ease…there was no, you know you can be a little scared sort of over-awed sometimes can't you with doctors…depending on the way they speak and the way they handle things but it was so…relaxed the atmosphere to it was easy you know… and it makes you feel better because you tell them more."* (P01, known epilepsy, F, 78)

Two participants who initially reported being unhappy with their wait time from the ED to OPD appointment, were subsequently pleased with the follow-up service offered once seen in the OPD and with the time afforded them by HCPs.

> *"it was fine and once I got there, there was a woman straight away as soon as I walked in through the outpatient door, explaining how to self-check in and she was lovely and then yes it was dead dead easy from then… he [consultant] checked me over, he did a more of a thorough check on me erm and he explained that everything that he'd done was fine. He'd had no worries and he said he was just going to send me for a scan more so to be on the safe side than anything erm and he was dead dead nice and he explained everything dead clearly to me he was fine."* (P15, Unprovoked Non-epileptic Seizure, F, 25)

> *"they were dead quick in there as well like I mean I was bit it was probably about 30 minutes after my appointment time when I actually got seen which is you know sometimes it happens doesn't it…but like the fella there he was yes he was nice the neurologist, he sort of went into detail with me you know asking me about what happened and they also phoned one of my colleagues when I was there with him so he could get her point of view of you know what happened as well just to make sure it all tally's up."* (P23, Unprovoked Non-epileptic Seizure, M, 30)

Following a distressing seizure presentation in the ED where the participant was unhappy with the level of care received, these narratives demonstrate the potential to enhance perceptions of quality care through good interpersonal communication skills and development of a trusting patient-professional relationship.

A variance to these findings was reported by one participant who perceived a negative experience of both the ED and follow-up process, particularly regarding communication and time spent with HCPs:

> *"when we got in there [OPD appointment] we told her everything that was going on and we felt like we were being dismissed because the change in seizures she said it wasn't standard you know it wasn't normal and that's how it doesn't usually happen that way… he didn't even believe I'd had a seizure it was all in my mind. I had anxiety and the next time I had a seizure my husband should video it, so we walked out of there fuming."* (P05, known epilepsy, F, 43)

In summary, experience of HCPs who demonstrate *"time"* for care helped participants to feel as though they were valued, and their experiences were listened to. In turn, this gave rise to a more positively perceived care experience. More commonly in the ED, where participants perceived "time" to be limited, potentially due to the acuity and busyness of the department, participants felt care was less responsive in nature. Consequently, participant worries were not alleviated. Overall, where encounters with HCPs promoted rapport through communication and develop a non-judgemental, patient-professional relationship, demonstrably reassured participants and improved their confidence in HCP's.

6.6.3 Patient as an active participant in health care

Self-management in epilepsy is important in giving patients autonomy to manage their own condition (Snape et al., 2017). As an example, within our study, one participant with known epilepsy and her partner were particularly confident in their ability to cope with seizures and felt confident to use resources that they had established over years to prevent the need, on the majority of occasions, to attend ED.

> “*that sort of works because of the fact that for her condition it’s easier to manage everything ourselves so we know what’s going on….we’ve got all the numbers, we know who to phone, we know what to do next. Anyone suspected epilepsy where someone’s not used the Walton Centre on a regular basis they might not know that they need to follow it up.”* (P06, known epilepsy, Carer)

Active participation and self-management may be necessary to support the patient when the care system has otherwise failed. Within this study, participants reported actively seeking follow-up care for themselves when they perceived the health care system had failed them. This was evident in several participant interviews. One participant, who had experienced non-epileptic attack disorder, had ongoing experience of actively chasing up follow-up appointments following ED attendance. Lost notes, missing records and confusion with another patient (with similar demographic details) led to long delays in her follow-up care:

> “*it was literally the loss of paperwork that was frustrating that’s what like I say started from A&E because if I hadn’t of mithered how long would it of took before I would have got seen you know because it took weeks as it was and then I was most probably at the bottom of the list again.”* (P14, Unprovoked Non-Epileptic Seizure, F, 45)

Not only was communication to follow-up an issue between ED and the Walton Centre, it was also problematic following up to the GP. One participant reported communication to be a major barrier to effective follow-up, including referral back to the GP and other specialists.

> “*it’s just I would say its communication between departments that’s the issue, because that just drags on for ages…by the time we get to the Walton Centre everything’s quick but it will take the GP two or three weeks to actually follow it up.”* (P06, known epilepsy, F, 26)

While some participants wanted to be actively involved in their health care, others reported a more passive approach to their care, with heavier reliance on the system (i.e. clinicians) to manage their condition on their behalf.

> *"he [ED clinician] was going to get in touch with Walton Centre concerning what has happened and why hasn't certain things been done in the last year or so, last couple of years because I haven't been there for a few years that's the problem."* (P34, known epilepsy, M, 62)

> *"you're waiting weeks or months to see someone…you can't pick up a phone and get advice off anybody, you have to book in to speak to the nurse who I'm not being funny but she's not a part you know she's not a neurologist. She can give advice but you shouldn't have to wait weeks to speak to her."* (P05, known epilepsy, F, 43)

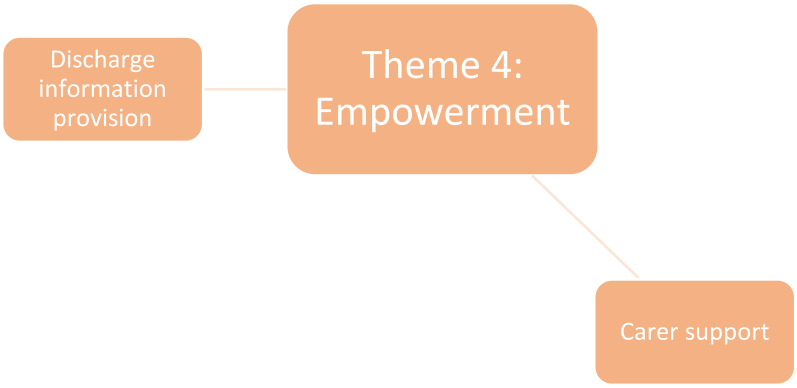
6.7 Empowerment

The theme of empowerment came through strongly during participant interviews. Provision of tailored, individualised discharge information has potential to empower patients to make decisions about their ongoing care (Merriman, 2008). Similarly, empowering carers, friends and family to support patients, particularly during their post-ictal state, is also important for patient advocacy (Etemadifar et al., 2018). The potential importance of information and support is demonstrated in the following two sub-themes (Figure 6-6) and these are discussed further below.

6.7.1 Discharge information provision

All patients discharged home from the ED should be provided with instructions for the ongoing management of their condition (Taylor and Cameron, 2000). In line with this, the seizure care pathway contains a tear off patient information leaflet that all patients should receive on discharge from the ED. This details ongoing management and safety advice, including driving advice, seizure triggers and first aid (see Appendix A).

Figure 6-9 Theme 4: Empowerment



However, when asked about discharge information received from the ED, participant responses and experiences varied extensively. Some participants reported receiving little advice on discharge in relation to ongoing care or about what would happen next in their follow-up journey:

> *"no...I don't think they did give any advice."* (P28, Unprovoked First Epileptic Seizure, M, 17)

> *"no no they [ED] didn't say anything until I actually went. Like I say I waited 13 weeks to get into the Walton Centre but I went to see the neurologist first….they said it's going to take up to 2 weeks well let's just see what happens within 2 weeks and then nothing happened."* (P26, Unprovoked First Epileptic Seizure, M, 38)

Another participant spoke of having no recollection of having received any discharge information but argued for the need of having it and its potential benefit:

> *"I think it would have been handy a bit more information about yes because I don't personally know I mean….i don't know from that visit how to deal with….if it was you know it's a seizure so you know a fit or anything what do we do…I wouldn't have a clue….i think some advice maybe just a leaflet or something saying as you said a bit of advice and how to deal with it better."* (P28, Unprovoked First Epileptic Seizure, Carer)

Several participants were unsure as to whether they received any advice leaflets on discharge, often attributed to their post-ictal state. Post-ictal memory loss, a common symptom following an epileptic seizure (Farrell et al., 2016), was discussed throughout numerous participant interviews. Such post-ictal episodes meant it was often difficult to establish accurately what had happened during the ED episode. Many participants had little to no recollection of the events that had occurred; specific detail in relation to the information they may have been given was especially lacking. Although some participants remembered being told they would be seen in the OPD, they were often hesitant, when asked about the verbal and/or written advice they received on discharge.

> *"...I think they did from what I can remember I think they did."* (P21, Unprovoked First Epileptic Seizure, F, 24)
>
> *"oh yes that's right they right they give you a leaflet but they never actually told us anything did they….just like a leaflet and there you go sort of thing….I mean I wasn't bothered on the day because I was still dead fuzzy you know."* (P12, known epilepsy, M, 63)

Only one participant appeared to be quite clear on his memory of the advice given on discharge, which he found to be extensive and very helpful to himself and his partner.

> *"it was first aid, there was quite a lot of paperwork that they give us that we went through, it was explaining everything really of like first aid sort of stuff right the way through to just information sheets about all that, all the different stuff of what to do of who to contact if there's a problem and sort of like research sheets and stuff like that so they could help us which did help."* (P03, Unprovoked First Epileptic Seizure, M, 37)

One participant reported being told to return to the ED should any further seizures occur but was given no further advice on seizure management.

> *"all's we were told if she has another one bring her straight back to A&E"* (P08, Unprovoked First Epileptic Seizure, Carer)

6.7.2 Carer Support

A second sub-theme to emerge, discussed both by PWE and those experiencing first seizures, was that of support offered to their partners or family members during the crisis. Commonly, those experiencing the seizure were in a post-ictal state during the initial ED episode and so the impact of the experience had greater effect on the family member attending the ED with the patient.

> *"as I say my wife was upset erm because of the shock because she didn't know it was a seizure so she thought I might have been having a brain haemorrhage or anything. She was you know the shock sort of hit her and as I say there was a specialist nurse…. and you know she was really sort of motherly towards my wife and you know she gave my wife a big hug sort of thing and helped it was really it was really nice."* (P03, Unprovoked First Epileptic Seizure, M, 37)

The support offered through communication and provision of information in the case of this participant had a positive impact on his and his family's experience of the ED and follow-up. However, another participant's wife reported dissatisfaction with the way they were treated on attendance at the ED. During previous ED attendances she had been able to remain with the participant to advocate on his behalf during his post-ictal state. On this occasion, she was asked to remain in the family room. She believed her absence may have had a negative impact on the care her husband received:

> *"I'd rather have been in with him…so if they ask him questions he doesn't give the wrong answer which he would do."* (P29, known epilepsy, Carer)

6.8 Continuity of care

This theme reveals the importance of care continuity to a patient's journey through the seizure care pathway, in particular the transition across services as provided by different health care providers; that from ED to the Walton Centre neurology OPD and back into the community. The sub-themes identified within the concept of continuity of care are underpinned by various identified features of significance including accessibility to services, barriers and facilitators, and the suitability and responsiveness of services in relation to patient need. Individual perceptions and understanding of what should transpire post-discharge in comparison to what occurred is an important determination in assessing potential differences between participant expectations and reality. Furthermore, the sub-theme of abandonment is one of integral importance within this study; it promotes awareness in relation to current service provision and is enlightening in providing a framework for improvement within the service (Figure 6-10).

6.8.1 Perceptions of care continuity

According to the seizure care pathway proforma, the patients' attending doctor within the ED is responsible for informing the patient of the subsequent stages in their care process. This should be a timely referral for a neurology outpatient appointment. When asked about their understanding of this process, most participants acknowledged being told about the follow-up procedure, highlighting a positive example of communication within the ED. In the few cases where participants were not told about the pathway, or when their waiting time for follow-up was delayed, this led to concern and anxiety, particularly among first seizure participants.

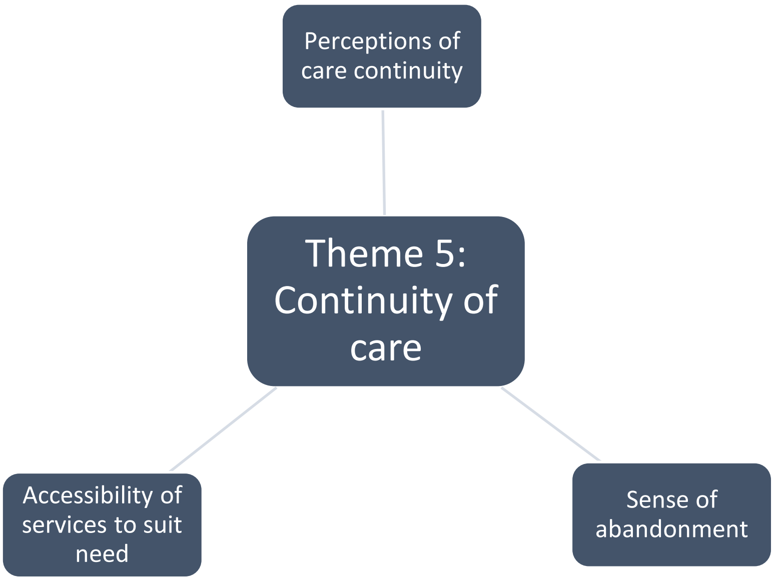
Conversely, those with known epilepsy expressed lower levels of anxiety in response to lack of advisement around follow-up procedures. Such participants frequently demonstrated their knowledge of the health service system, often proactively accessing services they have previously used to obtain the follow-up care they wanted or perceived that they required (Department of Health, 2001). This finding highlights that participants with known epilepsy within the current study, when provided with appropriate means, can proactively seek care to address their needs.

> *"it's like we have our own pathway that just sort of made ourselves… but that sort of works because of the fact that for her condition it's easier to manage everything ourselves so we know what's going on."* (P06, known epilepsy, F, 26)

Epilepsy specialist nurses (ESN) were only mentioned by participants with known epilepsy. Their role was spoken about positively; being described as "*absolutely brilliant"* and "*very helpful"* (P6, known epilepsy, F, 26).

Participants who were new to the service did not demonstrate any knowledge or understanding of the ESN role or related service provision.

Figure 6-10 Theme 5: Continuity of care



6.8.2 Accessibility of services to suit need

Participants experienced numerous barriers when transitioning from emergency care to follow-up ambulatory services. Important barriers were predominantly organisational whereby participants frequently recounted experience of difficulty in negotiating the appointment system, delays in receiving referral appointments, difficulty in accessing hospital/ clinic locations and related transport problems.

Some participants noted that travelling to appointments was difficult. A combination of ill-health, inability to drive due to seizures, cost of taxis, and poor public transport connections, were noted as barriers to accessing services. This led to patients being reliant on family members to support them to get to their appointments; increasing a sense of burden and dependence in patients who were otherwise independent.

When attendance was required for more than one follow-up appointment (e.g. where scans and further tests were required), participants felt this compounded the level of inconvenience they experienced. Questioning the current process around follow-up care provision, participants suggested ways by which the level of inconvenience they experienced might be reduced. These suggestions included;

combined appointments to reduce the number of visits, and/or appointments conducted in a local district general hospital (DGH) appropriate to patients' location, thereby reducing the resources required for access.

> *"I've missed a couple of appointments at [tertiary clinic] just because it's tricky to get there. Because if I can't get anyone to give me a lift and look after the children it's hard for me to get there... it would be easier if they could come to my local doctors and do a clinic there."* (P35, known epilepsy, F, 38)
>
> *"I had to go back to [tertiary hospital] every day… and obviously from here it's like an hour and it was all that petrol so my [relative] had to take the week off work and take me back there every day before 9am which was tiring."* (P36, Unprovoked First Epileptic Seizure, F, 23)

6.8.3 Sense of abandonment

Participants' reporting of follow-up care after ED attendance varied significantly, demonstrating that not all patients who had access to the pathway at ED necessarily receive the same benefits of the intervention post-ED discharge. Frequently, and irrespective of the level of information provided at ED discharge, this lack of continuity left patients feeling "*abandoned*". This situation occurred predominantly at two time points; immediately after discharge from ED and following outpatient review at neurology clinic.

After discharge from ED, participants reported expecting to receive a follow-up appointment letter from the Walton Centre. In some instances, participants spoke of experiencing significant delays in receiving this appointment, or not receiving an appointment. These experiences led participants to feel anxious, expressed as not knowing where to turn for further support. In addition, participants reported being faced with feelings of uncertainty about what to do and how long to wait before seeking further help.

> *"it was just frustrating not knowing what was going on and then the fact I had to chase it up the appointment. If I hadn't chased it up three times I'd have never got the see the neurologist… I even went to the doctors [GP] and they [GP] left it up to me to chase them up and that is definitely wrong."* (P14, Unprovoked Non-Epileptic Seizure, F, 45)

The above quote reflects the actions of other participants within the study. Those having problems with hospital follow-up appointments often reported accessing their general practitioner (GP) for assistance. This scenario however was seen to create further frustration with several participants often feeling disappointed with GP care. Not least because it was felt the GP could not deliver the level of support needed by the participant and that clinical decisions were often referred to neurology services.

> "*its my GP more than anything but again there is only so much they can do 'cause sometimes they just say oh we are going to have to ring Walton we are going to have to talk to them and if it's late afternoon I'm going to have to wait until the next day to find out what's going on"* (P36, Unprovoked First Epileptic Seizure, F, 23)

Conversely, some participants reported feeling well supported by their GP regarding their seizures. Although it was noted that GPs were often reluctant to make decisions regarding anti-epileptic drugs, the support and advice offered by GPs, through liaison with neurology services, had helped some participants feel aided to manage their condition without having to access emergency care.

> "*she's [GP] been brilliant, she's been amazing, really, really good… I can't complain and you know if there was a problem I could just speak to the GP or I could ring someone at [Walton Centre] that's not a problem. I know there's always somebody available if you've got concerns."* (P35, known epilepsy, F, 38)

The second juncture participants recounted a sense of abandonment was following their follow-up outpatient appointments. This most frequently occurred in participants who had experienced a first seizure, or where a formal epilepsy diagnosis had not yet been confirmed. These patients were typically discharged back to their GP after any necessary tests. When seizures continued, participants were uncertain about what to do; often not seeing the GP as adequately trained to deal with such situations. This sense of abandonment was underpinned by beliefs that the service could not meet the needs of individuals. This led to frustration in relation to care, increasing anxiety and feelings of low mood within participants.

> *"I did take the letter in that the neurologist sent to me but all she [GP] kept doing was reading through it and typing what that letter says onto there's. She wasn't doing her own, I don't know, her own idea of what it could be or something I think she was just copying what the neurologist said because she didn't have… in my eyes she didn't have a clue in that doctors."* (P26, Unprovoked First Epileptic Seizure, M, 38)

Participant accounts reflected the need for GPs to be better trained to deal with epilepsy and seizures. Participants believed this would enable GPs to provide appropriate interim support while patients waited for outpatient appointments, or during times between outpatient appointments and following discharge from neurology. In one case - a participant diagnosed with non-epileptic attack disorder (NEAD) - lack of knowledge and understanding of the specific condition by the GP was felt to have hindered further follow-up care in the primary care setting resulting in a significant negative impact on her quality of life.

> *"I don't think she [GP] really knows what it is to be honest with you or how it affects you…it's such a new thing NEAD that they don't know what it is. Like I said I've never heard of it…if you had a seizure you had epilepsy basically that's what people think isn't it… I think there needs a lot more training in it because the way it seems, because they say it's in your head and you get people saying well if it's in your head you can get rid of it.''* (P14, Unprovoked Non-Epileptic Seizure, F, 45)

This sense of abandonment and not knowing where to turn in time of 'crisis', on occasion, resulted in participants reporting overuse of the ED. Returning to the ED following each seizure, although recognised as not clinically necessary, was seen by some participants as a way back into the system. As one participant explained:

> *"'I mean a lot of the time obviously again they email [tertiary hospital], they email your GP to say you've been there [A&E] you know and the doctor will look at that and just go right what's going on here why has she gone to A&E again and that's when they probably bring the appointment forward but yeah it makes you more inclined definitely to go to A&E… just to get seen and not have to wait weeks on end, months on end just for an appointment that's going to take 10 minutes… at least then even if you tell them what's going on at least they know what they're doing."* (P36, Unprovoked First Epileptic Seizure, F, 23)

In summary, evidence from the current study suggests GPs have a pivotal role to play in the coordination of responsive services for PWE. Those with positive experiences of their GP discussed how symptoms and concerns were taken seriously, with GPs advocating for their patients' and organising timely care and ongoing referrals. Where participants were unhappy with the role their GP played in the co-ordination of ongoing care, this dissatisfaction was compounded by a sense of having no other place to turn to receive help. These feelings manifest themselves in a perceived sense of abandonment by the service.

The development of relational continuity of care with GPs, ESNs and neurologists may be a way forward to improve quality and experience for patients. Where participants knew their GP, ESN and neurologist and their HCPs knew them on a more personal level, there appears to be a more positive overall experience reported. Continuity of care at both a professional and organisational level must be improved to enhance and progress the service offered to PWE.

6.9 Discussion

As illustrated by the systematic review presented in chapter five, previous research exploring patient-reported experience measures (PREMs) have neglected the specific disease population of epilepsy and seizures. Analysis of data elicited from patient participant interviews serves to address the current knowledge gap in literature around health care of seizure patients through their ED and follow-up journey, along a seizure care pathway.

My research addresses this gap by utilising a qualitative approach to provide insight into the health care experiences of participants with seizures as they seek emergency and follow-up care in the NHS, during a time of rapid service change and uncertainty in funding and support provision (Robertson et al., 2017).

6.9.1 Summary of findings from people with seizures and their carers

The data presented in this chapter reflects the five main themes of patient experiences of health care services for seizures supported by the seizure care pathway:

- Decision to seek care
- Navigation
- Service engagement
- Empowerment
- Continuity of care

Concern was reported, by the majority participants, about optimum seizure care in the 'crisis' phase and its (successful) outcome, rather than the ongoing care. The acute presentation of a seizure resulted in fear and anxiety in many participants, particularly those experiencing their first seizure episode. Participants reported the need for reassurance from HCPs, the need to be valued as a patient and the need to be listened to. Provision of information and effective communication was an integral finding. Whether this was in the form of discharge information, detail in relation to waiting times, or the provision of patient support, it was perceived to be of utmost importance to many participants. Some participants reported reservations about the inconsistent and conflicting advice they had received from different members of their health care team. It is understandable that in the emergency, advice may be fluid, changing as the patient situation evolves and more information is obtained, and may also be dependent on the expertise of the HCP. We know though, that patients will understandably put a lot of weight, in time of the health crisis, on every word that the HCP says, and this is something HCPs should be conscious of. Within this participant group, such feelings of uncertainties led to participants feeling concerned about their own general lack of knowledge about what was going on, resulting in a sense of lack of control and a fear of the unknown.

