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LEVERAGING HEALTH INFORMATION to ENABLE the TRANSFORMATION of CHRONIC DISEASE MANAGEMENT

The Epilepsy Exemplar

Student

Mr Jarlath Varley

PhD Scholar

Trinity College, Dublin 2

Student No: 99178541

Research supervisor

Professor Charles Normand

Department of Health Policy & Management

Trinity College, Dublin 2

Declaration sheet

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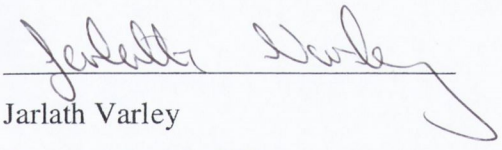

Jarlath Varley
Student No: 99178541

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Thesis summary

Like most chronic conditions, the diagnosis and optimum management of epilepsy relies on contributions from a number of healthcare disciplines in a variety of geographically diverse number of healthcare settings e.g. community based general practice, secondary and tertiary care. As a consequence the health care delivery for patients can sometimes lead to uncoordinated care, inconsistent advice for the patient, inappropriate or unnecessary investigations, and delays in diagnosis and the initiation of treatment. All of this poses a significant challenge to achieving optimal healthcare for patients.

Using epilepsy as an exemplar of chronic disease the Epilepsy Programme at Beaumont Hospital, Dublin through an iterative research and development programme have designed and implemented into clinical practice an electronic information exchange system. This epilepsy-specific Electronic Patient Record (EPR) consolidates electronically the medical information of people with epilepsy (PWE). It is web-based so that patient information can be securely accessed via the Internet by authorised users within and external to the epilepsy service at Beaumont Hospital and facilitates the timely sharing and exchange of patient information both within and across organisational boundaries.

The objective of the project was two-fold. Firstly, it was to use the assimilated epilepsy-specific information contained within the EPR to improve the quality and efficiency of epilepsy care and contribute to a new model of epilepsy care in Ireland. The second objective was to identify the opportunities where optimum information management and communication via the epilepsy-specific EPR could support and facilitate the integration of key components of CDM reform policy. Research evaluation both social and technical was proposed to support, identify and understand the critical factors influencing the outcomes produced in the project.

A part of this overall evaluation (Appendix 1) was the documenting of existing epilepsy services in Ireland in the context of optimum CDM. Inappropriate implementation of technologies like the epilepsy-specific EPR into preexisting complex healthcare organizations exposes clinicians, patients and healthcare systems to unacceptable levels of risk. Existing research evidence suggests that the greatest risk for ICT in healthcare relates to the absence of evidence that tells how best to implement the technology into the clinical environment. Guided by CDM policy and the objective of improving care for people with epilepsy the use of information, its management and communication was explored and how its use could contribute to a model of shared care for epilepsy. Understanding the structure and process of care for a particular chronic illness elucidates where better and more timely information sharing and exchange could improve the quality, safety and efficiency of healthcare services.

Summary of thesis chapters

People with chronic disease such as epilepsy can expect to have multiple encounters with the healthcare system. To ensure continuity of care and integration of various clinical encounters, all key stakeholders involved in patient care must access the same clinical information regardless of their geographical location. Otimimising information management by adopting clinical information systems like the epilepsy-specific EPR has the potential to inform models of shared care that support CDM reform programmes.

In chapter I the concept of clinical information sharing in chronic disease management (CDM) reform is introduced. The vision and objectives of a specific research and development project (Appendix 2) is discussed and the role of evaluation research within the project is qualified. The web-based epilepsy-specific, electronic patient record (EPR) is discussed in the context of the thesis objectives and outlines clearly the objectives and direction of the proposed research.

In chapter II the shortcomings of existing healthcare services to meet the needs of those with chronic illnesses are explored. The essential principles driving chronic disease health policy are introduced and discussed in the context of implementing models of shared care for specific chronic diseases. Current healthcare structures are struggling to meet the essential requirements of CDM. The chapter examines the literature specific to CDM and explores the drivers informing health policy as it transitions to newer models and concepts of care aiming to improve continuity, quality, safety and efficiency of care services provided.

Chapter III provides meaningful insight into the general and specific complexities of epilepsy and its impact on the individual's physical, psychological and psychosocial well being. The research evidence supporting the current approaches to the care and management of PWE is described in the international and Irish context. The challenges to effective and efficient information management and communication are highlighted as

are the opportunities where improved information management could support a strategic model of shared care for epilepsy.

CDM reform initiatives recommend that healthcare services become more patient-centric with patients supported in taking a more proactive role in their own self-management. In chapter IV the results of a study exploring the experience of people with epilepsy (PWE) as they navigate their healthcare journey in Ireland is presented. The aim of this study was to understand how the structure and process of epilepsy care impacts on the patient's perception of care and to identify opportunities for improving its continuity. This understanding from the patient perspective identifies the opportunities where optimum information management and communication could be used to improve services, inform health policy reform and contribute to a model of shared care for PWE in Ireland based on the principles of CDM.

It is believed that once appropriate treatment interventions have been delivered many patients with chronic disease will be stabilised and their on-going care should be managed in the community by primary care services. The objective is to protect specialist hospital-based services for those who most require it. This pre-supposes that the primary care sector is ready to take on this chronic disease management role. In chapter V of this thesis, the role of Irish general practitioner is examined specific to epilepsy care. The aim is to better understand the structure and process of epilepsy care in Ireland from the GP perspective and how information management and communication is currently supporting CDM in the primary care setting.

CDM policy recommends that models of shared care for chronic diseases must improve the sharing of care across organisational boundaries that are facilitated and supported by information and communication technology. In chapter VI a study exploring the interface between primary care and specialist epilepsy services in Ireland is presented. The study documents strategically the healthcare professionals' experiences of providing epilepsy care, identifies healthcare professionals' perspectives on the factors that enhance or inhibit the provision of quality epilepsy care.

In chapter VII an audit of the primary care records of PWE in Ireland is described. The first of its kind in Ireland, this study provided quantifiable information and evidence regarding the structure and process of epilepsy care in a representative region of Irish society. The audit quantified epilepsy related activity within primary care, the nature of epilepsy information recorded by GPs in the records of their patients with epilepsy, and to establish to what extent the data required to assess the quality of epilepsy care is available. Furthermore, by examining what GPs record about PWE, the barriers and facilitators to sharing and exchanging clinical information across traditional organisational boundaries (a requirement of successful CDM) could be explored.

In the ultimate chapter (chapter 8) the findings of the research thesis are summarised. The conclusions are discussed and contextualised using the key principles proposed in the policy framework guiding CDM in Ireland. Opportunities where improved information management via information technology could enhance service integration, coordination and management of chronic diseases like epilepsy are highlighted. The actions required to develop a new model of shared care for epilepsy that includes the essential principle of CDM are outlined. Finally, the research limitations of the thesis are highlighted and the implications for future research are discussed in the context of improving CDM.

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The people with epilepsy who on a daily basis carry the burden of their condition with dignity and courage.

Finally, I dedicate this work to the memory of my beloved brother Jimmy (RIP) who helped me to keep things in perspective at all times…Ar dheis De go raibh a anam…..

Key abbreviations

AEDs: Anti Epileptic Drugs

CDM: Chronic Disease Management

CCM: Chronic Care Model

EPR: Electronic patient record

GP: General practitioner

HSE: Health Care Executive

ICGP: Irish College of General Practitioners

ICT: Information and Communication Technology

IP: Interpretive Phenomenology

IPNA: Irish Practice Nurse Association

PWE: People with epilepsy

UK: United Kingdom

Chapter 1

Leveraging health information to enable the transformation of Chronic Disease Management: The Epilepsy Exemplar

The management of chronic disease increasingly imposes a significant cost at all levels of society where efforts continue to better estimate and understand its overall burden (Suhrcke, Fahey and McKee, 2008). Global spending on chronic disease management (CDM) is becoming unsustainable as healthcare systems struggle to deliver high quality care to an escalating numbers of patients (Nolte and McKee, 2008; Busse et al, 2010). As a consequence, healthcare policy makers in many countries have prioritised the reconfiguration of CDM, with the key objectives of maximising disease prevention and health promotion opportunities while increasing the availably of effective medical interventions for the majority of patients (Epping-Jordan, 2005, Busse et al, 2010).

Internationally, health policy frameworks specific to CDM are promoting the establishment of disease specific programmes that prevent and/or delay disease occurrence, appropriately treat existing illness and reduce acute hospital admissions (Nolte and McKee, 2008). This systematic approach aims to coordinate health care interventions across and between the various healthcare interfaces, be they individual, organisational, local or national (Singh, 2008). Similarly in Ireland, the Department of Health and Children have set out a national framework targeting the reconfiguration and reform of chronic disease care and management (Department of Health and Children, Ireland, 2008a). Central to this strategy has been the establishment of disease specific national clinical directorates by the Health Service Executive of Ireland (HSE Transformation Programme, 2007-2010). These clinical directorates are responsible for defining how health services are delivered, measured and resourced for individual chronic diseases, including epilepsy. Each directorate has targeted improvements in primary care, out-patients, emergency services, surgical services and disease prevention and management (HSE Transformation Programme, 2007-2010). These programmes are joint initiatives with the medical colleges and have an overall responsibility to deliver

integrated care that is of high quality, equitable and accessible to all patients (HSE Transformation Programme, 2007-2010).

Irrespective of the specific chronic disease, such CDM strategies invariably recognise the importance of health information and its communication as a valuable resource and enabler of healthcare reform. It is now widely recognised and accepted that optimal information management and integration should underpin the delivery of care for individuals with chronic disease within and across healthcare boundaries (Singh, 2008; Nolte & McKee, 2008). Adopting and integrating Information and Communication Technology (ICT) to strategically manage and reform healthcare services is now an essential cornerstone of CDM health policy (Marchibroda, 2008).

In this context health policy initiatives in Ireland have increasingly advocated for health information to become more readily available, appropriately communicated and integrated throughout the healthcare sector (National Health Information Strategy 2004; Quality and Fairness: A Health System for You 2001; Primary Care: A New Direction 2001; Tackling Chronic Disease, A Policy Framework for the Management of Chronic Diseases 2008a; Health Service Executive (HSE) Transformation Programme 2007-2010). ICT is now widely acknowledged as having unrealised potential in respect of improving the quality, safety and efficiency of healthcare services by optimising information management and communication (Marchibroda, 2008; Westbrook et al, 2009).

ICT has the potential to unlock a number of recognised barriers to effective CDM by providing reliable and accurate information when and where it's needed (Singh, 2008; Nolte and McKee, 2008; Busse et al, 2010). Because of this, ICT is increasingly recognised as an essential element to support a number of the innovative concepts underpinning modern day CDM policy in Ireland and should be suitably integrated to support appropriate solutions to challenges with healthcare systems (Health Service Executive, Transformation Programme 2007-2010, Department of Health and Children, 2008a).

1.0 Revolutionising Chronic Disease Management (CDM) with Information and Communication Technology (ICT); A Socio- Technical Project Applied to Epilepsy Care in Ireland

1.1 Introduction

Funded by the Health Research Board (HRB) in Ireland, the Epilepsy Programme at Beaumont Hospital, Dublin www.epilepsyprogramme.ie has developed and integrated into clinical practice an electronic information exchange system to support and improve the quality of care delivered to patients. The Epilepsy Programme in conjunction with the Information and Technology (IT) department of Beaumont Hospital collaborated with the Centre for Health Informatics and the Department of Health Policy and Management at Trinity College, Dublin and the Centre for Health Informatics and Medical Education at University College, London. The purpose of this health services research and development programme was to align people (patients with chronic disease, families, carers, healthcare providers), healthcare processes (access to healthcare services, the interfaces of service delivery, procedures for follow-up care, and the interface between clinical care and clinical research environments), and technology (the application of ICT in healthcare practices) towards a common goal of optimimising CDM (Appendix 2).

Using epilepsy as an exemplar of chronic disease the Epilepsy Programme through an iterative process of collaboration and engagement with members of the epilepsy multi-disciplinary care team at Beaumont Hospital, incrementally developed and implemented into clinical practice an electronic information exchange system (McQuaid et al, 2010). This eHealth domain, namely the epilepsy-specific Electronic Patient Record (EPR) consolidates electronically the medical information of people with epilepsy (PWE). The EPR is web-based so that patient information can be securely accessed via the Internet by authorised users within and external to the epilepsy service at Beaumont Hospital. It facilitates the timely sharing and exchange of patient information both within and across organisational boundaries thereby promoting a continuum of healthcare services.

This research and development project had two primary objectives in respect of deliverable outcomes (Appendix 2). The first was to utilise the assimilated epilepsy-specific information contained within the EPR to improve the quality and delivery of epilepsy healthcare services both locally within Beaumont Hospital and nationally throughout Ireland. The second objective was to identify the opportunities where optimum information management and communication (via an eHealth domain like the epilepsy-specific EPR) could support and facilitate the integration of key components of CDM reform policy. In essence the challenge was not only to design and implement the epilepsy-specific EPR locally at Beaumont Hospital, but to realise its full potential in reconfiguring the strategic delivery of epilepsy care nationally and to identify the opportunities where optimum information management and communication within healthcare processes of care could support key components of CDM reform policy.

Intuitively, the potential benefits of this research and development project were recognisable. However the proposed formative and summative evaluation components within the project allowed clinicians, health managers and health policy makers to appreciate, understand and document the value added to care processes in respect of not only epilepsy care and management but the wider context of CDM reform. Through iterative socio-technical evaluation lessons learned from the model applied in this programme, i.e. clinician led eHealth development and strong clinical, IT expert and organisation stakeholder collaboration will benefit others who undertake similar projects in the future.

Appropriate research evaluation of ICT initiatives in healthcare is essential as it informs similar related healthcare projects and guides future ICT decision making in the context of CDM reform (Moehr, 2002; Westbrook et al, 2009). The initial technical evaluation research in this project focused on "champion" users in the clinical and research environment and mainly concerned issues pertaining to usability, reliability, safety and its impact on work practices (McQuaid et al, 2010). This early evaluation work provided iterations of feedback to the developers and clinical users regarding the reliability, quality and usability of the system in the initial design and implementation of the EPR at

Beaumont Hospital. Weaknesses and inconsistencies in the EPR were corrected and strong technical support was made available to early pioneering clinical users (McQuaid et al, 2010). Identifying relevant success and failure criteria provided feedback to direct the project in respect of designing and implementing the EPR incrementally (McQuaid et al, 2010).

One of the most widely reported obstacles to successful ICT implementation is failing to recognise deficits and challenges within the structure and process of existing healthcare services (Dorr et al, 2007). This under appreciation of the paradigm shift that occurs between pioneer work in local development sites and subsequent general application of the information technology to a wider organisation can be catastrophic with significant risk for policy makers, clinicians and patients (Ammenwerth et al, 2004; Westbrook et al, 2009). Failing to recognise these challenges at operational level increases dramatically the possibility of failure at both the development and implementation phases of a project (Dorr et al, 2007).

In this context, social research evaluation was conducted in this project in tandem with technical evaluation (Appendix 1). While it is clear that many benefits exist for patient care and healthcare delivery, inappropriate implementation of the epilepsy-specific EPR could have exposed clinicians, patients and healthcare organisations to significant avoidable risks. Dorr et al (2007) suggest that the greatest risk for ICT in healthcare relates to the absence of research evidence that tells how best to implement the technology into the clinical environment. In this context, pre-implementation evaluation of existing epilepsy services was required to inform how best to utilise the epilepsy-specific EPR in clinical practice.

In addition, documenting the structure and process of pre-existing epilepsy services in Ireland, which forms the basis of this proposed PhD identifies objectively and methodically the opportunities where optimum information management in the care process could support and inform the development of a model of shared-care for PWE

underpinned by the essential elements of effective CDM. Lessons learnt could inform a template to guide the management and reform of similar complex, chronic diseases.

1.2 The Key Challenge to Effective Information Sharing in Healthcare

While certain service industries have benefited enormously from the adoption of electronic information and communication technologies, their integration into the healthcare service remains challenging (Kawamoto, et al, 2005; Dorr et al, 2007). Despite this, the development and application of innovative information and communication technologies as enablers of effective modern healthcare delivery are well chronicled (Singh, 2008; Nolte and McKee, 2008; Busse et al, 2010) although significant challenges persist in respect of realising their full potential (Ammenwerth et al, 2004).

Pre-existing uncoordinated systems of healthcare delivery are inflexible and resistant to change/reform for a variety of complex reasons (Nolte and McKee, 2008). Successful implementation of ICT projects such as the epilepsy specific EPR requires existing healthcare processes to be transparent and accessible to measurement (Kawamoto, et al, 2005; Dorr et al, 2007). As a consequence, such information systems can only support CDM strategies if pre-existing structures and processes of care are adequately understood. If not, then the technology may likely only serve to add further complexity irrespective of its technological capability (Kawamoto, et al, 2005). As a consequence the ICT initiative may be reported as a failure when in fact the problem was not the technology but an under appreciation of limitations and pre-existing challenges within a service.

Because of the complexity of healthcare systems, ICT solutions are difficult to develop, implement and evaluate in the healthcare setting (Kawamoto, et al, 2005). In many instances, healthcare systems continue to reimburse and reward volume and fragmentation of service rather than aligning incentives with the goals of CDM that are supported by effective implementation and usability of information technology (Marchibroda, 2008). As a consequence the emphasis may erroneously focus on the technology rather than its potential as an enabler of service reform (Wyne, 2008;

Westbrook et al, 2009). A major challenge to effective integration of ICT into healthcare is the absence or underdevelopment of appropriate and reliable evaluation methodologies that measures overall function and capability (Ammenwerth et al, 2004). Historically, evaluation research has focused on the economic and organisational impact of ICT, reporting on positive outputs such as user satisfaction, financial benefits and improved local organisational work processes (Grimson, 2001; Ammenwerth et al, 2004). In many instances, ICT projects do not realise their full potential as enablers of healthcare reform, failing to recognise the complex social issues that exist within all levels of healthcare organisations (Ammenwerth et al, 2004; Dorr et al, 2007).

ICT projects like the epilepsy-specific EPR through optimum information management and communication have the potential to transform disease prevention, disease management, health surveillance, health promotion and clinical research. The following section outlines the rationale supporting the research direction of this PhD in the context of the EPR project objectives and the subsequent contribution the research makes to CDM reform.

1.3 The Epilepsy-specific EPR and the Role of Research Evaluation

Like most countries, chronic disease management (CDM) is the biggest challenge facing the Irish healthcare system where gaps in healthcare quality and safety together with escalating costs are driving a programme of health service reform (Chapter II). The reform of CDM is a priority for healthcare providers, healthcare managers and health policy makers where some limited success has been achieved despite the absence of a generic healthcare model that is suitable for all chronic diseases and healthcare systems (Chapter II).

In the reform of CDM, healthcare organisations are striving to incorporate electronic information systems based on the assumptions that their adoption will automatically transform and reconfigure existing services. Many of these initiatives however have failed to deliver their full potential by over emphasising the technology and under appreciating the complexity around significant non-technical social issues (Dorr et al,

2007; Westbrook et al, 2009). While some examples of successful ICT projects in healthcare exist, many projects fail to deliver true reform (Moehr, 2001; Ammenwerth et al, 2004; Westbrook et al, 2009).

There is inconclusive evidence regarding the essential factors for successful implementation of ICT in healthcare, however structured pre and post implementation evaluation research is necessary to understand success and failure criteria (Ammenwerth et al, 2004). As government policies show continued commitment towards the funding of ICT initiatives in healthcare, the relationships between systems, individuals and organisational characteristics and how the effect each other requires constant research evaluation (Mandl and Kohane, 2008; Westbrook et al, 2009).

The technical evaluation research conducted in this project examined iteratively the issues pertaining to the usability, reliability, safety and the impact of the epilepsy-specific EPR on work practices locally. These technical evaluation research methodologies were conducted simultaneously during the life-time of the project and contribute to but do not form an integral part of this thesis. The social evaluation research specific to this project conducted pre-implementation research evaluation and utilised methodologies to measure its human, organisational, and potential strategic impact. The research findings from these studies documented the current structure and process of epilepsy care in Ireland and formed the basis of this PhD thesis (Appendix 1).

The primary objective of this pre-implementation evaluation approach was to explore and understand the structure and process of epilepsy care in Ireland which highlighted objectively the potential role of the epilepsy-specific EPR to enable the reform of healthcare services for patients with epilepsy. In turn, this learning informs the management and reform of similar complex, chronic diseases and demonstrates how optimum information management and communication can enable CDM reform.

1.4 The Epilepsy-specific EPR and the Hypothesis of the Thesis

As stated previously, the efficient and timely sharing and exchange of standardised medical information and its efficient communication both within and across organisational boundaries is essential to achieving effective and efficient healthcare management (Marchibrode, 2008). Any eHealth domain such as the epilepsy-specific EPR, that links healthcare services to healthcare constituencies (i.e. patients and healthcare professionals at any location) facilitates information sharing and exchange and promotes a continuum of healthcare services for the benefit of the patient. eHealth is defined as the transaction of healthcare services over an electronic medium such as the Internet (including the World Wide Web, intranet, extranet).

The specific research aims around the epilepsy-specific EPR project was to conduct systematic evaluation research specific to:

- Establishing an Irish epilepsy eHealth domain for patients and healthcare professionals based on the epilepsy-specific EPR infrastructure already in place at Beaumont Hospital, Dublin
- Evaluate the impact of this eHealth domain on the structure, process and outcome of care provided to patients

The current capacity of epilepsy services in Ireland would suggest that significant unmet patient needs exist (Chapter III). While the reform of epilepsy services in Ireland is currently under review, the quality, safety and efficiency of existing services are poorly understood. The interpretation of the current structure and process of epilepsy care may unintentionally rely upon local service provider's assumptions or interpretation of existing services. Evidence supporting such assumptions may often be anecdotal and may simply reflect the interpretation and frustration of a particular individual or group.

The long-time absence of a national strategic epilepsy framework in Ireland has facilitated the evolution of non-integrated epilepsy services that deliver care locally

(Chapter III). In addition, an environment of inertia has developed over time in which the key stakeholders (patients, clinicians, and policy makers) may be unsure or isolated within their own roles and responsibilities. Therefore it is likely that current stakeholders view their roles in isolation rather that a component of care that needs to be integrated into the overall provision of a strategy for people with epilepsy (PWE) in Ireland.

The research thesis is designed to test the hypothesis that existing structures and process of chronic disease care (in this case epilepsy) must be understood and explored prior to implementing a potential enabler of CDM reform such as the epilepsy-specific EPR. This thesis forms an integral component of the overall research component of the project (Appendix 1). It captures the essence of current structure and process of epilepsy care services in Ireland and identifies the opportunities where better information management and communication could inform the transformation of healthcare services. The structure and process of epilepsy care in Ireland is examined from the unique perspective of patients (Chapter IV), primary care services (Chapter V and Chapter VII) and specialist care services (Chapter VI) reporting on the current standards of epilepsy care, its management and the gaps in services that exist in the Irish healthcare system.

1.5 Proposed Outcomes of the Thesis

The evaluation research component of the overall project contains dimensions of both technical and social research evaluation (Appendix 1 and Appendix 2). The social research evaluation findings of this thesis contribute significantly to the pre-implementation and implementation phase of the epilepsy-specific EPR project (Appendix 1). The research outcomes can be summarised as following;

- Documenting the current structure and process of epilepsy care in Ireland will inform how best to utilise the epilepsy-specific EPR to improve the quality, safety and efficiency of epilepsy care both locally (epilepsy service at Beaumont Hospital) and nationally (epilepsy services in Ireland).
- Documenting the current structure and process of epilepsy care in Ireland will identify the critical interphases of care processes where improved information

management using technologies like the epilepsy-specific EPR could improve and assist in reconfiguring healthcare delivery.

- Documenting the current structure and process of epilepsy care in Ireland has informed the technical aspect of the project in respect of critical feedback to direct the design and implementation phase of the project.
- Understanding the deficits in existing structures and processes of epilepsy care services informs the development of an innovative model of shared care for epilepsy care in Ireland. Such a model should incorporate the essential principles of effective CDM including optimum information management (chapter VIII).
- Appropriate evaluation of health care ICT projects, like the epilepsy-specific EPR will inform related healthcare projects and can guide future ICT decision making in the context of CDM reform. While the chronic disease in this project was specific to epilepsy, it will provide a good learning model that will be generalisable to other similarly complex chronic diseases.

1.6 Conclusion

The delivery of chronic disease care requires patients to engage with multiple care providers at various geographically diverse healthcare settings. This process is further complicated by the fact that chronic disease rarely occurs in isolation for many individuals. Current healthcare structures are struggling to meet the challenges of chronic disease care and as a consequence healthcare is transitioning to new models and concepts of care to improve continuity, quality, safety and efficiency of services provided. Chapter II will highlight the challenge of CDM, its impact on society and patients. The chapter will also discuss the modern day health policy approaches to CDM and the essential elements that must be integrated to optimise patient care. The role of information and communication technology (ICT) is discussed in respect of its unrealised potential as an enabler of reform. Technology like the epilepsy-specific EPR can support a number of the innovative essential elements underpinning modern day CDM policy.

Chapter II

The Challenge of Chronic Disease Management

2.1 Introduction

The structure and process of healthcare delivery towards acute, episodic, hospital based care is not suitable in many instances to the requirements of patients with chronic disease (Wagner, 1998; Wagner et al, 2002; Singh, 2008). Modern day approaches to chronic disease management (CDM) should be healthcare system-wide, integrated, coordinated and proactively engaged with healthcare providers, patients and the wider community (Wagner, 1998; Nolte, Knai, and McKee, 2008). Patients with chronic disease should be supported in self-management of their disease with ongoing care and education provided (Bodenheimer et al, 2002; Bodenheimer, Wagner, and Grumbach, 2002). When secondary or tertiary care services are required, the process should be integrated and coordinated across the care continuum which ensures that patients are treated by the appropriate clinician, at the right time in the correct geographical location (Von Korff, Glasgow, and Sharpe, 2002).

In striving to achieve optimum CDM, policy makers are striving to develop innovative models of chronic disease care (Department of Health and Children, 2008; Nolte and McKee, 2008). Such reform is challenging because of the historical evolution of healthcare and its diversity throughout the world in respect of policies, structures and legislation (Busse et al, 2010). Some success has been achieved regionally for certain chronic diseases such as diabetes and heart disease which provides valuable insight and knowledge for healthcare authorities in individual countries seeking their own healthcare solution (Nolte and McKee, 2008). This reflects the vision of the epilepsy-specific EPR project which contributes to the knowledge base regarding CDM reform and the optimum use of clinical information as an enabler of service reform.

2.2 Defining Chronic Disease and Chronic Disease Management

Chronic diseases are long-term, incurable, progressive medical conditions lasting more than six months and involve some degree of dysfunction and/or disability (WHO, 2002; Dorr et al, 2007). Patients with chronic disease require a coordinated input from a wide range of healthcare professionals working collectively to a common goal (Unwin, Epping-Jordan and Bonita, 2004). Developments in medical science and technology have transformed some chronic diseases from rapid progressive fatal conditions into controllable health problems which allow those affected to extend their life span (Nolte and McKee, 2008). As a result the socio-economic implications of this evolution from acute illnesses into chronic health conditions have become more significant (Mattke, Seid, and Sai, 2007).

Chronic diseases now include some communicable diseases, such as the human immunodeficiency virus and the acquired immunodeficiency syndrome (HIV/AIDS). They also include certain mental health conditions such as depression and schizophrenia, and also extend to defined disabilities and impairments such as blindness and musculoskeletal disorders (WHO, 2002). Cancer is now considered a chronic disease health issue although it is recognised that CDM models of care may not be appropriate for managing and delivering healthcare services to such patients (Nolte and McKee, 2008).

A lack of common definitions specific to the concept and boundaries of chronic disease and CDM are acknowledged (Singh and Ham, 2006). For example, the literature relating to CDM refers to and exchanges various descriptive terminologies such as; "integrated care", "coordinated care", "collaborative care", "managed care", "chronic disease management", "case management", "patient-centred care", "chronic care", "transmural care" and "seamless care" (Nolte and McKee, 2008). These terminologies are often applied from the perspective of various disciplines or professional groups and frequently lack specificity, clarity and conceptual definition (Singh and Ham, 2006).

Two of the more commonly cited terms in respect of chronic disease include "integrated care" and "chronic disease management" (Nolte and McKee, 2008). "Integrated care" in Europe relates to publicly funded healthcare systems aiming to integrate different services across healthcare sectors while the US version refers to the integration of different healthcare functions such as financing and human resources (Busse et al, 2010). The latter can be considered as "a network of organisations" that provides or arranges to provide a coordinated continuum of services to a defined population and is subsequently willing to be held clinically and fiscally accountable for the outcomes and the health status of the population served (Nolte and McKee, 2008).

In contrast, "chronic disease management" traditionally targeted individuals with a single (chronic) disease. Initially described in the US, such strategies were adopted by the healthcare industry because of their potential to curb the costs of chronic disease care (Krumholz et al, 2006). The association of comorbidities with chronic disease however has diluted this unilateral approach to a single condition (Nolte and McKee, 2008). As with the concept of "integrated care", there now exists a broad range of definitions of "chronic disease management" that vary in scope, focus, purpose and range, with the boundaries between becoming increasingly blurred (Norris et al, 2003).

2.3 The Escalating Burden of Chronic Disease on Healthcare Resources

From a medical and social perspective chronic disease impacts significantly on the quality of a person's life and is a reality for a significant proportion of the world's population (Glasgow et al, 2008). 125 million (40%) people in the United States have at least one chronic medical condition with that figure expected to reach 157 million (50%) by the year 2020 (Marchibroda, 2008). In the United Kingdom it is estimated that 17.5 million (30%) people are living with a chronic disease and that by 2030 the incidence of chronic disease in people over the age of sixty-five years will have doubled (Dixon et al, 2004). WHO data reflects this trend globally with 75% of the world population living with a single chronic disease and 50% of those having two or more chronic diseases (Department of Health, 2007).

From a fiscal perspective CDM consumes 70-80% of all health care spending in the United States accounting for 76% of acute hospital admissions, 88% of all prescriptions filled and 72% of all primary care presentations (Nolte and McKee, 2008). Two-thirds of health care spending in the US is attributable to the increased prevalence of treated chronic disease. The economic burden of chronic disease is similar in the United Kingdom accounting for over 60% of inpatient bed days (Department of Health, 2007).

The costs associated with CDM are not restricted to the direct cost of health service provisions. There are also significant socio-economic costs, both direct and indirect, such as lower economic productivity as workers become sick and disabled, and the social cost of various coping mechanisms e.g. taking children out of school to care for an ill family member (McCally, Haines and Fein, 1998). Such indirect costs are equally detrimental to patients, their families, communities, employers and economies (Busse et al, 2010). Such costs continue to rise rapidly in tandem with the chronic disease burden and their impact is often under-appreciated (Busse et al, 2010).

Despite the continued allocation of financial resources to CDM, international research has consistently highlighted significant shortfalls in the quality, safety and efficiency of care provided (Busse, and Mays, 2008). Reform has proven to be a diffuse, evolving process as new evidence tends to highlight further competing complexities and challenges (Nolte and McKee, 2008). For example, more recent research has demonstrated a strong correlation between mental and physical health through a conduit of common socio-economic determinants (e.g. inadequate housing, poor nutrition, substandard education) that until relatively recently was poorly understood (Nolte and McKee, 2008).

In Ireland, the patterns of chronic disease incidence, morbidity and mortality mirror the international landscape (Department of Health and Children, 2008). Mortality rates in Ireland for certain chronic diseases such as heart disease and stroke have been reduced through the introduction of specific strategies aiming to improve services and outcomes

for patients (Department of Health and Children, 1999). Despite the falling mortality rates however, the incidence and prevalence of chronic disease rates remain among the highest in Europe with corresponding lower life expectancies (Department of Health and Children, 2008a). Chronic disease and its management is the biggest challenge facing the Irish healthcare system and requires the implementation of long-term sustainable solutions (Department of Health and Children, 2008).

As discussed earlier, chronic disease prevalence increases with age as does the incidence of co-morbidities. Three quarters of people over 75 have a least one chronic condition and over one third of men over 60 year's age have two or more chronic diseases (Nolte and McKee, 2008). For these patients there is a six fold increase in the financial costs of their management (Colin-Thomé and Belfield, 2004). The implications of this are significant for the Irish healthcare system where demographic studies have projected that by 2041 there will be between 1.3 and 1.4 million persons (25%) aged 65 years and over in Ireland compared to 460,000 (11%) in 2006 (Department of Health and Children, Ireland (2008b).

The Irish healthcare system is currently developing and implementing a strategic approach to the care and management of chronic disease in Ireland (Department of Health and Children, 2008a). A key factor driving Irish health policy is the increasing demand for health and social care services secondary to population increases. The total Irish population in 2006 was reported as 4,239,848 persons, compared with 3,917,203 in April 2002, representing an increase of 8.2% in four years (CSO, 2006). The objective is to redirect healthcare delivery away from the reactive, acute, hospital based episodic model of care to a proactive, population-based, multi-disciplinary care model that is delivered predominantly in primary care. Included in the list of chronic diseases targeted for reform is epilepsy, the most common neurological condition after stroke.

2.4 The Challenge for Patients with Chronic Disease

Because chronic diseases are rarely cured, the objective of care is to enhance and maintain the patient's functional status, alleviate any distressing symptoms, prolong their lifespan through secondary prevention and enhance their quality of living (Grumbach, 2003; Epping-Jordan et al 2004). Individuals will have significant healthcare needs and effective CDM requires significant alterations and compromises to their existing lifestyle. For example, people will be required to engage in activities that promote physical and psychological well-being, engage with clinicians, adhere to sometimes unpalatable treatment regimens, monitor their health status, make associated care decisions, and manage the impact of illness on their physical, psychological and social functioning (Clarke, 2003).

Such are the demands placed on patients regarding their healthcare that the majority will invariably prioritise certain aspects of care depending on the importance they place on health outcomes (Nolte and McKee, 2008). For some a priority will be maintaining their functional independence over intense medical interventions. Others will tolerate the inconvenience and risk of adverse side effects associated with such complex medical interventions if their life expectancy can be increased irrespective of its quality (Tinetti, Bogardus, and Agostini, 2004).

A challenge for all patients with chronic disease is their participation in the development of individualised care plans, a recognised critical component of effective CDM (Department of Health, 2007). Modern day consumerism and the ready availability of information via the Internet have created empowered individuals with the capabilities and expectations to engage with this concept (Nolte and McKee, 2008). This in itself has created inequalities in favor of more privileged or knowledgeable patients who can take advantage of available opportunities (Stroetmann et al, 2002). Patients with certain chronic diseases such as epilepsy and neuropsychiatry disorders however, may have difficulty engaging with the concept of patient empowerment and self-management as

their condition may negatively impact on their cognitive ability (Gilliam, 2002; McCorry, Marson and Jacoby, 2009).

Chronic disease may affect individuals of any age although patients are likely to be older, engaged with healthcare services regularly and coping with more than one chronic disease (Colin-Thomé and Belfield, 2004). Co-morbidities challenge patients attempting to assume responsibility for their own self-management where aggravation of one condition may be stimulated by the appropriate treatment of another (Bayliss et al, 2003). Increasingly complex treatment regimes and technological advances in respect of diagnosis and treatment add further to the complexity of care. For example, patients may be prescribed a combination of pharmaceutical preparations which increases the likelihood of inappropriate or erroneous prescribing (Junius-Walker, Theile and Hummers-Pradier, 2007; Hajjar, Cafiero and Hanlon, 2007).

Beyond the biological factors, various socio-economic, cultural, environmental and individual patient behaviour factors can impact on an individual's health status and influence the effectiveness of specific treatments (Ritchie, 2007; Safford, Allison and Kiefe, 2007). It is essential therefore to consider all factors when attempting to define and implement a strategy of care for any chronic illness. Irrespective of the chronic disease and the difficulty defining an effective model of care, patients need to participate and be supported in their own self-management in order to optimise their health outcomes (McCorry, Marson and Jacoby, 2009).

2.5 Patient Self-Management and Chronic Disease

Patients vary in their preference and ability to self-manage their care and the importance they place on particular health outcomes (Nolte and McKee, 2008). Empowering patients towards self-management is complex and challenging especially in the context of providing support to patients who are disadvantaged because of their educational, ethnic or socio-economic background (Singh, 2008). While the importance of self-management is recognised in optimum CDM, few countries have developed or implemented strategies to promote the process appropriately (Nolte and McKee, 2008).

CDM should enable and facilitate as many patients as possible to manage their conditions effectively as part of a coordinated strategy; with equal emphasis on both the physical and psycho-social dimensions of life (Mackay and Mensah, 2004). Furthermore, there is a need to appreciate and understand the patient's perceptions and understanding of their healthcare experiences so that shared expectations between the clinician and patient can be established and decisions can be made jointly in striving to achieve realistic and desired outcomes (Glasgow et al, 2003).

Empowering patients towards self-management is a social process that supports an individual's ability to attend their own needs, to problem solve and to activate necessary resources to control their own care (Anderson, 1996). Core concepts of empowerment are "self awareness" and "self determination" with the latter defined as the ability to make choices and accept responsibility for them (Aujoulat, d'Hoore and Deccache, 2007). Empowerment however may not or can not be a desirable outcome or process for all patients given that patients will interpret it differently in different situations.

For example, the clinical manifestations of certain chronic diseases like intractable forms of epilepsy may be so profound as to restrict the actual realisation of full patient autonomy (McCorry, Marson and Jacoby, 2009). In these instances patients may be directly or indirectly cognitively impaired by their disease making self-management almost impossible. The objective should be to engage patients and manage the realities of their limitations in the context of their disease, reduce their sense of powerlessness and loss, and appreciate their expectations specific to the individual case (Larsen and Lubkin, 2009). Chronic disease care models that include and promote patient self-management must target and engage meaningfully with patients (Nolte and McKee, 2008). Adopting this approach will improve perceived quality of life, increases patient satisfaction and may elevate patients self esteem (Larsen and Lubkin, 2009). The escalating burden of chronic disease requires policy makers to remain cognisant of its psychosocial burden on patients and families as well as the economic burden to the wider society. In addition the patient's perspective of the essential elements of effective care must be understood.

2.6 Health Policy and Chronic Disease Management

This section summarises the more recent interventions that health policy-makers are utilising to tackle the reform of CDM. It provides background analysis of the drivers of reform policy and will assist the reader in interpreting the research findings of the thesis in the context of 1) the epilepsy-specific EPR project and 2) the wider mandate of contributing to CDM reform.

2.6.1 Prevention and Early Detection of Chronic Disease

Internationally, the trend is towards holistic approaches to disease prevention and early detection that coordinates primary, secondary and tertiary care (Nolte and McKee, 2008; Singh, 2008; Busse et al, 2010). Such strategies attempt to integrate all aspects of a target population's health. However regional healthcare system variations in association with political influences have resulted in countries placing a different emphasis on disease prevention and early detection (Busse et al, 2010). For example, Scandanavian policies emphasise environmental factors and social conditions while the US focuses on the individual's attitude to risk factors such as tobacco, alcohol and nutrition (Nolte and McKee, 2008). The United Kingdom and Canada promote broader integrated approaches with clinical care systems involving public health services, health promotion strategies and support for self-care programmes (Novotny, 2008). While chronic disease prevention has been found to be cost-effective only a few countries have set up programmes that demonstrate an ability to prevent chronic diseases (World Health Organisation, 2003).

2.6.2 Reconfiguring Roles and Responsibilities

The transformation of CDM requires the reconfiguration of roles, responsibilities, and professional activities (Dubois, Singh, and Jiwani, 2008). Such changes are generally target driven with the emphasis on shorter hospital stays, expeditious access to required services and the increased provision of community based care services (Pinnock et al, 2009). Such transformation requires the education and professional development of

health care providers to meet the requirements of evolving health services (Dubois, Singh, and Jiwani, 2008).

Historically, physicians have focused on the clinical aspect of care exclusively and were not trained to effectively coordinate and manage service activity (Martin et al, 2009). These traditional demarcation lines between healthcare professionals are increasingly viewed as obstacles to healthcare reform. In response there is a move to extend the roles of many health care professionals (Nolte and McKee, 2008). For example, specialist nursing roles while continuing to administer traditional nursing duties have also expanded their scope of practice to include duties that were historically exclusive to the role of doctors (Lupari et al, 2011).

Such changes are also occurring outside the traditional hospital based environment. Community roles such as liaison nurses, community nurse specialists, and primary care managers are supporting patients in their community, facilitating appropriate and timely access to secondary/tertiary care and coordinating services for patients post discharge from hospital (Nolte and McKee, 2008). Other healthcare groups such as pharmacists and social workers have also been able to perform new roles and responsibilities (Edmunds, and Calnan, 2001). In the United Kingdom for example, pharmacists have expanded and redefined their roles in respect of prescribing issues, reviewing medication and pharmacological compliance (Dubois, Singh and Jiwani, 2008).

The role and responsibilities of families and carers has also been transformed. The importance of family acting as carers is recognised for many chronic diseases in respect of monitoring, treating and managing patient care (Wilkins, Bruce and Sirey, 2009). With the escalation of chronic disease burden, this role has expanded although in many instances it happens mainly by default as such roles are neither formalised, adequately resourced nor appropriately incentivised in many healthcare systems (Wilkins, Bruce and Sirey, 2009).

The true value of reconfigured healthcare roles and responsibilities is difficult to evaluate in terms of health outcomes and patient quality of life (Dubois, Singh and Jiwani, 2008). Generally, role reconfiguration occurs within a larger reform strategy aimed at reorganising care. For example, the arrival of primary care nurses with specialised training in the United Kingdom has improved care when benchmarked against previous services (Connor, Wright, and Fegan, 2002). However, the long term effects of such reform including the impact on patient outcomes are not completely understood (Anderson et al, 2002; Gravelle et al, 2007). In fact it can be argued that role reconfiguration in some instances may in fact introduce more complexity into the health care system (Sargent et al, 2007).

Of course there are examples where reconfigured roles have been associated with better clinical outcomes for patients (Connor, Wright and Fegan 2002) and higher patient satisfaction levels (Horrocks, Anderson and Salisbury 2002). How and why such improvements are achieved remains somewhat unclear although optimum family care support occurs when healthcare provider competence regarding roles and responsibilities is clearly defined (Greenberger and Litwin 2003).

2.6.3 Reconfiguring Chronic Disease Management within the Healthcare System

A major reform in the delivery of healthcare services is the development of models of care in which the doctor works within a multi-disciplinary care team (Wagner, 2000). The multi-disciplinary team comprises of allied healthcare professionals all working collaboratively to deliver high quality, evidence based care in the appropriate location. Within this culture of multi-disciplinary care, a primary objective is to transition from unilateral prescribed clinician care to a primary health care system that is more patient focused, oriented towards the needs of patients, efficiently coordinated and accessible twenty-four hours a day (Busse et al, 2010). Where strong primary care teams are well established such as in the United Kingdom and Sweden the overall CDM objective is to expedite the return patient care to the community (Nolte and McKee, 2008).

The transition and reconfiguration of healthcare delivery away from acute, hospital based services to primary care led community services has proved highly challenging and complex to implement (Singh, 2008). Driving this transition is the objective of providing safe, high quality, efficient care to patients although superior outcomes for patients have not been demonstrated (Nolte and McKee, 2008). Two central approaches have evolved over the past twenty years that attempt to coordinate and integrate chronic disease care; Disease Management Programmes (DMPs) and Chronic Disease Management (CDM) models (Busse et al, 2010). Both of these approaches to CDM are now discussed.

2.6.3.1 Disease Management Programmes for Chronic Disease

Disease Management Programmes (DMP's) specifically target the integration of care for individual chronic diseases (Velasco-Garrido, Busse and Hisashige, 2003). It is accepted that integrated care should comprise of three essential elements; a knowledge base, a delivery system to coordinate care and a continuous improvement process for a specified disease within a specified population (Hunter and Fairfield, 1997). As suggested previously (section 2.2) integrated care and disease management are in some respects similar in that they both aim to provide coordinated, evidence-based care that empowers patients over the lifetime of their disease.

In some instances DMP's have demonstrated improvements in the structure and process of care for certain chronic diseases (Mattke, Seid and Sai, 2007) and increasing evidence of adherence to evidence-based standards of care (Velasco-Garrido, Busse and Hisashige, 2003). However, evidence of effectiveness is restricted to certain diseases and it is suggested that DMP's are most effective in changing the behaviours of patients and healthcare providers (Nolte and McKee, 2008) with inconsistent evidence regarding improvements in quality of life, health outcomes or cost effectiveness (Ofman, Badamgarav and Henning 2004; Mattke, Seid and Sai, 2007).

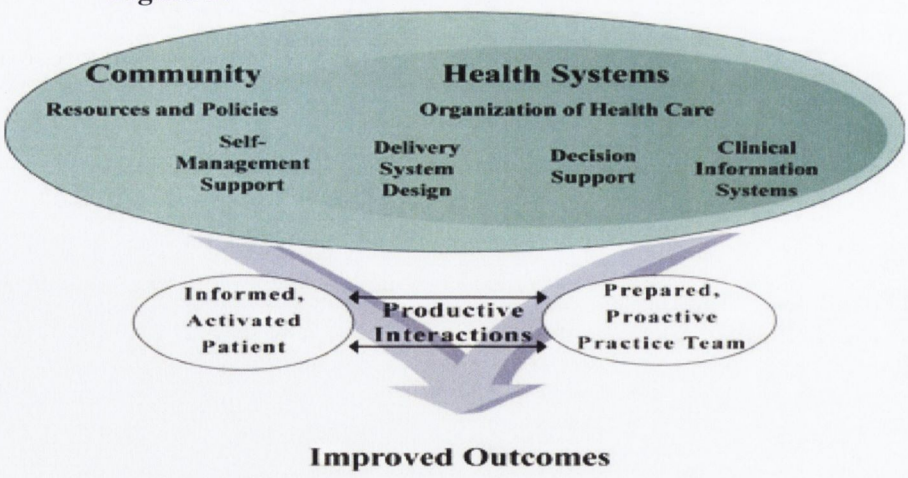
2.6.3.2 Chronic Disease Management (CDM) Models

The focus of Disease Management Programmes (DMP's) on a single disease is self-limiting in that chronic diseases rarely occur in isolation and are generally associated with comorbidities (Busse et al, 2010). Coordinating healthcare services for patients with multiple chronic diseases requires a more systematic and proactive approach to healthcare that is increasingly achieved through CDM models (Nolte and McKee, 2008). To achieve this transformation and integration of services, CDM models should include;

- the promotion of patients' active participation in managing their health
- the development of shared care that is integrated across organisational boundaries
- the implementation of guidelines that support clinical management decisions
- the use of clinical information systems such as electronic health records, to provide timely access to comprehensive patient information

Although developed in the United States, The Chronic Care Model (Figure 1) is now the most commonly used generic CDM model used in Europe and has been particularly influential in the United Kingdom and Ireland (Wagner et al, 1999). Different countries approach and implement this model in different ways; however they share an emphasis on CDM at the level of service delivery.

Figure 1: The Chronic Care Model



Different countries approach and implement The Chronic Care Model in different ways however they share an emphasis on CDM at the level of service delivery. The Chronic Care Model advocates for six interdependent, essential components (Figure 1):

1. health care organisation
2. delivery system design
3. community resources and policies
4. self-management support
5. decision support
6. clinical information systems

The proven effective components of this model include self-management support and delivery system redesign especially when combined with decision support and clinical information systems (Solberg et al, 2006). Zwar et al (2006) in a review of CDM in Australia highlighted the difficulty in demonstrating the specific effect of this model within the constraints of healthcare organisational complexities. While acknowledging the benefits of the Chronic Care Model as a conceptual framework, caution has been advised in respect of competing priorities, change management issues, disagreement about the care process, and non-engagement by health care professionals (Hroscikoski et al, 2006).

Overall economic evaluation of such integrated care models has not been completed or results have been conflicting (Nolte and McKee, 2008). For example, research in the US has provided some cost benefit evidence for CDM models, yet similar economic evaluation in the United Kingdom did not concur with these findings (Gravelle et al, 2007). Results of economic evaluation of the Chronic Care Model have also been mixed with some evidence for the self-management support component and delivery system redesign for certain diseases (Bodenheimer, Wagner and Grumbach, 2002b).

Additionally, it is not clear if all components of such models are required to achieve previously demonstrated benefits (Singh and Ham, 2006).

2.7 The Organisational Challenges in Chronic Disease Management Reform

In reforming CDM a number of institutional and organisational challenges must be overcome in order to facilitate optimum, long-lasting, effective reform (Nolte and McKee, 2008; Busse et al, 2010). Nolte and McKee (2008) in exploring these challenges summarised the following issues:

- the availability of newer effective pharmaceuticals and medical devices
- the design and strategic implementation of appropriate financial incentives
- improved strategic organisational coordination and cooperation
- the adoption of information and communication technology
- appropriate evaluation research measuring the efficacy, cost effectiveness and equity of reform strategies

2.7.1 Newer Effective Pharmaceuticals and Medical Devices

Despite the important role of pharmaceuticals, the chronic disease debate tends to concentrate on structures and programmes of disease management (Bangalore et al, 2007). Of course, patients are more likely to receive appropriate drug therapy if care structures are appropriately coordinated and integrated. While a comprehensive review of new pharmaceutical approaches and medical innovations is beyond the scope of this thesis, their importance is acknowledged.

Evidence has demonstrated that adherence to long-term pharmacological therapies has been an obstacle to effective CDM (WHO, 2003). The causes are complex and multi-factorial and many methods have been proposed to improve adherence including technical interventions; behavioral interventions; educational interventions; social support interventions and structural interventions (Van Dulmen et al, 2007). This is necessary as improvements in pharmacological adherence have been linked to

improvements in quality of life and clinical outcomes for patient with chronic disease (Kheir et al, 2004).

In order to tackle CDM successfully policy makers must recognise the importance of newer effective pharmaceuticals and medical devices in the context of current health service delivery. Reformed and integrated structures and processes of chronic disease care will ensure that patients receive appropriate, timely and efficient treatment regimes including the use of appropriate pharmaceutical therapies (Bangalore et al, 2007).

2.7.2 Implementing Financial Incentives

Using financial incentives to deliver effective and rapid change in CDM is often contentious as it sometimes requires the removal of incumbent incentives that are supporting less effective care strategies (Nolte and McKee, 2008). Financial flows influence most of the relationships in a health system, that is, they act as incentives with intended or unintended effects and consequences (Busse et al, 2010). In certain instances motivated stakeholders may want to improve chronic care but to do so require them to act against their own economic self interest (Leatherman, Berwick and Iles, 2003).

Policy-makers must therefore exercise caution and insight when linking compensation or funding to mid/long term objectives of healthcare reform strategies (Busse and Mays, 2008). There are a number of mechanisms that can be used to apply changes in healthcare systems that are financially incentivised however the challenge is too appropriately and equitably remunerate providers (Busse and Mays, 2008).

Financial incentives tend to focus on the structure, processes and outcomes of care (Busse and Mays, 2008). In the United Kingdom the National Health Service (NHS) contract for general practitioners specifically includes incentivised payments that focus on the delivery and maintenance of specific disease outcomes and accounts for approximately 25% of general practice incomes (Smith and York, 2004). While this programme remains controversial, it has had a positive effect on the care processes of certain chronic diseases including epilepsy (Campbell, Reeves and Kontopantelis, 2007).