The way in which participants experienced the seizure care pathway varied significantly, with some perceiving positive experiences while others regarded aspects of their care as sub-optimal. Where participants felt their progression through the service was slow and uncertain, they often sought out information and advice for themselves to proactively advance their progress through the system. Progress through the system was, however, problematic at times, with participant accounts conveying experience of a lack of discharge information, and a lack of guidance and support in the transition between the ED and outpatient neurology service. These findings may help HCPs to better understand the challenges faced by those experiencing seizures. This knowledge and understanding can subsequently be used to inform strategies for service change.

An integral and pertinent finding to emerge from the interview data is that of seizure patient 'recall'. Many participants expressed difficulty in recalling the events they encountered in the ED setting, giving vague answers and often relying on family members who had been present, to recount details of the event on their behalf. This circumstance requires due consideration as it is central to decisions made for the permanency of the development of a PREM as initially proposed in the research design and will be discussed further below.

6.9.2 Comparison with the literature

In this section I discuss the encouraging experiences of care as perceived by participants, highlighting both positive and negative aspects of the currently in use seizure care pathway. This discussion will also consider how these finding relate to and expand upon existing research evidence and practice policy.

6.9.2.1 Decision-making

How a patient understands their seizures, including the unusual manifestation of a seizure event, is likely to underpin their decision-making about attending the ED. Social cognitive theory assumes a mutual causation between self-efficacy and outcome expectancies (Bandura, 1989). Self-efficacy affects health status by directly influencing the adoption of healthy habits and coping skills. Consequently, if the patient perceives themselves to be in a situation, they are unable to self-manage, then this may lead them to believe they require hospital care.

Seizure patients recalled insightful accounts around the role of family members in their journey of chronic disease and how they influence decision-making and attitudes regarding attending the ED. Findings in this study indicate family members often make decisions on behalf of epilepsy patients, particularly regarding ED attendance following a seizure, whether deemed clinically appropriate or not. There are few previous studies which focus specifically on the impact and influence the condition has on family members, however literature does note that family members often bear much of the caregiving responsibility and are heavily relied upon by PWE, often with detrimental consequences to their own well-being and quality of life (Bautista et al., 2014; Etemadifar et al., 2018; Saada et al., 2015). It is important to recognise the role that family have when caring for those with chronic conditions.

Participants in our study recalled family member anxiety and fear as a reason for calling an ambulance. This resonates with work by Anderson (Anderson and Barton, 1990) and more recently Saburi (Saburi et al., 2006), who noted fear of seizures to be a common feature in caregivers to people with epilepsy (PWE), as well as those living with the condition themselves. Booker et al. (2014) noted that anxiety and feeling out of control were reasons that often influenced decisions of family members to call an ambulance. Booker et al.'s (2014) observations concur with the interviews in this study in which some participants noted how family members or members of the public dealing with the 'crisis' made a decision to call an ambulance based on a feeling of helplessness and wanting to avoid a situation of feeling guilty that they hadn't done enough or made the right decision.

We must also consider that some participants may have felt their ED attendance somewhat unnecessary. Although initial perception, by family/carers and paramedic staff, is that a patient needs to attend ED following a seizure, some patients may feel guilty about this decision, particularly if there is a perceived sense of burden towards paramedic staff and emergency care services. A similar position was reflected by respondents in a study conducted by Peterson and colleagues (2019) where participants reported they *"hate wasting hospitals' time with standard seizures"* (pp.230). It is important that careful consideration is given by paramedics when conveying patients to hospital about their clinical need for ED and judgement should be made as to whether self-management at home may be more appropriate.

6.9.2.2 Navigation

Our findings indicate significant variations around ED patient care. Here, both positive aspects of clinical care as well as aspects of clinical care thought to be lacking were articulated by participants. This is similarly reported in the second National Audit of Seizure Management in Hospitals (NASH2) (Dixon et al., 2015). While NASH does not report on the relational aspects of care considered in the current study, findings from a recent study in Australia concur with our own. Namely, participants demonstrated some frustrations at being taken to the ED, felt a loss of autonomy, and reported not wanting to waste ED time as they felt all they needed in post-seizure state was rest to allow time for recovery from the seizure event (Peterson et al., 2019).

In addition, our participants reported frustration in a lack of seizure knowledge in the ED. Participants expressed interest in receiving advice in person from HCPs with more in-depth knowledge of seizures (i.e. neurologists) so that advice could be tailored accordingly, and they felt better informed. Patients' values, beliefs and circumstances all influence their individual expectations of, their needs and use of medical services (National Institute for Health and Care Excellence, 2012). It is important to recognise that individual patients are living with epilepsy and/or seizures on a daily basis and so the way this affects their broader life as well as their immediate health and care needs should be taken into consideration (National Institute for Health and Care Excellence, 2012). Much research has previously been conducted around HCP (Nishina and Yoshioka, 2018) and public (Holmes et al., 2019; Jacoby et al., 2004; Lim et al., 2011) attitudes and perceptions of seizures and epilepsy and a recent survey study by Holmes et al. (2019) identified that stigma still exists towards PWE and seizures, despite ongoing education to improve awareness and understanding of the condition within the general population. It is important to continue to try to address the stigmatisation of epilepsy as a condition if we are to move forward with developing epilepsy care in the future and improving health care experiences.

Within our study, navigation of the care system, particularly at discharge, was a common feature of many participant interviews. Strong evidence about the benefits of appropriate discharge information and follow-up from emergency care suggest that providing such information not only improves communication between patient and clinician, but also assists patients' with ongoing management, protecting them from confusion and complications resulting from ignorance (Taylor and Cameron, 2000). Despite this persuasive evidence, a shortfall in incorporating adequate discharge information in care has been emphasised in several studies (Engel et al., 2012; Sheikh et al., 2018). Concerns around the adequacy of discharge information is also echoed in patient accounts in this study. Emphasising the importance of providing adequate discharge information, particularly around home care instructions and follow-up plans is imperative. This will ensure patients' feel confident in the knowledge that a plan is in place and that they know from where to seek further assistance or support as required, during the period between their ED attendance and follow-up appointment. Written ED instructions, when used to complement verbal instructions, have been shown to improve communication and patient management, potentially reducing re-attendance rates (Taylor and Cameron, 2000). Without such information, evidence suggests that repeat ED visits and hospitalisation, as well as increased risk of adverse events and resource use is likely (Engel et al., 2012). These findings have again reverberated in our study and the participants were vigilant enough to express the need for more supportive discharge information to prevent such events occurring.

Even though the current seizure care pathway has been implemented, fear and uncertainty regarding follow-up remains an issue and has led participants to re-attend the ED unnecessarily in order to access further care. Ensuring the permeability of GP practices to patients with seizures may be an area of improvement. Some individuals may envisage GP practices to be an accessible service, with their local availability and designated systems for urgent care needs. However, for PWE, as recognised in our study, they may be impermeable for several reasons; to include, receptionists' gatekeeping, travel costs, and accessibility issues. In this study, the combination of high permeability and technological expertise led most participants to choose the hospital ED as opposed to GP services in times of perceived urgent need (Hunter et al., 2013). The provision of additional patient support during this time period, such as an ESN phone service or improved access to GP services, may help to lessen fear and anxiety experienced by these patients, potentially reduce unnecessary ED attendances, and, in turn, lead to a better experience of care.

6.9.2.3 Memory recall and understanding

As noted above, participants' perceived lack of knowledge around seizure management is of concern, highlighting the need and the importance for ED clinicians to provide adequate discharge information to enable patients to be discharged home safely. While there may be disparity in the level of information provided by HCPs, (this will be explored via interviews with HCPs; chapter seven) the information deficit, identified by participants, may be the result of diminished understanding and recall ability in seizure patients who are in a post-ictal state.

Due consideration to issues of memory recall and post-ictal memory loss, discussed as a significant problem for participants in this study, must therefore be afforded. We know from previous evidence that post-ictal states can result in some degree of memory impairment which varies from patient to patient in terms of its severity and length (Farrell et al., 2016). In the current study, many participants had little to no recollection of certain time periods following their seizure event and ED presentation; often relying on family members to recall information on their behalf. We found participants more able to discuss events around their OPD appointment than in relation to their initial ED attendance.

6.9.2.4 Patient expectations

Whether patients are expecting too much from the NHS is a matter of debate within the literature (Duffy, 2018; McKenna, 2018). Evidence advises that the public, in recent years, have worsening views of the service the NHS provides. Conversely, some research suggests that expectations have been shown to be more likely to be met, which is only possible if there has been some downward shift in expectations themselves (Duffy, 2018).

Nevertheless, if National Institute for Health and Care Excellence (NICE) are evidencing best practice guidelines, and care pathways are being utilised to recommend evidence-based treatment for conditions then one may argue that these should be the minimum standards of practice, to meet patient care expectations. For example, NICE epilepsy guidelines state that first seizure patients should be reviewed by a neurologist within two weeks of their initial presentation following a seizure episode (National Institute for Health and Care Excellence, 2016b). Within our study only 7% (n=2) of participants were seen within this time frame. This is reflected by a study by Grainger et al. (2016) who reviewed hospital episode statistics (HES) data for seizure presentations and reported that of the seizure recorded (n= 129, 933) 65%

had not been under specialist review (including first seizure patients) and of these, only 11% were offered review within three months, and only 2% in two weeks.

Chronic disease is commonly associated with increased burden from various perspectives; from family and time burdens, to financial and resource use (Sav et al., 2015). Those with chronic conditions have often had numerous previous encounters with health care services. Positive previous experiences serve to build a foundation of trust which strengthens patients’ confidence in using particular services in the future (Rowe, 2008). The theoretical concept of ‘candidacy’ (Hunter et al., 2013), provides an interpretative framework for illustrating how future service demands and help-seeking behaviours are influenced by previous experiences of health care (Rogers et al., 1999). Patients' previous experiences, particularly in chronic disease, are relied on to guide future help-seeking behaviour; influencing expectations of care (Hunter et al., 2013).

Expectations vary considerably, for example, in this study, one participant reflected on their short wait time and expressed a positive care experience. Conversely, others reported being unhappy with the length of time they had to wait, particularly referencing their “*wait to see a doctor*” and reporting this as “*frustrating*”. Where participants perceived waiting times to be “*long*”, there was an association with the reporting of a poor experience of care; a finding congruent with previous research within the emergency care population (Huang et al., 2004). Long wait times were reflected by participants’ increased sense of distress and anxiety. These feelings are perhaps not unsurprising given the onset of symptoms, the nature of the acute admission, and the unfamiliar environment of an ED in such a situation.

One could argue that difference in service provision acceptability may be attributed to varying patient expectations. Even with the seizure care pathway in place, inconsistency in service provision may likely be an outcome, given the widespread variability in service as noted in the NASH study (Dixon et al., 2015).

6.9.2.5 Communication

As an overarching theme, communication was discussed widely throughout all participant interviews. If communication is not effective, anxiety and fears within patients may increase, which in turn leads to negative experiences. Previous research suggests that ED staff tend to be more task-orientated and therefore neglectful of psychological aspects of care which may influence experience (Byrne and Heyman, 1997a). Reviewing the current seizure care pathway to better balance the task-orientated and prescriptive elements of care with relational aspects of care will be beneficial in securing a more holistic approach to meeting patient needs.

Some participants reported encounters with HCPs negatively, with time to communicate being a problem which hindered the development of positive patient-professional relationships. Where participants reported negative experiences with HCPs, this may affect their future experiences and perceptions of health care services (Dixon-Woods et al., 2006). One female participant within our study, with known epilepsy, expressed great concern about the lack of contact with HCPs during her ED visit. Although there is recognition among HCPs that patients' normally feel anxious in the health care setting, (Wolosin et al., 2006) a lack of visibility of staff, perceptions of being "short-staffed" and staff not being available when needed have all been cited in previous literature as adding to patients' anxiety and feelings of not being safe (Kenward et al., 2017).

Elmore et al. (2016) investigated the link between consultation length and patient experience in primary care and found no association between patient experience of communication and consultation length. It may be that consultation length is situation dependent and shorter consultations are sometimes more appropriate and adequately effective in the clinical circumstances, as judged by clinicians (Lemon and Smith, 2014). Given the unpredictable circumstance that many post-seizure patients find themselves in at the ED, longer consultations may work better to alleviate patient worries and therefore increase perceptions of a better patient experience.

Suggestions came from participants with regard to improving the experience of specific aspects of care waiting through better communication, a patient experience factor considered to be of upmost importance, in both this, and previous studies (Sonis et al., 2018; Thompson et al., 1996). An early study by Thompson et al. (1996) suggested that improving communication around perceived waiting times and information provision to manage waiting time perceptions and expectations could be more effective in improving care experience than reducing actual time to wait. Sonis et al. (2018) explores the fact that improving wait time may be difficult in the current climate of the NHS. However, if patients are treated with empathy and feel that communication is adequate, then they may be less dissatisfied with other, less easily improved factors such as waiting. It could be argued therefore that formal staff communication and empathy training may be the highest yield intervention for ED leaders aiming to improve patient experience (Sonis et al., 2018).

6.9.2.6 Empowerment

Actively participating in health care not only involves knowing how and where to access care services to suit clinical need, but also adopting health-promoting behaviours that may improve the condition. Self-management in epilepsy is important in giving patients autonomy to manage their own condition and therefore potentially lower their expectations of what the NHS can or should offer (Helmers et al., 2017). For example, in PWE, basic general health requirements are as important as medication management, and so maintaining a healthy diet, an adequate sleep pattern, and reducing stress, are all ways that patients can actively participate in the control of their condition (Kobau and DiIorio, 2003). Participants within our study recognised some of these as triggers for their seizures and realised the importance of having to take some responsibility for controlling these.

Active participation varied significantly and was more frequently reported by those participants with known epilepsy. This may be because they have the prior knowledge of and access to services that are not offered directly to new seizure patients; for example, the epilepsy nurse specialist. Supporting the active involvement of all patients in their care, not only those with known epilepsy, will not only empower patients, but may also help to improve services on long-term outcomes (Vahdat et al., 2014). Previous research has demonstrated that patients who have high levels of self-efficacy and possess positive attitudes towards self-management behaviours are more likely to perform those behaviours, leading to an improvement in condition and a reduction in GP and ED visits (Lorig et al., 2001).

Research suggests a shift away from the clinician's role as a professional expert who instructs and decides, towards a more supportive and navigating approach to care (Greenhalgh, 2009). While not all patients want an active role, HCPs should endeavour to create a service environment whereby patients feel able to participate and take ownership of their health care choices should they wish to do so (National Clinical Guideline Centre, 2012; National Institute for Health and Care Excellence, 2012). Supporting patients' through the care pathway and signposting services available to them throughout should improve patient's care experiences by providing a context in which patients feel able to participate and share decision-making.

6.9.3 Implications for our research study

6.9.3.1 Seizure care pathway development

Our findings suggest a need to make improvements to the seizure care pathway to provide a more holistic assessment of patient needs. Where most patients reported transactional processes of care occurring in the ED, (e.g. blood pressure monitoring, scans etc.) there was limited report of relational aspects of care (e.g. communication). When participants reported positive relational care, they were generally more satisfied with their treatment, highlighting the importance of including relational aspects of care as a reminder within the care pathway.

There needs also to be clearer provision of advice for ongoing care post-ED and a more supportive pathway for patients during this time period. For many, this is a worrying period of their lives, where they are unsure about their diagnosis/prognosis and often left feeling uncertain about what will happen next and within what time frame. Identifying a mechanism by which to keep patients better informed of the discrete stages of their journey along this pathway, including transition between ED and outpatient care will make the passage smoother for patients to follow.

Clinical necessity of re-attendance is not always the reason for re-presenting at the ED. Sometimes, despite the best evidence-based discharge information being provided, individuals will re-attend for reasons out of ED control, such as fear or the perception of quicker access to the neurology service (Noble et al., 2012). Evidence suggests inappropriate use of the ED to be attributed to various factors, not limited to inadequate discharge information (Carret et al., 2009).

6.9.3.2 PREM Development

In relation to the development of a PREM and the finding from our study that many patients had limited/little memory of their ED experience, Peterson et al.’s (2019) recent study may highlight the difficulties associated with questioning patients about their ED experiences. Within Peterson’s study, there was a significant proportion of missing data when asking questions about factors associated with their ED visits and their perspectives (Peterson et al., 2019). Although this is not directly attributed to a lack of memory or post-ictal state, it may be useful to consider this as a limitation to the dataset, but also that the post-ictal state of participants may have been a reason for these missing cases. This highlights a concern and the potential challenges associated with the design of an appropriate and valid audit tool for measuring patient experience of the seizure care pathway.

Reflecting on the issues of memory recall in patients within this study, along with the issues identified in potential recall bias of PREM instruments in the previous systematic review (chapter five), we took the decision to change the scope of the thesis at this point and move away from developing a PREM for this patient population, due to concerns around the validity of the results such a tool would obtain.

6.9.3.3 Change of scope

Reflective practice has benefits of increasing self-awareness, as well as that of others around you. Throughout the design and development, I reflected on previous research and incorporated expertise through my supervisors, colleagues, and the advice of patient representatives involved in the study. Reflexivity on practice enabled recognition not only in relation to positive aspects of this study but also in relation to its limitations (full reflection outlined in Appendix O).

One predominant feature borne out of reflection and worthy of note here, was a change to the scope of the project. Several participants reported difficulty in recalling events that occurred in the ED post-ictally, leading to a reliance on family members to ‘fill in the gaps. As recall bias had already been highlighted as a limitation in a PREM identified within the systematic review for general ED patients (Bos et al., 2013) and participant interview findings in this study developed, it became evident that this was a recurring problem. I therefore began to question the validity of such a measure for this patient group and whether a better approach to improving care, namely improving the approach of the care pathway to encompass a more holistic approach to care, was possible. It was decided, after numerous discussions within the supervisory team that developing a specific PREM for seizure patients, based solely on patient data, would be futile. The need to gather information on the delivery of the pathway in practice by speaking to those responsible for its implementation became evident. I envisaged that findings from both patient and professional data could then be integrated to provide a more ‘rounded’ perspective on service provision. This expanded data collection approach would likely improve the integrity and validity of further developments to the PREM, as well as highlighting key areas for future practice change and research.

This change in project scope required a major amendment to the study protocol and subsequent REC submission and approval. This process provided an important learning opportunity. Although it created a delay in study processes, I believe this was offset by benefit to my own professional development. Not only in my ability to submit a full REC application - I had not had the opportunity to do this in the initial bid – but, and perhaps more importantly, to gain confidence in my ability to make a significant decision to change the direction of the research study, which I believed would enhance the contribution that the research findings would make.

6.9.3.4 Understanding the HCP perspective

Participants reported that some of the advice offered by HCPs could be inconsistent and conflicting, raising their concerns. Ideally, participants wanted information and advice that was tailored to individual need, as well as providing empathy and care to alleviate any worries or fears they may have in their 'crisis' situation. Hence, there is a need to investigate the current practice of HCPs using the care pathway and the clinical care and management that they are currently offering patients during their care pathway journey. This has been assessed through in-depth interviews with various professionals involved in the operation of the care pathway and is reported in chapter seven.

The benefits of the seizure care pathway as highlighted by participants have been considered. Until we can provide optimal care for patients along their seizure care pathway it seems arbitrary to attempt to find a way to further evaluate the service in a more objective manner. However, when doing so we must consider findings from this chapter also. Participants frequently reported problems recalling their experiences of the ED, largely conversing more in-depth data about their outpatient experience than that in the ED. For this reason, we need to carefully consider options for an evaluative tool that would provide valid and reliable results that could be used to inform future practice. Utilising a patient-reported experience measure as discussed in the systematic review presented in this thesis may not be the answer for this patient group. Chapter eight also provides ideas for future measurement methods for this specific patient population and makes recommendations for consideration for future research.

6.10 Summary

The exploration of patient responses has provided evidence to answer research questions one and two, has worked towards answering research question three, and has informed questions to be asked in part two of the qualitative investigation; exploring both clinical and non-clinical staff experiences of implementing the seizure care pathway in practice (chapter seven).

Qualitative inquiry has demonstrated that the seizure care pathway offers some support to clinicians in the delivery of effective seizure care in the ED, but patient's experiences of the pathway vary significantly. These variations are particularly dependent on patient expectations of care, communication transactions with health professionals involved in care, waiting times and information provision. Contextual and social factors likely influence patients' expectations, so it is important to consider these influences in the interpretation of findings.

Despite evidence that the use of care pathways for specific conditions enhance patient care, there was lack of consistent evidence within this qualitative inquiry to support this finding. Rather, the evidence highlights need for improvement in care delivery along the seizure care pathway continuum. The next chapter further explores the issues through a qualitative inquiry with health professionals and other staff who are responsible for the clinical and operational delivery of the seizure care pathway to patients.

Chapter Seven: Results

Qualitative Study Three: Staff Interviews

7.1 Introduction

In this chapter I present data from interviews conducted with staff and health care professionals (HCPs), to include; clinicians, epilepsy research nurses and administrative staff. The purpose of this endeavour is to compare the perspectives of a range of staff responsible for the care of people with epilepsy (PWE) and others who are experiencing seizures, on the seizure care pathway. Consensus and difference between patient and HCPs findings will then be considered in chapter eight.

It is important to consider the inter-relatedness of themes identified within this aspect of the study, as strengths and weaknesses in any one area may impact on outcomes in other areas. The three main themes from analysis of HCP data were; practice development, multidisciplinary team (MDT) performance and pathway impact (Figure 7-1). Within these three themes, nine sub-themes evolved through data analysis by the researcher. These will be discussed accordingly below.