Incentivised CDM reform strategies must demonstrate evidence of improved service performance and disease specific patient outcomes. Measurements should reflect different aspects of quality in the structure, process and outcomes of care. Getting the balance right in respect of a financial incentivisation strategy is difficult and more positive outcomes have resulted from targeting small-to-medium multi-disciplinary care teams (Bodenheimer et al, 2002; Bodenheimer, Wagner and Grumbach, 2002b).

2.7.3 Improving Strategic Organisational Coordination and Cooperation

The poor coordination of healthcare services is frequently reported as a major obstacle to effective CDM (Busse and Mays, 2008). Structured approaches such as Disease Management Programmes's [section 2.6.3.1] and Chronic Disease Management models [section 2.6.3.2] are challenged by the different layers of increasingly differentiated, complex healthcare systems (Epping-Jordan et al, 2004: Busse et al, 2010). Policy makers implementing CDM reform strategies must address these organisational issues and challenges.

Common barriers to coordinated care can be structural, organisational and/or operational. Nolte and McKee (2008) highlighted the significance of competing operational cultures and management approaches such as social care versus health care; primary care versus secondary/tertiary care; home care versus general practice. In addition, healthcare ownership structures and responsibilities may not be clearly defined such as the interface between public and private sectors. There may be no recognised incentives to cooperate collectively and a lack of clarity may exist in respect of competencies and accountability e.g. national versus regional policy initiatives; general practice versus specialist care (Nolte and McKee, 2008).

Patients can and do interpret the quality of their healthcare based on its level of coordination which has implications for successful patient self-management (Busse et al, 2010). Preston et al (1999) stressed that coordinated care from the patients perspective should include access to appropriate services, adapting care to their requirements and

continuity in respect of communication between clinicians and healthcare organisations. Any strategy or initiative proposing to improve an aspect of patient care must have an appreciation of the patient's perspective and its significance on the coordination of care.

Other challenges specific to healthcare coordination arise in countries like Ireland where general practice has a central gatekeeping role in guiding and coordinating care for patients with chronic disease. The GPs primary function is to manage the use of specialist services, coordinating the continuity of care and encourage the system to be more responsive especially in the context of CDM (Calnan, Hutten and Tiljak, 2006). Despite this, the traditional hierarchy of the medical profession may undervalue the role of primary care clinician and/or in many instances GPs themselves are unsure of their role and responsibility once the patient passes the "gate" into the wider system (Calnan, Hutten and Tiljak, 2006).

Many European countries are now adopting strategies that promote and improve the coordination and integration of care in the knowledge that it leads to better outcomes (Nolte and McKee 2008), improved patient care experiences (Schoen, Osborn and Doty, 2007; Turner, Tarrant and Windridge, 2007) and is more cost effective. Coordination and continuity problems still exist although the challenges are more significant for patients navigating healthcare journeys in isolation of such strategies (Calnan, Hutten and Tiljak, 2006).

There is no generic solution for optimum coordination of CDM with problems reported from all European healthcare systems (Busse et al, 2010). Improvements will not occur spontaneously and therefore legislators and policy makers must recognise the need to act collectively, to improving cooperation and overcome deeply rooted vested interests irrespective of its complexity (Nolte and McKee, 2008). Policy-makers must be decisive in deciding whether change in the current system is plausible or whether fundamental reform is required especially in the presence of significant structural barriers to cooperation within healthcare (Glasgow et al, 2003).

2.7.4 Adopting Information and Communication Technology

Information management via modern information technologies is a recognised enabler of CDM reform (Marchibroda, 2008). It can support improvements in the quality of chronic disease care, the effective use of resources and consequently engage more appropriately the needs and wishes of patients (Busse, Zentner and Schlette, 2006; Dorr et al, 2007). Such technologies can provide timely access to knowledge about guidelines and safety, information about patient's conditions, treatment and reminders to providers at the point of care regarding important clinical steps and support the integration of shared care management plans (Dorr et al, 2007).

In the modern world, clinical decision-making is increasingly supported by a wide range of electronic decision support systems (Marchibroda, 2008). The aim is to increase the quality and efficiency of care by aligning care processes with evidence-based practice while simultaneously containing costs (Nolte and McKee, 2008). Evidence has demonstrated the benefits of decision-support systems especially in reducing variations thereby improving the quality of outcomes and the reduction of medical error (Marchibroda, 2008).

The capability of information systems to capture and store vast amounts of healthcare information creates challenges for policy makers and clinicians. Patients with chronic disease interact repeatedly with healthcare systems at different levels over their lifetime or over the lifetime of their disease(s). A major challenge therefore is to condense, aggregate, interpret and merge information in a meaningful way that can be used by health professionals to provide optimum safe, reliable, efficient care to patients (Dorr et al, 2007). Therefore policy-makers should insist that information systems are developed and appropriately evaluated pre and post implementation in order to optimise their true potential (Dorr et al, 2007). Research to date has clearly indicated the urgent need for bilateral social and technical evaluation to assess the benefits of information technology and its long-term cost benefit (Tuffs 2004; Scott et al, 2005).

2.7.5 Developing a Culture of Evaluation

To date there has been inadequate and sometimes inappropriate evaluation of CDM reform strategies (Nolte and McKee, 2008). Appropriate evaluation research can address the specific questions of decision-makers looking to measure the efficacy, cost effectiveness and equity of reform strategies (Singh, 2008; Busse and Mays, 2008). Evaluation research can support ongoing continuous improvement and subsequently facilitate measurement of service performance, service quality and patient outcomes.

Research evaluation however should not obstruct innovation or development and neither should it be sacrificed to facilitate uncontrolled implementation (Nolte and McKee, 2008). At the outset there must be an appreciation and understanding of the problems that need to be resolved and the challenges that must be overcome. Such pre-implementation evaluation can contribute to the implementation phase of reform, be that a policy, strategy or technology innovation. This should be followed by post implementation evaluation to determine if the desired outcome has been achieved and should be a continuous cycle of planning and reviewing aimed at achieving a "best-practice" model of care (Busse, Zentner and Schlette, 2006).

2.8 Conclusion

The delivery of chronic disease care requires patients to engage with multiple care providers at various geographically diverse healthcare settings. Current healthcare structures are increasingly struggling to meet the essential requirements of effective CDM. This process is further complicated by the fact that chronic disease rarely occurs in isolation for many individuals. Consequently, healthcare organisations and policy makers are transitioning to new models and concepts of care to improve continuity, quality, safety and efficiency of services provided.

In Ireland, the Department of Health and Children have set out a national framework targeting the reconfiguration and reform of chronic disease care and management. Such disease specific reform strategies must include the development of models of shared care

that contain the effective elements of CDM. One such essential element underpinning CDM reform is the efficient availability and sharing of reliable and relevant clinical information within and across organisational boundaries.

Because epilepsy is the exemplar chronic disease utilised in the project, an overview of the disease is presented in the subsequent chapter (chapter III). This chapter will highlight the opportunities and challenges to integrating more effectively the use of patient information within epilepsy services. As stated previously, the effective integration and exchange of clinical information is an essential element of optimum CDM. Chapter III will identify the opportunities where the existing structure and process of epilepsy care can be improved and reformed through better information management and communication.

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Chapter III

Chronic Disease Management; The Epilepsy Challenge

3.0 Introduction

Healthcare systems including Ireland are implementing strategies that target the reform of CDM (HSE Transformation Programme, 2007-2010; Department of Health and Children, Ireland, 2008a). The objective is to redirect healthcare delivery away from the reactive, acute, hospital based episodic model of care to a proactive, population-based, multi-disciplinary care model that is delivered predominantly in primary care (Department of Health and Children, 2001). Included in the list of chronic diseases targeted for reform in Ireland is epilepsy. It is the most common neurological condition after stroke and is estimated to affect 37,000 Irish people (Linehan et al, 2009).

As discussed in chapter II optimum CDM requires the coordination and integration of care services across the entire healthcare spectrum and should be inclusive of health promotion, disease prevention, early disease detection and treatment (Singh, 2008; Nolte and McKee, 2008; Busse et al, 2010). Disease specific reform strategies should include the development of models of shared care that contain the effective elements of CDM (Nolte and McKee, 2008; Busse et al, 2010). One such essential element is the ready availability and sharing of reliable and relevant clinical information (Chapter 11 - section 2.7.4).

International research has consistently highlighted deficits in epilepsy care services that are directly and/or indirectly attributable to the inefficient availability, reliability and communication of essential patient information between clinicians, healthcare organisations and patients (Fisher et al, 2000; Couldridge, Kendall and March, 2003; Crawford and Hudson, 2003). In addition, the fragmentation of existing epilepsy services adds further structural complexity which may unintentionally impede and/or delay the exchange of information between healthcare providers, patients and healthcare interfaces (e.g. GPs and specialist services).

From the CDM perspective, a chronic disease like epilepsy offers a good model for health policy makers and managers to target in respect of healthcare reform. Firstly, health outcomes for people with epilepsy (PWE) are recognised to be highly sensitive to

the quality of care provided (Nolte and McKee 2008; Zarcostas, 2010). Secondly, a high proportion of people with epilepsy may also suffer with more than one chronic disease (Gaitatzis, Trimble and Sander, 2004), which makes planning appropriate care more difficult. Epilepsy is therefore a useful probe condition for assessing the challenges in CDM more widely in the context of reform and reconfiguration of services.

Reconfiguring any healthcare service irrespective of the disease or the drivers/enablers of change (e.g. strategic national policies/information technologies) is challenging and requires existing structures and processes of care to be recognised and fully understood (Lenz et al, 2005). Implementing change or reform in isolation or as part of a national strategy, without understanding the context, may impact negatively on pre-exiting effective structures of care. In addition implementing a solution without fully appreciating the context of the problem increases the potential for failure given the complexity of healthcare organisations (Lenz et al, 2005; Williams et al, 2007).

Therefore, the objective of this chapter is two-fold. Firstly, because epilepsy is the exemplar chronic disease utilised in the project, an overview is provided regarding its specific complexity and the impact the disease may have on the individual's physical, psychological and psychosocial well being. This includes a review of the research evidence supporting the current approaches to the care and management of people with epilepsy (PWE). Secondly, this understanding of epilepsy care internationally is then discussed in the context of Irish epilepsy services. This review highlights the opportunities and challenges to integrating more effectively the use of patient information. As stated previously the effective integration and exchange of clinical information is an essential element of optimum CDM (Chapter II - section 2.7.4). The opportunities where the existing structure and process of epilepsy care can be improved and reformed through better information management and communication will be highlighted.

3.1 Defining Epilepsy

The word epilepsy is derived from the Greek word *epilambanein* meaning to be seized or overwhelmed by surprise with the earliest detailed written account recorded 1000 B.C as part of a Babylonian text on medicine (The Epilepsy Atlas, 2005). The different epilepsies are linked to abnormal cerebral electrical activities that despite originating in various locations manage to produce identifiable characteristics and localisations (Chadwick, 1993). The disease is characterised by spontaneous recurrent seizures

caused by focal or generalised paroxysmal changes in neurological functions triggered by abnormal electrical activity in the brain (Chadwick, 1993).

A seizure may produce an intermittent, stereotyped disturbance of consciousness, behaviour, emotion and motor function (Chadwick, 1993). The type of seizure and its subsequent clinical manifestations are dependent on where the abnormal electrical activity takes place in the brain, its aetiology, and factors such as the patient's age and general state of health (Engel, Pedley and Aicardi, 2008). Seizures are generally divided into two groups, partial and generalised seizures (The Epilepsy Atlas, 2005). Partial or focal seizures have clinical or EEG evidence of local onset and may spread to other parts of the brain during a seizure, whereas generalized seizures begin simultaneously in both cerebral hemispheres (Chadwick, 1993). Loss of consciousness is not an essential characteristic of an epileptic attack although impairment of consciousness frequently occurs during seizure activity (Chadwick, 1993).

3.2 The Historical Evolution of Epilepsy and its Management

Historically, many misconceptions regarding epilepsy have existed and were generally associated with the popular culture of a particular era or in a particular part of the world (Austin and Caplan, 2007). The dramatic clinical manifestations of witnessed seizures caused fear and misunderstanding and resulted historically in severe social consequences including exorcism, incantations and other religious or social approaches (Reynolds, 2002). The stigmatism while not so profound in modern times continues to impact significantly on the quality of life for many people with epilepsy (Jacoby, 2002).

In the last thirty years there have been remarkable scientific advancements to assist clinicians in making a correct and timely epilepsy diagnosis such as improved neuro-imaging techniques, improved pharmacological interventions and the advent of neuro-surgery as a treatment modality for certain types of epilepsy (Engel, Pedley and Aicardi, 2008). From the research perspective there is accelerating interest in the genetic pathways associated with seizures and epilepsy which is increasingly driven by recent advancements in genetics, molecular biology, neuro-physiology and functional imaging (Kullmann, 2002).

Known with more certainty is that epilepsy is the most common neurological condition after stroke, occurring equally in men and women, and is not limited by race, gender, geography, age or social class boundaries (Hadjikoutis and Smith, 2005). It is estimated

that at least 50 million people worldwide suffer with epilepsy although the majority (80%) live in developing countries where the condition is likely to remain undiagnosed or untreated (ILAE/IBE/WHO, 1999).

3.3 The Epidemiology of Epilepsy

Epidemiological data provides insight into the incidence, prevalence, associated mortality and potential risk factors for any disease which in turn informs the delivery and expenditure of subsequent healthcare resources (WHO, 2005). Epilepsy specific epidemiological studies have been reported as "challenging" because of a persistent non-standardisation of epilepsy diagnosis and seizure classification, an absence of universally accepted disease specific terminology, the subjective nature of the diagnosis and persistent variations in case ascertainment (ILAE Commission Report 1997; WHO 2005). These challenges contribute to the challenge of clearly defining optimum care for PWE.

3.3.1 Incidence of Epilepsy

Despite the deficits reported in epilepsy-specific epidemiological studies there is a general consensus in respect of published epidemiological conclusions (Sander and Shorvon, 1987). The overall incidence of epilepsy (excluding febrile convulsions and single seizures) in developed societies has been reported at 50 cases per 100,000 persons per year (Engel, Pedley and Aicardi, 2008). The figures for developing countries are generally higher in the range of 100-190/100,000/year. The reason for this is not entirely clear although social deprivation has been suggested as the most likely cause (Engel, Pedley and Aicardi, 2008).

3.3.2 Prevalence of Epilepsy

The most typical prevalence figure quoted for epilepsy is approximately 5-10 cases per 1000 persons excluding febrile convulsions, single seizures and inactive cases (Engel, Pedley and Aicardi, 2008). The lifetime prevalence of seizures (the risk of having a non-febrile epileptic seizure at some point in an average lifetime) is between 2 and 5% (Engel, Pedley and Aicardi, 2008). For the majority of people who develop epilepsy the condition remits or the patient dies, which explains the difference between lifetime prevalence and the prevalence of active epilepsy.

Similarly, epilepsy and its clinical manifestations may be relatively short-lived. Two thirds will enter long-term remission and once remission has occurred then subsequent

relapses are uncommon (Smithson and Hukins, 2008). The course of the condition in its early years is an important predictor of prognosis; the longer epilepsy remains active the poorer the long-term prognosis (Engel, Pedley and Aicardi, 2008). This illustrates the need for epilepsy care to be accurate, timely, and coordinated so that a diagnosis can be confirmed or excluded to facilitate the expeditious initiation of the most clinically effective and cost efficient treatment. Optimum information management and communication via information technology like the epilepsy-specific EPR can support this process by enabling the compilation of patient-centric information related to care delivery by multiple clinicians at various geographically diverse healthcare settings.

Linehan et al (2010) examined the prevalence of epilepsy in Ireland using a multiple case ascertainment methodology that examined five nationwide data sources. The study reported 10 per 1,000 persons (n = 31,000) 18 years and older having self-reported lifetime prevalence of epilepsy and 8.3-9 per 1,000 (approximately 33,000-36,000) persons 5 years and older are being treated for epilepsy using anti-epilepsy drug (AED) therapy. While estimating a likely prevalence of 37,000 PWE in Ireland the authors acknowledge the limitations of existing databases in respect of information accuracy and reliability. The successful adoption of information technologies like the epilepsy-specific EPR can function as a singular, accurate data source that captures specific epilepsy information (McQuaid et al, 2010).

3.4 The Unique Characteristics of Epilepsy

Chronic disease impact significantly on a person's quality of life (Singh, 2008; Nolte and McKee, 2008; Busse et al, 2010). Diagnostic and therapeutic procedures can be difficult physically and emotionally while uncertainty in diagnosis and side effects of treatment regimes can induce psychological and emotive stressors. Maintaining normal routines can be challenging and requires many patients to make significant alterations to their lifestyle even in individuals who feel their medical condition is well controlled (Fisher et al, 2000).

The physiological, psychological and psychosocial challenges of chronic disease are compounded for people with epilepsy as its clinical manifestations impact on the individual's social, cognitive and emotional functioning (Chadwick, 1993). Epilepsy as a public health issue is significant because of the physical, emotional, and financial costs associated with uncontrolled seizures and the subsequent impact on education, employment, and psychosocial functioning (Schactner, 2008) While the majority of

PWE aspire to becoming seizure free, there is no intervention that can prevent the onset of epilepsy in patients at high risk (The Epilepsy Atlas, 2005). Consequently, there can be significant implications for a persons quality of life and the level of burden experienced by individual patients, dependents, families and society at large (Zarcostas, 2010). Treatment may often be accompanied by significantly negative side-effects of variable duration impacting on employment, education, finances and social interactions (Sample et al, 2006).

Epilepsy is also associated with particularly vulnerable groups of people. It is the most common serious neurological disorder affecting people with intellectual disabilities with a prevalence rate thirty times higher than the general population (Forsgren et al, 2005). The severity of the intellectual disability may also increase the risk and severity of epilepsy and its clinical manifestations (Amiet et al, 2008) which may further debilitate an individuals cognitive ability (Bowley and Kerr, 2000).

Even in the absence of a learning disability an individual's intellectual capacity may be affected which has a significant bearing on their ability to self-manage their care and/or use critical thinking skills in decision making. Increasingly, the well being of patients with chronic diseases including epilepsy are considered beyond the domain of science and biology where the long-term effects of physiological responses such as stress are thought to contribute significantly to patient outcomes (Sample et al, 2006). In the context of epilepsy it is likely that patients experience such responses and its effect on patients should not be underestimated especially in the context of patient self-management.

3.4.1 The Stigma of Epilepsy and its Impact on Self-efficacy

Self-efficacy refers to an individual's ability to manage challenging encounters. It has been defined in the context of epilepsy as "the personal conviction to initiate and complete tasks associated with the daily management of epilepsy" (Dilorio et al, 1992). Irrespective of its severity, the stigmatisation of PWE is known to lower patient's levels of self-efficacy in managing their condition, increases their seizure worry and impacts on family support mechanisms (Austin and Caplan, 2007). The extent to which stigma is associated with epilepsy is significant. It has been demonstrated to compare with highly stigmatised health conditions such as HIV/Aids as opposed to lower levels of stigmatisation associated with chronic diseases like diabetes and renal disease (Fernandes et al, 2007). The stigmatisation of epilepsy correlates to inferior health-

related quality of life issues and emotional well-being (Sample et al, 2006). In addition a significant number of PWE may experience significant comorbid psychiatric and neuropsychological symptoms although access to mental health services is often inadequate despite the evidence linking depression and self-efficacy in respect of seizure management (Kobau and Dilorio, 2003).

In the pursuit of improving care, individuals must be given positive feedback as increased satisfaction with care has been correlated with increased self-efficacy (Dilorio et al, 2006). Multi-disciplinary care for PWE needs to incorporate evidence-based educational interventions as part of a comprehensive approach that targets self-efficacy for seizure management, social support and seizure worry. This is essential as stigma associated with epilepsy continues to negatively affect individuals in respect of quality of life and health outcomes. However the true impact of epilepsy related stigma on an individual's life course is not fully understood (Fisher et al, 2000; Sample et al, 2006).

3.4.2 The Legislative Implications of an Epilepsy Diagnosis

Because of the social stigma associated with epilepsy, the legal implications are generally considered under the rubric of disability with most ramifications primarily relating to employment and educational issues (Beran, 2008). In this sense there is an opportunity for PWE, albeit a last resort, to seek restitution and individuals should be advised of this prerogative when and where appropriate. There are of course less conflicting means of seeking restitution such as mediation, conciliation, and the intervention of advocates such as hospital-based patient liaison services and external advocates such as epilepsy specific advocacy groups (Beran, 2008). Such individuals or groups may provide support, advice and information to resolve the grievance or direct the individual to legal representation that is affordable and appropriately experienced.

There are a number of specific areas of concern in respect of epilepsy care and management that must be viewed from the perspective of the clinician and the PWE. A duty of care exists for clinicians to provide optimal care consistent with his/her level of competence ensuring that patients have access to appropriate care, interventions and ongoing management (Beran, 2008). For example in Ireland, PWE must be seizure free for at least one year before being permitted to drive (Road Safety Authority, 2010). This is often of high priority for PWE given that driving is considered an integral component of modern day living. In certain jurisdictions there is a duty of care on clinicians to report recalcitrant patients (Beran, 2007). In such instances information from health

information systems like the epilepsy-specific EPR could trigger alerts and enable decision support at the point of care.

Additional areas of concern relate to obtaining informed consent, involvement of PWE in research, recreational pursuits, disclosure and privacy issues relating to the diagnosis, employment discrimination, airline travel restrictions and obtaining insurance (Beran, 2008). For the majority of these concerns, the adoption and integration of decision support systems in conjunction with ICT can empower clinicians and patients alike in making appropriate clinical decisions that fulfil and meet legal standards of care.

3.4.3 Epilepsy - Making the Correct Diagnosis

The epilepsy diagnosis is primarily a clinical one and is based on the interpretation of the clinical manifestations reported to a specialist neurologist and/or an epileptologist in order to maximise diagnostic certainty (Angus–Leppan, 2008). This is an important consideration that must be clearly explained to patients who may have an expectation that investigations and tests will provide a definitive diagnosis. Despite the overwhelming evidence that supports the early and accurate diagnosis of epilepsy in the context of improved patient outcomes and cost effectiveness (Langfitt et al, 2002) the condition is frequently misdiagnosed and/or inappropriately treated (Montouris, 2000; Minshall and Smith, 2008).

International classification systems for epilepsy syndromes and seizures do exist, however the unavailability of validated criteria for diagnosing purposes remains problematic (Van Donselaar et al, 2005). This absence of definition criteria in conjunction with the subjective nature of the diagnosis increases the risk of misdiagnosis or inappropriate treatment (Juarez-Garcia et al, 2006). The consequences of such events can have serious implications for the physical, psychological, psychosocial and socio-economic well being of patients/carers and their families (Shinnar et al, 2000; Juarez-Garcia et al, 2006).

Care structures for PWE should facilitate a rapid and accurate diagnosis and the initiation of effective treatment that achieves optimum seizure control at an earlier stage and a better overall outcome (Reynolds, 2002; SIGN 2003; NICE 2004). Studies have demonstrated that outcomes for PWE are significantly inferior for patients who experience greater numbers of seizures before diagnosis, confirmation and initiation of treatment (Lambert and Bird, 2001; NICE, 2004). People with recent-onset of seizure

activity or clinical suspicion of epilepsy should be reviewed urgently by a neurologist and/or an epileptologist to ensure a precise, accurate and early diagnosis of the disease and initiation of therapies appropriate to the individual's needs (SIGN 2003; NICE 2004).

The fragmentation of healthcare services however allows relevant patient information to be dispersed across various health care settings any may not be optimally available. For example the diagnosis and treatment strategy initiated in a specialist epilepsy service should be shared with the patient's primary care givers. While information may be communicated (e.g. GP letters) there are many risks involved in such processes of information sharing. As a result there is no way of knowing if the information has been shared as opposed to having been communicated.

3.5 The Constituents of Quality Epilepsy Care and Management

While the prevalence and overall cost of epilepsy care is known to be significant (Zarcostas, 2010) the evidence regarding the essential parameters of high quality epilepsy care remain ambiguous (Pugh et al, 2007; Pugliatti et al, 2007). A significant proportion of PWE (70%) have the potential to be seizure free yet in many instances patients do not receive adequate care (Moran et al, 2002). In this section the evidence relating to international best practice standards for epilepsy care and management are discussed. This includes a review of recent strategies aimed at improving the quality and consistency of care for PWE. Patient satisfaction levels in relation to their care are explored and the section concludes with a review of existing models of care for PWE.

3.5.1 Epilepsy Specific Guidelines

A number of international guidelines are available to inform and guide the diagnosis and management of epilepsy (SIGN 2003; NICE, 2004). The NICE epilepsy clinical guideline for example informs the diagnosis, treatment and management of epilepsy in children, young people, adults and older people (NICE, 2004). The guideline recommends urgent referral (occurring within 2-4 weeks) from primary to specialist care for all individuals with suspected epilepsy. This is essential where there is evidence of behavioural/developmental regression and/or ambiguity regarding syndrome classification for particularly vulnerable groups of patient's e.g. intellectual disability.

Similarly, the SIGN guideline produced a national template to guide evidence based recommendations on the diagnosis and treatment of epilepsy (SIGN, 2003).

Recognising the limitation and fragmentation of existing epilepsy services the guideline in particular gives broad recommendations on initial AED treatment, management of drug-resistant epilepsy, management of status epilepticus, management of provoked seizures and the management of people with learning disability and epilepsy.

The SIGN and NICE guidelines are relevant to all health professionals in primary and secondary care involved in the management of PWE, including general practitioners, practice nurses, epilepsy specialist nurses, general hospital-based physicians, emergency care staff, neurologists and obstetricians. However, limitations of such guidelines are acknowledged (Frost et al, 2003; Sheldon et al, 2007) where it is argued that guidelines should be construed as a standard of medical care and adhering to them does not guarantee a successful outcome for every patient. Similarly many of the guideline recommendations are difficult to implement in the complexity of current healthcare settings (Williams et al, 2007).

3.5.2 Quality Indicators in Epilepsy Care

Concerns have been highlighted regarding the quality and safety of care provided to patients with epilepsy (McGlynn, Kerr and Asch, 1999; Institute of Medicine, 2001; Pugh et al, 2007). As a result, clinicians and health policy makers are increasingly held accountable for the quality of care delivered to patients and their families (Caplin et al, 2006). In many countries, quality indicators specific to various chronic diseases have been developed (Pugh et al, 2007). Such indicators facilitate the measurement of healthcare processes, allowing policy makers and clinicians to identify the gaps between evidence-based practice (e.g. NICE guidelines) and the reality of delivered care.

For example, monitoring the blood pressure of patients with hypertension and glycosylated haemoglobin levels for patients with diabetes are reliable and validated disease specific indicators that facilitate measurement of quality of care (McGlynn, Kerr & Asch, 1999). However, the quality of epilepsy care cannot be measured exclusively by measuring seizure control. Outcomes that reflect high quality epilepsy care have proven difficult to define as they are influenced by complex, inter-linked physical, psychological and social factors associated with the disease (Pugh et al, 2007). In their absence, measuring the quality of epilepsy care or the deficits in existing structures and processes of care processes remains a challenge.

Pugh et al (2007) have highlighted these deficits in epilepsy care and recommend that any reform initiatives must recognise these issues when attempting to improve care for PWE. Of course, the complexity of epilepsy is a contributing factor as clinicians must balance seizure control with significant adverse pharmacological side effects, complex psychological issues (e.g. mood disorders) and the consequences of long term treatment with AEDs (Pugh et al, 2007; Fountain et al, 2011). Attempts are being made to develop and validate quality indicators that are focused on the care of adults with epilepsy with a view to defining gaps and improving the quality of care for PWE (Pugh et al, 2007; Fountain et al, 2011). For example, Fountain et al (2011) have reported eight measures that should be performed and documented during the clinician's encounter with a patient. The measures include seizure type and frequency, etiology, investigations, AED side-effects, surgery referral where appropriate, safety issues, contraception and pregnancy.

Capturing this data during the clinical encounter does not infer automatic improvement in the quality and efficiency of epilepsy care. However, collating and interrogating this data through an appropriate ICT medium like the epilepsy-specific EPR could support the development of important measures reflecting quality and efficiency of epilepsy care. Consequently, interrogation of this data could enable the strategic planning of epilepsy care through the proactive monitoring of service performance and identifying gaps in current care processes.

In the United Kingdom, the recent General Medical Scheme contract has components aimed at improving quality of care for a number of chronic diseases including epilepsy (National Health Service, 2004). The scheme releases financial incentives for general practitioners who can demonstrate that nationally agreed quality indicators for PWE have been achieved and recorded annually (Minshall and Smith, 2008). While early studies have demonstrated some local improvements in the structure and process of epilepsy care, it is too early however to draw any long term conclusions from this strategy (Williams et al, 2007). Information in this process is managed electronically and is used to strategically link financial remuneration with service performance.

3.5.3 Patient Satisfaction and Epilepsy Care

Patient satisfaction is defined as the extent to which an individual's general health care and condition specific medical needs are being met (Asadi-Lari, Tamburini and Gray, 2004). Increased patient satisfaction occurs as a consequence of fulfilled healthcare expectations and is consistently associated with improved quality of life (Guldvog, 1999; Mah et al, 2006). While the factors that influence patient satisfaction are likely to be disease specific there are a number of common variables that influence patient satisfaction irrespective of the disease (Bautisa, Glen and Shetty 2007).

Interpreting and correlating patient satisfaction levels within the care provided remains difficult. Until relatively recently, health service delivery has largely been designed to meet the needs of the health care provider rather than the consumer. In many instances the perceptions of healthcare professionals in respect of patient expectations may differ significantly from those of the patients (Tucker, 2002). There can be distinct variations between the problems identified by health professionals and those raised by patients where research has demonstrated that the individual characteristics of any one group of patients can subjectively influence the results of satisfaction surveys (Tucker, 2002).

PWE have reported high levels of patient satisfaction in studies where significant information deficits and inadequate clinical services were also reported (Goldstein et al 1997; Poole et al, 2000). While such inconsistencies are likely to be attributable to variations in individual patient characteristics this ambiguity contributes to the overall difficulty of defining optimum epilepsy care (Pugh et al, 2007; Bradley and Lindsay, 2009). However, the development of integrated models of shared care for chronic diseases like epilepsy that include a information exchange "network" have the potential to improve patient engagement (Bu et al, 2007). Increased patient engagement creates the mechanism by which the person with the chronic disease can contribute meaningfully to the work of the care team and their own participation in self-management.

For some PWE, persistent medical and psycho-social problems may continue even where good control of seizures is reported (Fisher et al, 2000). Therefore, it should not be assumed that seizure control/reduction which is often the primary clinical objective does not automatically equate to patient satisfaction. In the United States for example, higher educational levels and improved quality of life are the main variables associated with increased patient satisfaction (Bautista, Tannahill, and Shetty, 2007).

3.5.4 Models of Care for People with Epilepsy

Bradley and Lindsay (2009) completed a review of the effectiveness of specialised or dedicated epilepsy interventions compared to standard epilepsy care. Two interventions, the specialist epilepsy nurse and self-management education programmes were identified as providing some benefit. However the authors concluded that these benefits are likely to be situation specific and may not be generalisable to other healthcare settings. While there is no convincing evidence that specialist epilepsy nurses can improve overall outcomes for PWE (Bradley and Lindsay, 2009) it is accepted that such roles can support and improve patient knowledge and communication pathways (Kendall, Thompson, and Couldridge, 2004). They may also have a role in meeting the requirements of patients in respect of supporting patients and families and to address psycho-social issues in respect of their disease (Kendall, Thompson, and Couldridge, 2004).

Epilepsy care delivery has been criticised for its lack of impact and as a consequence various strategies have been developed and implemented with the intention of improving the efficiency and quality of care (Bradley and Lindsay, 2009). With the exception of localised improvements to structures and process of care, no one model of epilepsy care has emerged that is generalisable to the wider population of PWE (Bradley and Lindsay, 2009). There is an increasing urgency to develop robust quality indicators specific to epilepsy care and management so as to further understand the issues promoting patient self-efficacy and the adoption and resourcing of international best practice guidelines (Pugh et al, 2007). While this does not automatically infer that care for PWE will improve, it can collectively inform the development of an appropriate and strategic model of care.

3.6 The Current Structure of Epilepsy Care and Management

60-70% of PWE who become seizure free or achieve optimum control of seizure activity can have their care managed and delivered by their general practitioner, consulting with specialist neurology services when clinically indicated (Frost el al, 2003). The remaining 30-40% of PWE will continue to experience more intractable forms of the disease requiring more frequent engagement and sharing of care with specialist neurology services (Pugh et al, 2003).

3.6.1 Epilepsy and Primary Care Services

In the United Kingdom, 90% of patients presenting to their GP with suspected epilepsy are referred to a hospital-based neurology specialist service to confirm the diagnosis, initiate treatment and monitor the response to the treatment regime (Thapar et al, 1998; Lambert and Bird 2001). According to best practice guidelines, the initial specialist review should take place within 4 weeks (SIGN, 2003) and should be completed within four months (SIGN, 2003). After this process has concluded, the majority of patients (approx 66%) can have their on-going care primarily managed by their GP who monitors the response to treatment, documents seizure activity and screens regularly for the development of any associated co-morbidities (e.g. depression). If there is deterioration in the patient's condition then the GP should consult and/or refer the patient back to specialist neurology services.

The reality for PWE is that review arrangements in primary care are frequently reported to be inadequate and such services have been criticised for not implementing systematic improvements (Minshall and Smith, 2006). Despite the presence of best-practice guidelines, primary care for PWE remains fragmented and inconsistent (Lambert and Bird, 2001; Sample et al, 2006; Pugh et al, 2007). The more common challenges relate to lack of support in the community, inefficient information management and communication across the primary-specialist care interface and inaccessibility to specialist services (Minshall and Smith, 2006).

In Ireland, PWE are referred by their GP to local hospital-based general medical services or to regional hospitals that provide dedicated neurology services (Neligan et al, 2006). Currently, these pathways of referral and care are undefined strategically and like many other countries, the demand for neurological services far exceeds availability (Comhairle na nOspideal, 2003). As a consequence, GPs may feel professionally compelled to more actively participate in initial patient management despite the fact that he/she may feel clinically incompetent (Neligan et al, 2006).

3.6.2 Epilepsy and Hospital Based Services

The epilepsy diagnosis remains largely clinical and should be confirmed by a neurologist (Angus–Leppan, 2008). Estimates of mis-diagnosis range from one-quarter to three quarters of patients with some studies suggesting that approximately half the

patients referred to specialist neurology services do not subsequently have their initial diagnosis confirmed (Zaidi et al, 2000). The rate of misdiagnosis is a strong argument for specialist care for PWE where advances and increased choice of pharmacological agents and other treatment interventions further support the rationale for hospital-based care.

Extrapolating from an Irish epilepsy prevalence study (Linehan et al, 2010) it is estimated that between 7000-14000 individuals have a more intractable and complex forms of the disease. This requires more frequent and continued specialist led care with an emphasis on the more vulnerable groups such as women of child bearing years, adolescents, people with intellectual disability and older people. It is likely that the majority of these patients will continue to receive there care and management from hospital-based epilepsy services.

3.6.3 Epilepsy and the Emergency Department

Individuals with a first time seizure, a history of seizures or an acute exacerbation of symptoms may require medial intervention within a local emergency department. The source of referral is inconsistent and in most instances is dependent on where and when the individual became symptomatic. Unfortunately significant variability exists in the standards of care provided and in many situations such episodic interactions results in patients being discharged into inappropriate pathways of care (Krumholz et al, 2007). This process may inadvertently add further complexity to patient care journeys which increases the possibility of poor outcomes for patients (Huff et al, 2001).

3.7 Epilepsy Care in Ireland – What is Known?

Historically, in the Irish healthcare system the general practitioner has fulfilled the role of care co-coordinator or "gatekeeper" to services for all chronic diseases including epilepsy. In this arrangement the emphasis is on patient care being provided in the community with subsequent referral to hospital based services for specialist review when clinically indicated (Department of Health and Children, 2001). Subsequently, patients are discharged back to their GP when their condition is confirmed and stabilised for follow up care and management.

Recent health policy in Ireland has sought to formalise strategically the management of patients with chronic disease (Department of Health and Children, 2008a). This has achieved some improvements for certain diseases where clearly defined quality

indicators of care exist e.g. diabetes and hypertension. In addition Irish GPs are clinically more comfortable in their competency to manage such conditions (Smith, Bury and O'Leary, 2004; Meade, Buckley and Boland, 2009).

Epilepsy on the other hand by its nature and complexity requires general practitioners to initially refer patients with suspected epilepsy or poorly controlled epilepsy to a specialist neurology service. The availability of these services are limited and in many instances PWE are referred to a local hospital based service without neurology services or a regional hospital with a neurology service but without dedicated epilepsy services. While frequently reported as the second most common neurological condition after stroke, specialist epilepsy care tends to get consumed within the context and resource allocation of general neurology services in Ireland (Comhairle na nOspideal, 2003).

The capacity of these neurology services in Ireland have been persistently criticised over the last twenty years with a number of reports highlighting major resourcing and structural deficits (NAI, 1999; NAI 2002; Comhairle na nOspideal, 2003). A key recommendation of these reports was to increase the appointment of neurologists in Ireland to adequately serve the Irish population (NAI, 2005). However, a deficit continues in this respect and as a result Ireland has one of the worst ratios of patients to consultant neurologists reported in Europe (World Federation of Neurology, 2000).

While the reform of epilepsy services in Ireland is currently under review, the quality, safety and efficiency of existing services are poorly understood. The interpretation of the current structure and process of care for PWE may unintentionally rely upon local service provider's assumptions or interpretation of existing services. The evidence supporting such assumptions may often be anecdotal and may simply reflect the interpretation and frustration of a particular individual or group.

The long-time absence of a national strategic epilepsy framework in Ireland has facilitated the evolution of non-integrated epilepsy services that deliver care locally. In addition, an environment of inertia has developed over time in which the key stakeholders (patients, clinicians, and policy makers) may be unsure or isolated within their own roles and responsibilities. Therefore it is likely that current stakeholders view their roles in isolation rather that a component of care that needs to be integrated into the overall provision of a strategy for PWE in Ireland.

3.8 The Future Direction of Epilepsy Care in Ireland

As discussed in the introduction to this chapter, the Health Service Executive (HSE) in Ireland is currently implementing a chronic disease framework for specific medical conditions which includes epilepsy (HSE Transformation Programme, 2007-2010). The purpose is to deliver integrated care that is of high quality, equitable and accessible to all patients. While the emphasis of reform may initially focus on capacity and geographical configuration, it is likely that realising quantifiable improvements in the quality of care delivered to PWE will require the essential elements of optimum chronic disease management to be addressed.

Caution therefore must be exercised for any reconfiguration/reform strategy claiming to be a panacea for epilepsy care. The provision of additional resources such as the appointment of more neurologists, increased bed capacity and the implementation of nurse led services can be strategically justified yet it does not automatically infer a long-lasting, sustainable improvement in the quality, safety and efficiency of epilepsy care services. For example, the addition of nurse led clinics and specialist epilepsy nursing roles in the UK have been criticised for their lack of clarity and the absence of rigorous evaluation examining the true impact on patient outcomes and service performance (Bradley and Lindsay, 2009).

This of course is not exclusively an Irish epilepsy problem. Strategically improving epilepsy care has proven difficult even in healthcare systems that are adequately resourced (Pugh et al, 2007). In such instances the biggest challenge is the non-integration of primary and specialist care services whose geographical and organisational boundaries limits their ability to efficiently integrate care and communicate information (Dorr et al, 2007).

In the dynamic of modern healthcare delivery the expectations and demands have shifted away from clinician needs to the more appropriate needs of patients. Empowering patients and promoting self-efficacy within a strategic model of shared care for epilepsy is required. Such a model should incorporate the essential elements of effective CDM including a system of information exchange and management that facilitates effective, coordinated care, long-term measurement of service performance and evaluation of patient outcomes. Technologies like the epilepsy specific EPR have

an essential role in supporting many of the core concepts of effective CDM. However, irrespective of the enabler of change, understanding and documenting the current structure and process of epilepsy care in Ireland is an essential prerequisite to any service reform. If epilepsy services are to be nationally reformed as part of the chronic disease management strategy then an appreciation of current epilepsy services from the perspective of all key stakeholders is also required.

3.9 Conclusion

Effective epilepsy management requires the provision of an integrated service that facilitates early detection, optimum control of symptoms and complications of treatment while simultaneously empowering patients to allow them to take control of their lives. Understanding and appreciating the existing challenges and deficits from the perspective of all key stakeholders is an essential prerequisite prior to implementing any one or combination of potential solutions. In this chapter the nature of epilepsy together with the unique challenges to optimal care of PWE has been presented. The key points are summarised;

- Epilepsy is a highly prevalent chronic disease with significant physical, physiological and social ramifications for patients, carers, families, clinicians, health policy makers and the wider society.
- The provision of care for PWE is commonly reported as inadequate with significant organisational challenges in defining, implementing and measuring optimum epilepsy care.
- At present it is not possible to advocate any single model of service provision for PWE.
- There is an urgency to improve the quality, safety and efficiency of epilepsy care by improving the knowledge and awareness of epilepsy among clinicians and patients; ensuring the delivery of healthcare in the appropriate setting; integrating and coordinating the primary/secondary/tertiary care interphase and improving communication between clinicians and patients.
- An innovative model of shared care is required for epilepsy care in Ireland that incorporates the essential principles of effective CDM.
- Health information and information technology can enable this transformation of epilepsy care by leveraging information and communication to support a strategic programme of CDM reform.
- Before implementing potential reform solutions, there is a need to understand and

document pre-existing structures and processes of care from the key stakeholder's perspectives.

Subsequent chapters in this thesis (chapters IV; V; VI; VII) contribute to the process of documenting and understanding the current structure and process of epilepsy care and management in Ireland. It begins with an exploration of the healthcare journeys of Irish patients with epilepsy (Chapter IV). This was the first study of its kind in Ireland and was unique in the context of the international epilepsy literature. The increased recognition of the importance of patient self-management and self-efficacy in CDM requires the health service industry to engage with and incorporate the opinion of patients in chronic disease reform strategies.

Chapter IV

The Healthcare Journeys Experienced by People with Epilepsy in Ireland: The Implications for Future Service Reform and Development?

4.0 Background

As outlined in chapter 1 this socio- technical project aimed to revolutionise CDM using ICT as an enabler of healthcare reform and reconfiguration. Using epilepsy as an exemplar of chronic disease the Epilepsy Programme at Beaumont Hospital developed and implemented incrementally an epilepsy-specific Electronic Patient Record (EPR). The primary purpose of the EPR was to assimilate epilepsy-specific information electronically and make it available via the Internet to authorised users within and external to the epilepsy service at Beaumont Hospital. Driving this initiative is the well documented role of ICT in modern day healthcare delivery as an enabler of service reform and reconfiguration.

Within this research and development project evaluation research both technical and social were prioritised as many ICT healthcare initiatives fail to deliver on their true potential. Indeed, in some instances inappropriate development and implementation of ICT into preexisting complex healthcare structures have resulted in negative outcomes. In this respect inappropriate implementation of the epilepsy-specific EPR could have exposed clinicians, patients and healthcare organisations to significant avoidable risks

During the design phase of the EPR project at Beaumont Hospital much of the early technical evaluation focused on issues pertaining to the usability, reliability, safety and the impact of the epilepsy-specific EPR on work practices locally. These technical evaluation research methodologies were conducted simultaneously during the life-time of the project and do not form an integral part of this thesis. However, the findings from technical evaluation were conducted in parallel with social evaluation studies and form the basis of a second PhD thesis (McQuaid, 2010).

As highlighted in chapter I, very little is known empirically of the structure and process of epilepsy care in Ireland. Observational studies, audit and process mapping techniques were used initially to explore and document the structure and process of epilepsy care within Beaumont Hospital, the site in which the EPR was being developed and implemented. The epilepsy service at Beaumont Hospital, Dublin is the only tertiary referral centre in Ireland offering dedicated epilepsy services that includes the treatment option of neurosurgery for the specific management of certain types of epilepsy.

A significant finding of this early research work revealed that while existing patients within the epilepsy service were receiving high quality, multi-disciplinary care, a number of organisational and operational challenges existed which impeded and delayed the delivery of services. In 2007 an audit of all patients referred to the epilepsy service at Beaumont Hospital (Varley, 2007) revealed that 50% of patients were referred directly by their GP from geographically diverse locations, the average waiting time for an appointment was 16 months, with the majority (65%) waiting more than one year and having a documented history of epilepsy (64%). Subsequent process mapping exercises within the epilepsy clinic at Beaumont Hospital revealed an absence of referral and discharge criteria within the service. Similarly patients managed within the epilepsy service tended to remain there indefinitely with significant delays for patients requiring radiological tests and investigations, neurological review and inpatient video monitoring.

These initial research findings suggested that significant deficits existed regarding the structure and process of epilepsy care in Ireland. In many instances the deficits and challenges within existing epilepsy services at Beaumont Hospital were significantly added to by the undefined processes of referral which directed a significant number of patients to its service. This situation is further complicated by the fact that neurology services capacity in Ireland is known to be significantly under resourced (Comhairle na nOspideal, 2003) and that epilepsy service at Beaumont Hospital are not funded as a tertiary care centre but rather as part of the overall neurology service. In addition and from the international perspective, the provision of care for PWE is commonly

reported as inadequate with significant organisational challenges in defining, implementing and measuring optimum epilepsy care.

The successful implementation of ICT into healthcare requires existing healthcare processes to be transparent and accessible to measurement (Kawamoto, et al, 2005; Dorr et al, 2007). If the epilepsy specific EPR were to improve the quality and efficiency of epilepsy care services locally (Beaumont Hospital) and strategically (national context) then pre-existing structures and processes of care must be adequately understood. Implementing the technology as a solution without fully understanding the problem (preexisting organisational complexity) may only serve to add further complexity irrespective of its technological capability.

This early evaluation work suggested that significant challenges existed in existing epilepsy services and that many of the essential components of effective CDM were absent. As described in chapter III (section 3.7) the long-time absence of a national strategic epilepsy framework in Ireland has facilitated the evolution of non-integrated epilepsy services that deliver care locally. The key stakeholders (patients, clinicians, and policy makers) may be unsure or isolated within their own roles and responsibilities allowing an environment of inertia to develop where stakeholders work in isolation rather that collaboratively and strategically.

If the epilepsy-specific EPR were to fulfill its potential as a catalyst and enabler of epilepsy service reform then the pre-implementation phase of its evaluation required a full appreciation of the extent of the problems within existing epilepsy services. This mixed-methods approach to evaluation investigated the core issues from the key stakeholder's perspectives and highlights the opportunities within healthcare where optimum information management and communication can be used to support key components of CDM reform policy.

4.1 Introduction to the Study

Aside from anecdotal evidence, little has been documented regarding the quality and efficiency of epilepsy care in Ireland despite the obvious inadequacy of existing services. Early evaluation work informing the research direction of this thesis (Varley, 2007) had identified significant deficits in respect of access and referral to the specialist service at Beaumont Hospital. As part of the mixed methods approach to evaluating epilepsy services in Ireland and documenting the structure and process of epilepsy care this chapter reports on a specific research study exploring the healthcare journeys of people with epilepsy (PWE) from the patient's own perspective.

Because the patient is one of the arbiters of healthcare quality, understanding their healthcare journeys can reveal important insights into the challenges and burdens experienced within existing services (Oliver, 2008; Molassiotis et al, 2010). The findings assist in identifying the opportunities where improved information management and communication via the epilepsy-specific EPR could 1) improve the quality and efficiency of epilepsy care 2) support a strategic reconfiguration of epilepsy services and 3) inform the wider CDM reform debate.

In the context of the wider CDM debate, promoting patient self-management has been identified as an essential element of optimum care (Nolte and McKee, 2008). It is increasingly recognised that patient's perceptions and understanding of their healthcare experiences must be appreciated so that shared expectations between the clinician and patient can be established and decisions can be made jointly in striving to achieve realistic and desired outcomes (Glasgow et al, 2003). Empowering patients towards self-management is complex and challenging however understanding their requirements improves perceived quality of life, patient satisfaction, self esteem and compliance with prescribed treatment (Larsen and Lubkin, 2009).

4.2 Selecting the Research Approach

The aim of this study was to document and interpret the experiences of PWE in Ireland as they journeyed along the epilepsy care continuum. The findings were not intended to be a reflection of the quality of epilepsy care. Rather, the purpose was to reveal important insights into the current structure and process of epilepsy care from

the unique perspective of patient's which would contribute valuable insight into the wider project aims of strategically improving epilepsy care and informing the wider debate of CDM reform (chapter I). Adopting a qualitative approach in designing the study would enable participants (PWE) to provide a fuller, richer account of their care journeys rather than a standard quantitative instrument which would be less flexible in probing areas of interest. The challenge therefore was to utilise an appropriate qualitative methodology to capture how PWE perceive their healthcare experiences within the Irish healthcare service and its subsequent impact on their daily lives.

Traditional quantitative research has been criticised previously for failing to capture the impact of epilepsy on the lives of patients and their families, focusing primarily on quality of life issues using questionnaires and generic health surveys (Sample et al, 2006). As a consequence an increasing number of studies have employed a qualitative research approach when exploring patients experiences of accessing epilepsy-related services and health care journeys (Bishop and Allen, 2003; Elliott, Lach, and Smith, 2005; Prinjha et al, 2005; Räty et al, 2007; McCorry, Marson and Jacoby, 2009). In the majority of such studies however the study design favours focus groups to report on patients understanding of their health care journey (Sample et al, 2006; Räty et al, 2007; McCorry, Marson and Jacoby, 2009).

As discussed in the introduction to this chapter, early observational studies, audit and process mapping techniques were used initially to explore and document the structure and process of epilepsy care within Beaumont Hospital. These interactions allowed the researcher to gain insight into the significant variability between PWE in respect of their physical, emotional, psychological and physiological well being. For example, the type and severity of each individual's epilepsy in conjunction with their medication regime may affect their cognitive function e.g. concentration levels and memory impairment (Gauffin, Flensner and Landtblom, 2011). The researcher suggests that inviting a cohort of PWE to participate in a focus group study could be biased in favour of individuals with lesser forms of the disease or less complications of treatment interventions.

Previous qualitative studies have explored the healthcare experiences of PWE underpinned by theoretical frameworks developed for qualitative research purposes,

including thematic analysis (Prinjha et al, 2005; Gauffin, Flensner and Landtblom, 2011), phemenology (Sample et al, 2006) and grounded theory (McCorry, Marson and Jacoby, 2009). The studies used focus groups which may limit data extraction to more dominant members of groups as opposed to gauging the needs of individual patients. Smith, Flowers, and Larkin (2009) conclude that despite the fact that most IPA research uses semi-structured interviews to collect data, there is no reason why other qualitative data collection methods cannot be used. For the purpose of this study, individual one-to-one interviews were conducted rather than a focus group which is unique in the context of exiting research literature exploring patient's interpretation of epilepsy care.