7.2 Sample characteristics

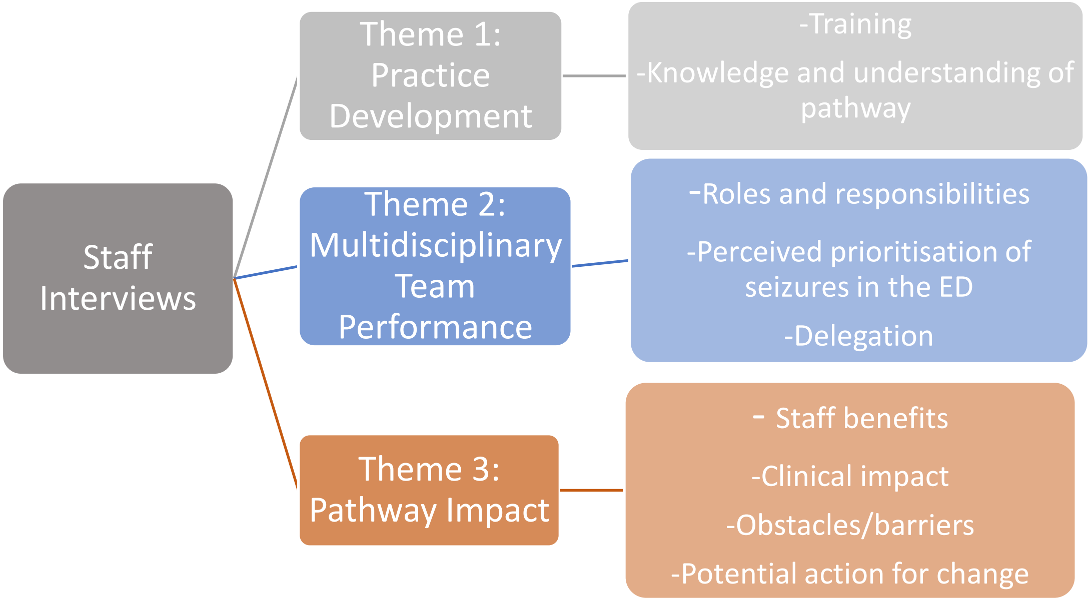
In total six interviews were conducted with members of staff involved in various clinical and operational aspects of the seizure care pathway process. The sample consisted three Foundation Level 2 (F2) ED clinicians, two research nurses and one bookings team supervisor. Five of the six (83%) professional participants were of White British ethnicity. Staff members were involved at different points along this process, from the initial point of patient ED attendance, through to follow-up outpatient appointment bookings and attendance.

All interviews were conducted face-to-face or via telephone in an office on the hospital site, recorded using the Olympus

DM-650 audio recording device. None of the interviews were subject to interruptions and all participants were happy with the level of confidentiality.

Traditional models of ED care have often relied on patients being seen by one of the more junior members of the medical team, such as an F2 clinician, prior to review by a middle grade staff member, and finally, if necessary, a consultant (National Institute for Health and Care Excellence, 2018). Most persons who have experienced a seizure and present to the ED are no longer seizing (Dickson et al., 2016). As such, more junior staff predominantly bare management responsibility for the treatment of these patients; leaving more critical presentations to senior clinicians and consultants. NASH2 found that 41% of those who had experienced a seizure are discharged from ED without evidence of review by a senior clinician (i.e., no-one above speciality trainee year 4 (ST4) level was involved) (Dixon et al., 2015). As such, we were best positioned to interview less senior clinicians (F2 doctors) who most commonly manage seizure patients presenting to the ED.

Figure 7-1 Main themes for health care professional interviews



7.3 Practice development

This theme addresses two main sub-themes; training and knowledge and understanding of the pathway. Training was a predominant feature in all interviews, including discussion around who delivered training, where it was delivered, to whom it was delivered, its effectiveness, and how training could be improved going forward. Prior knowledge and understanding of epilepsy in the ED were discussed by research nurses and clinicians, including how knowledge developed and improved practice. The prioritisation of epilepsy in the ED was discussed by participants.

7.3.1 Training

Training around the seizure care pathway was discussed across five of the six interviews and was particularly important to those clinicians delivering the care pathway in the ED. All three clinicians interviewed discussed the introduction of the care pathway by the research nurses in the ED. This occurred either at their department induction or during one of their shift handovers.

> *"in our induction we had a lady [research nurse] come round to our handovers and really try to push the pathway…that sort of made us aware of it, I don't think I would have really known it existed other than that"* (FY2 clinician 03, Aintree ED)
>
> "*when we did our first meeting, induction meeting in A&E, she [research nurse] came and gave us some information about it otherwise I didn't know there was a pathway for that"* (FY2 clinician 07, Aintree ED)

As F2 doctors, it may be assumed they are still learning and for this reason, may not have been familiar with the pathway. Lack of knowledge about the existence of the seizure care pathway was re-enforced by one of the research nurse participants:

> *"I knew it [seizure care pathway] had been there for a couple of years…when I got there, I didn't think there was much promotion of it. You know, there wasn't many people knew about it. A couple of the consultants did, but a couple of the junior staff didn't really and the nursing staff didn't really"* (Research Nurse 05)

The fact that the clinicians were unaware of the pathway without the presence of the research nurse to augment this knowledge highlights the importance of the need for support in the identification of seizure patients and subsequent completion of documentation for follow-up. Both research nurses also highlighted a lack of clinician knowledge around the seizure care pathway within the hospital trust prior to their appointment and subsequent receipt of training.

> *"training mainly the consultants in accident and emergency with a view to cascade. So they have a safety briefing so I'd do that…I did that probably two or three weeks…constant talking about the pathway and trying to get them to use the pathway which did have some effect and that effect has been fairly long-lasting"* (Research Nurse 09)

Although both research nurses recount providing augmentation of the pathway through education, differences in approach to educating staff about the pathway were evident. In one trust, the research nurse targeted foundation year doctors, delivering training at every induction session and during daily clinical handovers. In another trust, education was provided more frequently to consultants with the assumption that information would be disseminated downwards to junior staff. Augmentation and delivery of training will be discussed in more depth in section 7.6.2.1.

7.3.2 Knowledge and understanding of the pathway

Lack of teaching around seizures during medical training was highlighted by one clinician as being a barrier to delivering effective seizure care to patients. However, use of the seizure care pathway as a mechanism for enhancing clinician knowledge to support seizure management was acknowledged as being beneficial:

> *"it has some good steps…it's not the pathway's problem. I think it's the training problem in the hospital they don't give us enough training about how to manage you know the seizure and possibly seizure on somebody who is already epileptic. But I think the pathway gives us the basic stuff we need to go through like do bloods, do a pregnancy test, do an ECG and it will be sorted out in a clinic…so I think it was quite useful if I'm honest"* (FY2 clinician 07, Aintree ED)

Once the purpose of the pathway is understood, evidence suggests clinicians are more receptive to using it and recognise its benefit in relation to care and practice. Arguably, the seizure care pathway has the potential to support the delivery of high-quality care through enhancing junior doctors' confidence in decision-making.

> *"I think the quality of care is improved, in terms of you know what to do…what to check before I send them home…it's easier for you to do the clinical stuff you have to do."* (FY2 clinician 07, Aintree ED)
>
> *"I think that from day one when we were told about it, I would grab the proforma if I saw they'd had a seizure. But I think it did help that it having all of the boxes, like 'have you checked ECGs or these medical causes?' were really useful pointers because it was not something I had really dealt with before."* (FY2 Clinician 03, Aintree ED)

One clinician highlighted the value of the pathway for their clinical development and knowledge, but recognised that despite there being a clinical proforma, more senior clinicians may be reluctant to use it or may not view it as being an important aspect of the care process.

> *"As an F2 I am more likely to follow a proforma because I don't have as much clinical experience, so I'd be happy to just follow a flow chart and that kind of guides me…I don't think registrars would use it mainly because they have probably managed so many previously…same with consultants, I don't think they would probably know that it was there or that it needed filling out I guess."* (FY2 Clinician 03, Aintree ED)

As well as the in-hospital management side of the care pathway, clinicians need to be aware of the discharge information advice sheet for patients and the ongoing referral process involved within the seizure care pathway. The clinicians interviewed reported awareness of the information sheet to be given to patients and demonstrated awareness of the importance of providing such information to support patient ED discharge:

> *"I think the guidance sheet that we have to give them to go home, I think my clinical knowledge wouldn't have known all of the things that the sheet told them so I think that's quite reassuring for patients to say that we have ruled out everything…and to send them home with the advice leaflet will be helpful for them I think."* (FY2 clinician 03, Aintree ED)
>
> *"that [information leaflet] generally has everything on but just a bit of general advice as well about not driving until they have been seen…and then just if*

> *anything was to happen again just to come straight back in."* (FY2 Clinician 02, Aintree ED)

7.4 Multidisciplinary team performance

This theme predominantly features discussion around the roles and responsibilities of different members of the MDT in the functioning of the pathway. There appears to be a significant amount of delegation, particularly in the referral process. In some instances, it is unclear from the seizure care pathway proforma as to who should take responsibility for particular jobs, for example, completing the referral paperwork and faxing this to the Walton Centre.

7.4.1 Roles, responsibilities and delegation

Each HCP interviewed was aware of their job role. What appeared to be unclear was how the seizure care pathway fitted into their role and which aspects of the pathway they were responsible for implementing; not least because the current pathway does not specifically designate role responsibility for discrete steps along the process. Clinicians in the ED reported they viewed their role in the pathway clinically. Patient management commenced at initial presentation at the ED through to patient discharge, with clinicians taking responsibility for the actions described in the pathway throughout this section of the patients' journey. However, once the patient was discharged from the ED it became unclear whose responsibility it was to refer and follow-up patients between services. Doubt was also cast on whether, in fact, referral practice was an area of service that the pathway provided.

> *"my only issue with the pathway is that, the referral process…I think it's the communication between the two [hospital] trusts"* (FY2 Clinician 07, Aintree ED)

Sometimes, clinicians delegated responsibility for sending documentation and seizure patient referrals to the Walton Centre to ward clerks or administration staff in the ED. Current referral practice was a reported area of concern for clinicians; it was unclear on the pathway whether delegating this task to administrative staff was an acceptable and effective practice. In some cases, clinicians reported feeling uneasy because they were unsure whether their patients were receiving the follow-up care they required:

> *"I don't have any feedback so I don't know how well it works [the pathway] …I don't know when they get the referral, when they get an appointment…I just tell the patient they will be seen at some point by the Walton Centre but I don't know when."* (FY2 Clinician 07, Aintree ED)

> *"…the only problem I can find is that I always had the anxiety if that the clerical staff would have sent the forms because you just leave them in the notes and you just write down a quick note, could you please just send to that fax number and especially overnight there are not many clerks in A&E….so my anxiety was that, was it sent?"* (FY2 Clinician 07, Aintree ED)

Working alongside clinicians were research nurses who were, in principle, employed to augment use of the pathway. These nurses also reported feelings of uncertainty around their role in relation to the pathway, particularly regarding patient follow-up practice. One research nurse, reflected on a previous conversation she had had with a seizure patient who felt like they had *'fallen off a cliff'* following discharge from the ED. The patient said how having been told they would receive a referral, had to wait several weeks before receiving a response from the neurology service. This research nurse's health care experience and expertise led to her wanting to take greater responsibility for follow-up and to reassure patients herself. While this practice was not within her role remit, she felt compelled to provide this additional care to patients; noting this element of care was currently a missing feature of the pathway.

> *"patient's comments have been that once they've been to accident and emergency that it's almost like falling off a cliff…they could do with speaking to someone within a week of being discharged"* (Research Nurse 09)

I move now from the roles and responsibilities of clinicians on patients' first presentation at the ED, to the role of the booking team in managing the incoming referrals from ED onto neurology services. Although there were positive factors regarding referrals they made from the ED, such as use of correct paperwork (pathway proforma), there remained some shortcomings which made onward processing of patients difficult.

> *"sometimes they just come through with a front sheet…they won't have anything attached…that's why we have to read them, they'll sometimes just be handwritten and they'll just have a patient sticker on the top of it and we have the gauge from that if it's a first fit referral [which is prioritised and booked for an appointment differently to someone who has established epilepsy]"* (Administrative Staff 01)

Bookings team staff reported that often referrals received from EDs were incomplete with missing information. This included for example; patient NHS numbers, demographics, and information related to their seizure presentation. Provision of such information is an essential pre-requisite for effective onward referral of patients. Currently the booking service system enables persons who have experienced a potential first seizure to be fast-tracked into a first seizure clinic; chronic or known epilepsy patients are triaged by consultants before a decision is made about their care. If insufficient information is provided by the ED, this creates delay in referral and an increased workload for the booking service who must then chase up this information from ED.

> *"the referrals we get across a lot of the time we do have to call up because they'll either come with lack of information…lack of patient demographics or they won't come with casualty booklets, they won't have patient history attached to them…it just delays their time because by the time we've got it and the we have got to call back up and get the extra information…it's just delaying the process for them"* (Administrative Staff 01)

These identified referral process issues are enlightening. Without a decision being made and clear instruction within the pathway about who is responsible for the provision of patient information from the ED, it will likely be difficult to resolve these issues which will negatively impact on referral. If administrative staff are allocated responsibility for faxing referral forms, effective training needs to be provided in order to ensure referrals are actioned successfully. Similarly, if the ED clinicians take responsibility for the referral faxing, as some reported they would feel more comfortable doing, then they to need to be made aware of the necessary requirements.

> *"I: …so who is it that is responsible for sending that information over to you in A&E is it the doctors that send all that [referral information] through?*
>
> *R: Yes I think it is the doctors…well I'm not sure but I assume it's the doctors…usually it's the ward clerk that will get us the additional information because I think obviously the doctors are busy."* (Administrative Staff 01)

7.4.2 Perceived prioritisation of seizures in the ED

The role and responsibilities of the MDT caring for patients in the ED varies significantly. When questioned about the importance of seizures in the ED, participants referred to the presenting condition of the patient as an important determining factor.

> *"I think if they go to resus because of status epilepticus then that's obviously a massive high priority…I think sometimes it's seen…if people come in post fit…I think people sometimes think I don't know why they have come in….we don't really manage it or they just need to be seen in clinic…that's more appropriate after a fit than ED."* (FY2 Clinician 03, Aintree ED)

> *"it depends on how acute it is…some patients just say yes I had a seizure three days ago…so why have you came today?"* (FY2 Clinician 07, Aintree ED)

> *"I remember I had quite a lot of people who were just coming in like 'oh I've had a fit, I just want to make sure that I'm ok?' which is like I need a check over…and it's kind of like we're not especially…it wasn't necessarily a priority"* (FY2 Clinician 03, Aintree ED)

We were also interested in whether clinicians perceived new-onset seizure patients and patients with established epilepsy differently. Clinicians whom we interviewed reported not seeing chronic epilepsy patients in the ED as frequently as new-onset patients.

> "often *the chronic patients don't come in if they have had a seizure. I don't often see chronic patients and the ones that come in tend to be the ones that are needing to have a lot of medication to terminate their seizures rather than just coming in with a one-off."* (FY2 Clinician 02, Aintree ED)

7.5 Pathway impact

This theme focuses on the impact that the seizure care pathway had on staffs' ability to care effectively for patients presenting to the ED with seizures and the perceived clinical impact on patients. Barriers to delivering care in line with the care pathway were frequently discussed within interviews, including operational and logistical issues which affected HCP's ability to deliver quality care. Solutions to these problems were suggested and will be discussed within this theme and in more detail in the discussion and recommendations sections (chapter eight).

7.5.1 Clinical impact

Clinicians from the ED and research nurses perceived that use of the seizure care pathway had resulted in a positive clinical impact on patients, particularly improving their quality of care. All professionals stressed the importance of making sure care was patient-centred. While this is seen as essential to all patients, it may be particularly important for seizure patients, where the unpredictability of the disease carries the potential for increased anxiety and ongoing concerns; this can only be recognised and addressed through a holistic approach to care.

> *"some people are quite anxious about it especially young people who present with a new seizure…I imagine if it was me…I can understand their anxiety about it"* (FY2 Clinician 07, Aintree ED)
>
> *"it's always going to be a bit…upsetting and worrying for the patient. Often when I say I'm going to send a referral over to the Walton Centre people start to panic a bit…I think it's just more reassuring them that its follow-up for their benefit…I think as long as we communicate reasonably well at our end, the transition should be ok"* (FY2 Clinician 02, Aintree ED)

It is important for ED staff to recognise and facilitate the broader aspects of good care rather than treating the medical aspects of the patient's condition in isolation. Focus needs to be given to the interrelated social, psychological and physical needs of the patient, and where necessary, their carers.

> *"all the leaflets we give so it's more for their information when they go home because I understand sometimes they don't get all the information when we tell them in the department…it's all about the family too so for them, they can read through the paper and respond if there is any emergency"* (FY2 Clinician 07, Aintree ED)

Clinicians perceived improvement in quality of care for seizure patients which they attributed to use of the pathway:

> *"I think the quality of their care was improved, in terms that you know what to do…I check what I need to check before I send them home, or you don't have to search all the fax numbers to see if you should refer to neurology, shall I not. It's easier for you to do the clinical stuff you have to do, then you just fill the proforma, it's one to three [list] and then you say yes I will send it."* (FY2 Clinician 07, Aintree ED)
>
> *"I think as an F2 I am more likely to follow a proforma because I don't have much clinical experience, so I'd be happy to just follow a flow chart and that kind of guides me."* (FY2 Clinician 03, Aintree ED)

7.5.2 Obstacles and barriers

HCPs reported numerous barriers to the effective implementation of the seizure care pathway. Most frequently highlighted were logistical barriers, including lack of paper copies of the pathway and lack of access to facilities to employ the pathway proforma, for example, fax machines to send referrals.

> *"…if you're running round trying to find a pathway…often if you try to print it out the printer has only got printer labels, the patient sticky labels in so you've got to find paper…I'd spent about 20 minutes trying to locate some normal A4 paper to print it out on….just the ease of access to it mainly."* (FY2 Clinician 03, Aintree ED)

> *"there is a lot of frustration about faxing the documentation over because a lot of the faxes tended not to work in accident and emergency so it wasn't clear that all the faxes were actually getting to the Walton Centre."* (Research Nurse 09)

Also discussed were barriers such as time constraints, particularly in relation to workload and acuity of the ED which clinicians felt had a bearing on the level of care and time that could be spent with patients. One research nurse reported feeling constrained by the remit of her post; unable to complete the caring aspects of her role left her with a sense of not working to her full capacity:

> *"in busy times things do get missed…pressure of time and human failings, basically…I am an epilepsy specialist nurse my first…call is for the patient who has had a seizure really…and having had the advice not to give any advice, not being able to talk to patients and help them through that, I just found that really really hard"* (Research Nurse 09)

With regard to referral processes, the booking team participant noted doctors' knowledge in relation to the importance of providing adequate referral information may be limited. It was suggested provision of further training around this issue would likely improve the referral process.

> *"I think obviously the doctors are busy and they just get it faxed and then they don't realise the knock-on effect of the information that we need to be able to process it"* (Administrative Staff 01)

7.5.3 Potential action for change

From a clinical perspective, HCPs expressed various ideas they believed may assist with problems encountered when using the care pathway. Predominantly, refining the patient referral system, by utilising an electronic referral system rather than the current fax system.

> *"…if it was electronical then I would be more confident that I did it [sent referral]. Rather than leave it to somebody else who I trust of course because they do their job but if you do it yourself, you can close, you can do a discharge letter and say already referred to seizure clinic."* (FY2 Clinician 07, Aintree ED)

Utilising the pathway during the triage process was also suggested as a solution to improve access to and usage of the pathway proforma.

> *"one of the things that would be good was if the triage nurses were aware of it they could print it out and attach it to the notes…if they even just put seizure on it that might be useful."* (FY2 Clinician 03, Aintree ED)

Raising awareness of the pathway proforma and embedding it into practice was highly important within HCP interviews. Clinicians reported how they were made aware of the pathway, outlining they did not see it directly as training, rather raising awareness of the pathway, which they had not known previously existed;

> *"a lady came over from the Walton who I think does the seizure care pathway and she sort of highlighted it…it wasn't really training it was just the beginning of one of our handovers, so it was more just to highlight that the form [seizure care pathway] is available."* (FY2 Clinician 02, Aintree ED)
>
> *"I think there was an epilepsy nurse I think who…when we did our first induction meeting in A&E, she came and gave us some information about it otherwise I didn't know that there was a pathway for that."* (FY2 Clinician 07, Aintree ED)
>
> *"…as part of our induction we had a lady come round to our handovers and really try to push the pathway…that made us aware of it, I don't think I would have really known that it existed other than that"* (FY2 Clinician 03, Aintree ED)

Although the pathway was introduced, one clinician suggested that more could be done to train junior doctors about seizures. It was argued that seizure training, received at medical school and more recently within the hospital environment as continuing professional development (CPD), is limited.

> *"it's not the pathways problem I think it's the training problem in the hospital, they don't give us enough training about how to manage you know the seizure"* (FY2 Clinician 07, Aintree ED)

A clinician and one of the research nurses recognised that one group of staff; namely nurses, were particularly difficult to engage regarding using the pathway. The clinician recognised that nurses on triage often do not use the pathway as intended and this may be an area for improvement in its use.

> *"if the nurses on triage…they're now doing a 'pit stop' thing in A&E…so a consultant casts an eye over people and tries to get the ball rolling with things like that so it might be useful if they are more aware of it…probably the nurses that re on the triage part is where it is not used"* (Clinician 03, Aintree ED)

One research nurse also expressed difficulties in getting nurses *on board* with using the seizure care pathway as part of their normal practice.

> *"we tried to get into the nurses, who really…didn't respond very well. They were busy, they knew the pathway was there because I told them, they knew where to get it, but they weren't looking for it. They had a patient, they weren't sort of thinking, oh here is my patient, are they query epilepsy, are they query seizure when they come in, have they got a pathway, they weren't looking…even today they're not looking. So it was very difficult to get into the nursing…system"* (Research Nurse 05)

Another concern for clinicians was their lack of ability to follow-up patients and/or to provide follow-up support. One clinician expressed worry, not only in relation to how lack of support might negatively impact on patient perceptions of care but also in relation to consideration of appropriate referrals and development of their own clinical judgement skills. A suggested solution to this issue, proposed by one participant, was to put in place a system like that used in other hospital services; as for example, in ophthalmology.

> *"I don't have any feedback so I don't know how well it works, how quickly the patients are seen…it's like any other appointment in the hospital…for example, if somebody wants an ophthalmology appointment, you can go to SIGMA, and you can see when the appointment was arranged so you know that they'll be seen in a couple of days' time and I can check the letter later on."* (ED Clinician 07, Aintree ED)

Although not a solution directly associated to issues with the current pathway, one clinician, now working in a general practice (GP) setting, raised suggestions about the value of using the pathway in a primary care setting for those presenting with seizures to the GP rather than to the ED.