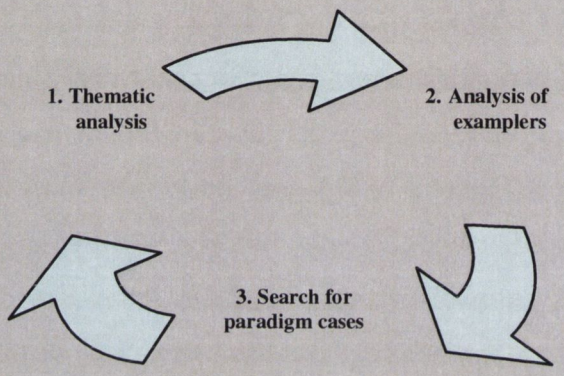
As described by Benner (Benner, 1984; Benner, 1994) interpretive phenomenology analysis (IPA) was used to inform and structure the interrogation and interpretation of the collected data (Figure 1). IPA was developed more recently and specifically within psychology, however it is now widely used by researchers in health, clinical and social science research particularly in the United Kingdom (Smith, Flowers, and Larkin, 2009). This approach has been used previously to explore and provide insight into the experiences and perspectives of people with various chronic conditions (Wallace and Solomon, 1999) including epilepsy (McCorry, Marson and Jacoby, 2009). IPA, because of its flexible and open design allows researchers to explore in detail how individuals are making sense of their personal and social world, and the meanings that are attached to their experiences and events (Larkin, Watts and Clifton, 2006).

IPA accommodated the dynamic process of this research approach and allows the researcher to actively participate and get close to the participant's personal world (Benner, 1994). The researcher's own conceptions and interpretations are required to understand the individual's personal world through a process of interpretative activity. A theory like IPA facilitates two way interpretations in that it supports individuals making sense of their world and the researcher attempting to make sense of the participants trying to make sense of their world (Streubert Speziale and Carpenter, 2003). Facilitating both aspects in the research enquiry results in deeper and richer data analysis and does "greater justice to the totality of the person" (Smith and Osborn, 2008). This is particularly of value for individuals in whom cognitive

ability may be impaired and the person struggles to self-disclose information and express what they are thinking and feeling. Using one to one interviews in this study was unique in that it engaged with patients with significant and intractable forms of the disease on an individual basis, thereby facilitating the interpretive dimension of IPA.

Figure 1

Interpretive Phenomenology:
A philosophical school of thought in which the researcher is considered inseparable from assumptions and preconceptions about the phenomenon of study and seeks to reveal and convey deep insight and understanding of the concealed meanings of everyday life experiences (Witt and Ploeg, 2006)



Exemplars:
Stories or vignettes that capture the meaning in a situation in such a way that the meaning can then be recognised in another situation that might have very different objective circumstances (Benner, 1994).

Paradigm cases:
Strong instances of concerns or ways of being in the world, doing a practice, or taking up a project (Benner, 1994).

4. 3 Methodology

4.3.1 Study Setting

This study was conducted in the epilepsy outpatient department of Beaumont Hospital, Dublin, Ireland. This epilepsy programme is the main tertiary referral centre for patients with complex epilepsy and related disorders in Ireland. Although not formally acknowledged or resourced as a national specialty centre for epilepsy care, it is the only centre offering neurosurgery as a treatment modality for certain types of epilepsy. One of the epilepsy programme services is a weekly out-patient clinic in which new and returning patients receive multi-disciplinary care in respect of epilepsy specific diagnosis, investigation, treatment and follow-up care. This is also the clinical environment in which the epilepsy-specific EPR was initially designed, tested and implemented.

4.3.2 Recruiting Participants

The weekly epilepsy out-patient clinic which is attended by approximately fifty individuals contains on a weekly basis approximately 8-10 "new" patients referred to the service. New patients are referred to the epilepsy out-patient service from all over Ireland by their GP, other neurological and non-neurological specialists at Beaumont Hospital or other hospitals throughout Ireland that may or may not have a dedicated neurology service. Many of the patient's treated by its multi-disciplinary care team tend to have intractable forms of the disease. On average referred patients to this service wait between 6-18 months for their initial review, which is prioritised based on clinical need.

To construct a reasonably homogenous sample consistent with the chosen methodology, potential participants were recruited from "new patients" referred to the epilepsy service at Beaumont Hospital. Patients already treated and managed within the epilepsy service at Beaumont Hospital were excluded as the start point of the journey was the onset of symptoms and/or an epilepsy diagnosis while the end-point was their initial review in the epilepsy OPD clinic at Beaumont Hospital. Obviously the experience of patients previously treated and managed within existing services could and would be significantly different.

Potential participants were identified prospectively from letters of referral sent to the epilepsy service at Beaumont Hospital. This information specific to potential participants was extracted from the original letter of referral to the epilepsy service. Having identified potential participants prospectively, the lead researcher then dispatched letters of invitation to one month prior to the individuals scheduled appointment.

4.3.3 Selecting an Appropriate Sample Size

The size of the purposive sample in this study *(n=20)* was not known prior to data collection. The sample size in interpretive phemenology studies is dependent on several factors including the topic under investigation, the richness of the individual cases, the extent and dept of reporting and the practical constraints of individual research projects. Unlike quantitative research design, the sample contained within an

IPA study cannot demonstrate a statistical power, rather it is judged by the illumination it casts on the broader context. It is unlikely that a sample size is too small within an IP study as previous studies support the use of small samples sizes of between three and ten participants which facilitates detailed analysis of similarity versus difference and convergence versus divergence (Smith and Osborn, 2008). Rather a more inherent risk in IP sampling is the recruitment of too large a sample in which the researcher becomes overwhelmed by excessive data that is intractably difficult to penetrate in respect of analysis.

Published IPA studies generally tend to use sample sizes from one to fifteen participants as a distinctive feature of IPA is its commitment to a detailed interpretative account of the cases which in reality can only be carried out on small samples (Smith and Osborn, 2008). Because of this, the reader should think of theoretical rather than empirically generalisable conclusions when interpreting the findings. Smith and Osborn (2008) suggest that the reader interprets the results of IP studies through the conduit of their own personal and professional experience and existing claims and evidence in the existing literature.

The inclusion criteria for potential participants included:

- Patients having a scheduled appointment to attend the epilepsy outpatient department.
- Patients having not attended the clinic previously or were discharged from the service greater than three years ago.
- Patients having a diagnosis of epilepsy or suspected epilepsy at the time of their referral.
- Patient's referral to the service being epilepsy related.
- Documented informed written consent from patients or their carers.
- Potential participants could read and understand English language.
- A lower age limit of 16 years of age.

Exclusion criteria for potential participants included:

- Patients who were employees of Beaumont Hospital
- Patients under 16 years of age
- Patients already known to the service i.e. reviewed in the last three years

Eligible participants were contacted by written mail one month prior to their out-patient appointment inviting them to participate in the study. The letter of invitation included an information leaflet outlining the aims and objectives of the study together with a consent form. Individuals wishing to participate were asked to complete the consent form and either return it by post or present it on the day of their scheduled out-patient appointment at the clinic.

4.3.4 Data Collection

In this qualitative study, one-to-one, semi-structured interviews were conducted with consenting participants guided by open ended questions (Table 1). While data may be collected in many ways, the majority of IPA studies use this methodology because of its flexible design (Breakwell, Smith and Osborne, 2008). This type of interviewing allows the researcher and participant to engage in a process whereby initial questions may be modified and restructured in response to initial participant answers while simultaneously the investigator can probe interesting and important areas which arise (Breakwell, Smith and Osborne, 2008).

In this study, the interviews were conducted after the participant's clinical engagement was concluded. The participant was directed to a dedicated research room where he/she was interviewed by the lead researcher. The interviewer and interviewee were not previously known to each other. Before commencing the interview the research process was clearly explained to each individual. Participants were made aware that the interview could last up to one hour and would be tape-recorded using a digital voice recorder. Participants were aware that they could terminate the interview at any time and/or the interview could be terminated at the discretion on the researcher. Anonymity and confidentiality regarding management of collected data was stressed to all participants before and after their scheduled

interview. Participants were offered refreshments and afforded bathroom opportunities prior to commencement of the interview.

Guided by open-ended questions (Table 1) the interviewer invited the participant to describe and reflect upon their epilepsy specific healthcare journeys. The start point of the journey was the onset of symptoms and/or a provisional epilepsy diagnosis while the end-point was their initial review in the epilepsy OPD clinic at Beaumont Hospital. The interviewer's role during the semi-structured interview was to facilitate and guide the scheduling of the questions (Table 1) rather than dictate exactly what would happen during the encounter. The schedule of questions (Table 1) was used to indicate the general area of interest for the participant however the participants were facilitated to determine the direction of the interview.

The interview technique adopted in IPA does not have to follow the sequence on the schedule or ask questions in the listed order (Breakwell, Smith and Osborne, 2008). For example, in the exploration of topics II, III and IV (Table 1) certain responses could prompt the interviewer to ask certain questions in a different order if it followed on from what the participant had just said. Similarly, how a question was phrased depended on the participant responsiveness and how the interviewer felt the participant was responding. Where necessary the interviewer probed and sought clarification from the participant or repeated or rephrased the question if indicated. In addition to tape-recording the interview, the interviewer also took field notes. At termination of the interview each participant was advised that revision, clarification and/or deletion of the interview or part of the interview were possible.

Table 1: Semi- structured schedule of questions

Topics explored	Prompts for patients
I. The origin of the journey	Can you state your full name and address? Tell me about when you first discovered you had epilepsy? What impact did this have on your life at that time? What was the severity of the disease (e.g. seizure type and frequency)?
II. The patients interpretation of their subsequent healthcare journey	Tell me about your healthcare experiences from that time and how you came to be referred to this service? How did you feel during this process? What services helped you most during this journey? What were the major challenges you encountered during that time? What were your expectations prior to coming here today?
III. The patient experience of current care processes	Who do you think is responsible for your care? What is the role of your general practitioner in relation to your epilepsy? What is your experience of the service provided by your GP? What is the role of your local hospital in relation to your epilepsy? What is your experience of the service provided by your local hospital?
IV Patients interpretation of their role in epilepsy care	What do you see as you responsibilities regarding your epilepsy care? To who/whom do you look to for guidance and/or support? If specific how have they been helpful? Whom do you share your feelings with specific to your epilepsy? How much do you know or want to know about your epilepsy (e.g. medications, treatment options)?
V. Information and Communication Needs	How important is knowing specific information about your epilepsy to you? How well is information communicated to you? If you want to know more about epilepsy where do you look for information? Are there any groups or organisations that you engage with specifically? Do you use a computer? If yes what do you use it for? How do you feel about your epilepsy specific information being available electronically via the internet? Would you be interested in accessing your own epilepsy medical record if available via the internet? If yes; why? If no; Why?
VI Patients interpretation of the major challenges for PWE	In your experience what are/were the most challenging issues in relation to your epilepsy care journey How could things be made better for people with epilepsy If you have the power to change it what is the one thing you would change? Is there anything further you would like to ask or comment on prior to ending this interview?

4.3.5 Data Analysis

Data analysis began when text from initial interviews became available. In IPA studies, data analysis requires careful balancing of phenomenological description with insightful interpretation by the researcher which should culminate with evidence of the interpretations embedded within the individual's story (Smith, Flowers, and Larkin, 2009). The process of data analysis in this study facilitated the interrelated processes of thematic analysis, analysis of exemplars and the search for paradigm cases (Fig 1). Adopting sequentially the steps of IPA maintained idiographic focus within the study which minimises the risk of loosing particular variations of the data or following implied causal relations rather than focusing on data interpretation (Breakwell, Smith and Osborne, 2008).

Each tape-recorded interview was carefully transcribed by the researcher onto paper. Each interview was carefully read several times to gain an overall impression of the text and to annotate it its content for insights into the participants' experience of their healthcare journey. Annotating or "coding" identified the most common recurrent themes prior to organizing them into categories. Emerging codes are categorised and patterns within these codes are identified. These patterns are considered themes which are the recurrent patterns of meaning throughout the text. Themes are likely to represent things that matter to the participant and contextualise its meaning in that situation. Some themes were grouped under much broader categories. The research literature in many instances refers to these categories as subordinate themes (Smith, 2008).

Each interview was transcribed and analysised in the order of which they were conducted using the same sequential steps to explore the data. Themes emerging from the initial transcripts helped to orientate the analysis of subsequent interviews and identify new issues emerging from these interviews. A priority was to respect convergences and divergences in the data, which assisted the researcher in recognising subtle similarities and differences within the individual transcripts.

Themes and categories were then compared across the transcripts to further refine their classification. Concurrently, exemplar and paradigm cases (Benner, 1994) were

searched for throughout this interpretive research process to illustrate interpretations that were meaningful irrespective of the individual's situation and/or circumstances (Figure 1). The text analysis was based on hard copies of the transcripts and tables organising the themes and categories were produced manually. No coding software programme was used in this study.

The National Institute for Clinical Excellence (NICE) guideline for the care and management of epilepsy (NICE, 2004) was used to frame the significance of the major themes that emerged from the data. Bracketing which is used in qualitative research to curb the influence of the researcher's previous experiences, judgments and beliefs (Gearing, 2004) was used during data analysis. Further rigor was added to the study by eliciting the assistance of a qualitative research expert who examined some of the interviews and concurred with the research process being used and the consistency of the results. This level of transparency in the methodology increases the plausibility and transferability of the results to a wider population.

4.3.6 Ethical considerations

Formal ethical approval for this study was sought and sanctioned by the medical ethics committee of Beaumont Hospital.

4.4 Results

Letters of invitation were sent to thirty-eight individuals who met the inclusion/exclusion criteria over a five month period from November 2007 to March 2008. Twenty-one individuals agreed to participate in the study. While fifteen invited participants did not respond, they subsequently did not attend for their scheduled appointment and were not contacted again. Two individuals declined to participate in the study. Three participants were represented by carers while seven participants had a spouse/partner present during their interview. One participant had a seizure during his clinic consultation and the interview was conducted by telephone with his carer (Mother) two days later. Two participants had previously attended the service; however both individuals satisfied the inclusion/exclusion criteria having being discharged from the service more than three years previously. In total twenty individuals met the inclusion/exclusion criteria and were admitted into the study after written consent was obtained. However, one female consenting participant withdrew

after her clinic consultation but prior to her interview citing time constraints. This left a sample of nineteen patients and/or their carers who completed an interview.

At the end of their interview no participant asked for deletions however three individuals sought to clarify certain remarks and four participants sought reassurance regarding confidentiality of their disclosures. Interviews were coded numerically from one to twenty in sequential order as interviews were completed. Each numerical code carries the prefix M for male and F for female. Recruitment was discontinued when no new themes were emerging from the data. The participants' socio-economic, geographical and demographic profiles were diverse and were not stratified as part of data analysis (Table 2).

Table 2: Characteristics of sample *(n=20)*

Gender		**Dependents (under 18 years)**	
Male	10 [50%]	Yes	8 [40%]
Female	10 [50%]	No	12 [60%]
Age in years		**Marital status**	
0 – 18	2[%]	Single	7 [35%]
19 – 35	11[%]	Co-habitating	2 [10%]
36 - 55	5[%]	Married	9 [45%]
>55	2[%]	Separated	2 [10%]
Address		**Additional health insurance**	
Dublin city/county	7 [35%]	Yes	4 [20%]
Leinster	8 [40%]	No	16 [80%]
Munster	3 [15%]	**Computer literacy**	
Connaught	2 [10%]	Yes	8 [40%]
Ulster	0 [0%]	No	12 [60%]
Employment status		**Referred to specialist service by;**	
Professional	1 [5%]	General practitioner	7 [35%]
Skilled manual	1 [5%]	Hospital with no neurology service	8 [40%]
Unskilled manual	6 [30%]	Hospital with neurology service	2 [10%]
Retired	2 [10%]	In house (Beaumont Hospital) referral	1 [5%]
Student 2nd level	1 [5%]	Paediatric services	2 [10%]
Student 3rd level	1 [5%]		
Unemployed	8 [40%]		

In all cases this was the participant's first visit to the dedicated epilepsy-specific outpatient department of Beaumont Hospital. The type, severity and consequences of each individual's epilepsy were unique; however, all participants were experiencing active symptoms and were taking prescribed anti-epileptic drugs (Table 3).

Table 3: Epilepsy specific characteristics of the sample *(n=20)*

Age at seizure onset		**Most recent seizure activity**	
< 5 years	2 [10%]	< 1 week	1 [5%]
5-18 years	7 [35%]	< 1 month	5 [25%]
19-50 years	11 [55%]	< 1 year	8 [40%]
>55 years	0 [0%]	> 1 year	5 [25%]
		Unknown	1 [5%]
No of anti-epileptic drugs		**Associated co- morbidities**	
1 AED	11[55%]	Yes	9 [45%]
2 AEDs	7 [35%]	No	9 [45%]
3 or more AEDs	1 [5%]	Unknown	2 [10%]
None	1 [5%]		

A final table of superordinate themes was developed when all transcripts had been analysed using the interpretative process (Table 4). It must be remembered that these themes were not selected on the basis of their prevalence within the data. Each theme is supported by various direct quotations from the individual texts to illustrate and support their inclusion however for practical reasons not all supporting material that emerged during the interpretive process could be included.

Table 4: Superordinate themes

I. Delayed access to specialist care significantly impacts on the healthcare experiences of people with epilepsy
II. People with epilepsy are insecure regarding the function and competency of their general practitioner in respect of epilepsy care and management
III. Significant unmet needs exist specific to epilepsy care for women in Ireland
IV. The current structure and process of epilepsy care in Ireland contributes to a culture where patients feel disempowered and isolated
V. The unmet information and communication needs of people with epilepsy contributes to discordance in their care

4.4.1 Theme 1: Delayed access to specialist care significantly impacts on the healthcare experiences of people with epilepsy (PWE)

The NICE guideline for epilepsy (NICE, 2004) recommends that all patients with a recent onset of suspected seizure activity should be

"*...reviewed urgently by a specialist to ensure precise and early diagnosis and initiation of appropriate treatment specific to their needs. Should seizures remain uncontrolled and/or there is diagnostic uncertainty or treatment failure such individuals should be referred to tertiary services as soon as possible for further assessment...*"

The guideline considers 'urgent' as occurring within 2 weeks and "soon" as occurring within four weeks (22). All participants including those with significant clinical risk endured significant protracted waiting times for specialist review. PWE referred from primary care to specialist services by their general practitioner (GP) reported negatively on the process. Participant F-1 stated "*I thought it was very bad to have to wait two years*" while M-14 received an "*appointment in 2006 for 2008...I mean I thought it was a joke*".

This pattern continued for patients referred from secondary care hospitals both with and without neurology services. For example F-5 became aware of her referral to specialist care when "*the appointment arrived in the post*". The carer of participant M-6 recalled receiving the appointment but "*it was two years from when he had it (the seizure)...I thought it was a typing error*". Similarly the carer for M-18 stated that "*being honest you know we had to wait 18 months for this appointment, it's an awful long wait in case anything would happen to him*".

At times individuals attempted to expedite their appointment and/or circumvent the process of referral using alternative methods and approaches. M-6 got "*my sister onto the patient's council*" while F-12 said "*my local TD (political representative) stepped in and got me an appointment faster*". Many patients simply reiterated their concerns to the referring clinician usually to no avail. The carer of M-18 recalled "*she said it had nothing got to do with her (patients GP)...I said you're transferring him there you should be able to put pressure on somebody...he should have been seen within*

days". Three individuals suggested that their social and financial circumstances influenced the waiting time. F-1 thought that *"it's got a lot to do with having a medical card you know" while* F-12 suggested that *"if you had the money you could go private and maybe then its better"*. F-2 went *"for a private EEG in the xxxx, because the waiting list at yyyy was a year and a half"*.

For many patients the delay in accessing specialist care prompted negative psychological emotions. Participant F-2 felt *"disappointed and shocked"* and *"a sense of frustration"* while M-4 reported feeling *"frustrated and annoyed having to wait 14 months for this appointment"*. Other participants spoke of enduring *"fear and worry"* while waiting and the potential that their impending appointment could be deferred or cancelled. The mother of M-6 who cares for her teenage son spoke of her relief in *"getting to this day as I have been so worried"*. The patient F-3 was *"nervous that it (appointment) would be cancelled or something ...and that's worse...waiting all that time and then they cancel it...moving it forward or moving it back...well that's one thing ...but cancelling it"*. F-9 described *"the waiting list is crazy...I was housebound for a year and a half having drop outs and seizures and dropping confidence...in my GP waiting room...in front of people"*.

4.4.2 Theme II: People with epilepsy are insecure regarding the role and competency of their general practitioner in respect of their care

The NICE guideline for epilepsy (NICE, 2004) recommends that
"...all people with epilepsy should have a comprehensive care plan that is agreed between the individual, family and/or carers where appropriate, and primary care and secondary care providers. Such care-plans should include lifestyle issues in addition to medical issues"

While empathetic to their illness many participants expressed the view that GPs lack the expertise to manage their condition and/or continue to remain passive in respect of patient needs. For example the carer of M-16 finds the family GP *"very good...but not used to something like this"*. Similarly F-1 whose care has been fragmented between various service providers finds her GP *"does listen"* but feels her *"care should be shared with the people here...where the expertise is"* Participants were more critical

of GPs who were less clinically proactive in certain circumstances. F-3 when discussing the role of her GP stated "he *tends to be a bit slow on things...he tends to let things go a bit...before he actually does anything about it*" while F-5 expressed disappointment that she was misdiagnosed and subsequently put on incorrect medication for a significant period of time by her GP. She stated "*at the time I wasn't happy...cause I was going down (to the GP) like and sometimes I was thinking probably it was all in my head like...and she was saying they were only panic attacks...there nothing to worry about...I couldn't concentrate or talk to anybody... and then today they told me they are more like seizures than panic attacks*".

A mother of three children, F-9 has epilepsy since childhood and was re-referred to the epilepsy service after an exacerbation of seizure activity. The patient reported that her GP "*put me on loads of medications but I was still getting the seizures...I changed doctor and he classed me as severe when he saw me...and the other doctor just kept giving me medications and not sending me nowhere*". This patient while "*not putting anybody down*" expressed a preference for "*doctors who actually deal with epilepsy*".

For the majority of participants in the study the GP role was confined to re-filling prescriptions for anti-epileptic drugs (AEDs). The carer of M-17 stated that the GP "*just does prescriptions*", while M-8, a thirty-four year old married man who developed epilepsy three years previously goes "*to the GP just to renew my prescription, that's all*" and felt his GP incorrectly informed him that he "*might be able to come off them someday*". The patient "*knew well that this would never happen*".

One participant did express satisfaction with the care received from her GP. F-7 was eleven weeks pregnant when interviewed and had "*total and utter confidence in him...if I had any problems or questions over it I would go straight to him*". While waiting for her neurology review she had become pregnant and her appointment was subsequently expedited by her GP. However the patient does not "*know how this happened*" and was not aware of same until her "*appointment arrived in the post*". Similarly F-2 thinks her epilepsy care should be "*managed between all of them*". She acknowledged that it "*was nice to be seen by the specialist*" but she was "*happy to be managed by her GP* if *the knowledge was passed back (to her GP)...and they communicated better*".

4.4.3 Theme III: Significant unmet needs exist that are specific to epilepsy care for women

The NICE guideline for the management of epilepsy recommends (NICE, 2004) that *"...women with epilepsy and/or their carer should be given accurate information and counseling regarding contraception, conception, pregnancy, caring for children, breastfeeding, and menopause with care plans tailored to the individuals needs. In women of childbearing age the risk of AED therapy causing harm to an unborn child should be discussed and a risk versus benefit analysis performed regarding individual drugs"*

A total of 10 women participated in this study ranging in age from 28 to 41 years. Nine of the women interviewed had children less than eighteen years of age. F-1, a twenty-seven year old female had her first seizure four months post partum and subsequently had a second child while waiting *"to see the specialist"*. She recalled being told in her local hospital *"that if I took a second fit they might put me on medication...but my own doctor said we'll wait until you go to xxxx for your tests, and then they'll see after that whether to go on medication"*. The patient waited almost two years for neurology review however and did not receive any epilepsy specific counselling during her second pregnancy.

F-2, a twenty eight year old secondary school teacher recalled being prescribed Sodium Valproate for her epilepsy by a medical consultant in her local hospital. Subsequently, after becoming pregnant she *"went to my GP and I said what drugs should I be on...is this proper?...and they were like, yeah, as long as you're on your folic acid and you're on the medication with your folic acid"*. When later becoming aware that this drug was not suitable during pregnancy she reported feeling "q*uite shocked...the first thing I did obviously, as a mother was panic and I was asking...is he okay? (her son)*". The patient felt *"really disappointed with the whole care I got... through being pregnant and having the epilepsy... I thought I was being so perfect, because I actually planned to conceive my son"*.

F-5, a thirty-two year old mother of five children could not recall any specific epilepsy care during her pregnancies and was continued on Phenytoin during the first

two pregnancies. The patient's situation was exacerbated by an incorrect diagnosis and subsequent delay in accessing appropriate specialist care. A forty-one year old married woman F-9 with three teenage children and a history of epilepsy since childhood stressed the importance of being "*aware more so if little girls have epilepsy...that it could work out more serious in adult life and when girls go into puberty...that's the time it really hits and if it could be crumbed [sic] down more at that time and age it might save them from having it more serious through their life*"

Females interviewed in this study commonly reported small children as the first responders and/or eye witnesses to significant seizure activity. For many this caused psychological stressors such as F-2 who's most recent "*frightening seizure*" activity required hospitalisation and was witnessed by her five year old son. Likewise F-7 reports that her four year old daughter may often be the first responder and describes her mother's seizures as "*mammy blowing bubbles again*". The mother and carer of M-16 spoke of the "*big problems psychologically for our younger child (13 year old brother)...I think you know there is not enough awareness out there for kids or siblings (of PWE) regarding seizures*".

4.4.4 Theme 4: The current structure and process of epilepsy care in Ireland contributes to a culture where patients feel disempowered and isolated

The NICE guideline (NICE, 2004) recommends that
"*...healthcare professionals should adopt a consulting style that enables the individual with epilepsy, and their family and/or carers as appropriate, to participate as partners in all decisions about their healthcare*"

Data analysis in this study suggests that participants do not experience a sense of empowerment or have insight into the concept of integrated shared care. Rather they interpret their care journeys linearly culminating in review with specialist neurology services. The patient F-5 recounted a journey of care that began sixteen years previously. This thirty two year old mother of five children has received care from her GP, her local hospital and local Emergency Department. She was in contact with neurology services initially but subsequently discharged "*because everything seemed to be okay like, you know for a good few years*". The patient had increasing seizure

activity in the past six years which was mis-diagnosed as anxiety attacks by her GP and was left untreated. The patient was eventually referred back to neurology services where her diagnosis was confirmed and her medications adjusted appropriately. While the patient "*thinks shared care is a good idea*" she expressed reservations about "*her GPs knowledge*" and ability to manage her condition appropriately.

M-6 is an eighteen year old boy who is cared for by his mother following traumatic brain injury. His initial diagnosis and treatment was confirmed in a paediatric hospital, however his seizure activity has increased in recent years. According to his carer he has been waiting "*almost two years*" for review in adult neurology services. His mother felt that he had "*outgrown his medications*" and "*it didn't dawn on me that he needed bloods taken and his medication might need to be changed...and when I look back now I should have been doing things like getting his blood checked*". She was of the opinion that her son's care "*would not happen unless I went chasing things*" adding "*nobody said anything to me except just go now...he's fine...it should have dawned on me to get it done earlier (Valproate levels) but I didn't you know*". The transition from paediatric to adult epilepsy services "*was a very difficult time*".

F-9 expressed a preference for her care to be provided by "*people who actually deal with epilepsy...who know what they were doing*" while M-12 a sixty-four year old gentleman from the West of Ireland feels his GP "*doesn't care enough*" and "*only gives me my tablets*". Regarding integrated care the carer of M-16 feels "*there was definitely a gap there...like different hospitals were doing different things*". She felt that "*we would be quiet good at making sure that people follow up on things, but if you were the type who didn't go out there and look for answers, you know you would be just be left*".

The complex and chronic nature of epilepsy in conjunction with its negative impact on cognitive ability adds significantly to the impact of the disease on patient's lives. In the absence of integrated structured care we explored the support mechanisms that PWE utilise and/or specific epilepsy organisations they may engage with. The majority of patients reported little or no interaction with formal epilepsy support groups relying predominantly on their GP and/or the experiences of other individuals; predominantly friends and family members. F-1 receives support "*mainly from my*

Aunt like...she gets very bad fits" and F-2 who *"talks to my husband and my sister because she's a nurse"*. For many individuals (F-3, M-4, and F-12) there was no awareness of available epilepsy support groups. Other participants who were aware of epilepsy support groups had chosen not to engage with such services (F-7, M-8, F-9, M-16, M-17). There were exceptions such as M-11 a sixty-four year old gentleman with epilepsy since childhood. He reported a period in his adult life where he was *"tortured (by co-workers) and felt suicidal...everything was getting on top of me"*. He credits the *"Epilepsy Association"* for *"helping me overcome it"*.

4.4.5 Theme 5: The unmet information and communication needs of people with epilepsy contributes to discordance in their care

While the NICE guideline (NICE, 2004)
"does not make recommendations on service delivery issues" it concludes with recommendations on *"the process of care necessary for PWE and/or their carer to achieve the best possible health outcomes"*

The efficient availability, sharing and communication of patient information may increase the likelihood that optimum patient outcomes in the correct environment can be achieved. Participants in this study tended to be polarised between those who saw information as an important issue and those who were unaware and/or apathetic to its relevance. For many the availability of essential clinical information reduced the emphasis on them to recall their disease history and/or specific management details at various, frequent and often lengthy clinical consultations.

For example, F-2 tells *"the same story every time which is frustrating"* and *"at the end of the questioning the answer is going to be the same anyway"*. For others the interaction with the healthcare provider is intimidating while the lengthy time scale between specialist review and onset of symptoms may negatively impact on the patient's ability to recall events and relevant clinical information. For one patient F-3 meeting the clinician made her *"nervous"* stating *"I don't know what to say to them (doctors) at all honestly"..."I had butterflies in my stomach because I was worried"*. Similarly, F-5 described feeling *"silly"* and *"embarrassed"* when discussing her medical history with clinicians and M-14 suggests that *"it would be better if I was*

treated with a bit more thoughtfulness...you know, a little bit more thought about people's nerves".

The carer of participant M-16 reiterated the sense of "*frustration*" and "*annoyance*" with the lack of "*communication between the hospitals*" which results in "*different people doing and saying different things*" and no sense "*of an overall care-plan for him (patient)*". She suggested that people who do not have a proactive "*advocate*" would "*just be left there*". Similarly F-2 felt that carers often "*make presumptions*" about her and that "*seeing someone different every-time*" had resulted in "*rescue medication*" not being made available to her much earlier because "*everyone thought I had it already*".

Nine participants (47%) in the study considered themselves computer literate with literacy defined as using a computer at their main residence to carry out daily activities including purchasing items, information searching and/or paying bills. No participant and/or carer irrespective of technology literacy objected to their epilepsy specific medical information being available via the internet. Participant M-15 did emphasize the importance of "*confidentiality and security*". Six individuals who were classed as computer literate expressed a positive interest towards engagement with the epilepsy specific electronic patient record (EPR) via the internet. The carer of M-16 interpreted the use of such technology as "*a way to improve bad management*".

4.5 Discussion

This study demonstrates that the current structure and process of healthcare in Ireland frequently results in a negative experience for PWE. Participants shared their experience of delays in accessing specialist epilepsy care, uncertainty regarding primary care practitioner's epilepsy specific competency, unmet needs for women with epilepsy, poor integration between different healthcare sectors and lack of communication and information sharing between different healthcare providers. The findings suggest significant and unacceptable delays in diagnosis and treatment, increased anxiety for the patient and their families, and sub-optimal use of limited health care resources.

While previous studies have used similar qualitative research methodologies in capturing and reporting the experiences of patients with epilepsy (Bishop and Allen, 2003; Elliott, Lach, and Smith, 2005; Prinjha et al, 2005; Sample et al, 2006; Räty et al, 2007; McCorry, Marson and Jacoby, 2009) this is the first study of its kind in Ireland and is unique in that it engages with patients with significant and intractable forms of the disease on an individual one-to-one basis rather than in focus groups.

Recognition that gaps exist in quality, safety and efficiency is driving health service transformation programmes internationally (Institute of Medicine, 2001; Kings Fund, 2007). However, many of these initiatives have been criticised for their "top down" approach that over-emphasises the requirements of the healthcare providers and policy makers at the expense of the patient experience (Martin et al, 2009). This lack of attention to the patient perspective may be a contributor to the poor return on substantial healthcare investment that to date has been witnessed in some chronic disease reform strategies.

Prudent re-design of health services requires a 360 degree perspective to incorporate the needs of all individuals including patients, clinicians and policy makers. The importance of our study is that it helps to further understand the needs and expectations of the health service user. These needs and expectations must be aligned with what the healthcare provider can deliver so that there is mutual understanding and a realistic and desired healthcare outcome is achieved. This is especially important in respect of promoting patient self-management, identified as a crucial element in the reconfiguration of health care services for chronic diseases.

The themes that emerged from this study further support previously documented inadequacies regarding epilepsy care and management (Bishop and Allen, 2003; Prinjha et al, 2005; Sample et al, 2006; McCorry, Marson and Jacoby, 2009). For example, delays in access to specialist care and management (Pugh et al, 2007; Hayes et al, 2007) knowledge deficits amongst healthcare professionals (Hayes et al, 2007) and care deficits for particularly vulnerable groups including women with epilepsy (McAuley, Casey and Long, 2009) and adolescents (Elliott, Lach and Smith, 2005) are previously well documented. However, the combined observation of deficiencies within this study creates an impression of an environment of inertia between

healthcare providers and patients in which neither has a high expectation of what the health service delivers nor do they feel empowered to make any improvements to the care process.

Almost all of the study participants had little or no insight into the concept of integrated care. Very few participants belonged to self-help or patient advocacy groups. Indeed, many were unaware of the existence of organisations for supporting PWE although research has demonstrated that PWE actively engage with epilepsy specific support groups (Sample et al, 2006). Participants in this study however believe that the epilepsy specialist service was the most competent resource to meet their specific needs. This is a particular challenge for epilepsy support groups in Ireland who are trying to engage with highly vulnerable people already likely to be isolated within the healthcare system.

Participants in this study tended to view their journey of care as a linear process which helped them justify to themselves the protracted delays between different stages of the journey. It also appeared to reinforce the passive role adopted by them in their epilepsy care and management. It has been suggested that people with long standing epilepsy are fearful of their condition and the potential for increased seizure activity (McCorry, Marson and Jacoby, 2009). Therefore patients with intractable forms of the disease may not fit the profile of patients who can be autonomous and self-managing of their condition. It is likely that such patients become conditioned to a passive role from which clinicians take their cue. In the current structure of epilepsy care it remains difficult to extrapolate this specific population of patients from the general population of PWE.

In this study participants reported negatively on the process by which they are expected to recall and repeat specific information regarding their epilepsy and its management to various healthcare providers at geographically diverse healthcare facilities along their care journey. Given that epilepsy can have an impact on memory and learning (Davidson et al, 2007) together with their anxiety during interactions with the clinician, this reliance on the patient's recall may also contribute to sub-optimal care. Moreover, each healthcare agency maintains its own exclusive record of a patient's care and medical records are still often paper-based. This limits the

sharing and communication of information required to provide continuity of care across multiple healthcare agencies (Marchibroda, 2008). Participants in this study indicated that the lack of information sharing can lead to conflicting clinical advice and no sense of an overall care plan. This is a recurrent theme reported in the literature for PWE (Kendall, Thompson and Couldridge, 2004).

This study has implications for future epilepsy service reform and development. It highlights the need to more fully understand the expectations of people with epilepsy in terms of health service delivery and to ensure that these are taken into account in any plans for service transformation. Chronic disease management strategies recommend that patients be empowered to self-manage their healthcare. The participants in our study appeared largely to play a passive role, indicating a need for education programmes for those patients with capacity to take on this active role. Similarly, clinicians must listen to the patient so that shared expectations can be established and decisions are made jointly in striving to achieve realistic and desired outcomes.

Epilepsy poses a significant socio-economic burden at individual, family, health services and societal level (Pugliatti et al, 2007). The introduction of various strategies including evidence based guidelines (SIGN, 2003) monetary incentivisation schemes for clinicians (Department of Health, UK 2002) and the development of indicators of quality technical care (Pugh et al, 2007) have to date demonstrated minimal quantifiable improvements in outcomes for PWE (Sheldon et al, 2007).

Furthermore, health services incur significant costs related to the inadequate management of epilepsy where higher healthcare costs are associated with poorly controlled epilepsy (Juarez-Garcia et al, 2006). Considerable opportunity costs have been identified with unnecessary hospital admissions and misdiagnosis of epilepsy (Juarez-Garcia et al, 2006; Langfitt et al, 2007). The opportunities for improving the quality, safety and efficiency of epilepsy care are substantial. New models of epilepsy care requires addressing the needs of all stakeholders and a realistic action plan mapping out a programme of work that must continue over several years.

4.6 Limitations of the Study

In order to recruit a representative sample of people with epilepsy who were first time attendees at a specialist epilepsy service, a letter of invitation was sent to thirty-eight individuals. Recipients of the letter could then decide whether or not they wished to participate. It is not clear why those who participated decided to do so as this question was not explicitly asked. However patients who participated in the study also attended for their scheduled OPD appointment. The remainder did not refuse to participate rather they ignored the letter for whatever reason and the majority did not subsequently attend for their scheduled appointment. This may have contributed to some level of sampling bias in the study given the sense of passivity observed among the participants.

The majority of participants in the study, although first time attendees at the Beaumont Hospital epilepsy service had established epilepsy and it was reasonable to expect that they would have developed a good understanding and knowledge of their condition. However, this was often not the case. The majority of the sample had moderate to severe epilepsy and therefore may not be representative of all PWE in Ireland. Additionally, given the often debilitating impact of epilepsy on cognitive function and the retrospective nature of the data collection, there was potential for recall bias within the study.

It is acknowledged that the collection and interrogation of data by a single researcher potentially limits the validity of the study findings. The methodological underpinning of this study however with interpretive phenomenology required us to interpret the phenomen of interest without recourse to theory, deduction, or assumptions from other disciplines. Data collection and interrogation by multiple researchers could have created significant multiple biases between the researchers based on individual personnel assumptions and/or an inability to "bracket" out ones personal knowledge from their life experiences, consequently interfering with the research dialogue.

Non-intentional researcher bias was additionally minimised by a second researcher who independently reviewed a sample of the transcripts and provided feedback in the context of identified themes although this feedback did not contribute to the final data

analysis. The research process was also reviewed incrementally by an independent academic qualitative researcher regarding the design process of the study. This individual did not analyze the collected data.

4.7 Conclusion

This study documented and interpreted the healthcare journeys of a relatively homogeneous group of PWE in Ireland. With little exception the participants in this study were dissatisfied with the care they received prior to their arrival at a specialist epilepsy out-patient clinic. In describing their journeys of care the patients shared common experiences and while not a reflection of the actual care they received, the negative commonality of their experiences suggests that major challenges exist in current service delivery.

As highlighted in chapter III (section 3.7) the primary care strategy in Ireland proposes that much of the ongoing care of people with chronic illness can take place in the community. Historically, review arrangements for PWE in primary care have consistently been reported as inadequate (Minshall and Smith, 2005). The perception of PWE in this study regarding primary care services was largely negative with most patients feeling insecure regarding the role and competency of their general practitioner (GP) in respect of their epilepsy care.

The perspective and role of Irish GPs in respect of epilepsy care was not previously documented. Given the direction of CDM transformation in Ireland, understanding the GP role from their own perspective would identify some of the major barriers and challenges to achieving the desired transformation. Chapter V examines the role of GPs in Ireland in managing PWE as reported by GPs themselves. The results presented in chapter V identify the opportunities where better information management and communication supported by electronic patient records could improve structures and process of epilepsy care and ultimately contribute to a model of shared-care specific to epilepsy.

Chapter V

The Role of the Irish General Practitioner in Epilepsy Care

5.0 Introduction

National and international health care transformation programmes have identified that primary care is the most appropriate setting for on-going management of people with chronic illness (Department of Health, 2007: Department of Health and Children, Ireland, 2008a; Singh, 2008; Nolte and McKee, 2008; Busse et al, 2010). As outlined in chapter I this research and development project aimed to revolutionise the management of chronic disease by improving and optimising the use and communication of patient information. The chronic disease exemplar was epilepsy and it was envisaged that the design and successful adoption of the EPR would contribute to improving the quality, safety and efficiency of epilepsy care in Ireland and how optimum information management contributes to the wider debate of CDM reform.

Early evaluation research (process mapping and audit) conducted during the design and pre-implementation phase of EPR development identified significant challenges and deficits within existing structures and processes of epilepsy care. These challenges suggested that introducing the EPR as an enabler of change and reform into such an over burdened service increased significantly the risk of not meeting projective objective (Chapter I) or even project failure.

The hypothesis of this PhD argues (Chapter 1) that existing structures and processes of epilepsy care must be explored and documented prior to implementing a potential enabler of disease reform such as the epilepsy-specific EPR. In chapter IV, patient perspectives were explored in respect of their healthcare journeys and central challenges were identified relating to primary care services, in particular the role of the general practitioner.

It is estimated that the majority (60-70%) of people with epilepsy (PWE) can be cared for and managed by their GP collaborating with specialist neurology/epilepsy services when clinically indicated (Hodgson, Beardmore and Hall, 2000; Frost et al, 2003; Minshall and Smith, 2006; Minshall and Smith, 2008). This is assuming of course that pathways of care exist that facilitate the sharing of care between primary and specialist services in an appropriate and timely manner. Based on the literature there is an expectation that GPs should conduct annual reviews, appropriate medication reviews and document consistently and accurately their associated seizure response (NICE, 2004). However, such a model of care assumes a readiness of primary care to adopt this role.

When benchmarked against evidence-based standards of care, inadequacies in epilepsy care by general practitioners has been consistently reported (Thaper et al, 1998; Hodgson Beardmore and Hall, 2000; Meinardi et al, 2001; Jacoby, 2002; Minshall and Smith 2006; Minshall and Smith 2008). For PWE, primary care is frequently reduced to medication management and reaction to seizure exacerbations while proactive information provision, psychosocial support and the inclusion of patients in decision making is generally lacking (Elwyn et al, 2003). Subsequent studies and policy advisory groups have highlighted the extent of primary care deficits and have forewarned the extent of the challenges facing primary care services in reorganising services for PWE (Kitson and Shorvon 2000; Minshall and Smith, 2006).

As part of documenting and understanding the overall structure and process of epilepsy care in Ireland, this chapter (chapter V) explores the role of the general practitioner (GP) and the challenges that exist from the primary care perspective. The findings reported in this study in conjunction with the findings of associated studies (chapters IV and VI) highlight the challenges and opportunities that must be addressed strategically within primary care services. The epilepsy-specific EPR as an enabler of service reform is more likely to succeed when such challenges are clearly identified and increases the likelihood that it will be successfully adopted into the clinical environment and inform appropriately an integrated model of epilepsy care (chapter III).

5.1 Selecting the Research Approach

Attitudes of general practitioners to the care of people with epilepsy have previously been reported in the literature (Thaper et al, 1998; Thaper and Roland, 2005) with limited reporting specific to the Irish context (Neligan, Renganathan and Sweeney, 2006). Predominantly and repetitiously since the 1960s research has demonstrated that general practitioners consider epilepsy and its treatment to be complex and self report knowledge deficits in respect of confirming a diagnosis, counseling and the prescribing of anti-epileptic drugs (Thaper, 1996: Thaper et al, 1998: Thaper et al, 2002; Minshall and Smith, 2006). In many instances authors have focused on the attitude of general practitioners to people with epilepsy rather than exploring their attitude to providing and organising care for their patients (Minshall and Smith, 2006).

The purpose of this research study was to examine the general practitioners role and attitude to providing care and management to people with epilepsy. Understanding and documenting this perspective, identifies objectively the challenges that exist in current epilepsy services and the opportunities where optimum information management and communication via the EPR could enable the transformation of such services. As the majority of chronic diseases are managed in primary care, lessons learnt can inform the wider CDM reform debate.

Initially, an extensive review of the literature was conducted to identify the research approach used in similar studies. Predominantly, researchers used a quantitative approach that employed postal questionnaires to target a specific population of general practitioners in respect of attitudes to epilepsy care (Frith, Harris and Beran, 1994; Lambert and Bird, 2001; Thaper and Roland, 2005; Elliott and Shneker 2008) although limited use of qualitative focus group studies was also noted (Gélineau, Grimaud and Toffol, 2008).

Using this knowledge the research objectives of the proposed study were discussed in formal consultation with the Epilepsy Programme at Beaumont Hospital, a sample of

local general practitioners *(n=5)* and Research Programme team within the Irish College of General Practitioners (ICGP). The ICGP is the professional body responsible for education, training and standards in Irish general practice with a primary aim of fostering and maintaining the highest standards of general medical practice. Within the ICGP, the Research Programme is responsible for developing and emphasising the promotion of methodologically rigorous research within primary care. The consensus from this collaborative work proposed and supported the use of a quantitative approach to the study that would require the development and testing of an epilepsy specific questionnaire.

The composition of the questionnaire (Appendix 3) was informed by

- Existing evidence the research literature
- Research expertise and consensus provided collaboratively by expert groups; The Epilepsy Programme and the Research Programme of the ICGP
- Feedback from general practitioners
- Pilot Testing
- Feedback from the medical ethics committee of Beaumont Hospital

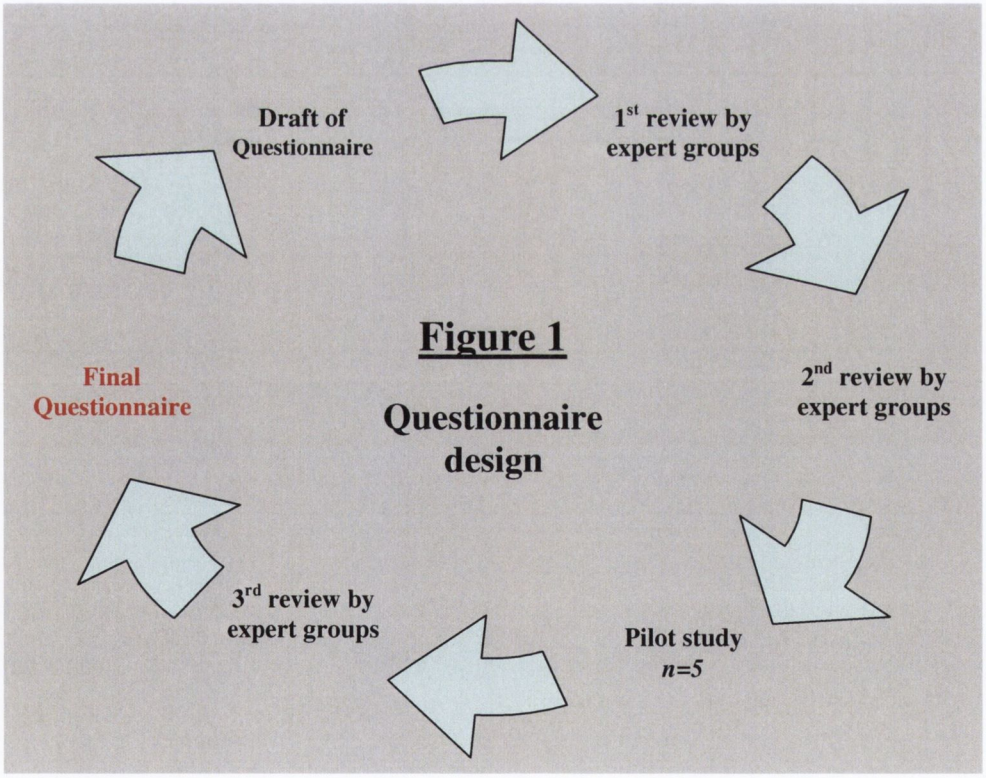
5.2 Methodology

For many years postal surveys have been used by researchers to obtain information about the attitudes, knowledge and self reported behaviour of general practitioners (Kaner, Haighton and McAvoy, 1998). While it is frequently reported that poor response rates somewhat threaten the validity of the research findings only a few studies have examined objectively the impact of a low response rate (Stocks and Gunnell, 2000).

Roberts et al (2009) in a Cochrane Methodology Review identified several ways to increase response rates in postal surveys including, contacting potential participants prior to sending the postal questionnaires, sending them by first class post, including a stamped-return envelope, personalising the request and keeping the content relatively short. In addition one or more reminders can be sent with a copy of the questionnaire to people who do not reply. General practitioners who do not respond to postal surveys are more likely to be older, do not to possess a post graduate medical qualification or belong

to a practice that is not involved with postgraduate or undergraduate training (Fielding et al, 2005).

The initial draft of the questionnaire was formally evaluated in the context of appropriateness, reliability and feasibility by the Epilepsy Programme at Beaumont Hospital and by the Research Programme of the ICGP. Following the initial review the questionnaire was modified and a subsequent secondary review was performed by the research teams. Following this second phase of critique the questionnaire was reviewed by five practicing GPs for feedback relating to content validity. Subsequent to these changes the questionnaire underwent a third review by the research groups. This iterative process underpinning the design of the questionnaire has been summarised (Fig 1).



5.2.1 Selecting the Sample

A random sample of general practitioners *(n=700)* was generated by the Research Programme of the ICGP from the total number of registered general practitioners in Ireland *(n=2515).* A registered general practitioner in Ireland is defined as a doctor who meets or has completed an approved specialist general practice training programme as set out by the ICGP. A sample of potential participants were targeted (*n=700*) from the total number of registered general practitioners *(n=2515)* which equates to 30% of the overall population. Historically, response rates in general practice surveys tend to be low for a variety of reasons, not least of all time constraints of the potential participants. It was predicted prior to data collection that a response rate of 30-50% was most likely. The random sample identified by the Research Programme of the ICGP was also stratified to reflect larger and more densely populated regions of the country and to increase the likelihood of a homogenous sample of in respect of practice size and geographical location. The size of the sample does not correlate to a statistical power of analysis.

5.2.2 Data Collection

Prior to mailing the surveys, the aim and objectives of the study were advertised on the ICGP website and its dedicated monthly published journal. Each potential participant received a personalised information leaflet with the questionnaire outlining the context of the survey and also included a pre-paid return address envelope. Respondents remained anonymous although their geographical location (county) was identified.

The questionnaire was divided into four sections (Appendix 3). Section 1 described the characteristics of the practice and the current use of computerisation. Section II recorded the extent of computerised clinical functions in daily practice while section III examined the GPs perceived role in respect of epilepsy care and management. Section IV reported on access to specialist services including tests and investigations. A free text box facilitated additional comments from participants. The initial response rate *n=211* (30.1%) was increased to *n=247* (35.2%) after a reminder letter was issued at a two week interval.

5.2.3 Ethical considerations

Formal ethical approval for this study was sought and sanctioned by the medical ethics committee of Beaumont Hospital and the Irish College of General Practitioners.

5.3 Results

A total of 247 GPs (35.2%) returned completed questionnaires. Respondents were male (56%), working in mid to large sized practices (i.e. 3000-5000 patients) (66%) for greater than ten years (70%). A response was received from every county in the Republic of Ireland. The majority of GPs practiced less than 10 miles from their local hospital (67%) and less than 30 miles from a hospital with dedicated neurology services (60%).