> *"…if you offer it in the hospital then surely we should be able to offer a similar referral in GP you know just that simple form we've got in A&E, you know just have some of them here, print a copy of your consultation, tick it and fax it over…I guess it might prevent people…as many people going to the A&E department if they knew they could you know, could come and have similar sort of access in the community. I think it would be useful."* (ED Clinician 02, Aintree ED)

7.6 Discussion

7.6.1 Summary of main findings

This study, exploring the views expressed by staff and HCPs, portrays varied accounts in relation to caring for seizure patients throughout their journey along the seizure care pathway; from ED up to their OPD appointment. Three main themes generated through data analysis:

- Practice Development
- Multidisciplinary Team Performance
- Pathway Impact

While ED clinicians reported their substantial involvement in the acute clinical care for patients presenting with seizures, experience varied based on perceptions of patient need, their own level of clinical experience, and their confidence in managing the acute presenting condition. Research nurses employed as part of the wider Care After Presenting with Seizures (CAPS) project, to support the implementation of the pathway into practice in EDs, perceived their role to be limited in relation to the management of patients with epilepsy, with the exception of tasks such as chasing follow-up appointments and ensuring pathway documentation was completed appropriately; which I believe may or may not enhance clinical care. The role of administrative staff was important in the process. However, they perceived the effective execution of their role to be hindered by lack of support and co-ordination in supplying relevant information to them. This was seen to have a detrimental effect on patient care experience and on the quality of pathway delivery. All interviewees recognised that access to care varied for a wide range of reasons, specifically the acuity and busyness of a shift in the ED, and/or the volume of referrals being made to tertiary care services. Professionals perceived untimely access and unresponsive services could potentially cause decreased psychological and physical wellbeing for patients. Individual professionals (from all professional groups) felt that they could facilitate or block access, depending on their practice and relationships with other professionals, highlighting the importance of good MDT work.

7.6.2 Comparison to previous literature

In this section, findings from the current study will be considered in relation to previous literature and current health policy. The experiences of care as perceived by HCPs will be discussed, highlighting both positive and negative aspects of the current seizure care pathway and how these aspects relate to previous evidence from the relevant literature.

7.6.2.1 Training and education

Clinician interviewees were F2 level doctors. They spoke of the seizure training they received, both during medical training and as a continuing professional development (CPD) opportunity in the ED. Predominantly, however, they viewed this training as limited, particularly in relation to seizures and seizure care. The UK Foundation Training (FT) programme was introduced in 2005 to replace the House Officer model (Department of Health, 2004); offering a more structured and focused postgraduate training programme. Literature recognises that limited professional development opportunities are given to clinicians to further enhance their skills and knowledge across all conditions presenting to the ED (Hughes et al., 2018).

Although recognised as important among medical regulatory bodies such as the General Medical Council (GMC), time constraints, lack of clinical cover and lack of funding have all been cited in previous literature as barriers to CPD (Ikenwilo and Skåtun, 2014). This is intensified in an environment such as the ED, due to system pressures both within and outside the hospital and a workforce crisis caused by, amongst other things, recruitment shortages (Health Education England, 2013).

Evidence suggests that such manifold pressures are likely to cause strain between service demands and the education and training needs of postgraduate doctors (Health Education England, 2013).

Our findings support this. It needs to be recognised that greater efforts are required to ensure F2 level doctors feel adequately supported in their training and professional work in the ED. A recent study by O'Keeffe et al. (2017) interviewed F2 doctors and suggests that generic teaching was not relevant to practice and that more specific teaching relevant to the work in the ED was needed. Although all enjoyed the experience in the ED, decision-making around care was viewed as challenging, predominantly due to the perceived lack of support from more senior staff; conclusions that were re-enforced by our study (O'Keeffe et al., 2017). Although it is not possible to outline a "one size fits all" approach to staffing in EDs, some recommendations and guidance from the Royal College of Emergency Medicine for senior staffing ratios is available (The Royal College of Emergency Medicine, 2019). As evidence suggests consultant levels in EDs are low, this may, in turn, increase the workload for less senior clinicians. Our study highlighted that workload and decision-making was aided by the specificity of some aspects of the seizure care pathway – helping clinicians to ensure that they did not exclude any possible reasons for the seizure event. In this regard, the F2 clinicians viewed the care pathway as particularly helpful in supporting both their decision-making and confidence. This finding is supported by O'Keeffe and colleagues (2017) who found that where specific clinical pathways did not exist, there remained a potential gap in knowledge and lack of confidence for some foundation level doctors delivering clinical care in the ED.

Clinicians interviewed in the current study did not view seizures as being of particularly high priority in the ED, unless the patient was experiencing a seizure on attendance or presented as status epilepticus. Post-ictal patients were not seen as a priority. For this reason, it was largely F2 clinicians who were in charge of caring for such patients, with consultants' role being set aside for higher priority attendees (National Institute for Health and Care Excellence, 2018). Despite the benefit of support to F2's in their clinical decision-making afforded by the pathway, it nevertheless remains imperative for senior colleagues also to provide appropriate support. Re-affirming clinical decisions helps to grow sureness in less senior staff; provision of positive feedback and perceived patient satisfaction, are all factors which help improve confidence (O'Keeffe et al., 2017). The lack of feedback loop within the process of the seizure care pathway was equally apparent. Improving this, through the use of audit may help to improve the use of the pathway and subsequent patient experiences (Ivers et al., 2012).

Accounts from clinicians and research nurses' interviews highlight awareness of the pathway was provided by research nurses rather than senior ED clinicians. While research nurses were sometimes present to augment pathway awareness, this was often made difficult by the nature of 24/7 emergency care, high staff turnover and staff rotation in emergency care.

It is unknown what constitutes the most appropriate model for dissemination of the seizure care pathway. An analysis of patient-reported experience data across the various hospital recruitment sites provides no evidence to indicate patients received better information from any one trust; with care being perceived as variable across all recruiting hospitals.

It is likely that each approach has both benefits and drawbacks and that these will vary between hospital trusts. One could argue that cascading information downwards from consultant to F2 clinician will likely require fewer consultant training sessions than would be required when using the F2 training model (consultants remain in post considerably longer than rotating F2 clinicians). Conversely, consistent reminders about the seizure care pathway articulated at handovers will likely strengthen the message to use the pathway paperwork (Coomarasamy and Khan, 2004). Within 'teaching hospitals' there should be a consultant or specialist responsible for organising education programmes for trainee doctors (Johnson, 2001). Either way, this research highlights the importance of the presence of a practitioner responsible for the training and development of clinical staff on the use of the pathway. It is unsustainable within the financial constraints of the health service for all potential pathways to have "human interaction" to augment use.

Preliminary findings from the wider Care After Presenting with Seizures (CAPS) study suggest variation in the effect of the research nurse augmentation of the pathway. A multilevel logistical regression model has been used and found that for those presenting to the ED with known epilepsy, there is no significant beneficial effect between hospital sites where the nurse augmented the use of the pathway, compared to sites where the pathway was used alone. However, for those with no previous epilepsy diagnosis presenting to the ED, results suggest a significant beneficial effect of the nurse's input to use of the pathway, when compared to sites using the pathway alone (Personal communication, Dr Pete Dixon, CAPS project, University of Liverpool, 10/02/2020). This is an interesting finding and one that is yet to be offered reasoning to. It is possible that ED clinicians offer more attention to those with no previous diagnosis of epilepsy experiencing seizures for unknown reasons and therefore those patients are more likely to be put on the seizure care pathway. Future research may be useful to consider reasons for these findings through further in-depth exploration with ED clinicians. We should consider how best to make the pathway sustainable for both patients with known epilepsy and those presenting with first seizures.

One of the most important leadership and management activities for senior ED clinicians is to assist teams to manage change. Change is a challenge for any team, but prior research suggests that is it made more difficult by shift work and the 24/7 working environment of emergency care (Seow, 2013). Communication is key to change management, with it being suggested that ED senior management would need to arrange for "structured time to talk to staff individually, to explain changes" (Seow, 2013). As part of the augmentation of the pathway, we must recognise that it is rare for change to be immediately adopted. Time is required to ensure the effective use of the seizure care pathway for every patient attending the ED (Seow, 2013). Continual reminders at team handovers, training for new clinical staff (particularly at the start of a new trainee rotation), and communication during clinical care, will all contribute to successful seizure care pathway implementation in ED care provision.

Discharge information provided to patients was discussed through clinician interviews. Clinicians were aware of the importance of providing adequate discharge information to patients. However, they highlighted issues managing patient expectations for follow-up, something that was also highlighted by the bookings team. NICE guidance (National Institute for Health and Care Excellence, 2016b) states that first seizure patients should be seen in a rapid access clinic within two weeks. This is the information some clinicians in our study have relayed to patients on discharge from the ED. However, due to the current demands on the service and operational issues, the two-week target waiting time, at time of writing, is not being met. This can be seen in data provided in chapter six, figure 6-4, which provides average wait time for first seizure patients in this study. Clinicians were aware of the problem with discharge information provision, and this has also been highlighted in previous research (Sheikh et al., 2018). The observational study conducted by Sheikh et al., (2018) highlighted that patient understanding of discharge information is poor, particularly around their follow-up plan and return to ED instructions. Patients from socially deprived backgrounds and those with lower educational attainment, trended towards lower levels of understanding of their diagnosis and treatment plan (Sheikh et al., 2018). Many seizure patients meet this demographic profile and therefore when planning discharge information, it is important for clinicians to consider the information they are providing to seizure patients on discharge and the methods by which this information is offered. Research also suggests that lower-income patients have a preference for receiving a follow-up phone call from a nurse, while higher-income patients' preferred online resources (Sheikh et al., 2018). These are potentially important considerations and should be reflected when determining discharge information provision in the future care pathway.

7.6.2.2 MDT performance

Patient referral to tertiary care services forms part of the pathway. It remains a contentious aspect of the care pathway in relation to delegation of responsibility for making the referral and in the level of information provided in the referral. The organisational procedure to refer a patient (i.e. paper copy faxed across to Walton Centre) was highlighted by all participants as a limitation to effective pathway process. Clinicians highlighted it is unclear who carries responsibility to complete the referral; with some clinicians faxing patient referrals themselves, while others delegated this responsibility to administrative staff. However, delegating this task to administrative staff did not ease clinician burden and clinicians often felt anxious about whether the referral had been made correctly. Booking team administrative staff also highlighted the limitations of the care pathway in a paper format, in that essential patient demographics were frequently missed off, leading to delays in processing of referrals and appointments. There is no previous research around clinicians' feelings on discharging patients from the ED and transitions between ED and OPD appointments, but our study highlights that agreeing a definite plan for referral is essential to ensuring appropriate and adequate referral information is provided, as well as relieving clinician anxiety.

7.6.2.3 Pathway impact

Overall HCPs perceived the seizure care pathway as a positive move towards improving quality of care and patient experience. Previous studies exploring HCP views of care pathways, in different clinical contexts, support this finding (Roy et al., 2003; Wood et al., 2014). This underscores the need for the pathway, in some form, to remain as a key part of care delivery for seizure patients in the ED.

Some clinicians highlighted that the transition from ED discharge to OPD was unclear. This caused a degree of anxiety, as clinicians were unaware of the patient's post-discharge journey and would have liked to have known the onward outcome of patients' care.

In other care areas success of e-referral systems is evident. This has been shown to not only lead to better patient care, but also enable monitoring of activity (Batura et al., 2016). This may help to alleviate patient referral worries expressed by HCPs as an electronic system provides visibility of referral progress, as well as reducing the numbers of errors in communication and missed referrals (Batura et al., 2016). The NHS is has recently rolled out the NHS e-Referral Service (e-RS) in primary care to electronically refer patients to secondary care (NHS Digital, 2018). NHS England envisages that eventually, all health care referrals, whether to or from a hospital or community setting, will be made through the e-Res system (NHS Digital, 2018).

In the interim, it may be advisable to put measures in place to help overcome some of the organisational and logistical barriers that have been raised by clinicians as issues which hinder the use of the pathway in practice. Access issues such as the lack of paper copies of seizure care pathways have been reported to hinder its use. The use of a local electronic Directory of Services (DoS), similar to that used by NHS 111 services, may be of value when accessing and using the seizure care pathway (Murphy, 2017). In recent years, electronic medical record (EMR) systems have been introduced into many EDs to facilitate the documentation of patient care episodes (Neri et al., 2015). Some evidence suggests that EMRs can improve guideline adherence and therefore using an electronic system for the completion of the care pathway documentation where possible may prove advantageous (Lorenzetti et al., 2018).

7.7 Summary

Seizures and the diagnosis of epilepsy are events that can have long-term impact on those living with them. Professional support plays a major role in the continuation of care along the seizure care pathway. Despite the implementation of the seizure care pathway, evidence from both patient participant and HCPs interviews demonstrate that care remains subjectively and operationally variable, resulting in lack of consistency in the care provision throughout the pathway. Various barriers that hinder care have been highlighted.

The next chapter further explores these issues, highlighting how the work in this thesis addresses the research questions. Direct comparison will be made between patient and staff interviews, highlighting mutual aspects of the pathway - both in terms of its positive impact and its limitations. Development of the thesis over time, particularly around the perceived appropriateness of developing a patient-reported experience measure (PREM) for this specific patient population, together with suggestions for future practice and utilisation of the pathway will be further discussed.

Chapter 8: Conclusions and Recommendations

8.1 Introduction

This chapter concludes the thesis and is structured to provide an overview of the work undertaken. Study aims and objectives will be re-visited, reflecting on how they were developed and achieved throughout the research process. The chapter highlights significant findings from the overall project considering research questions posed at the outset. Consideration is also given to the appropriateness of applied methods, underpinned by the Medical Research Council's (MRC) framework on how to develop and evaluate complex interventions (Moore et al., 2015). This final chapter also seeks to illuminate the novel contribution of this work, its fit within the contemporary context of existing evidence and its implications for clinical and operational practice. The chapter concludes with consideration of different approaches by which to take this research forward. Recommendations for further research, supported by findings from the current study, will be discussed; including, proposing changes to be made to the current seizure care pathway.

8.2 Aim and objectives

The overall aim of this project was to explore patients' perspectives of the seizure care pathway as a service intervention through process evaluation, and to design and develop an evidence-based patient-reported experience measure (PREM) for auditing patient experience of the seizure care pathway.

The MRC framework for development of complex interventions was used to underpin the methodological approaches (Moore et al., 2015). The detailed objectives were presented earlier in chapter one, section 1.5, and are listed below:

1) Conduct a literature review
2) Conduct a systematic review (study one)
3) Conduct a qualitative study (study two: patient and carer interviews)

4) Conduct a qualitative study (study three: health care professional interviews)
5) Develop a PREM for auditing of seizure care pathway
6) Synthesise findings for dissemination

The first objective was achieved by exploring the current evidence-base around service provision in emergency seizure care and identifying the theoretical underpinning that guides quality improvement and service evaluation approaches, presented in chapter two.

The second objective was achieved by undertaking a systematic review to enable the synthesis of current evidence of evaluative methods for measuring patient experience in the emergency department (ED) and their psychometric development. This work is presented in chapter five.

Chapter six addressed the third objective by exploring seizure patients' experiences of receiving care based on the seizure care pathway. This included exploring perceived facilitators and barriers to effective care and suggestions for refinement of the intervention. Following this, a second qualitative study was conducted, presented in chapter seven, to address objective four. It examined staff perceptions of using the seizure care pathway in practice.

Objective five has not been met within the conduct of this study. Reasons for this are addressed within discussion section 6.9.3.3, chapter six and revisited below.

Objectives 1-4 and objective six, to provide a synthesis of findings and dissemination plan, will be discussed in more depth below.

8.3 Principal findings

This section will describe the novelty and contribution of this thesis to the research field by presenting a summary of main project findings.

Development of theoretical knowledge and underpinning of health care service evaluation was formulated through an in-depth exploration of literature exploring methods previously used in other health care evaluations away from epilepsy and seizures (chapter two). This helped to inform the use of the MRC guidance as a framework for the evaluation of complex interventions as outlined in this project. The scoping review identified a lack of research conducted around care pathways, using in-depth mixed methods approaches, to develop and implement a pathway effectively. It also highlighted an absence of studies utilising PREMs to assess patient experience in the ED. I set out to address this through a systematic review, and the qualitative study, to evaluate patient experience of emergency care for seizures through the seizure care pathway.

To the best of my knowledge, the systematic review conducted for the evidence synthesis phase of this project (chapter five) to explore current patient experience measures for use specifically in ED and their development, is the first of its kind. Findings from this review indicated that there are several PREMs designed specifically for use within the ED setting, however, little attention has been given to the validation of such measures. I suggest future research should consider drawing on the most promising existing PREMs as a starting point for the development of a new measure, while ensuring a focus on psychometric development to ensure credibility of findings.

In-depth semi-structured interviews conducted with patient participants and their carers who had experienced ED care using the care pathway allowed for exploration of their experience, knowledge and perceptions of the care process (chapter six). Results indicated that patients' experience of care in the ED varied significantly, with no hospital site performing better or worse than another. Shortcomings in discharge information, communication and waiting times in the ED were most commonly discussed as issues which affected experience and care quality. Participants often struggled to recall specific events that occurred during their time in ED, relying on carers to provide finer detail or giving a more general overview of their feelings about the experience. Overall, patients reported more positive perceptions of their follow-up care with specialist neurology consultants in the OPD but felt the transition between services was inadequate and a lack of co-ordination and communication led to mismanagement and delays in ongoing care in several cases.

In relation to the development of a PREM and the finding from the qualitative study of patient experience (chapter six), that many patients had limited/little memory of their ED experience, and memory recall limitations emphasised in previous instruments highlighted in the systematic review (chapter five), raised concerns associated with the design of an appropriate and valid audit tool for measuring patient experience of the seizure care pathway. After consideration of this finding and in-depth discussion with the supervisory team the decision was made to change the scope of the thesis at this point and move away from developing a PREM for this patient population, due to concerns around the validity of the results such a tool would obtain.

The findings from the first qualitative study with patient participants informed the changes in the thesis plan and led to the conduct of a second qualitative study, where staff responsible for delivering the pathway were interviewed (chapter seven). Study two informed the questions for the third study. Interviews with health care professionals (HCPs) centred around delivery of the pathway from their perspective to determine whether they perceived the pathway to be effective in delivering high-quality patient care and how the clinical environment might impact on this. Findings from HCPs data were congruent with some findings from patient interviews; specifically, issues around lack of discharge information, delivery of care dependent on clinical workload and time of day, and the importance of holistic patient-centred care. Interviews with professionals also acknowledged limitations of the pathway including; access to it, knowledge around seizures, and the referral process and transition of patients from ED to OPD and other care services. Health professionals generally appeared to value the contribution made by the pathway in relation to some aspects of their roles, however all offered suggestions for change around how the pathway could be improved to augment future practice.

Findings from this body of work likely have significant future health care implications, not only for HCPs involved in seizure care, but also for researchers involved in the field of care pathway development and evaluation of patient experience for seizure patients.

The qualitative approach underpinning data collection provided patients with the opportunity to express their views. In doing so, various issues of patient concern were highlighted including for example, poor communication and lack of discharge advice provision. Similarly, patient data exposed a gap in service provision related to the transition between acute and ambulatory care services. Here, patients reported losing continuity of care and contact with care teams while transitioning to follow-up care. This appeared to produce anxieties and uncertainties leaving patients feeling as though they had *"fell off a cliff"*. Similar findings have recently been reported about transitional phases of care in individuals with mental health conditions (Cranwell et al., 2016) and a focus group study with health professionals in Ireland exploring the interface between primary and tertiary care services for seizure patients (Varley et al., 2010). Utilising our study findings, alongside those of previous research, we can make suggestions to improve the health care experiences of patients, particularly during the transition between secondary and tertiary care services.

To change the way in which patients utilise the health service, focusing in particular on incidences where ED use is not clinically necessary, policy change should place emphasis on patient-clinician relationships and on improving self-management. Patient's previous experiences, particularly in chronic disease, are relied on to guide future help-seeking behaviour (Hunter et al., 2013). Service provision, both in emergency care and long-term follow-up should be sufficient to support and frame patients' future decisions and health care choices (Hunter et al., 2013).

8.3.1 Similarities and differences between experiencing and providing acute care for seizures

Access to health care services was the most comparable theme for people with seizures and professionals. Both groups reported a range of positive and negative experiences they had had when accessing, or providing access to, services. People with seizures reported knowledge and logistical access problems as barriers to navigation. Difficulties identifying and navigating services were also experienced by HCPs, reporting concerns that patients were not provided with appropriate follow-up after their ED experience and were often left not knowing when they would be contacted by the OPD for follow-up. Although those with known epilepsy discussed how they facilitated their own access to services, through contact with their known epilepsy specialist nurses (ESN); those without this prior knowledge were often left in unfamiliar circumstances.

Barriers to timeliness of care were reported by people with seizures in the ED but less so by HCPs. Some clinicians mentioned difficulties in ensuring quick and responsive access to specialist neurology services. This lack of timely access was felt to be detrimental to the physical and psychological wellbeing of PWE.

In some circumstances presentation at the ED was both futile and unnecessary and this was recognised by both HCPs and patients alike. One patient recognised how their seizure was completely typical for them, they had no injuries and there was no clinical reason for their ED attendance. Similarly, some ED clinicians recalled circumstances where PWE had presented to ED three days post-seizure, with no other complaints or injuries. It could be argued that such ED attendances constitute a waste of ED clinician time; non-acute situations being better suited to a primary care service.

PWE described their experiences of communication with HCPs, whilst professionals described a more generalised concept of patient-centred care and quality of health care delivery. People with seizures discussed some of the concerns they had with communication, particularly around miscommunication and feelings that HCPs were not listening. HCPs did not mention these negative issues but instead discussed the individualised and holistic care they aimed to provide to those with seizures presenting to the ED, to try as far as possible, to alleviate their worries and concerns. One issue that less senior clinicians alluded to was the rarity of seizures in the ED and their general lack of specialist knowledge in this clinical area, requiring more coordination with, and access to, specialist services than other chronic conditions that may present to emergency care services.

Both HCP and patient participants discussed coordination of care. For people with seizures, co-ordination of care was important, particularly between multiple HCPs and providers. Views on this varied significantly with some participants reporting positive experiences of continuity while others viewed their experience as poor. Professionals described coordination in terms of their role coordinating the continuation of care through to other health care services.

In summary, these findings suggest that people with seizures and professionals experience many similar challenges in receiving and delivering seizure care.