In this study GPs accepted responsibility for assessing and arranging investigations for patients following suspected seizure activity (66%) and/or refer such patients to neurology services when indicated (74%). However, GPs reported difficulty accessing urgent neurology services and investigations and as a consequence patients may be referred to the emergency department for assessment and treatment (Table 1). GPs were dissatisfied with availability and accessibility to existing neurology services and reported that patients with private health insurance access neurology services more expeditiously (Table 1).

Table 1: In general practice.....	**Always**	**Some times**	**Occasionally**	**Never**
can you access urgent CT (within 4 weeks)	12%	23%	22%	33%
can you access urgent MRI (within 12 weeks)	8%	30%	26%	38%
can you access urgent EEG (within 12 weeks)	6%	24%	14%	56%
can you access an urgent neurology appointment (within 4 weeks)	5%	15%	29%	61%
do you refer to the ED because of protracted neurology waiting times	31%	44%	16%	9%
do patients with private health insurance access neurology services faster	72%	20%	6%	2%

While respondents agreed with the concept of epilepsy care being shared between primary and specialist care services, over one third reported a knowledge deficit specific to managing PWE (Table 2b). A substantial number of GPs who responded would not initiate or adjust anti-epileptic drug (AED) therapy prior to neurology review, although they would monitor the clinical response to such therapy once it has been prescribed by a specialist (Table 2a). Respondents perceived their role as educationalists, providing advice/education to PWE regarding lifestyle issues (e.g. work, lifestyle, driving). The majority of GPs would not be clinically confident to manage PWE during pregnancy. Respondents acknowledged positively the role of clinical nurse specialists (CNS) as a means of improving the quality of epilepsy care delivered (Table 2b).

Table 2a: The GP should....	**Agree**	**Disagree**	**Un-certain**
initiate AED therapy prior to neurology assessment	20%	59%	21%
monitor the response to AEDs when prescribed by a specialist	71%	20%	9%
change dose and/or type of AED as indicated....	45%	33%	22%
discontinue AED if clinically indicated.....	37%	38%	25%
Table 2b: In the management of epilepsy do you feel that	**Agree**	**Disagree**	**Un-certain**
GP knowledge deficits could adversely affect pts with epilepsy	80%	8%	12%
GP knowledge is adequate regarding epilepsy management	35%	39%	26%
care should be shared between neurology services and GPs	96%	4%	0%
GPs should educate pts re epilepsy e.g. employment, lifestyle, driving	94%	2%	4%
GPs should manage epilepsy during pregnancy	10%	68%	22%
access to a CNS could enhance the quality of epilepsy care	83%	5%	12%
delayed access to neurology services contributes to sub-standard care	94%	2%	4%
existing referral pathways to neurology services are unsatisfactory	84%	7%	9%
poor communication contributes to sub-standard care	74%	11%	15%

Computerisation in general practice, broadband availability and the incorporation of a dedicated GP specific software system was widely reported (90%). Over half the respondents (54%) linked electronically to an external system such as Healthlink (www.healthlink.ie) which is a system that allows GPs to retrieve laboratory results from participating hospitals via the internet. A significant majority (93%) supported the concept of linking electronically to an external secure system, such as the epilepsy specific EPR being developed at Beaumont Hospital, Dublin. Poor communication between various healthcare providers was also perceived as a significant barrier to providing care to PWE (Table 2b). In clinical practice GPs use their computers predominantly for prescribing purposes (Table 3).

Table 3: For prescribing purposes GPs use their computer to	
prescribe and write medications	87%
record drug indications	85%
check for drug allergies	85%
update medication lists	87%
check drug-drug interactions	64%
check drug disease interaction	52%

GPs utilise information technology to record various clinical functions, including the recording of progress notes, storage of test results, the generation of health summaries and to write letters of referral (Table 4). Over half the respondents reported using information technology to create lists of patients with specific diseases and to run recall systems for routine review of patients although over one third do not use this chronic disease specific functionality.

Table 4: GPs use their computer to…..	Paper	Computer	Both
record progress notes	11%	76%	13%
store test results	11%	74%	15%
generate health summaries	9%	74%	17%
write letters of referral	11%	72%	17%
receive test results	25%	52%	23%
ordering lab tests & investigations	44%	28%	28%
	Paper	**Computer**	**Don't Do**
run recall systems for routine tests	11%	56%	33%
create lists of pts with a specific disease	5%	55%	40%

5.4 Discussion:

The unique and unpredictable nature of epilepsy requires multidisciplinary, long term, co-ordinated care that empowers PWE towards pro-active management of their condition. (Elliott and Shneker, 2008) While evidence to support a particular model of care for epilepsy does not exist, two intervention types have demonstrated some limited success, clinical nurse specialists and self-management education programmes. (Bradley and Lindsay, 2008) It is recognised however that knowledge deficits of primary care clinicians and long standing inadequacies of epilepsy care pathways repeatedly impedes strategies attempting to improve epilepsy care (Hayes and Melin, 2007: Thom et al, 2002) Consequently the healthcare needs for PWE may often go unmet (Bradley and Lindsay, 2008; Elliott and Shneker, 2008).

The GP is frequently cited as the primary care giver for PWE (Thaper et al, 1998; Thom et al, 2002; Montouris, 2000). In this study the majority of GPs agreed that epilepsy care should be shared between primary and specialist neurology services. At present however in Ireland, there is no formalised, resourced, integrated pathway of care between the various healthcare interfaces for PWE. This is further complicated by their own acknowledgment of significant epilepsy-specific knowledge deficits. This is previously

documented in the international literature (Thaper et al, 1998; Hayes and Melin, 2007; Elliott and Shneker, 2008) where a complex variety of factors may contribute to this deficit and can only be addressed by patients, practitioners and healthcare organisations changing their attitudes and behaviour towards PWE (Hayes and Melin, 2007; Elliott and Shneker, 2008). However, the aim is not to make all GPs experts in epilepsy care, rather it is about developing their role in on-going epilepsy management.

Like their international counter-parts, Irish GPs in this study perceive their role primarily as educationalists, providing information regarding epilepsy-specific lifestyle issues and monitoring responses to AED therapy (Elliott and Shneker, 2008; McInnes, Saltman and Kidd, 2006). Similar to previous findings (Neligan, Renganathan and Sweeney, 2006) Irish GPs are less likely to initiate or manage the more complex aspects of epilepsy care such as initiating AED therapy or managing PWE during pregnancy.

Internationally, attempts have been made to improve the quality of epilepsy care by introducing strategies such as dedicated educational programmes for clinicians (Chappell and Smithson, 1999; Frost et al, 2003), evidence based epilepsy-specific clinical guidelines (SIGN 2003; NICE 2004) and pay-related performance (Williams et al, 2007). Despite this, the management of PWE often remains fragmented and polarised between hospitals and primary care services. (Moran et al, 2000) There is at best a poor understanding of what constitutes high quality epilepsy care in adults (Pugh et al, 2007). For example, clinical guidelines do not intrinsically modify practitioner behaviour as change may be dependent on the ability of the practitioner to identify the problem and implement the appropriate changes in clinical practice (Lindenauer et al, 2000; Sheldon et al, 2007).

While changing existing behaviours and attitudes can be difficult and complex, basic components of established behavioural theory suggest that perceived benefits or rewards can be effective (Sheldon et al, 2007). For example, the recent Quality Outcomes Framework and General Medical Services contract in the United Kingdom has resulted in a financial reward to GPs for fulfilling certain criteria of an epilepsy specific clinical

guideline (National Health Service, 2004). Although significant changes in service delivery or improved patient outcomes resulting from this incentivisation have not yet been demonstrated (Williams et al, 2007), the level of primary care activity regarding PWE in the UK has significantly increased (Sheldon et al, 2007).

Acknowledging their own knowledge deficits, GPs in this study face significant barriers in managing PWE in the primary care setting. For example, international best practice guidelines recommend that patients with suspected epilepsy be reviewed and diagnosed by a neurologist within two weeks (NICE, 2004). However in this study GPs reported significant difficulties accessing neurology services for PWE. Consequently many patients may be referred inappropriately to the emergency department, and the cost of this is unknown. Similarly, the more expeditious access to certain neurology services for patients with private health insurance does not infer superior clinical outcomes for these patients.

Despite its social and economic burden little has been documented regarding the care of PWE in Ireland (Neligan, Renganathan and Sweeney, 2006). The Department of Health and Children in Ireland has introduced reform strategies targeting certain chronic diseases which aim to improve the quality of service delivered and reduce morbidity and mortality of patients by providing structured and integrated pathways of care (Department of Health and Children, Ireland, 2008a; HSE Transformation Programme, 2007-2010). It recommends identifying the barriers to effective care, establishing evidence based standards of care thereby improving patient and service outcomes.

Increasingly ICT is viewed as a critical tool for enabling chronic disease management strategies although the efficacy of such technology remains unproven. (Dorr et al, 2006; Marchibroda, 2008; Nizamuddin et al, 2008; McInnes, Saltman and Kidd 2006). The epilepsy-specific EPR currently being developed and deployed at Beaumont Hospital provides web-based, comprehensive, accurate information about PWE to authorised individuals within the hospital. Ultimately, this EPR could support improvements in

health service integration by providing timely access to this information via a secure internet connection to authorised healthcare providers at any location, e.g. GPs.

As previously reported, many Irish GPs are engaging with ICT to improve the efficiency and effectiveness of their practices (ICGP, 2003). While computerisation at one level in GP practices is widespread, electronic functionality specific to chronic disease management appears underused. GP specific electronic systems seldom link or communicate with external electronic sources. The challenge now is to exploit the technology to improve the interface and integration of care between primary, secondary and tertiary care services using information as an essential element of the reform.

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While acknowledging the limitations of this study, the findings suggest that significant barriers to quality care for PWE exist in the Irish healthcare system. Continuity of care for PWE can be improved by establishing shared care networks, between healthcare sectors which is supported by health information systems. However, before implementing the solution the problem requires further analysis. Additional studies on current standards and pathways of care are required to more fully understand the need for and availability of health care services for PWE in Ireland. The results in this study can contribute to the future development of a patient-centred national framework for epilepsy care in Ireland. Such a framework would improve patient outcomes while optimising the use of healthcare resources to support a more cost effective and efficient service.

5.5 Conclusion

The results of this study suggest that significant barriers exist within the structure of primary care that obstruct the delivery of high quality, evidence-based, integrated and coordinate care for PWE. The existing pathways of care for PWE in Ireland has allowed a sub-optimal and fragmented service to develop in primary care. Many of the issues reported in this study are not just particular to the Irish context but they do highlight the extent of the challenges that need to be overcome. Even in the presence of adequate pathways of care for PWE in Ireland, the knowledge deficits reported by GPs and

dissatisfaction levels reported by PWE in Ireland with their GP (Chapter IV) need to be addressed as a matter of urgency.

The optimum management of any chronic disease requires care to be "shared" between primary and specialist care. In evaluating the structure and process of epilepsy care in Ireland prior to implementing the epilepsy-specific EPR the interface between primary and specialist epilepsy care required exploration. Motivated by the need to improve co-ordination of epilepsy care in Ireland, key informants from primary care and hospital-based specialist epilepsy services were invited to participate in a study exploring this interface. The objective of this study (Chapter VI) was to assimilate opinion, knowledge and lived experiences of the current status of epilepsy care in Ireland. Participants in this study revealed important insight into the potential barriers to implementing a new model of care, and offered potential solutions for overcoming such challenges including the role of information management and communication.

Chapter VI

Epilepsy Care in Ireland;
Towards the Primary – Tertiary Care Continuum

6.0 Introduction

Chronic illness is a key feature in the pattern of health for children and adults today because of advances in medical science and technology, medical and nursing care and improved socio-economic conditions. Such advances in medical science have led to improvements in health outcomes and a greater life-expectancy associated with many chronic diseases. It has also led to considerable increases in diagnostic and therapeutic complexity and a consequent additional strain on health care systems. Current models of health service delivery are struggling to meet the existing demand of chronic disease management and are unlikely to cope with demand in the future unless services are reconfigured (Department of Health and Children, 2008).

To maximise the benefits of medical science advances for the patient while minimising the burden on healthcare systems, there is an international move to transform the way chronic disease is managed (Weingarten et al, 2002; Battersby, 2005; Wilson, Buck and Ham, 2005; Royal College of Physicians of London 2004; Bodenheimer, Wagner and Grumbach, 2002). Among the recommendations for chronic disease management is a call for a shared care model that is integrated across organisational boundaries (Pritchard, J. Hughes, 1995) and supported with information and communication technology acting as an enabler of reform (Wagner, 1998; Marchibroda, 2008; Bødker and Granlien, 2008).

Epilepsy is a common chronic neurological disease which affects people of every age, gender, race and socio-economic background. Characterised by the occurrence of recurrent unprovoked seizures, its prevalence is estimated at between 4.5 and 8 per 1000 (Forsgren, Beghi, Oun and Sillanpää, 2005). Hence epilepsy is recognised as a major

chronic disabling condition with consequent burden on the healthcare system and individuals. There are many different types of epilepsy and its diagnosis and optimal management relies on integration of clinical data from a number of healthcare disciplines in a variety of healthcare settings, e.g. community based general practice, secondary and tertiary cares. The patient's active participation in managing their condition is important in achieving a good health outcome.

The goal of treatment is a reduction or elimination of seizures to enable individuals to lead as productive a life as possible, without significant side effects of therapy. Best practice guidelines for the management of epilepsy make many recommendations regarding the nature and timing of diagnostic and therapeutic intervention (NICE, 2004; SIGN, 2003). For example, the NICE guidelines advise that 'all people with epilepsy should have a comprehensive care plan that is agreed between the individual, family and/or carers where appropriate, and primary care and secondary care providers. This should include lifestyle issues as well as medical issues'. However, the current fragmented nature of healthcare systems poses a significant barrier to the effective implementation of these recommendations as seen by reports of inconsistent/uncoordinated care, conflicting advice, delays in diagnosis and treatment, and inappropriate investigations (Marchibroda, 2008).

In Ireland the general practitioner (GP) in primary care is normally the first point of contact for people requiring health services. If required the GP will refer the patient to a consultant doctor at the local hospital for secondary care who in turn may refer the patient to a medical specialist in either the same or a different institution for tertiary care. There is no formally recognised expert epilepsy institution and specialist epilepsy care is incorporated into general neurology. However, as it is the only centre in Ireland offering surgical treatment for epilepsy, Beaumont Hospital in Dublin is the main referral centre for complex epilepsy. While a number of Irish neurologists have specialist epilepsy training, this capacity is not fully exploited as expert epileptologists are obliged to also provide general neurology services. Furthermore, an accident of geography means that for some of the population the local hospital includes neurology (with or without

epilepsy) services while for others there is no local neurology service. As a consequence there is often no clear distinction between secondary and tertiary care and the number of times people with epilepsy must access the system to have their needs addressed varies throughout the country. For the purposes of the study presented below, tertiary care refers to neurology services in Ireland with a special interest and specifically trained personnel in epilepsy.

The "tyranny of the urgent" has resulted in an historical emergence of health systems that respond to the needs of patients with acute conditions better than those with chronic conditions who require on-going care (Pritchard, J. Hughes, 1995; Marchibroda, 2008). The evidence suggests that effective epilepsy care requires re-shaping of healthcare delivery systems to improve patients' access to services, increase efficiency and enhance the continuity of care. In recognition of such issues, the Health Research Board (HRB) in Ireland has funded a 5-year research and development programme (Appendix 2) to examine challenges to epilepsy management in both primary and specialist sectors, and to consider how epilepsy management may be supported by adopting a shared care model. This paper reports on a project which aimed to explore healthcare professionals' perspectives and experiences of providing epilepsy care for adult patients in Ireland.

6.1 Methodology

6.1.1 Selecting the methodological approach

To meet the stated aim of exploring the interface between primary care and specialist epilepsy services in Ireland, three research objectives were proposed;

1. To explore healthcare professionals' experiences of providing epilepsy care.
2. To identify healthcare professionals' perspectives on the factors that enhance or inhibit the provision of quality epilepsy care.
3. To ask healthcare professionals to identify strategies/actions that could address challenges and assist them in their provision of quality epilepsy care.

A descriptive qualitative approach informed by appreciative inquiry (AI) was used as the focus was on identifying the issues from professionals' perspectives without any preconceptions or a 'blame culture'. AI is a form of action research theory that embraces and supports the cooperative search for the best in people, their organisations, and the world around them (Cooperrider et al, 2000). The primary assumption of AI is that every organisation is an open system that works well at some level and needs investment in its human capital to deliver a long-term positive change congruent with organisational vision and goals (Cooperrider et al, 2000).

Using AI to direct the research methodology of this study facilitated the exploration of the interface between primary care and specialist epilepsy services while simultaneously developing a culture of working together to better understand systems of care. AI "involves the art and practice of asking questions that strengthen a system's capacity to heighten positive potential and mobilises inquiry through crafting unconditional positive questions" (Cooperrider et al, 2000). In this study there was a need to ensure that participants could talk freely about issues/challenges they encountered on a daily basis in providing epilepsy care. Bringing practitioners together from both primary and specialist services provided rich data as such an event had not occurred before in the epilepsy services in Ireland.

6.1.2 Sampling and recruitment

The aim was to enrol information-rich participants who would provide and exchange perspective on (a) the role of primary care and (b) the role of tertiary care in the management of epilepsy in Ireland. As previously stated, tertiary care in this study refers to neurology services with a special interest in epilepsy care. We also aimed to attract input from Brainwave, The Irish Epilepsy Association, which is the main epilepsy support group for people with epilepsy in Ireland. In this regard the inclusion criteria were to work as one of the following in Ireland:

- a general medical practitioner (GP)
- a general practice nurse working in primary care
- a consultant neurologist with a special interest in epilepsy
- an epilepsy specialist nurse, and
- a patient advocate with Brainwave

It was intended that there would be up to 40 individual participants and that there would be an equal distribution of primary care and tertiary care representatives which would include both doctors and nurses.

Recruitment of primary care participants was facilitated by the Irish College of General Practitioners (ICGP) and the Irish Practice Nurses Association (IPNA). A letter of invitation was provided to the two organisations who in turn forwarded it to their registered members (ICGP membership = 2515; IPNA membership = 451). The letter outlined the research purpose and the format of the planned focus group discussions. Recipients were provided with a form which they were asked to return to the event organisers if they were interested in participating.

A purposive sample of tertiary care representatives was approached and invited to participate. These included consultant neurologists with a special interest in epilepsy and epilepsy specialist nurses. The former was the group of seven consultants from different centres who regularly attend a multidisciplinary epilepsy surgery review meeting at Beaumont Hospital. Epilepsy specialist nurses provided a list of 12 nurses who met the inclusion criteria.

6.1.3 Data Collection

It is difficult to organise focus groups with a diverse group of healthcare professionals from different settings due to participants' clinical commitments. Therefore it was decided to hold a number of concurrent focus groups on a single day. Participants were divided into five groups of six/seven participants so that each group had a mix of

healthcare professionals ensuring different perspectives. The focus groups were of 60 min duration. Each group was instructed to nominate a time-keeper, a note-keeper and a spokesperson and to discuss the following four topics over 60 min: epilepsy care in Ireland; gaps in service provision; challenges to shared care; strategies to meet current challenges. Each group ($n = 5$) was facilitated by a member of the research team which included: one lecturer in health informatics, one lecturer in health policy and management, and three health services researchers. The facilitators' role was one of active listening and when necessary he/she helped the discussion by introducing additional probing questions (Sarantakos, 1997).

6.1.4 Data Analysis

Data reduction was conducted during the focus group as the note-keeper within each group summarised and manually recorded in bullet point format the issues raised by participants. Following the focus group session a plenary assembly was conducted so that the individual groups could share the key points of their discussion. At the plenary session, feedback from each group was presented by their spokesperson and further discussion was facilitated. A note-keeper for the plenary session summarised and recorded the plenary discussion manually into a word-processor. All the data gathered, from each focus group and at the plenary session, were compared and contrasted to identify major categories which were then collated into four themes.

6.1.5 Ethical considerations

Ethical approval to conduct the research was obtained from Beaumont Hospital Ethics (Medical Research) Committee.

6.2 Results

In total 33 individuals (82% of the original target) agreed to participate in the focus groups. Of these 52% represented primary care and included 14 general practitioners and 2 practice nurses and 1 hospital based GP liaison nurse. Thirty-six percent represented the specialist care setting including 5 neurologists/epileptologists, 1 junior hospital doctor,

and 6 epilepsy/neurology specialist nurses. The remaining 12% were 3 nurses from learning disability services, and 1 patient advocacy group representative. Table 1 presents the key themes and categories from the analysis of the focus group data.

Table 1: Key themes and categories from analysis of focus group

Current Gaps in Epilepsy Care	**Striving for Shared Care**
➢ Lack of resources ➢ Poor access to services ➢ Communication between healthcare sectors ➢ Poor health ICT infrastructure ➢ No Irish best practice guidelines	➢ What defines shared care? ➢ Clarity of roles and responsibilities required ➢ Nurse led services ➢ Role of ICT ➢ National network of epilepsy care
Barriers to shared care	**Influencing change**
➢ Stigma means Epilepsy not on political agenda ➢ Availability and access to care ➢ Communication ➢ No formalised pathways of care ➢ Accountability and medico-legal issues ➢ Lack of incentive ➢ Education and training ➢ Challenges in ICT exploitation	➢ Political drive required ➢ Irish audit of epilepsy ➢ Establish a taskforce ➢ Clinicians and patient representative groups agitate for change ➢ Irish centre of excellence ➢ Irish based epilepsy research ➢ Education and training ➢ More GPs with special interest in epilepsy ➢ Devolved care ➢ Deployment of effective ICT

6.2.1 Gaps in Epilepsy Care in Ireland

According to participants, patients encounter poor access to epilepsy clinics, and experience lengthy waiting times. It seems that there is a geographic variation in availability and access to epilepsy services leading to considerable inequalities for patients with epilepsy and their families. Similarly, the public or private status of a patient (i.e. those with private health insurance) was perceived as causing inequities. It was thought that patients and families with private health insurance or better financial stability had better and faster access to care. Likewise, there was a perception that more proactive patients and parents manage to get faster access to care and treatment. Participants noted that there is poorer access to adult epilepsy clinics compared to paediatric clinics. At the same time it was noted that the transition from paediatric to adult services required special attention and that there is a need to develop adolescent specific services as epilepsy can be a life-time condition.

In terms of human resources there was general agreement that the current lack of adequate numbers of epilepsy nurse specialists and neurologists with expert training in epilepsy are leading to deficits in epilepsy care in Ireland. Also there is a need for additional clinical and administrative support to facilitate quality care. The concept of "reasonable delay" in waiting time to see a neurologist was discussed. Even when patients manage to see a neurologist, they then encounter difficulty accessing required clinical investigations for their condition.

Poor communication was seen as resulting in deficiencies in advice conveyed to general practitioners (GPs) about their patient after referral to the specialist service. The slow transfer of information between specialist services and primary care, and vice versa, contributes to inadequate communication. Similarly, participants believed that poor follow-up arrangements results in many patients being lost to follow-up after being seen by hospital based service. Non-computerised medical practices were seen as contributing to the gap in communication and transfer of information between services. The potential of electronic communication for exchanging information and advice between healthcare

providers was acknowledged. It was suggested that telephone advice provided by specialist epilepsy services could be very useful for GPs.

A lack of knowledge and confidence to manage epilepsy among practitioners at the primary care level was identified. Although participants recognised that international and UK best practice guidelines for epilepsy care exist, they questioned their appropriateness in the Irish context. The lack of Irish guidelines and protocols was considered a drawback. Similarly, patients understanding of, or ability to understand, their epilepsy was considered to impact on care and to sometimes result in unrealistic expectations. Some participants believed that epilepsy remains a taboo subject as many patients feel socially stigmatised. This stigma contributes to epilepsy and its care not being spoken about and consequently not receiving the social or political attention it deserves.

6.2.2 Challenges to Moving Towards a Shared Epilepsy Care Model

The concept of sharing epilepsy management between the primary and specialist health care sectors was discussed. Although most participants felt that a shared model of care could improve on the challenges identified earlier, there were barriers that would need to be overcome to implement such a model in Ireland. Overall, participants thought that more human and financial resources and changes in organisational structure of health care delivery would be required to implement a shared care model.

6.2.2.1 Patients' Preference for Specialist Care

Patients' attitude to shared care was considered a potential barrier to implementing the model. It was suggested that patients might prefer to communicate with the specialist in epilepsy care rather than the generalist at primary care level. Such attitudes may also vary depending on the insured (public or privately) status of the patient.

6.2.2.2 Need for clearly Defined Roles and Formalised Clinical Pathways

A lack of formalised clinical pathways outlining multidisciplinary plans of care to support clinical management of epilepsy was also considered a barrier. For example, a

requirement for pre-clinic assessment to support shared care was discussed. Such pre-clinic assessment would result in patients attending the specialist epilepsy service carrying appropriate investigation results thus ensuring optimum value from the clinical encounter.

Clear accountability in terms of healthcare provider roles in a shared care model was identified as essential. Participants referred to medico-legal consequences of indistinct roles and responsibilities and felt these would need to be unambiguous for the different healthcare sectors sharing epilepsy management. It was felt that the location of care for an individual patient should be with a designated clinician. Enhanced education and training in epilepsy management for primary care providers was identified as a requirement to advance shared care.

The two different concepts of management and diagnosis were considered. There was a general opinion that epilepsy diagnosis should be made at specialist care level and that once a diagnosis and care plan were established, ongoing management could be dealt with by the GP service. However, the timing and nature of the follow-up care itself required clear guidelines. Participants also believed that shared care of epilepsy should promote nurse-led services. In this regard, much of the follow-up epilepsy management at primary care could be taken on by general practice nurses with support from their epilepsy specialist nurse colleagues in the specialist centres. This approach would require strategies to ensure the confidence of patients and public in such nurse-led services.