8.4 Strengths and limitations

In this section I outline the strengths and limitations of my research based on the entire programme of work.

8.4.1 Strengths

Design and Development

A key strength of my research is the rigorous design and development, outlined in figure 1-1 (chapter one). I integrated a variety of approaches, including a literature review, a systematic review, and two qualitative studies, to understand how seizure care pathways can influence patient experience and quality of care delivered, as well as how best to measure patient experience in this patient population. While the literature review highlighted the gap in knowledge around patient experience of seizure care in the ED, the systematic review enhanced my understanding of current processes available to measure patient experience of emergency care. The qualitative patient and carer interviews detailed in chapter, informed the further development of the project and prompted reflection on the use of PREMs in the seizure patient population. The patient and carer interviews prompted the idea of interviewing professionals about their experience of delivering care using the seizure care pathway and findings help to elicit interview questions. The staff and HCP study helped to shape the study context and supported the development of a number of recommendations from the overall study findings.

I believe another study strength is that the sample was representative of the general epilepsy population covering a wide age range, both genders, a range of seizure types and a broad demographic area across Liverpool and the Wirral. Hence, the population fulfilled the aim of 'purposive sampling', as sample saturation was fulfilled. This became evident after the 22nd interview where no new themes were generated through analysis of the data. Five more interviews were subsequently conducted to clarify no further new themes.

8.4.2 Limitations

Patient Populations

One limitation of the study is that individual variables between participants may have influence their willingness to take part and potentially introduced a level of bias. Although invitations were open to all eligible participants who took part in the CAPS project, there is a possibility that their participation was based on personal experience being significantly positive or negative compared to usual care and their willingness to discuss this. Additionally, the lack of ethnic diversity within the patient population is a limitation, given the importance of ethnicity as influence on experience of care. Consideration should be given it how to increase the diversity of the population by overcoming potential barriers to recruitment (Frierson et al., 2008).

Another study limitation worthy of consideration was the low recruitment rate. One potential suggestion for the low recruitment rate seen in the patient/carer interview study is the finding of the perceived sense of burden on the service. These negative beliefs and lack of knowledge may have meant that PWE felt ashamed of their diagnosis, guilty and reluctant to take about their experience. Those attending ED appear to be particularly at risk of this. This could be a barrier to participating in research. It is currently unclear though how recruitment could be altered to mitigate against this.

A further limitation is that, although participants reported the perceived impact seizures had on their lives and their ED attendances/re-admissions, no standardised measure for recording this was utilised. Inclusion of such data within this study would have provided additional information to enable exploration of whether the perceptions of those with epilepsy, regarding their lived experience, were in any way related to the severity of their illness.

Health care professional perspectives

With respect to the staff and HCP interviews, sample size may be a limitation. The process of recruitment was difficult due to restraints caused by the clinical workload of participants. Clinicians were working predominantly out of hours, including night shifts and weekend work, as well as their being an unprecedented vacancy rate in ED clinicians (Royal College of Emergency Medicine, 2019). Additionally, the workload of more senior clinicians prevented them being able to take time out of their shift to take part in an interview. There were difficulties accessing some participant groups that I would have liked to interview, including ED administrative staff and ED nurses. Although attempts were made on several occasions to contact senior leads who could have potentially acted as gatekeepers to these staff, these approaches were ignored, which made access to this group difficult. Permission was needed by HCP's to take time away from clinical practice to participate in the interview; without gatekeeper buy-in this proved difficult. Furthermore, although some clinicians did volunteer to take part, often this failed to translate into actual interviews, for several work-related and personal reasons.

Evidently, various factors affected the ability to recruit and in hindsight, a more flexible approach to maximise recruitment and data collection may have yielded a wider sample size. For example, contact with gatekeepers across all HCP groups to facilitate staff participation; hospital newsletter and flyers posted on relevant department notice boards to promote study awareness, and presentation delivery at departmental meetings to promote interest in the study and to facilitate potential recruitment of prospective participants. Use of varied and alternative HCP recruitment strategies would likely secure a larger sample size and subsequent provision of a broader data set from those involved in the delivery of care under the seizure care pathway.

As a result of the low response rate in from the HCP interview sample, there may be variability in the richness of the dataset obtained. Although most qualitative work focuses on data saturation as a criterion for sample size, we may consider the concept of information power and the ability for the contribution of new knowledge from the data analysis as most important (Malterud et al., 2016). Information power of a sample is guided by items such as study aim, sample specificity, use of established theory, quality of the dialogue, and the analysis strategy. For this study, I may have considered that I am novice researcher with limited background knowledge of the condition which I was exploring, which may implore that a larger sample size would be of benefit. However, the study had a reasonably strong theoretical background and its aim somewhat narrow, implying that a smaller sample may suffice (Malterud et al., 2016). In hindsight, it may have been sensible to consider this concept before completing the interviews in order to enhance the richness of data, particularly for the professional staff sample.

8.5 Implications for practice

I now discuss the implications of my work in relation to both patient experience of receiving care using the seizure care pathway, HCP experience of delivering care, and consideration for how we could improve the current seizure care pathway and audit improvements to enhance future practice. Findings will also be discussed in relation to how they Suggestions for future research will be discussed.

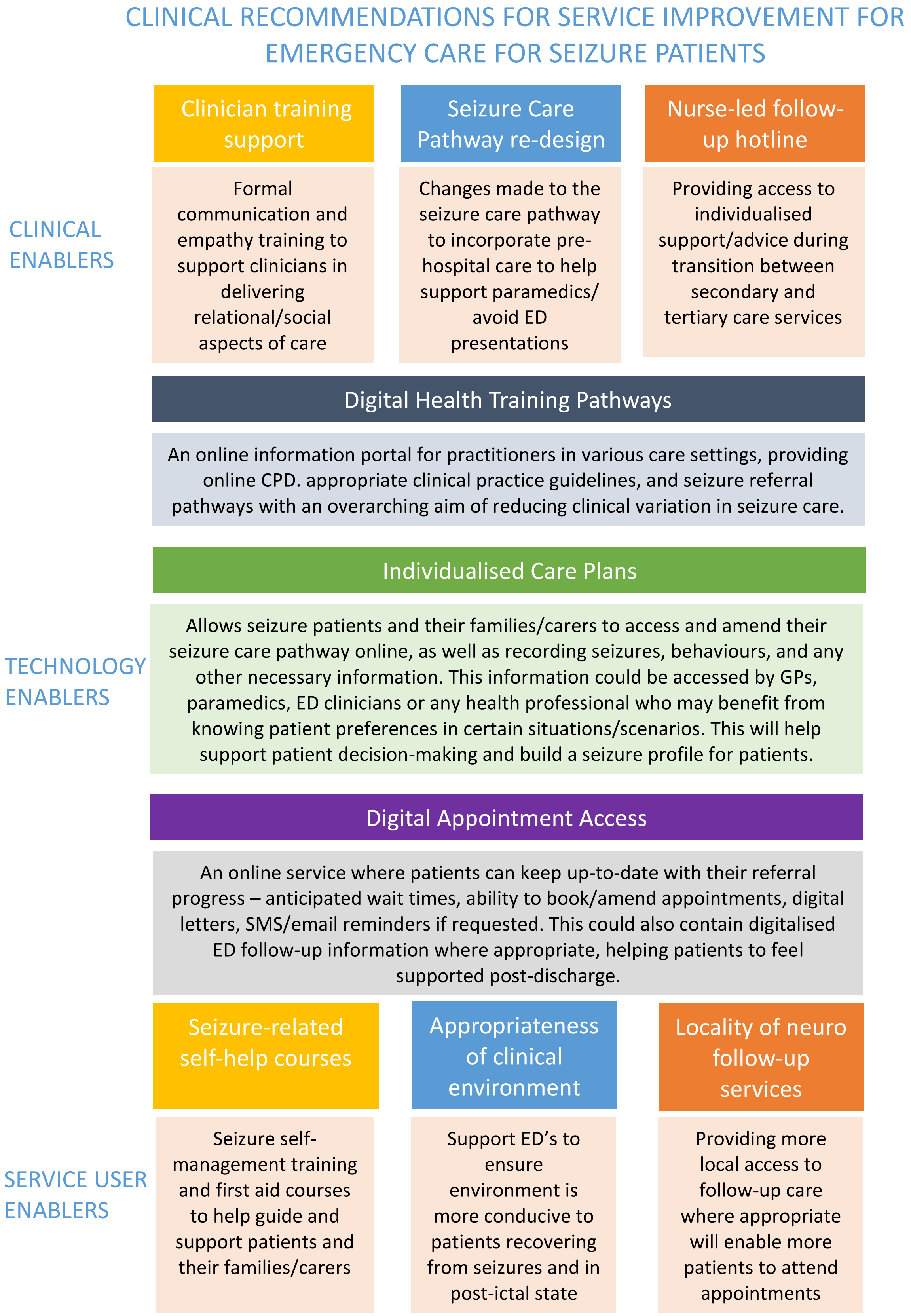
8.5.1 Clinical recommendations

The study has expanded the limited evidence-base for the seizure care pathway in relation to: how it is perceived by those who access it and by those who use it to deliver care, and provides suggestions for improvements. Recommendations for future clinical practice have been suggested by patients, their carers and HCPs, with some comparable recommendations being made. Figure 8-1 provides an overview of the recommendations that have previously been discussed in chapters six and seven, and additional recommendations are discussed below.

8.5.1.1 Paramedic knowledge

Some patient participants and their families suggested that improving knowledge and management of seizures by paramedics may help to reduce the number of patients conveyed to EDs unnecessarily. Previous research with paramedics has raised concerns about the level of pre- and post-registration training around seizure care and management (Noble et al., 2016; Sherratt et al., 2017). In addition, paramedics welcomed opportunities for CPD and identified gaps in knowledge around their own perception of when patients with seizures did or did not need to attend the ED. A reported lack of confidence by paramedics around awareness of seizure types and patients' 'typical' presentations often led to conveyance to hospital as a precaution (Noble et al., 2016). Paramedic training around seizures and epilepsy should be re-visited to try to address these issues. We could consider whether including pre-hospital care into the seizure care pathway may help to address such issues, providing clearer guidance to paramedics and potentially an alternative pathway should patients not require the full facilities of a Type 1 emergency care department.

Figure 8-1 Summary of clinical recommendations



CLINICAL RECOMMENDATIONS FOR SERVICE IMPROVEMENT FOR EMERGENCY CARE FOR SEIZURE PATIENTS

CLINICAL ENABLERS

Clinician training support

Formal communication and empathy training to support clinicians in delivering relational/social aspects of care

Seizure Care Pathway re-design

Changes made to the seizure care pathway to incorporate pre-hospital care to help support paramedics/ avoid ED presentations

Nurse-led follow-up hotline

Providing access to individualised support/advice during transition between secondary and tertiary care services

Digital Health Training Pathways

An online information portal for practitioners in various care settings, providing online CPD. appropriate clinical practice guidelines, and seizure referral pathways with an overarching aim of reducing clinical variation in seizure care.

TECHNOLOGY ENABLERS

Individualised Care Plans

Allows seizure patients and their families/carers to access and amend their seizure care pathway online, as well as recording seizures, behaviours, and any other necessary information. This information could be accessed by GPs, paramedics, ED clinicians or any health professional who may benefit from knowing patient preferences in certain situations/scenarios. This will help support patient decision-making and build a seizure profile for patients.

Digital Appointment Access

An online service where patients can keep up-to-date with their referral progress – anticipated wait times, ability to book/amend appointments, digital letters, SMS/email reminders if requested. This could also contain digitalised ED follow-up information where appropriate, helping patients to feel supported post-discharge.

SERVICE USER ENABLERS

Seizure-related self-help courses

Seizure self-management training and first aid courses to help guide and support patients and their families/carers

Appropriateness of clinical environment

Support ED's to ensure environment is more conducive to patients recovering from seizures and in post-ictal state

Locality of neuro follow-up services

Providing more local access to follow-up care where appropriate will enable more patients to attend appointments

It may also be necessary to consider how patients with known epilepsy could inform paramedics about their condition or how information could be shared across services to provide a more streamline approach that could potentially reduce unnecessary hospital attendances for PWE. Currently in the North West of England, there is no offer of direct access to medical records for ambulance crews. In line with the NHS Improvement Carter report (2018), which recommends that ambulance services should take action to improve accessibility to and use of patient information on the frontline (NHS Improvements, 2019), a recent project, PED4PED (People with Epilepsy sharing Data for care with Paramedics and the Emergency Department), has been initiated with the aim to improve outcomes for PWE and reduce unnecessary admissions to ED by connecting data from GPs, hospitals and ambulance services and making it available to paramedics and ED staff when they are called out to see a patient requiring urgent care (Health Data Research UK, 2020). Although only a local study, it will be interesting to see the results of this and whether it makes a difference to the number of patients being conveyed to the ED with seizures and their outcomes.

Beyond the use of medical records, PWE could be asked to develop a seizure care plan, kept electronically, that is accessible to ambulance crews, detailing what their care preferences would be under different seizure scenarios. This could help towards supporting paramedics, while giving some ownership of decision-making back to patients. These could then be considered by ambulance crews, alongside their own clinical judgement of the situation, when making decisions around conveyance of PWE.

8.5.1.2 Improved in-house training and support

HCPs identified several barriers to the use of the pathway, from both logistical and training perspectives. Firstly, improving dissemination of the pathway existence and use is essential. Incorporating this into clinical induction training, as well as consistent reminders at handovers, may help to embed the pathway into practice. This will, in turn, help to support less senior clinicians, who are primarily managing the post-ictal seizure patients presenting to the ED, to have more knowledge and confidence around their seizure care and management.

As well as disseminating to clinicians about the existence of the pathway, clinicians also need to feel confident in using it to clinically manage seizure patients. Some F2 doctors reported a lack of seizure training in their general medical training. There should be feedback provided to the General Medical Council (GMC) from as a result of this study, to allow for a review of the training provided around seizure care and management. In addition, in-house training around trust-specific pathways and proformas and ward-level support should be offered by senior clinicians. *The Doctor as a Teacher,* published by the GMC (General Medical Council, 1999), states that "*every doctor should be prepared to oversee the work of less experienced colleagues",* clearly articulating the obligations for the senior professional (i.e. consultants) in relation to those less experienced (Johnson, 2001). This could be achieved through the upskilling of consultants to translate clinical experiences into learning opportunities. For example, this may include working through specific problems or cases together (either on an individual basis or in groups) to support learning and help grow confidence of less senior clinicians and trainees (Johnson, 2001).

Another method to increase confidence in foundation level doctors could include the use of simulation-based training (SBT), which has been proven to reduce anxiety, improve self-confidence and improve feelings of being proficient (Cass et al., 2011). A recent study demonstrated the success of SBT with junior doctors, in supporting them to feel better prepared, improve their use of algorithms, and support them in feeling confident in decision-making (Marker et al., 2019). Utilising such methods to support foundation level doctors in their delivery of clinical care to seizure patients may not only improve their own confidence, but in turn, could improve patient outcomes and experiences.

8.5.1.3 Communication

Evidence from this research suggests that if communication is not effective, patient anxiety and fears may increase, which in turn leads to negative experiences. Previous research suggests that ED staff tend to be more task-orientated and forget psychological factors which may influence experience (Byrne and Heyman, 1997b). Where the current seizure care pathway is also very task-orientated and prescriptive in nature, it may be worthwhile incorporating some relational aspects of care into it to provide a more holistic approach to the needs of the patient. Amending the pathway to prompt clinicians to consider the relational aspects of the care they give, building rapport with patients and providing reassurance where possible, could result in a better overall experience of care for patients.

As an improvement suggestion, one patient participant proposed that alternative methods of contact could be used to improve communication to better suit the needs of the population. This suggestion included the use of up-to-date technology, moving away from simple letters, to texting and emailing appointments and updates. Some trusts UK-wide have already made the move to digital outpatient appointment letters (Honeyman et al., 2016), which also has valuable cost-saving benefits. Health and Social Care Secretary, Matt Hancock, has more recently challenged the NHS to ditch manual processes and outdated technology, such as fax systems, and move to more modern digital solutions:

> *‘Having to deal with outdated technology is hugely frustrating for staff and patients alike – and in many cases downright dangerous. A letter lost in the post could be the difference between life and death.’* (Department of Health and Social Care, 2019)

As well as having cost-saving implications, this may also help patients to keep track of where they are up to in the referral system, helping to reduce the feelings of uncertainty and abandonment reported by participants in their experience between ED discharge and OPD follow-up.

This move away from fax systems, has huge implications for the seizure care pathway, whose referral process is based around a system of faxing paperwork across to the tertiary trust. Alternative arrangements need to be considered promptly to ensure that this change does not impact patient care or cause further delays in follow-up services. As the referral fax system is an issue that has already been raised by HCPs within this study, merely removing the system will not, particularly in the short-term, help this problem, and could in fact, make things worse.

8.5.1.4 ED environment

The environment in which participants were cared for in the ED and OPD was prominent throughout interview discussions. Although consideration of the physical environment may not be an appropriate inclusion in the seizure care pathway, it remains an important reflection when discussing patient experience in the ED. Interview participants suggested ways in which the ED environment could be made more conducive to recovering post-ictally from a seizure, including the use of quiet, darkened spaces, with limited visual stimuli or noise. Previous qualitative work has made recommendations to improve the physical environment in other populations, such as the elderly (Kelley et al., 2011). The study found that an overcrowded, chaotic ED environment with lack of orientation and wayfinding cues, as well as appropriate equipment and furniture, made the environment difficult to negotiate and not conducive to providing appropriate care to the elderly population (Kelley et al., 2011). Although the specific epilepsy population is a small cohort of patients compared to the general elderly population, it is important for ED managers to consider how the environment could be adapted to best support these patients in the ED. A simple, dedicated ‘quiet room’, with less visual stimuli and noise, could be enough to help support these patients. Such an environment could be used by other patient populations, such as those with learning difficulties, when not being occupied by a patient recovering from a seizure.

8.5.1.5 Self-management and first aid

Participants' perceived ability to self-manage and their individual understanding of clinical need in relation to a seizure event is likely to underpin the decision-making process when attending the ED. It is important therefore, that practices are put in place to encourage and support self-management in this population and to increase understanding of seizures (Helmers et al., 2017). This will not only improve self-efficacy but also has potential to reduce unnecessary seizure attendances, where patients only attend the ED as they are ill-equipped to self-manage the situation.

Research has demonstrated that patients who have high levels of self-efficacy and possess positive attitudes towards self-management behaviours are more likely to perform those behaviours, leading to an improvement in condition and a reduction in GP and ED visits (Lorig et al., 2001). Actively participating in health care not only involves knowing how and where to access care services to suit clinical need, but also adopting health-promoting behaviours that may improve the condition. For example, in PWE, basic general health requirements are as important as medication management, and so maintaining a healthy diet, an adequate sleep pattern, and reducing stress are all ways that patients can actively participate in the control of their condition (Kobau and DiIorio, 2003). It is important that interventions, such as the seizure care pathway, are clear in encouraging these behaviours in order to support patients to be able to take control and manage their conditions appropriately. At present, the seizure care pathway contains a small section called 'Seizure Triggers'. It may be useful to expand on this to provide further information about the importance of looking after yourself as a PWE and how this can help with seizure control.

Improving self-management and supporting patients to be active participants in their own health care by providing a context in which patients feel able to participate and share decision-making if they wish, may make for a better overall experience for these patients (National Institute for Health and Care Excellence, 2016b). A recent study developed and assessed the acceptability of a first aid intervention for patients who attended the ED following a seizure (Snape et al., 2017). The intervention included an adapted version of a group-based seizure management course offered by the Epilepsy Society. Feedback was generally positive, highlighting both practical and psychosocial benefits (Snape et al., 2017). Further evaluation is needed to determine the effects of the intervention on participant behaviours' however, initial feedback holds promise that such interventions may be useful follow-up for those attending the ED and their carers.

8.5.1.6 GP and ESN access

Generally speaking, with their availability locally and designated systems for urgent care needs, patients should view GP services as their first line for care (Hunter et al., 2013). However, for patients such as those in this study, there remains a perceived lack of permeability of these services; due to receptionists' gatekeeping, travel costs, and accessibility issues. In this study, the combination of high permeability and technological expertise led most participants to choose the hospital ED in times of perceived urgent need.

Fear and uncertainty regarding follow-up, even now that the seizure care pathway has been implemented, leads patients to re-attend the ED unnecessarily in order to access care. By adding extra support services during this time period, such as ESN phone service or better access to GP services, this may help to reduce unnecessary ED attendances, reducing fear and anxiety in these patients, and, in turn, lead to a better experience of the care pathway. Integrating follow-up care processes into the seizure care pathway could help to eliminate some of this patient dissatisfaction and provide a clearer pathway for seizure patients once discharged from the ED.

The impact of the role of the ESN in care of PWE has been well documented and previously discussed within this thesis (Higgins et al., 2018; Räty et al., 2009; Ridsdale et al., 2013). The role of ESN should be highlighted to those experiencing their first seizure as a potential point of contact after leaving the ED and before accessing the neurology service. This may help to improve experience while supporting patients' during this time where there is increased anxiety and uncertainty about a potential future diagnosis. This could be highlighted through the information sheet on the care pathway, to allow support to patients on discharge from the ED, supporting feelings of abandonment during the transition period from ED to OPD appointment.

Arguably, this situation needs to be addressed if support to patients in the community is to improve and avoidable hospital admissions for seizures, where possible, are to be reduced. Inclusion of primary care into the care pathway, something that was discussed during HCP interviews, may help with transition and support GPs in feeling more empowered regarding their involvement in treatment and long-term management in less complex cases of epilepsy/seizures.

8.5.1.7 Outreach of neurological care

Another clinical recommendation, discussed by both patients and HCPs, was the potential for outreach neurology services, making services more accessible to patients. Some patients had to make significant journeys to attend the tertiary care centre for follow-up, which were made difficult by a lack of availability of transport and inability to drive following a seizure.

A report by the Neurological Alliance (2018) highlighted how local appointments are virtually non-existent across the North West regions. The call to integrate care services back into district general hospitals (DGHs), offering a ‘hub and spoke’ service, may be a model of care that could help better support seizure patients. Despite being proposed, this model of care has previously come under criticism for leaving DGHs and community services underserved, with neurologists rarely branching out to the ‘spokes’ (Morrish, 2015). There is potential that re-focusing epilepsy care services around community settings could ultimately reduce health inequalities through improved access to care.

8.5.2 Research recommendations

This programme of research has explored patients’ and professionals’ perspectives of a seizure care pathway for use in EDs, using a qualitative design, informed by MRC guidance for process evaluation. As stated by Glogowska (2011), given the increasing complexity of health and social intervention, mixed methods research can provide a more realistic and ultimately more useful picture of what is happening. A mixed methods approach should be considered more frequently in health care, as it can provide comprehensive in-depth answers to clinical research questions. In addition, such research could contribute substantively to the future development of mixed-methods research:

- Seizure-related research should include PWE wherever possible.
- Future research should explore the content and process of alternative seizure care pathways, utilising different health care organisations to compare findings of this study.
- Future seizure care pathway research should further consider the value of a national seizure care pathway to streamline services and reduce inequality in services to PWE and their families.
- A means to audit the use of the pathway, as well as its benefits to patient experience, may be considered to assess the use and effectiveness of the pathway in future.

8.6 Dissemination and audit

As initially outlined in the thesis plan, objective five set out to explore ways in which patient experience the seizure care pathway could be audited. At present, I feel that the seizure care pathway itself requires attention to further develop its acceptability to both patients and staff, as outlined in this thesis. To help support this development, conversations have taken place with the Walton Centre Vanguard Team, as a means to disseminating study findings, to promote dialogue in relation to seizure care pathway use and to seek assistance with advancing the evolution of the seizure care pathway.

It is important to question what is acceptable and what expectations patients have that are beyond the capacity of NHS care delivery. While perceived permeability of services and local operating conditions may result in patient dissatisfaction with their care experience, there must also be recognition that the NHS, with its finite resources, cannot always deliver everything that a patient may expect. While some of the suggestions posed in this chapter are high-level and would require whole system service change, such as the remodelling of neurology services and the increase in ESN posts, others, such as changes to the ED environment and increasing local in-hospital training in communication and use of the pathway, are more achievable short-term to improve patient experiences.

Research by Lowe et al. (2018) suggests the use of 'Always Events', asking patients questions based on what they believe should always happen in the ED, as a way to audit and improve patient experiences. While the study demonstrated improvements in patient experience in the ED through the minor injuries stream (MIS), it may be an approach that is transferable to disease-specific populations to support clinicians, trusts and policy makers in the management of patient expectations while maintaining high quality patient care (Lowe et al., 2018).

8.7 Conclusions

In this thesis I have reflected on previous research in relation to patient experience of seizure care and integrated knowledge gained from care pathways designed for other conditions to guide my research aimed at exploring patient experience of delivery of seizure care pathway in the ED. Throughout my research I took a rigorous, evidence-based and systematic approach in exploring, understanding and developing each stage to ensure the overall quality and novelty of the research. This helped to ensure that relevant changes were made to the scope of the thesis in response to my questions and to ultimately enhance the depth and breadth of study findings. I have found parallels between my research and existing seizure literature, whilst also generating novel insights around patient experience of ED, particularly relating to the transition from ED to OPD appointments and the gap in support that many patients reported. In adapting the initial research proposal, I have introduced a new perspective in exploring the seizure care pathway from the viewpoint of those delivering care, which may be particularly relevant in making comparison between their experiences and suggesting ways to improve the future use of the pathway. I hope my research will act as a benchmark for future developments; leading others to consider how best to use the seizure care pathway to improve the care quality and patient experience of patients, particularly in transition between care services, with the goal of improving experiences for people attending the ED following a seizure. The ongoing involvement of patients with epilepsy in future seizure care pathway research is also paramount.

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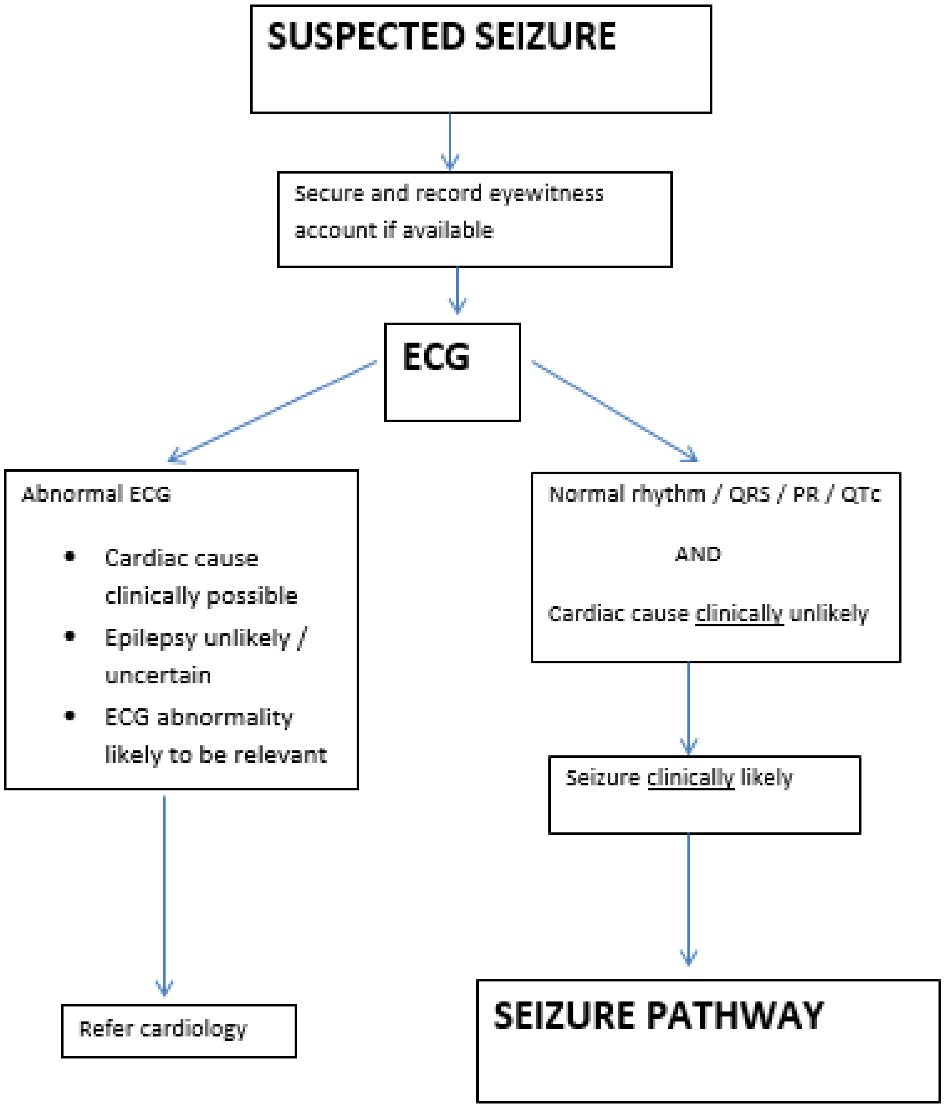
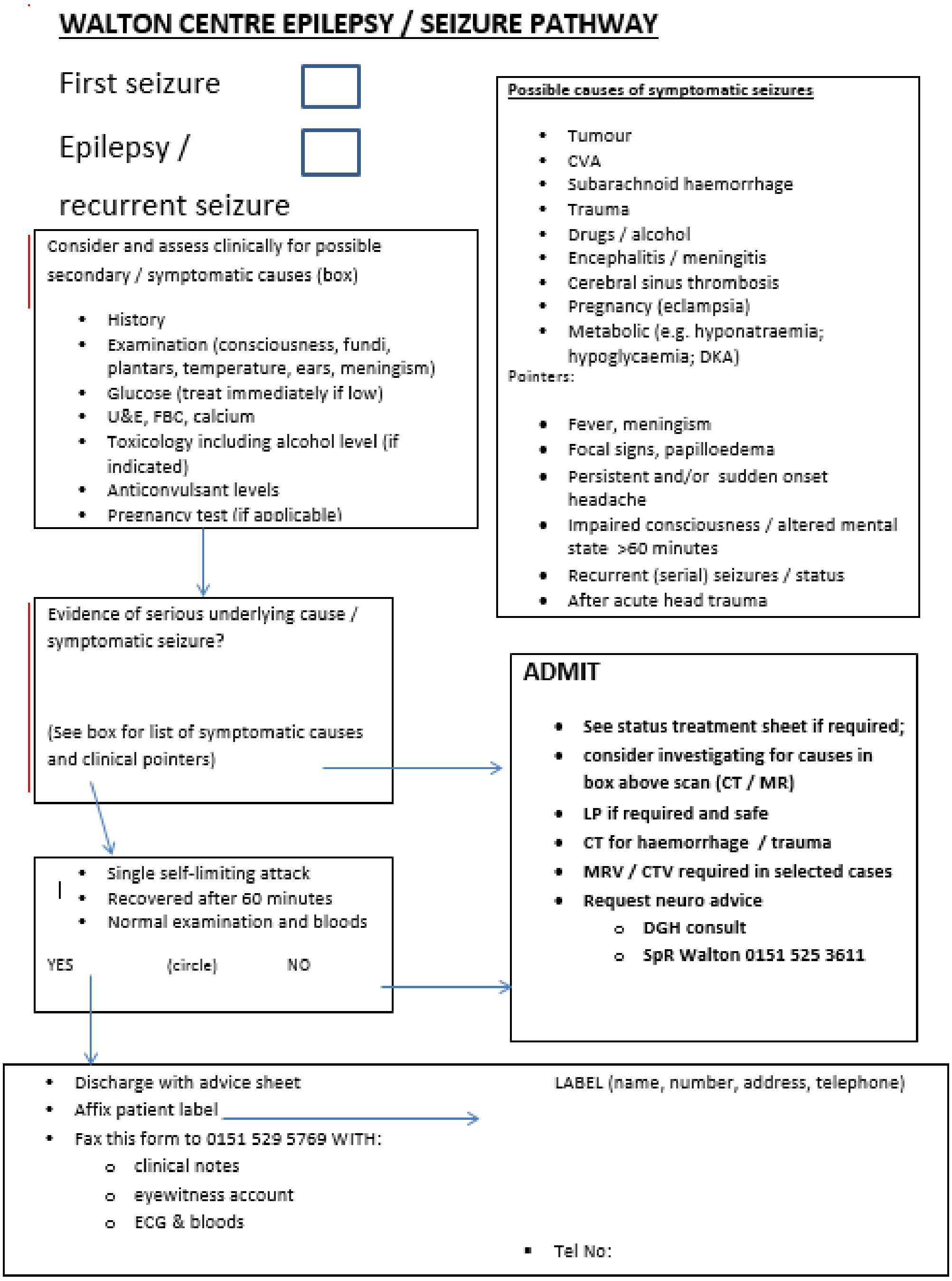
Appendix A: Seizure Care Pathway

Walton Centre Epilepsy / Seizure Management





WALTON CENTRE EPILEPSY / SEIZURE PATHWAY

First seizure ☐

Epilepsy / recurrent seizure ☐

Possible causes of symptomatic seizures

- Tumour
- CVA
- Subarachnoid haemorrhage
- Trauma
- Drugs / alcohol
- Encephalitis / meningitis
- Cerebral sinus thrombosis
- Pregnancy (eclampsia)
- Metabolic (e.g. hyponatraemia; hypoglycaemia; DKA)

Pointers:

- Fever, meningism
- Focal signs, papilloedema
- Persistent and/or sudden onset headache
- Impaired consciousness / altered mental state >60 minutes
- Recurrent (serial) seizures / status
- After acute head trauma

Consider and assess clinically for possible secondary / symptomatic causes (box)

- History
- Examination (consciousness, fundi, plantars, temperature, ears, meningism)
- Glucose (treat immediately if low)
- U&E, FBC, calcium
- Toxicology including alcohol level (if indicated)
- Anticonvulsant levels
- Pregnancy test (if applicable)

Evidence of serious underlying cause / symptomatic seizure?

(See box for list of symptomatic causes and clinical pointers)

ADMIT

- **See status treatment sheet if required;**
- **consider investigating for causes in box above scan (CT / MR)**
- **LP if required and safe**
- **CT for haemorrhage / trauma**
- **MRV / CTV required in selected cases**
- **Request neuro advice**
  - **DGH consult**
  - **SpR Walton 0151 525 3611**

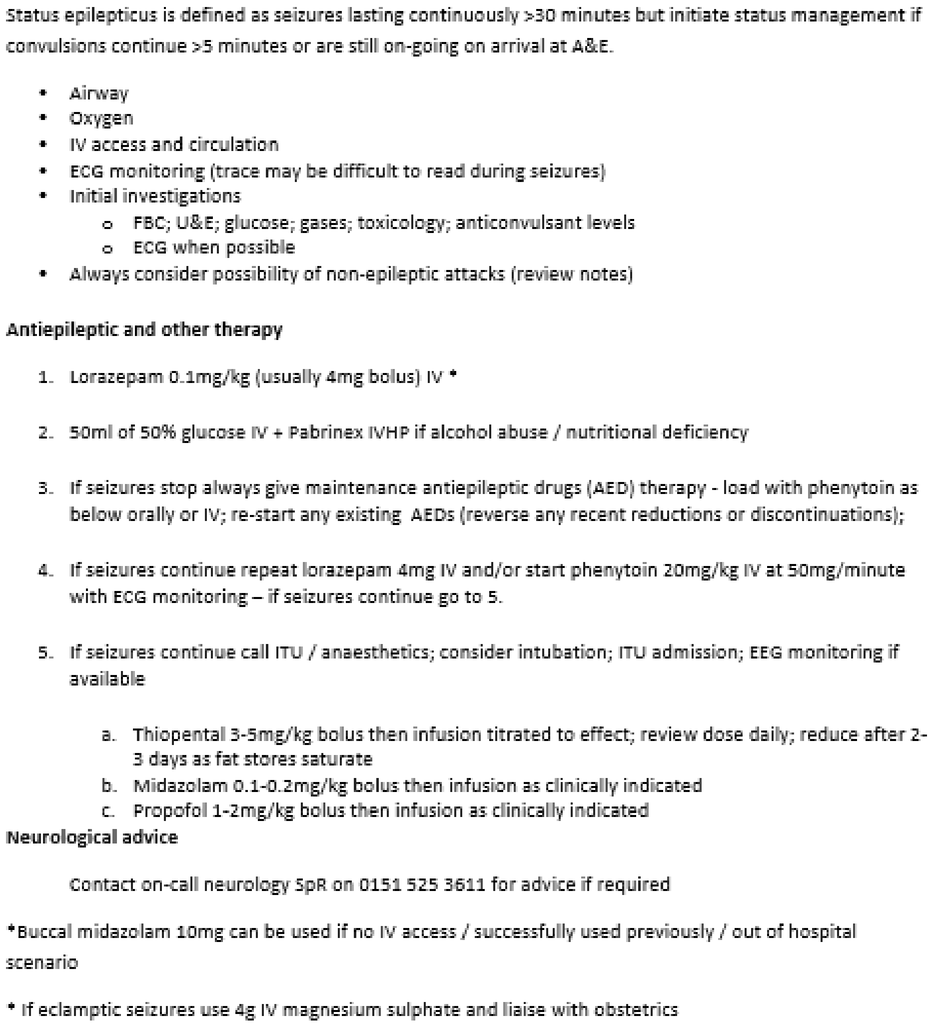
- Single self-limiting attack
- Recovered after 60 minutes
- Normal examination and bloods

YES (circle) NO

- Discharge with advice sheet
- Affix patient label
- Fax this form to 0151 529 5769 WITH:
  - clinical notes
  - eyewitness account
  - ECG & bloods

LABEL (name, number, address, telephone)

- Tel No:



Status epilepticus is defined as seizures lasting continuously >30 minutes but initiate status management if convulsions continue >5 minutes or are still on-going on arrival at A&E.

- Airway
- Oxygen
- IV access and circulation
- ECG monitoring (trace may be difficult to read during seizures)
- Initial investigations
  - FBC; U&E; glucose; gases; toxicology; anticonvulsant levels
  - ECG when possible
- Always consider possibility of non-epileptic attacks (review notes)

Antiepileptic and other therapy

1. Lorazepam 0.1mg/kg (usually 4mg bolus) IV *

2. 50ml of 50% glucose IV + Pabrinex IVHP if alcohol abuse / nutritional deficiency

3. If seizures stop always give maintenance antiepileptic drugs (AED) therapy - load with phenytoin as below orally or IV; re-start any existing AEDs (reverse any recent reductions or discontinuations);

4. If seizures continue repeat lorazepam 4mg IV and/or start phenytoin 20mg/kg IV at 50mg/minute with ECG monitoring – if seizures continue go to 5.

5. If seizures continue call ITU / anaesthetics; consider intubation; ITU admission; EEG monitoring if available

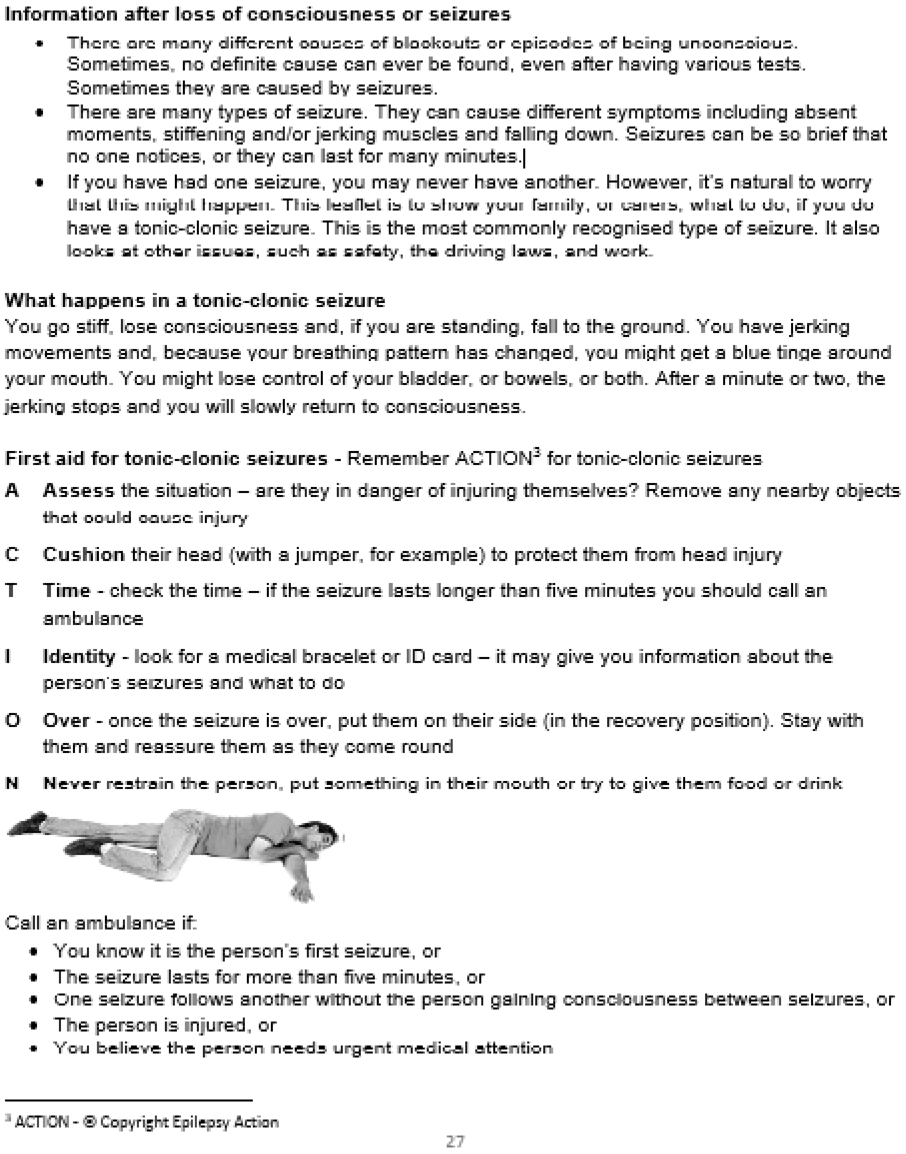
   a. Thiopental 3-5mg/kg bolus then infusion titrated to effect; review dose daily; reduce after 2-3 days as fat stores saturate
   b. Midazolam 0.1-0.2mg/kg bolus then infusion as clinically indicated
   c. Propofol 1-2mg/kg bolus then infusion as clinically indicated

Neurological advice

Contact on-call neurology SpR on 0151 525 3611 for advice if required

*Buccal midazolam 10mg can be used if no IV access / successfully used previously / out of hospital scenario

* If eclamptic seizures use 4g IV magnesium sulphate and liaise with obstetrics



Information after loss of consciousness or seizures

- There are many different causes of blackouts or episodes of being unconscious. Sometimes, no definite cause can ever be found, even after having various tests. Sometimes they are caused by seizures.
- There are many types of seizure. They can cause different symptoms including absent moments, stiffening and/or jerking muscles and falling down. Seizures can be so brief that no one notices, or they can last for many minutes.
- If you have had one seizure, you may never have another. However, it's natural to worry that this might happen. This leaflet is to show your family, or carers, what to do, if you do have a tonic-clonic seizure. This is the most commonly recognised type of seizure. It also looks at other issues, such as safety, the driving laws, and work.

What happens in a tonic-clonic seizure

You go stiff, lose consciousness and, if you are standing, fall to the ground. You have jerking movements and, because your breathing pattern has changed, you might get a blue tinge around your mouth. You might lose control of your bladder, or bowels, or both. After a minute or two, the jerking stops and you will slowly return to consciousness.

First aid for tonic-clonic seizures - Remember ACTION[3] for tonic-clonic seizures

A **Assess** the situation – are they in danger of injuring themselves? Remove any nearby objects that could cause injury

C **Cushion** their head (with a jumper, for example) to protect them from head injury

T **Time** - check the time – if the seizure lasts longer than five minutes you should call an ambulance

I **Identity** - look for a medical bracelet or ID card – it may give you information about the person's seizures and what to do

O **Over** - once the seizure is over, put them on their side (in the recovery position). Stay with them and reassure them as they come round

N **Never** restrain the person, put something in their mouth or try to give them food or drink

Call an ambulance if:

- You know it is the person's first seizure, or
- The seizure lasts for more than five minutes, or
- One seizure follows another without the person gaining consciousness between seizures, or
- The person is injured, or
- You believe the person needs urgent medical attention

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[3] ACTION - © Copyright Epilepsy Action

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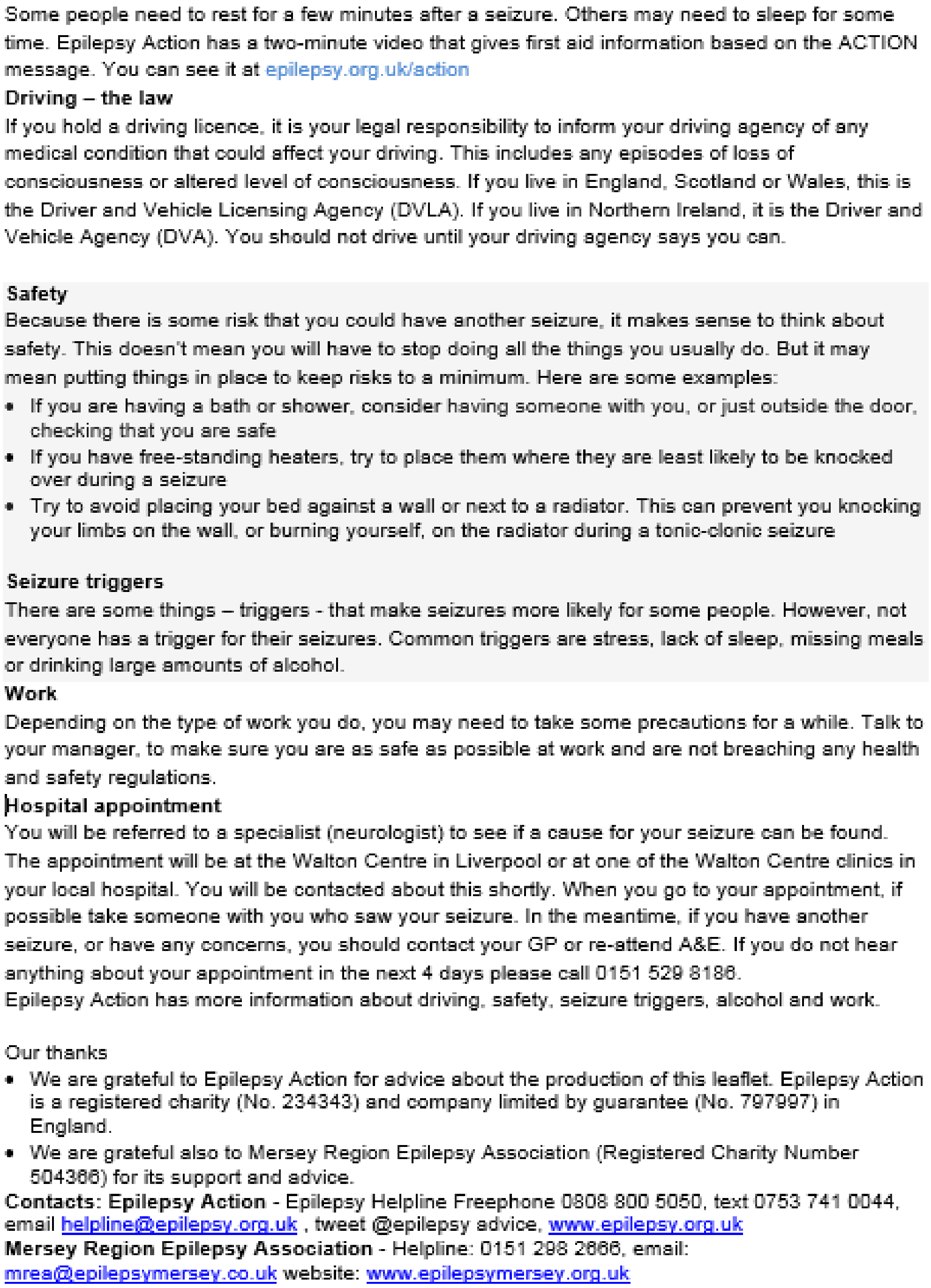


Some people need to rest for a few minutes after a seizure. Others may need to sleep for some time. Epilepsy Action has a two-minute video that gives first aid information based on the ACTION message. You can see it at epilepsy.org.uk/action

Driving – the law

If you hold a driving licence, it is your legal responsibility to inform your driving agency of any medical condition that could affect your driving. This includes any episodes of loss of consciousness or altered level of consciousness. If you live in England, Scotland or Wales, this is the Driver and Vehicle Licensing Agency (DVLA). If you live in Northern Ireland, it is the Driver and Vehicle Agency (DVA). You should not drive until your driving agency says you can.

Safety

Because there is some risk that you could have another seizure, it makes sense to think about safety. This doesn't mean you will have to stop doing all the things you usually do. But it may mean putting things in place to keep risks to a minimum. Here are some examples:

- If you are having a bath or shower, consider having someone with you, or just outside the door, checking that you are safe
- If you have free-standing heaters, try to place them where they are least likely to be knocked over during a seizure
- Try to avoid placing your bed against a wall or next to a radiator. This can prevent you knocking your limbs on the wall, or burning yourself, on the radiator during a tonic-clonic seizure

Seizure triggers

There are some things – triggers - that make seizures more likely for some people. However, not everyone has a trigger for their seizures. Common triggers are stress, lack of sleep, missing meals or drinking large amounts of alcohol.

Work

Depending on the type of work you do, you may need to take some precautions for a while. Talk to your manager, to make sure you are as safe as possible at work and are not breaching any health and safety regulations.

Hospital appointment

You will be referred to a specialist (neurologist) to see if a cause for your seizure can be found. The appointment will be at the Walton Centre in Liverpool or at one of the Walton Centre clinics in your local hospital. You will be contacted about this shortly. When you go to your appointment, if possible take someone with you who saw your seizure. In the meantime, if you have another seizure, or have any concerns, you should contact your GP or re-attend A&E. If you do not hear anything about your appointment in the next 4 days please call 0151 529 8186.

Epilepsy Action has more information about driving, safety, seizure triggers, alcohol and work.

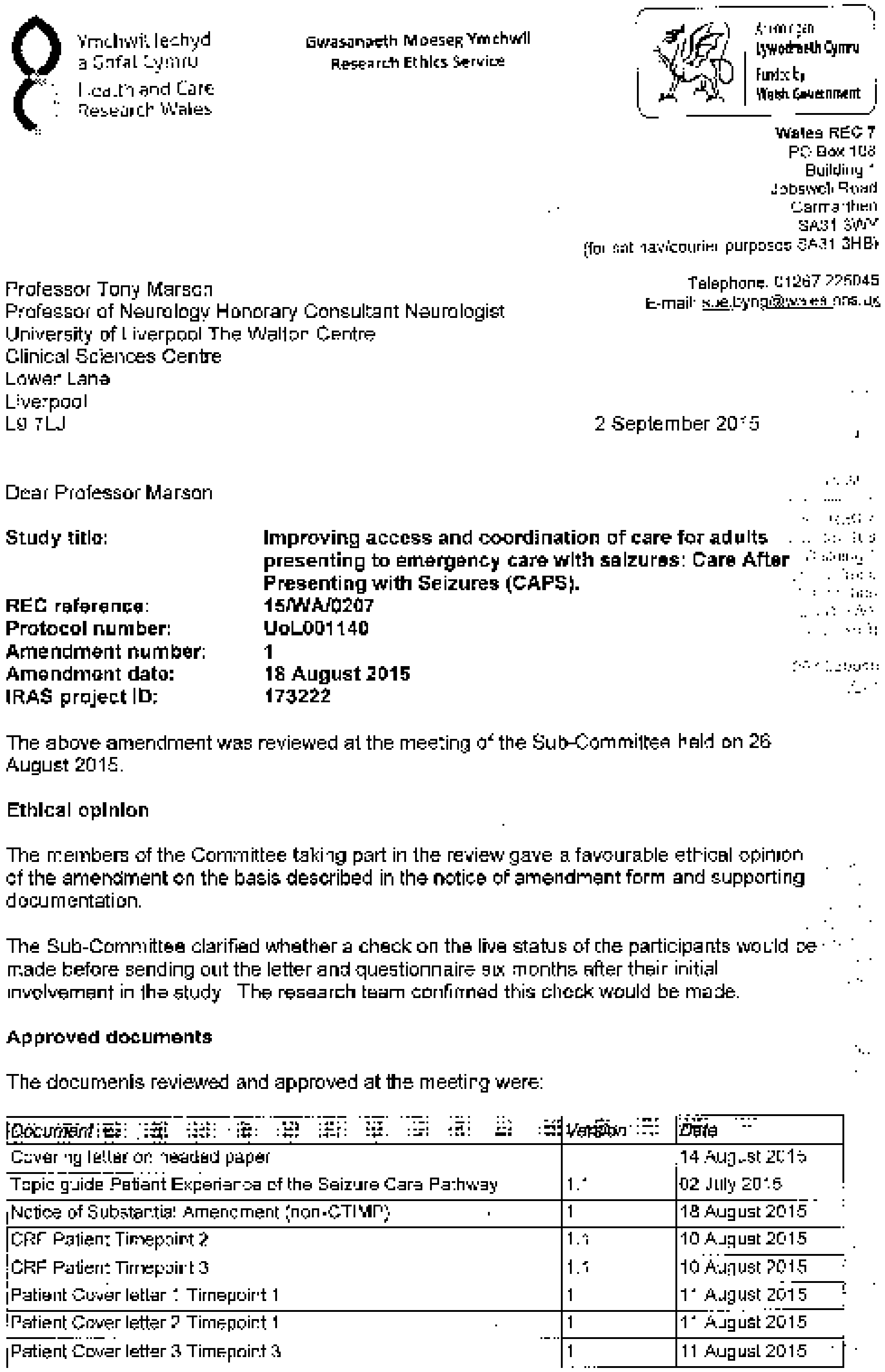
Our thanks

- We are grateful to Epilepsy Action for advice about the production of this leaflet. Epilepsy Action is a registered charity (No. 234343) and company limited by guarantee (No. 797997) in England.
- We are grateful also to Mersey Region Epilepsy Association (Registered Charity Number 504366) for its support and advice.

Contacts: Epilepsy Action - Epilepsy Helpline Freephone 0808 800 5050, text 0753 741 0044, email helpline@epilepsy.org.uk , tweet @epilepsy advice, www.epilepsy.org.uk

Mersey Region Epilepsy Association - Helpline: 0151 298 2666, email: mrea@epilepsymersey.co.uk website: www.epilepsymersey.org.uk

Appendix B: Ethical approval



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

Gwasanaeth Moeseg Ymchwil
Research Ethics Service

Ariennir gan
Llywodraeth Cymru
Funded by
Welsh Government

Wales REC 7
PO Box 108
Building 1
Jobswell Road
Carmarthen
SA31 3WY
(for sat nav/courier purposes SA31 3HB)

Telephone. 01267 225045
E-mail: sue.byng@wales.nhs.uk

Professor Tony Marson
Professor of Neurology Honorary Consultant Neurologist
University of Liverpool The Walton Centre
Clinical Sciences Centre
Lower Lane
Liverpool
L9 7LJ

2 September 2015

Dear Professor Marson

Study title:	**Improving access and coordination of care for adults presenting to emergency care with seizures: Care After Presenting with Seizures (CAPS).**
REC reference:	**15/WA/0207**
Protocol number:	**UoL001140**
Amendment number:	**1**
Amendment date:	**18 August 2015**
IRAS project ID:	**173222**

The above amendment was reviewed at the meeting of the Sub-Committee held on 26 August 2015.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

The Sub-Committee clarified whether a check on the live status of the participants would be made before sending out the letter and questionnaire six months after their initial involvement in the study. The research team confirmed this check would be made.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Covering letter on headed paper		14 August 2015
Topic guide Patient Experience of the Seizure Care Pathway	1.1	02 July 2015
Notice of Substantial Amendment (non-CTIMP)	1	18 August 2015
CRF Patient Timepoint 2	1.1	10 August 2015
CRF Patient Timepoint 3	1.1	10 August 2015
Patient Cover letter 1 Timepoint 1	1	11 August 2015
Patient Cover letter 2 Timepoint 1	1	11 August 2015
Patient Cover letter 3 Timepoint 3	1	11 August 2015

Appendix C: Patient participant information sheet

NHS
National Institute for
Health Research

Collaboration for Leadership in
Applied Health Research and Care
North West Coast

CAPS

UNIVERSITY OF
LIVERPOOL

The Walton Centre NHS
NHS Foundation Trust
Excellence in Neuroscience

Postgraduate Research Study
Care After Presenting with Seizures (CAPS)

Principal Researchers: Professor Tony Marson & Professor Mike Pearson

Development of a Patient-Reported Experience Measure (PREM) for patients accessing emergency care services following a suspected seizure.

Protocol Number: UoL001140

INFORMATION LEAFLET FOR PARTICIPANTS

You are invited to take part in an interview to find out about your experience when you recently visited the Emergency Department in your local hospital.

Before you decide to take part it is essential that you understand what the research is for, and what will be involved if you chose to take part. This leaflet is designed to explain this information.
Please feel free to discuss this study with your friends or family, and if there is anything that is unclear, or you want some further information, please phone or email me using the contact details at the end of this leaflet.

Why are we doing this research?

This research study is being done as part of a PhD thesis at the University of Liverpool. It is part of a wider project called CAPS (Care After Presenting with Seizures). The overall aim is to improve the care that people receive after presenting to emergency departments with a seizure or suspected seizure. We want to know how this process can be improved. We hope that these interviews will help us to develop a questionnaire that will help to improve your experience of care in the emergency department and in outpatient clinics for seizures.

Why have I been invited to take part?

You have been chosen because you attended the Emergency Department in a local hospital since the CAPS project began (23/10/2015). You were contacted by one of the team's research nurses and agreed to take part in our study, which included the possibility that you may be interviewed. We wish to interview adult patients (and where relevant their carers (i.e. a spouse or partner, close family member or companion)) who have received treatment in the Emergency Department following a seizure.

Do I have to take part?

No, you do not have to take part. Whether you choose to take part or not, or if you withdraw at any point, the care that you receive will be the same. You can change your mind at any time, and withdraw from the study up to the point of transcription, without having to give a reason.

What will happen if I take part?

If you decide to take part in the study the PhD student will organise a location and time for interview that is most convenient for you. The interview will last approximately one hour. You will be asked some general questions about your recent experience in the emergency department and in our outpatient clinic. You will also be asked if you had a good or bad experience and for any feedback about your care.

You will then be asked to complete a survey that is used nationally in hospitals to find out about patient experience. You will be asked to complete this thinking about your last attendance in the emergency department. Finally, you will be given an opportunity to give some general feedback about the survey.

What are the risks and benefits of taking part?

There are no risks in taking part in the study and there are no direct benefits to taking part.

Will my information be kept confidential?

All data will be protected in accordance with the Data Protection Act 1998. Interviews will be recorded on audio tape with your permission and then transcribed onto a computer. Audiotapes will always be locked in a secure place and the computer will be password protected. Audiotapes will be destroyed at the end of the study. As part of the presentation of results, your own words may be used in text form. This will be anonymised so that you cannot be identified by what you have said.

Will I be contacted again after I take part?

You may be contacted again to take part in a further interview to help in the development of a questionnaire based on your first interview. More information will be given about this at the time.

Who is funding the research?

This is a NIHR CLAHRC North West Coast funded project involving the following partners; Walton Centre, Aintree University Hospital, Wirral University Teaching Hospital and University of Liverpool.

What will happen to the results of the research?

The results will be used as part of a PhD thesis at the University of Liverpool. The results may also be disseminated through publication and conferences.

Who should I contact for further information?

If you have any further questions or require any more information regarding the study, please contact me on the details below.
Name: Leanne Male
Email: hllmale@student.liv.ac.uk
Telephone: 0151 529 8431

Who should I contact if I am not happy?

If you are not happy for any reason with the conduct of the study or you feel that the study has harmed you in any way, you can contact my academic supervisor using the following details:
Name: Prof. Tony Marson
Email: 0151 529 5705

Thank you for taking the time to read this information and considering taking part in this research study.

Appendix D: Staff participant information sheet

Postgraduate Research Study
Care After Presenting with Seizures (CAPS)

Principal Researchers: Professor Tony Marson & Professor Mike Pearson

A Qualitative Study Exploring the Experiences of Health Professionals
Working on Seizure Care Pathway Services.

Protocol Number: UoL001140

INFORMATION LEAFLET FOR PARTICIPANTS

Before you decide to take part it is essential that you understand what the research is for, and what will be involved if you chose to take part. This leaflet is designed to explain this information.

What is this research about?

This research study is being done as part of a PhD thesis at the University of Liverpool. It is part of a wider project called CAPS (Care After Presenting with Seizures). The overall aim is to improve the care that people receive after presenting to emergency departments with a seizure or suspected seizure.

I am requesting your participation in the study to look at the experiences of healthcare professionals working with patients on the seizure care pathway. This will involve an individual interview that will last approximately one hour. During the interview you will be asked about your experience of working with patients along the seizure care pathway and your understanding of this.

Why have I been invited to take part?

You have been identified as a clinician or other health professional involved in the care of patients along the seizure care pathway, from the emergency department through to being seen at Walton Centre neurology services.

Do I have to take part?

No, you do not have to take part. You can change your mind at any time and withdraw from the study up to the point of transcription, without having to give a reason.

What will happen if I take part?

If you decide to take part in the study the PhD student will organise a location and time for interview that is most convenient for you. The interview will last approximately one hour. During the interview you will be invited to share your opinions and experiences of working with seizure patients across the seizure care pathway, with a particular focus on the transition of care between emergency care services and neurology outpatient services. Once the interview is complete, there will be opportunity for you to ask further questions about the study.

What are the risks and benefits of taking part?

There are no risks in taking part in the study and there are no direct benefits to taking part.

Will my information be kept confidential?

All data will be protected in accordance with the Data Protection Act 1998. Interviews will be recorded using a digital audio recorder with your permission and then transcribed onto a computer. The digital audio recorder will always be locked in a secure place and the computer will be password protected. Audio recordings will be destroyed at the end of the study. As part of the presentation of results, your own words may be used in text form. This will be anonymised so that you cannot be identified by what you have said.

Who is funding the research?

This is a NIHR CLAHRC North West Coast funded project involving the following partners; Walton Centre, Aintree University Hospital, Wirral University Teaching Hospital and University of Liverpool.

What will happen to the results of the research?

The results will be used as part of a PhD thesis at the University of Liverpool. The results may also be disseminated through publication and conferences.

Who should I contact for further information?

If you have any further questions or require any more information regarding the study, please contact me on the details below.

Name: Leanne Male
Email: hllmale@student.liv.ac.uk
Telephone: 0151 529 8431

Who should I contact if I am not happy?

If you are not happy for any reason with the conduct of the study or you feel that the study has harmed you in any way, you can contact my academic supervisor using the following details:
Name: Prof. Tony Marson
Email: 0151 529 5705

Thank you for taking the time to read this information and considering taking part in this research study.

Appendix E: Patient consent form

NHS
National Institute for
Health Research
Collaboration for Leadership in
Applied Health Research and Care
North West Coast

CAPS

UNIVERSITY OF
LIVERPOOL

The Walton Centre NHS
NHS Foundation Trust
Excellence in Neuroscience

Care After Presenting with Seizures– CAPS
Qualitative Interview Consent Form Version 1 Dated 20/05/2015

Centre Name: .... Name of Investigator: ....

Study Number: |__|__|__|__|__|__|__|__|__|__|

Patient's date of birth |__|__|/|__|__|/|__|__|__|__|

IRAS Project ID: 173222

Please initial boxes

1. I confirm I have read and understand the information leaflet (version 1.0 dated 20/05/2015) for the above study, and I have had the opportunity to ask questions and these have been answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw from the study at any time without giving a reason and without my care or legal rights being affected. ☐
3. I agree for my consent form and contact details (which will include my name, address, telephone number, date of birth) to be held by the University of Liverpool for the administration of the study. ☐
4. I agree to take part in an interview where I will be asked about my recent experience of the new seizure care process. ☐
5. I give permission for the results of my interview and survey to be used and analysed by authorised members of the research team. ☐
6. I agree to take part in the above study. ☐

________________________ ______________________ _____________
Name of Participant Signature Date (dd mm-yyyy)

________________________ ______________________ _____________
Researcher Signature Date (dd-mm-yyyy)

Appendix F: Carer consent form

NHS
National Institute for
Health Research
Collaboration for Leadership in
Applied Health Research and Care
North West Coast

CAPS

UNIVERSITY OF LIVERPOOL

The Walton Centre NHS
NHS Foundation Trust
Excellence in Neuroscience

Care After Presenting with Seizures– CAPS
Qualitative Interview Consent Form (Carer) Version 2 Dated 25/04/2016

Centre Name: ....

Name of Investigator: ....

Study Number: |__|__|__|__|__|__|__|__|__|__|/ CARER

IRAS Project ID: 173222

Please initial boxes

1. I confirm I have read and understand the information leaflet (version 2.0 dated 25/04/2016) for the above study, and I have had the opportunity to ask questions and these have been answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw from the study at any time without giving a reason and without any care or legal rights being affected. ☐
3. I agree for my consent form to be held by the University of Liverpool for the administration of the study. ☐
4. I agree to take part in an interview where I will be asked about a recent experience of the new seizure care process. ☐
5. I give permission for the results of my interview and survey to be used and analysed by authorised members of the research team. ☐
6. I agree to take part in the above study. ☐

________________________	_____________________	__________
Name of Participant (Carer)	Signature	Date (dd-mm-yyyy)
_________________________	_____________________	__________
Researcher	Signature	Date (dd-mm-yyyy)

Appendix G: Staff consent form

CONSENT FORM

Care After Presenting with Seizures– CAPS
Qualitative Health Care Professional Interview Consent Form Version 2 Dated 24/04/2017

Centre Name: Walton Centre

Name of Investigator: Leanne Burton

Study Number: |__|_|__|__|

IRAS Project ID: 173222

Please initial boxes

1. I confirm I have read and understand the information leaflet (version 1.0 dated 07/03/2017) for the above study, and I have had the opportunity to ask questions and these have been answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my rights being affected. In addition, should I not wish to answer any particular question or questions, I am free to decline. ☐
3. I understand that, under the Data Protection Act, I can at any time ask for access to the information I provide and I can also request the destruction of that information if I wish. ☐
4. I agree to take part in an interview where I will be asked about my professional views and experience of the seizure care pathway. I agree to the audio recording of this interview. ☐
5. I give permission for the results of my interview and survey to be used and analysed by authorised members of the research team. I agree that interview results will only be used once I have seen and agreed to the transcript. ☐
6. I agree to take part in the above study. ☐

______________________	______________________	______________
Name of Participant	Signature	Date (dd-mm-yyyy)
______________________	______________________	______________
Researcher	Signature	Date (dd-mm-yyyy)

Appendix H: Interview appointment letter

Collaboration for Leadership in
Applied Health Research and Care
North West Coast

Clinical Sciences Centre
Lower Lane
Liverpool
L9 7AL

(DATE)

Dear (PARTICIPANT NAME),

The Care After Presenting with Seizures (CAPS) Study

You recently spoke to a PhD student on the telephone and kindly agreed to take part in this study. The aim of the study is to assess and improve care for patients who attend emergency departments with a suspected seizure.

Please find enclosed a Patient Information leaflet which will give you further information on the study. I will bring along a consent form for you to complete before the interview starts.

The interview will take place on (DATE) at (TIME) at (LOCATION). I will telephone you before the interview to confirm this.

If you have any questions about the CAPS study and the information you have received With this letter, please contact myself on 0151 529 8431.

Thank you

Yours Sincerely,

Leanne Burton

PhD Student

Appendix I: Interview topic guides

1. Experience of ED

Aim: to explore experience of ED attendance and what aspects of care are important to the patient. To understand the ED care processes and its significance for overall experience.

Can you tell me about what happened to make you attend the ED?
Tell me a little about your experience of the Emergency Department?
Probe experiences and feelings in relation to;

- ED arrival
- Care process(es)
- Interaction with professionals
- Involvement in decision-making process related to care
  - When did you feel most involved, why?
  - If not, why?
- Information sharing
  - Opportunity to discuss issues/care
  - Level of information received
  - Satisfaction with information received, why?
    - If not, why not
  - Supported enough to make decisions about your care, in what way?
    - If not, why not?
- How information and support was received?

BEFORE WE MOVE ON IS THERE ANYTHING ELSE YOU WISH TO COMMENT ON IN RELATION TO YOUR INITIAL EXPERIENCE(S) OF THE ED

2. Comparison to previous experiences

Aim: to explore whether the changes in service provision (i.e. nurse-led pathway and fast track follow-up) has had any effect on the quality of care received by patients.

‘Was the most recent experience any different from past admissions/ED attendances?’
Probe experiences in relation to;

- Similarities/differences.
- Likes/dislikes
- Levels of satisfaction
- Etc....

BEFORE WE MOVE ON IS THERE ANYTHING ELSE YOU WISH TO COMMENT ON IN RELATION TO THE CHANGES THAT HAVE BEEN MADE TO THE ED SERVICES

3. What is ‘good care’?

Aim: to ascertain what patients recognise as ‘good’ care in relation to their ED experience.

‘If I say ‘good care’, what does this mean to you?’
Follow up;

- Expectations of the ED
- Service provision
- Shortfalls- what is lacking?
- What sort of changes, if any, could have been made to improve your care through different stages in ED?
- Barriers/facilitators

BEFORE WE MOVE ON IS THERE ANYTHING ELSE YOU WISH TO COMMENT ON IN RELATION TO GOOD CARE?

4. Experience of transition between services

Aim: to explore patients understanding of the ‘pathway’ and how it works in practice.

Tell me about your experience of the changeover of care from ED to Walton Centre?
Follow up;

- Communication
- Time
- Similarities/differences to past

BEFORE WE MOVE ON IS THERE ANYTHING ELSE YOU WISH TO COMMENT ON IN RELATION TO YOUR EXPERIENCE OF THE TRANSITION BETWEEN SERVICES.

5. Experience of follow-up neurology/seizure services

Aim: to understand participants views on the follow-up service offered.

‘Can you tell me a bit about your experience when you went to your Walton Centre clinic appointment?’
Follow up;

- How useful did you find the follow up clinic? How/Why?
- Communication/ appointment letters etc.
- How well did you feel the Walton Centre responded to your ‘crisis’?
- How has the pathway been beneficial to you?
- Are there any areas you would like to see improved?

BEFORE WE MOVE ON IS THERE ANYTHING ELSE YOU WISH TO COMMENT ON IN RELATION TO YOUR EXPERIENCE OF THE OUTPATIENT SERVICES AT WALTON CENTRE.

Interview Schedule (ED clinicians)

1. **General background information**

   Aim: to gather background contextual information that may have an influence on their professional experience

- Please describe your position here at [hospital]?
- What is your role in the seizure care pathway

2. **Admission process to ED**

   Aim: to explore clinician experience of admission process

- Thinking about [scenario], please walk me through the steps you are involved in in admitting the patient to the unit. I would like to hear about all of the individuals, including health care providers involved?
  (Probe: What is your role? Who else is involved? How?)
- Who is responsible for sending information/getting information to you?
  (Probe: who gives this information?)
- What information is provided by patient or caregivers? What are the challenges with information provision in seizure patients?

3. **Discharge process from ED**

   Aim: to explore experience of discharge transition from ED

- Thinking about [scenario], please walk me through the steps you are involved in relating to discharging the patient from the unit. I would like to hear about all of the individuals, including health care providers involved?
  (Probe: What is your role? Who else is involved? How? Where are these patients discharged to?)
- What steps are taken to prepare patient for discharge?
- To what extent patient/care givers are involved in decision-making about further care?

4. **Improvement suggestions**

   Aim: to assess the process and explore any further improvement suggestions

- Thinking about [scenario], in your opinion what works well in the transition between the emergency department and outpatient neurology?
- What would help you to improve the care of seizure patients at the time of transition out of ED?
- What do you think can be done to improve how information is sent and received to and from one health care setting to another?

Is there anything that you would like to add that we haven't covered in the interview?

Interview Schedule (administration staff at Walton Centre)

1. **General background information**

   Aim: to gather background contextual information that may have an influence on their professional experience

- Please describe your position here at [hospital]?
- What is your role in the seizure care pathway

2. **Booking appointments**

   Aim: to explore booking team role in delivering appointments for patients

- Thinking about [scenario], please walk me through the steps you are involved in in booking a patient follow-up appointment?
  (Probe: What is your role? Who else is involved? How?
- Who is responsible for sending information/getting information to you?
  (Probe: who gives this information?)
- What are the challenges faced when trying to book patient appointments?
  (Probe: patients have suggested that time, communication may be issues? How do you view this?)

3. **Improvement suggestions**

   Aim: to assess the process and explore any further improvement suggestions

- Thinking about [scenario], in your opinion what works well in the transition between the emergency department and outpatient neurology?
- What would help you to improve the care of seizure patients at the time of transition out of ED?
- What do you think can be done to improve how information is sent and received to and from one health care setting to another?

Appendix J: Final analytical template participant interviews

Research Questions

What is the seizure patient's experience of the care pathway from ED to outpatient neurology services?

What recommendations can be made to improve clinical services offered to seizure patients?

Index
ED- Emergency department
GP- general practitioner
HCP- health care professional

1. Background
    - 1.1 Sampling Details
    - 1.2 Seizure/health background
    - 1.3 Household composition and personal relationships
    - 1.4 Employment history
    - 1.5 Interests/activities
    - 1.6 Other

2. Experience of 'crisis'
    - 2.1 Initial seizure experience/ getting to ED
    - 2.2 Symptom experiences
        - 2.2.1 Perceived duration
        - 2.2.2 Post-ictal state
    - 2.3 Tests and treatment experiences- ED
    - 2.4 Tests and treatment experiences- neuro OPD
    - 2.5 Symptom control experience
    - 2.6 Other
        - 2.6.1 Disruption
        - 2.6.2 Significant others
        - 2.6.3 Admission to hospital
        - 2.6.4 Reason for ED attendance (e.g. injury/ unusual seizure)
        - 2.6.5 Fear/anxiety issues
        - 2.6.6 Reason for seizure (e.g. missed medication, exhaustion etc.)

3. Management of 'crisis'
    - 3.1 Patient- ambulance HCP relationship
    - 3.2 Patient- ED HCP relationship
    - 3.3 Patient- neurology HCP relationship
    - 3.4 Patient- GP relationship

  - 3.5 Confidence/trust in judgement of HCP
  - 3.6 Involvement in decision-making related to care choice
  - 3.7 Involvement in decision-making related to care provision
  - 3.8 Other
    - 3.8.1 Self-discharge
    - 3.8.2 Mismanaged care/miscommunication
    - 3.8.3 Uncertainty
    - 3.8.4 Private treatment
    - 3.8.5 Feeling ignored

4. Patient expressed needs and expectations
  - 4.1 Information provision
  - 4.2 Accessibility of treatment/care
  - 4.3 Resources
    - 4.3.1 Human
    - 4.3.2 Environmental
  - 4.4 Waiting time
  - 4.5 Care continuity
    - 4.5.1 Signposting
    - 4.5.2 Discharge support
  - 4.6 Other
    - 4.6.1 Reassurance
    - 4.6.2 Being kept informed
    - 4.6.3 Consideration of patient feelings
    - 4.6.4 Acting in patient's best interests
    - 4.6.5 Professionalism
    - 4.6.6 Privacy

5. Views of care pathway/follow-up
  - 5.1 Conceptualisations/understanding of pathway (follow-up)
  - 5.2 Positive views of care pathway/ follow-up
    - 5.2.1 Relationship with HCPs
    - 5.2.2 Patient negotiated care management
    - 5.2.3 Communication between trusts/back to GP
    - 5.2.4 Involvement/role of GP
    - 5.2.5 Thorough
  - 5.3 Negative views of care pathway/ follow-up
    - 5.3.1 Inter-trust communication
    - 5.3.2 Appointment delays
    - 5.3.3 Involvement/role of GP
    - 5.3.4 Missing notes
    - 5.3.5 Lack of discharge information

6. Mediating factors related to current experience/outcome
  - 6.1 Conceptualisation of service provision

- 6.2 Self-knowledge/understanding
- 6.3 Previous experience
- 6.4 Visibility/contact time with HCPs
- 6.5 Anxiety related issues
- 6.6 Altruism
- 6.7 Sense of burden
- 6.8 Self-autonomy/patient proactiveness
- 6.9 Hindsight

7. ED Questionnaire
    - 7.1 Comprehension
        - 7.1.1 Ambiguity
        - 7.1.2 Inability to remember
        - 7.1.3 Straightforward
        - 7.1.4 Easy to understand
        - 7.1.5 Answers did not apply
        - 7.1.6 Long
        - 7.1.7 Comprehensive
    - 7.2 Improvement suggestions

8. Service Improvement
    - 8.1 Recommendations
    - 8.2 Barriers
    - 8.3 Facilitators
    - 8.4 Patient-focused approach

Appendix K: Participant sample matrix

Sample Matrix	**Gender**	**Male**	**Female**
Age	16-24 years	**4-5**	**4-5**
	25-40 years	**3-4**	**3-4**
	41-60 years	**3-4**	**3-4**
	60 + years	**1-2**	**1-2**
Seizure Status	First Seizure	**Min. 12**	
	Chronic Epilepsy	**Min. 12**	
Working Status	Paid employment (full/part time)	**Min. 8**	
	Not working	**Min. 10**	
	Full-time education	**Min. 6**	
Deprivation Deciles	1-3 (most deprived)	**Min. 5**	
	4-6	**Min. 10**	
	7-10 (least deprived)	**Min. 10**	
Total		**25**	**25**

Appendix L: Systematic review MEDLINE search strategy

Medline Search Strategy – search conducted 11/05/2015

#	**Advanced Search**
1	‘patient experience*’.mp.
2	‘patient reported experience*’.mp.
3	Emergency Medical Services/
4	Psychometrics/
5	1 and 3 and 4
6	2 and 3 and 4
7	1 and 3
8	2 and 3
9	3 and 4
10	‘Measure*’ or ‘tool*’ or ‘instrument*’ or ‘survey*’ or ‘score*’ or ‘scale*’ or ‘questionnaire*’.mp.
11	1 and 3 and 8
12	2 and 3 and 8
13	‘emergency care’ or ‘unscheduled care’ or ‘unplanned care’.mp.
14	4 and 13

Appendix M: Systematic review data extraction form

Data Extraction Form

Publication Details	
Author (s):	
Year:	
Title of Paper:	
Country of Development:	

Study Characteristics	
Aim of instrument and target population:	
No. of validation papers assessed:	
Patient recruitment (setting and eligibility criteria):	
Sample size:	
Mode of administration:	
Number of items/domains:	
Domains measured:	

Instrument Development	
Pre-study Hypothesis and Intended Population Pre-study specification of aims and intended population. Give the extent to which the intended population has been studied in the instrument. Was there an ample sample size >50 participants?	
Actual content area (face validity) The extent to which the content meets the pre-study hypothesis specifications	
Item Identification Selection of items relevant to target population. This includes consulting with patients, stakeholders, experts and literature review.	
Item Selection Determining items included in the final instrument. This may include Rasch analysis or factor analysis, floor/ceiling effects and missing data.	
Unidimensionality Demonstration that items fit within a single underlying construct. Rasch analysis with fit statistics within range 0.7 to 1.3. Cronbach's alpha >0.7	

Factor analysis on Rasch or raw scores (1st factor loadings >0.4 for all items)	
Choice of Response Scale	
Comments	

Instrument Performance	
Convergent validity Degree of correlation with a related measure. Pearson's correlation coefficient correlates between 0.3 and 0.9	
Discriminant Validity Degree to which an instrument is not similar to other instruments that it should not be similar to. Pearson's correlation coefficient correlates <0.3	
Predictive validity Ability to make predictions about future outcomes. Pearson's correlation coefficient correlates >0.3	
Test-retest reliability The extent to which results are the same when repeated by the same person at a different time point. Intraclass correlation coefficient (ICC) or Pearson's product moment correlation coefficient (*r*) >0.8	

Responsiveness The extent to which the instrument can detect clinically important changes over time.	
Comments	

Appendix N: Systematic review quality assessment criteria

Instrument Development		
Property	Definition	Quality Criteria
Pre-study hypothesis and Intended Population	Specification of the hypothesis pre-study and if the intended population have been studied.	✓✓- clear statement of aims and target population, as well as intended population being studied in adequate depth (>50 participants) ✓- only one of the above or generic sample studied X- neither reported
Actual Content Area (face validity)	Extent to which the content meets the pre-study aims and population.	✓✓- content appears relevant to the intended population ✓- some relevant content areas missing X- content area irrelevant to the intended population
Item Identification	Items selected are relevant to the target population.	✓✓- evidence of consultation with patients, stakeholders and experts (through focus groups/one-to-one interview) and review of literature ✓- some evidence of consultation X- patients not involved in item identification
Item Selection	Determining of final items to include in the instrument.	✓✓- Rasch or factor analysis employed, missing items and floor/ceiling effects taken into consideration. Statistical justification for removal of items ✓- some evidence of above analysis X- nil reported

Unidimensionality	Demonstration that all items fit within an underlying construct.	✓✓- Rasch analysis or factor loading for each construct. Factor loadings >0.4 for all items. ✓- Cronbach's alpha used to determine correlation with other items in instrument. Value >0.7 and <0.9 X- nil reported
Response Scale	Scale used to complete the measure.	✓✓- Response scale noted and adequate justification given ✓- Response scale with no justification for selection X- nil reported

Instrument Performance		
Property	Definition	Quality Criteria
Convergent Validity	Assessment of the degree of correlation with a new measure.	✓✓- Tested against appropriate measure, Pearson’s correlation coefficient between 0.3 and 0.9 ✓- Inappropriate measure, but coefficient between 0.3 and 0.9 X- nil reported or tested and correlates <0.3 or >0.9
Discriminant Validity	Degree to which an instrument diverges from another instrument that it should not be similar to.	✓✓- Tested against appropriate measure, Pearson’s correlation coefficient <0.3 ✓- Inappropriate measure, but coefficient <0.3 X- nil reported or tested an d correlates >0.3
Predictive Validity	Ability for a measure to predict a future event.	✓✓- Tested against appropriate measure and value >0.3 ✓- Inappropriate measure but coefficient >0.3 X- nil reported or correlates <0.3
Test re-test reliability	Statistical technique used to estimate components of measurement error by testing comparability between 2 applications of the same test at different time points.	✓✓- Pearson’s *r* value or ICC >0.8 ✓- Measured but Pearson's *r* value or ICC <0.8 X- nil reported

Responsiveness	Extent to which an instrument can detect clinically important differences over time.	✓✓- Discussion of responsiveness and change over time. Score changes >MID over time. ✓- Some discussion but no measure of MID X- nil reported

Appendix O: Self-Reflection

As part of this thesis I will reflect upon my own experiences of the past five years working towards a PhD, paying particular attention to the challenges I have encountered and what I have subsequently learnt about seizures and about myself as a result of this experience.

My decision to embark on a PhD was not taken lightly. As a newly qualified staff nurse, with several years of experience working in health care, I had recently transitioned from the *"student life"* into a paid work role. However, I wasn't fulfilled by my position and kept getting drawn back into the academic world, particularly mindful of my research proposal as part of my undergraduate degree being something I wanted to develop further. This experience had opened my eyes to the research world, particularly the potential of research as a way to explore the experiences of individuals, something I was keen to pursue. My background in health care and previous, although perhaps limited, research experience, led to a successful application for the studentship at University of Liverpool to study for a PhD.

Most of my prior experience lay within qualitative methods and so I felt reasonably comfortable with the proposed mixed methods study proposed as part of the studentship. As the studentship was funded by the Collaboration for Leadership in Applied Health Research (CLARHC NWC), the aims and objectives of the project had already been proposed and I felt this somewhat constrained my decision-making within the original proposal and design of the study. My interests lay primarily in people rather than processes and in understanding, not measuring, their illness, but I understand the values of both and that is why I considered the development of a measure as part of the process. I uphold my view that we must understand experiences before we can consider measuring them.

I found the initial phases of the research somewhat challenging, as it was a whole new world for me to negotiate. With the support of my supervisors and the wider research team on the Care After Presenting with Seizures (CAPS) project, I began to establish connections with groups of people whose lives are affected by neurological conditions, either as people with the condition or as those who work with them in a professional capacity. I attended coffee mornings of the Brain Charity, a local organisation which provides support for those with neurological conditions and their carers, meeting people and talking to them about their lives and my proposed research. I also made contact with HCPs working in emergency care and neurology services to care for patients with seizures and epilepsy.

As the wider CAPS project was designed prior to the commencement of my PhD study, approval had already been sought from NHS Research Ethics Committee (REC) and local trusts Research and Development (R&D) departments.

Once recruitment commenced there were several challenges to overcome. With support of the research nurses at the local trusts, I was able to access details of all participants who had consented to take part in the wider CAPS study. As part of this consent, they also consented to be contacted by myself about taking part in an interview about their experience; the qualitative aspect of my research study. It had been proposed in the ethics application that we would contact potential participants via telephone. However, due to a combination of individuals not answering calls, incorrect telephone numbers and participants declining to take part, this proved to be a difficult process. We did however, recruit a sufficient number of participants with seizures who had recently attended the ED and been put on the seizure care pathway to take part in the study and I am extremely appreciative of those who gave up their time to support the study.

Once I had undertaken several interviews as part of the initially proposed patient participant study of experience of the seizure care pathway, it became apparent that there may be some ongoing challenges with the remainder of the project. Although suggested in the aims of the thesis that this process would culminate in the development of a patient-reported experience measure (PREM) specifically designed for auditing patient experience of the seizure care pathway, this changed with the developmental findings of the project. I believed that the findings of this study, presented in chapter six, demonstrated that the seizure care pathway, at present, may not be an auditable tool and that the development of a PREM may not necessary be appropriate at this stage of the pathway's implementation process.

Further to this, several participants reported difficulty in recalling events that occurred in the ED post-ictally, leading to a reliance on family members to 'fill in the gaps'. As the participant interview findings developed and it became obvious that this was a recurring problem, I began to question to validity of such a measure for this patient group and whether there may be better approaches to improving care, namely improving the approach of the care pathway to encompass a more holistic approach to care. It was decided, after numerous discussions within the supervisory team, that developing a specific PREM for seizure patients would be futile and that we may gather further information on the delivery of the pathway in practice by speaking to those that are responsible for its implementation. By doing this, I envisaged that we could then integrate the findings to make suggestions for future practice and research, rather than developing a PREM with limited integrity and validity.

This change in scope of the project was evidently not in the original ethics proposal and therefore, I had to make a major amendment submission to the REC. Although a delay in the process, I believed this was an important learning opportunity, not only in my ability to submit an application which I had not had the chance to do in the initial bid, but also in my own capability to make a significant decision to change the direction of the research study, to enhance the findings and contribution that the research may make.

After the delay of obtaining ethical approval and R&D, I then began with the process of recruiting HCPs to take part. It was also difficult process to recruit HCPs to the study. Those who had lead clinically on the study from the various trusts, were happy to act as gatekeepers, and supported me by allowing me to attend handovers with clinicians to encourage participation. However, it proved challenging to recruit professionals who had no previous knowledge of the purpose of the research. In addition, clinicians, particularly junior doctors, were on rotational duties across different wards/trusts, and therefore, their overall experience of the seizure care pathway was limited. I remain highly appreciative of the number of HCPs who took their time to support the project.

Having limited experience of transcription and data analysis, I underestimated how time-consuming a process this would be, but in listening again to the interviews as I transcribed, I was able to immerse myself in the data and felt that this was the first step in the analysis process. Although I chose to follow the prescriptive method of Thematic Analysis (Braun and Clarke, 2006), I found the early days of transcription confusing. I struggled using NVivo and preferred to carry out the analysis by hand, using post-it notes and cut out quotes to develop themes and sub-themes. After spending some weeks coding data, the extraction of themes followed readily, and eventually, the development and organisation of themes and sub-themes.

On reflection, while findings of the study indicate that the ED care for patients experiencing seizures is variable, but on the whole, a fairly positive experience of care, some of the findings from each participant group came as a surprise and challenged my preconceptions. Prior to carrying out the interviews, I held the assumption that, to some extent, people with seizures would experience the same challenges and have similar perceptions regarding the care that they received. I also anticipated that the HCPs would express a uniformly empathetic attitude towards their patients and a common desire to fulfil the holistic needs of those they cared for. I now appreciate that, despite experiencing the same condition, people with epilepsy live very different and individual lives and that compounding factors in their perceptions of care are often physical and psychosocial. Similarly, the perceptions and attitudes of HCPs differ considerably according to their expertise, personality and pressures and expectations acting on them from a professional viewpoint.