6.2.2.3 Need for Additional Resources

While shared care was thought to have the potential to enhance care, participants felt that implementation of the model would require additional resources. Geographical inequities were considered a significant barrier to implementing a shared care model for epilepsy. From the GP perspective, shared care was considered achievable in group practices of four or more GPs but not as realisable in single GP practices. Participants also conjectured that the model would bring an increased work-load to GP practices that could not be catered for without improved support from the specialist services and improved

communication between the health care sectors involved. Furthermore participants felt that the current healthcare system provided no incentive to reshape services. It was particularly felt that GPs would require incentivisation to adopt a key role in the management of epilepsy patients. Related to this was a discussion regarding the cost to patients in a shared care model. For example, participants wondered how remuneration for services would be managed in the current Irish medical card system.

Participants believed that advancing a shared care approach required that, where appropriate, more epilepsy management needs to be devolved to the primary care sector. To achieve this requires that a number of GPs with a special interest and additional training in epilepsy care be identified in different regions of the country and that these GPs would become focal points for epilepsy care at primary level. This should be supported by access to GP helplines and rapid access clinics provided by a centre of excellence. Associated with this is an identified need for more community based epilepsy nurse specialists to help share the responsibility of epilepsy care across healthcare sectors. The idea of establishing a national network of epilepsy care centres staffed by trained epilepsy doctors, nurses and allied health professionals received support in the discussions. This network would be supported by ICT infrastructure and provide timely access to specialist epilepsy opinion, advice and service to patients, their families and healthcare providers.

6.2.3 Sharing Information — Role of ICT

Information communication technology (ICT) was considered an important ingredient in enhancing communication and sharing of information between the healthcare sectors to facilitate the shared care of patients with epilepsy. In this regard, participants identified a need to improve the computer literacy of healthcare providers and to ensure that appropriate ICT systems are deployed with adequate and available technical support. Participants believed that shared care would require an ability to share patient records between care providers and across organisational boundaries. The need for primary care to have access to information from hospitals in a timely fashion was stressed. Likewise,

computer based drug management systems were also considered as having potential to enhance epilepsy care.

While ICT was viewed as a key factor in improving continuity of care, the structure of the current epilepsy service was considered to pose a significant challenge to implementing electronic patient records. Already stretched resources mean that there are significant time constraints on services with little or no leeway for healthcare workers to participate in healthcare reform projects. Despite the advantages, there was also a recognised need to achieve "buy-in" for an ICT facilitated structure of care with assured security and performance of computerised systems.

6.2.4 Influencing Change

Having considered gaps in current epilepsy care in Ireland, agreeing that a shared care model could enhance continuity of care, and identifying barriers to re-shaping services, the participants identified requirements for influencing change. There was a general consensus that change could only be effected if there was political will to do so. Participants noted that reconfiguring health services for the benefit of individuals with epilepsy would need to be driven at government or ministerial level. There was a call for an Irish epilepsy audit to more fully understand the nature and scope of related health care needs. It was suggested that a taskforce on epilepsy care in Ireland, mandated to improve services for patients with epilepsy and their families, be established and that clinicians and patient advocacy organisations must agitate for political support. Engaging with health economists to sell the case for enhancing epilepsy care was proposed. Again the need to motivate the different healthcare sectors to institute change was considered.

In addition to this, improvements could only be realised with additional education and training, the development of a well-resourced national centre of epilepsy excellence for Ireland, and the deployment of effective information technology systems. The establishment of a centre of excellence for epilepsy care in Ireland was proposed. This centre would be staffed by experts in epilepsy care, have high quality facilities, be the leader in epilepsy care for the country and provide support, advice and service to patients,

their families and other healthcare providers. Related to this was identification of the need for more Irish based epilepsy research. Education to raise awareness and understanding of epilepsy was thought to be important in influencing change. This includes enhanced and continuing medical education with study days and workshops for health care providers as well as for patients and the general public.

6.3 Discussion

It is clear that healthcare professionals working at the epilepsy primary–tertiary care interface face many challenges in delivering effective care and there was general consensus with the concept of re-shaping services for the benefit of patients and their families. In Ireland, epilepsy is not considered a special case but subsumed in the overall national needs for neurology services.

By comparison, in the UK an all-party parliamentary group on epilepsy has become a very positive influence on epilepsy policy, while an action plan for improving services for people with epilepsy has been produced by the Chief Medical Officer of their Department of Health (Besag, 2004: Department of Health, 2002). Furthermore, the new UK General Medical Services (GMS) GP contract that came into effect in April 2004 includes a financial reward for the delivery of quality care in epilepsy. Under this contract GPs receive remuneration on the basis of the rate of medication review they conduct for their patients with epilepsy (Department of Health, 2002: Minshall and Smith, 2008). This incentivisation together with GP education in the diagnosis and management of epilepsy has been reported to significantly improve review and seizure remission rates as well as a reduce admissions to the accident and emergency department (Minshall and Smith, 2008).

The focus group participants felt that sharing care across the primary–specialty interface has the potential to improve outcomes in epilepsy, and equally recognised significant hurdles to be overcome to influence change and implement a new model of care. Despite this support for a shared model of care, a recent review of the effectiveness of shared care for the management of chronic disease (which did not include epilepsy) concluded that

there was insufficient evidence to support the introduction of shared care into clinical practice (Smith, Allwright and O'Dowd, 2008). However, length of follow-up in the studies examined may account for the lack of evidence and the authors recommend further research to test the effectiveness and sustainability of different models of collaboration across the primary care–specialty care interface. Therefore, the introduction of shared care should be accompanied by ongoing monitoring and evaluation so that continuous improvement goals and objectives are set with the aim of achieving an optimal model of epilepsy management for Ireland.

Poor communication, the need for access to shared medical records and more timely exchange of information between the healthcare sectors were repeatedly mentioned by participants as was the role of ICT and electronic patient records in alleviating these concerns (Grimson, 2001; Ruland et al, 2008). In a computer modeled 10-year projection, Bu et al. (2007) and Wyne (2008) demonstrated that ICT enabled management of diabetes, including diabetes registries, decision support systems and patient self-management systems, has the potential to improve healthcare processes, delay diabetes complications and reduce healthcare costs. The potential of ICT for reducing error, improving outcomes, and controlling costs is recognised (Wyne, 2008). However, it should not be seen as a panacea for the problems of modern medicine (Hartzband, J. Groopman, 2008).

On-going research and development is required to design and deploy effective health ICT systems that are best for patient care and to truly evaluate their impact on the structure, process and outcome for quality patient care. The socio-technical interface of ICT in healthcare must be carefully managed to realise the promise of improved healthcare yield (Trist and Bamforth, 1951). Furthermore, because of a perceived increased risk of health information leakage in ICT enabled health care, data protection is critical as people are understandably sensitive about the confidentiality of their health status.

We are at the dawn of a new age in healthcare with a shift from medical paternalism, more knowledgeable and better informed patients, and burgeoning health care costs

driving healthcare transformation programmes. The potential of personalised medicine continues to grow with pharmacogenomics promising more individually tailored and safer anti-epileptic drug and other therapies (Tate and Sisodiya, 2007). Its adoption into clinical care will require the integration of the individual's molecular and clinical information which will be dependent on substantial cooperation between a variety of medical disciplines. In addition, a move towards personally controlled health records (PCHR) will enable patients to manage their own health data (Mandl and Kohane, 2008; Steinbrook, 2008). Large corporations such as Google and Microsoft are aiming to offer on-line repositories which will allow patients to store, retrieve, manage and share their health data. The success of such initiatives will give rise to a transportable medical record that can be available via the Internet to authorised healthcare providers at any location. Thus negating the need for paper records, patients are able to share their data with multiple doctors and health care service providers (Steinbrook, 2008) to engage them in their optimum health care. Control over their health data may put patients more in command in health care delivery with consequences for the way healthcare is structured and in how information and communications technologies are utilised (Grimson and Grimson, 2002).

6.4 Limitations of the Study

In order to attract approximately 20 primary care representative, a letter of invitation was sent to almost 3000 individuals. While this approach may seem excessive we purposely spread the net wide for the following reasons. Targeting GPs and practice nurses with a special interest in epilepsy was not simple as the professional groups (ICGP and IPNA) did not have a register of such interest. In addition it was anticipated that clinical commitments might limit availability to attend the focus group meeting. However, it is not clear why those primary care representatives who participated decided to do so as this question was not explicitly asked and we recognise that this approach to recruitment may not have been ideal. By comparison 6 of the 7 consultant epileptologists and 6 of the 12 epilepsy nurse specialists who were invited did participate. Although invitees were not asked the reason for their participating or not participating, clinical and personal commitments are the most likely reasons for not attending.

In this study the experience of health professionals working in the primary and specialist care sectors in relation to epilepsy services in Ireland was explored. The experience of the journey through the health care system from the perspective of Irish people with epilepsy was examined in a separate investigation (chapter 4). It may be effective to incorporate all points of view in a single study by bringing patients, healthcare professionals as well as healthcare managers together in a joint workshop.

6.5 Conclusion

This examination of the primary–tertiary care continuum for epilepsy in Ireland revealed a need to shift from the current fragmented healthcare system to a shared care model for the benefit of the patient with epilepsy and their families. Furthermore, the aging of the population and the advent of improved therapies indicate a need to reform our healthcare structures to more adequately meet current and future chronic disease management needs. The shared care model may help in the integration of care across organisational boundaries thus contributing towards a structured seamless web of care for patients with epilepsy. Sharing of information is essential for quality disease management.

Electronic patient records accessible to authorised healthcare professionals at any location that incorporate decision support with links to evidence based clinical practice guidelines may facilitate improvements in communication and help in optimising care. However, effecting the necessary changes cannot happen at once and a realistic action plan mapping out at least a 10-year programme of work is required to develop a more integrated approach to epilepsy care in Ireland. For example, improved communication between the primary care and specialist care sectors might be advanced within a shorter time-frame than will reducing geographic inequities, training and education of additional personnel in epilepsy care, or the elimination of the stigma associate with epilepsy. A policy response from government together with a commitment of required resources is necessary to drive the change. While the focus was on epilepsy care provision and the setting is Ireland, the implications from this study may be applicable to other chronic diseases and other countries.

The structure and process of epilepsy care in Ireland have been explored from the perspective of PWE, clinicians from primary and specialist care services, educationalists and researchers (Chapters IV; V; VI). In chapter VII the quality and consistency of epilepsy specific information in the primary care records of PWE in Ireland is examined. By examining what GPs record about their patients with epilepsy, barriers and facilitators to sharing and exchanging clinical information across traditional organisational boundaries could be explored. In addition, the study would reveal if the data to assess quality of epilepsy care delivered by GPs is readily available in current healthcare records. Effective CDM reform requires the robust collection of information and data-sharing among all stakeholders, if improvements to care are to be achieved.

Chapter VII

Towards the Development of Integrated Epilepsy Services: An Audit of Documented Epilepsy Care in the Mid-West Region of Ireland

7.0 Introduction

There is a growing interest in monitoring and evaluating the performance of health service delivery to determine if the desired health outcomes for the population are achieved and if limited healthcare resources are used efficiently. However such evaluation depends on the ready availability of appropriate data. Furthermore, an essential requirement for successful transformation of CDM is the availability of reliable clinical information (Franklin et al, 2007; Marchibroda, 2008).

The study presented in this chapter was driven by three key concepts:

a. The assessment of the effectiveness of a health care intervention relies on the ability to analyse relevant data.
b. To determine if a new model of health care in achieving its objectives requires a comparison of pre- and post-intervention data.
c. The timely sharing and exchange of information between clinicians is required to promote improved integration and coordination of care. This assumes that the necessary clinical data is routinely captured by clinicians.

Specific to information management, health information technologies such as electronic patient records (EPR) have been recognised as key to supporting healthcare transformation compared to the traditional paper record (Grimson, 2001; Grimson and Grimson, 2002; Barretto et al, 2003). In addition to enabling the transformation of epilepsy care, EPRs could potentially support a national network of care for PWE facilitating the sharing and exchange of clinical information.

Previous chapters have explored the structure and process of epilepsy care services from the perspective of patients (Chapter IV) and clinicians (Chapters V and VI). This part of the evaluation process examines the readiness of different clinical sectors to adopt technologies that support improved information management. By examining what GPs record about PWE, the barriers and facilitators to sharing and exchanging clinical information across traditional organisational boundaries could be explored. In addition, the study would reveal if the data to assess quality of epilepsy care delivered by GPs is readily available in current healthcare records.

7.1 Methodology

The epilepsy research department at Beaumont Hospital, Dublin and the Irish Mid-West Specialist Training Programme in General Practice collaborated in this project. The audit was conducted in the Mid-West region of Ireland which includes Limerick city and County, County Clare and North Tipperary (Figure 1). The region provides health services for a population of 361,000 and is served by four regional hospitals. A consultant neurologist was appointed to the region approximately two years ago. However prior to this, there was no neurology service in the region and PWE had to travel beyond the Mid-West region for specialist care to Cork and Dublin.

Figure 1

All GPs registered with the Irish College of General Practitioners (ICGP) working in the Mid-West region of Ireland *(n=215)* received a written invitation to participate in the study. Four trainee GPs were recruited to collect epilepsy specific data under the supervision of a senior GP with a special interest in epilepsy care. The GP trainees travelled to the GP practices that agreed to participate to audit the health records of people with epilepsy.

At each participating practice a list of PWE was generated by interrogating the electronic patient management system and/or by manually searching through paper-based charts. A proforma was developed (Appendix 4) for the audit and aimed to capture data relevant to the care of people with epilepsy. Only information required to complete the epilepsy specific proforma was extracted from the patient's medical records. Ethical approval was granted by the medical ethics committee of the Irish College of General Practitioners.

7.2 Results

7.2.1 Profile of participating general practices

Of the original 215 GP practices invited to participate in the audit, fifty-three practices (25%) agreed and consented to participate. Fifty-two practices (24%) specifically declined to participate while ninety-seven practices (45%) did not respond to the letters of invitation. Ten practices (6%) remained undecided and/or changed their mind prior to data collection. In total, thirty- six practices (68%) that consented to the study were visited by the data collectors. Data collectors did not visit the remaining seventeen practices (32%) due to time constraints of the study and an outbreak of swine flu that restricted non-essential visits to GP offices. The characteristics of participating GPs and their practices have been summarised (Table 1).

Table 1: Profile of invited participating general practices (n=81*)			
GP gender		**Practice secretary**	
Male	27 (33%)	Yes	77 (95%)
Female	54 (64%)	No	4 (5%)
Practice location		**Practice nurse**	
Urban	42 (53%)	Yes	65 (80%)
Rural	27 (33%)	No	16 (20%)
Mixed	12 (14%)		
Practice Size		**Practice manager**	
<500 patients	0 (0%)	Yes	35 (43%)
500-1000 patients	7 (9%)	No	46 (57%)
1001-1500 patients	9 (11%)	**Patient List**	
1501-2000 patients	35 (43%)	GMS patients	(44 %)
2001-3000 patients	12 (15%)	Private patients	(56 %)
>3001patients	18 (22%)		
Practice computerised		**Maintain a register of PWE**	
Yes	62 (76%)	Yes	7 (8%)
No	11 (14%)	No	74 (92%)
Partially	8 (10%)	**Maintain a recall system for PWE**	
		Yes	5 (6%)
		No	76 (94%)
* = (Data from 53 participating practices and 28 non-participating practices)			

7.2.2 Profile of audited patients with epilepsy (PWE)

The primary care records of 374 PWE were audited. While patient gender was evenly distributed, 85% of patients were greater than 26 years of age and General Medical Scheme (GMS) cardholders (Table 2). A majority did not have their occupation, marital status or the incidence of alcohol and tobacco use documented (Table 2).

Table 2: Demographic profile of patients audited *(n=374)*			
Gender:		**Smoking status**	
Male	207 (55%)	Unknown/Not recorded	200 (53%)
Female	167 (45%)	Non-smoker	118 (32%)
Age Category		Smoker	37 (10%)
0-18 years	56 (15%)	Ex-smoker	19 (5%)
19-30 years	58 (16%)		
31-55 years	147 (39%)	**Hx of substance abuse**	
> 55 yrs	113 (30%)	No	107 (29%)
Marital status		Yes	8 (2%)
Single	157 (42%)	Not documented	259 (69%)
Married	82 (22%)		
Co-habitating	17 (4%)	**Occupation**	
Separated/Divorced	7 (2%)	Below working age	51 (14%)
Not documented	111 (30%)	Long term disability	47 (13%)
Alcohol use		Retired	29 (8%)
Non-drinker	101 (27%)	Unemployed	22 (6%)
Socially	72 (19%)	Sick leave	6 (2%)
Alcoholic	7 (2%)	3rd level student	4 (1%)
Ex- alcoholic	3 (1%)	Not documented	208 (57%)
Not documented	191 (51%)		

7.2.3 Documentation of epilepsy specific information

First seizure activity was well documented (87%), however seizure frequency, classification and aetiology were inconsistently recorded (Table 3). Diagnosis confirmation by a neurologist was documented for 132 patients (35%). The remaining 242 patients (65%) had their epilepsy diagnosis confirmed by various health professionals or had no documented record of where or by whom the diagnosis originated (Table 3). Epilepsy specific information relating to tests and investigations were not documented for over half the patients with significant geographical diversity in the availability of such services (Table 3).

Table 3: Documented epilepsy specific information in primary care records (n=374)

	Yes	No		Yes	No
Seizure activity documented	326 (87%)	48 (13%)	**Epilsepy specific CT**	116 (31%)	258 (69%)
			Mid-West regional Hospital	51 (44%)	
			Cork Regional Hospital	22 (19%)	
Seizure classification documented	188 (50%)	186 (50%)	*Unknown*	17 (15%)	
General	120 (64%)		*Other*	13 (11%)	
Partial	68 (36%)		*Beaumont Hospital*	7 (6%)	
			University Hospital Galway	4 (3%)	
			Waterford Regional Hospital	2 (2%)	
Epilepsy aetiology documented	165 (44%)	209 (56%)	**Epilsepy specific MRI**	95 (25%)	279 (75%)
Chromosomal abnormality	46 (28%)				
Brain trauma	18 (11%)		*Mid-West regional Hospital*	32 (34%)	
Stroke	11 (7%)		*Cork Regional Hospital*	22 (23%)	
Perinatal injury	8 (5%)		*Unknown*	15 (16%)	
Vascular malformation	7 (4%)		*Other*	16 (17%)	
Other	77 (45%)		*Beaumont Hospital*	5 (5%)	
			University Hospital Galway	4 (4%)	
Seizure frequency documented	134 (36%)	240 (64%)	**Epilsepy specific EEG**	116 (31%)	258 (69%)
Weekly seizure activity	9 (7%)				
Monthly seizure activity	28 (21%)		*Mid-West regional Hospital*	47 (41%)	
Twice yearly	67 (50%)		*Cork Regional Hospital*	26 (22%)	
Yearly	20 (15%)		*Unknown*	16 (14%)	
Regularly irregular	9 (7%)		*Other*	16 (14%)	
			Beaumont Hospital	7 (6%)	
			University Hospital Galway	4 (3%)	
Diagnosis confirmed by a neurologist	132 (35%)	242 (65%)	**Epilsepy monitoring unit**	9 (2%)	365 (98%)
			Cork Regional Hospital	5 (56%)	
			Unknown	2 (22%)	
			Beaumont Hospital	2 (22%)	
Dublin Hospital	45 (35%)				
Cork Regional Hospital	36 (27%)				
Mid-West regional Hospital	38 (29%)				
University Hospital Galway	6 (5%)		**An ECG as part of epilepsy specific investigations**		
Waterford Regional Hospital	2 (1%)			16 (5%)	358 (95%)
Unknown	5 (4%)				
Diagnosis confirmed by Non-neurologist					
GP		4 (2%)			
Local hospital physician		50 (21%)			
Paediatrician		34 (14%)			
Not documented / Unknown		154 (64%)			

7.2.4 Documented evidence of integrated epilepsy care (in past 2 years)

Over 70% of patients had not received a neurology review or had no documented evidence of their care being co-managed with specialist epilepsy services in the previous two years (Table 4). Clinical information specific to patient compliance with their advised treatment regime and/or life-style modifications specific to epilepsy was infrequently documented (Table 4).

Table 4: Epilepsy care & management (n=374)		
In the past two years was their documented evidence that the PWE was reviewed by	**Yes**	**No**
their GP	225 (60%)	149 (40%)
a hospital based non-neurology service	89 (24%)	285 (76%)
a hospital based neurology service	92 (25%)	282 (75%)
In the past 2 years was there evidence of		
epilepsy care outside of general practice with a private neurology service with a public neurology service with a public-private neurology service with a local hospital physician with a paediatric service	106 (28%) 30 (28%) 62 (58%) 4 (4%) 6 (6%) 4 (4%)	268 (72%)
acute emergency dept admissions	57 (15%)	317 (85%)
acute hospital admissions	67 (18%)	146 (39%)
patient non-compliance	44 (12%)	330 (88%)
non-compliance with AEDs	20 (45%)	
non-compliance with appointments	13 (30%)	
non-compliance with lifestyle advice	11 (25%)	

7.2.5 Documentation of Anti-epileptic Drugs (AEDs)

The majority of patients (93%) were taking one or more AEDs while 145 patients (43%) were taking two or more AEDs. The most commonly prescribed AEDs in order of frequency were Carbamazepine, Valproate Chrono, Valproate and Lamotrigine. Information documenting the prescribing and/or use of Buccal Midazolam was rarely available. Information specific to prior AED medications and indications of efficacy and non-efficacy was generally not documented for the majority (>90%) of patient's. 82 (22%) patients were women of childbearing age (16-50 years) with 33 (44%) currently taking Valproate. For the majority of these women documented evidence of specific

epilepsy care during pregnancies was unavailable (66%) as was evidence of integrated neurology review at time of pregnancy (76%).

7.3 Discussion

Using epilepsy as a probe, this study provides insight into the availability of data to support optimal management of chronic disease in primary care in Ireland. It revealed a disturbing lack of data recorded in the primary care records of PWE. Compared to quality indicators which have been developed for monitoring epilepsy care (Pugh et al, 2007; Fountain et al; 2011), this result suggests that the data for evaluating performance is currently not available. It is clear that without proper resources and adequate access to secondary care services GPs have great difficulty delivering and appropriately documenting the delivery of the desired standards of care. Furthermore, this has considerable consequences for establishing and implementing interoperable health record systems designed to share and exchange the clinical information required to support integrated, high quality patient care.

The inconsistency of the data recorded in the primary care records does not provide a dependable description of the frequency and nature of epilepsy patient review by GPs. The results suggest that the majority of interaction between Irish GPs and PWE is reactive and unplanned. Central to the optimum care of PWE for example is the monitoring of their AED therapy (Bradley and Lindsey, 2008). The results of this study implies that AED prescription renewal, which may take place twice or three times a year, occurs without clinical review by the GP to assess the patient's seizure control in response to medication, side-effects or any adverse events experienced. Best practice guidelines for the treatment of epilepsy recommend that PWE receive proactive planned and regular shared review while on long-term AED therapy (SIGN, 2003; NICE, 2004). It is clear from this study that such proactive primary care is not currently the norm in Ireland.

The inconsistent and/or absence of reliable epilepsy specific information in both hospital and primary care medical records complicates and fragments the delivery of epilepsy care

in Ireland (Varley et al, 2009). The availability of reliable standardised information through the adoption of appropriate information technology like an epilepsy specific EPR (Chapter II) that interacts seamlessly with General Practice patient management software systems can improve care by providing standardised EPR templates that prompt clinicians to ask appropriate clinical questions and store the required appropriate information. The management of information in this way facilitates the continuity and standardisation of care for people with any chronic illness and should be a key objective of any health service reform programme (Lenz et al, 2005). Such templates have been developed for diabetes care in General Practice and have been shown to be successful in optimising data recording and automated information retrieval (Hill et al, 2009).

Being sensitive to the quality of health service provision and its association with significant co-morbidity makes epilepsy a good model for studying the management of chronic illness. Therefore, this study provided insight into the management of chronic disease within the primary care sector in Ireland. However the problems highlighted are not exclusive to epilepsy nor to primary care services. Significant reform opportunities exist in Ireland and if implemented appropriately they could radically transform health services for PWE but as suggested above, this will require resources to follow the patient within a setting of modern contracts for service provision.

Bridging the existing information gap requires a strategic plan to facilitate the capture and communication of key clinical information by and between healthcare providers. Further research is required to better understand how information technologies like the epilepsy-specific EPR can be optimally exploited to transform the management of chronic diseases like epilepsy.

7.4 Limitations

As participating practices self-selected and a considerable number declined or ignored the invitation (69%) a sampling bias may have occurred. Participating GPs may have had a greater than average interest in epilepsy and were keen to gain insight and/or develop knowledge on how to better mange PWE. Nevertheless the number together with the

balance between urban and rural practices means that the study sample is reflective of the general population of GPs in Ireland. While the absence of evidence does not equate to evidence of absence (Lenz et al, 2005) the data assessed in this study suggests that primary care services for PWE in Ireland are lacking.

7.5 Conclusions

The findings in this study combined with the findings of studies presented earlier (chapter IV; V; VI) highlight the significant challenges facing health policy makers attempting to improve the care of people with epilepsy in Ireland. The collective findings of these research studies do not suggest that PWE cannot receive high qualify, safe and efficient care. Rather the fragmented and episodic delivery of care occurs within an environment not structured to meet the modern day requirements of patients with a chronic disease like epilepsy.

The ultimate chapter of this thesis (chapter VIII) will contextualise the findings of the research within the parameters of effective chronic disease management. The reform of epilepsy care in Ireland will require the adoption of a systematic approach to coordinating health care interventions across all levels (individual, organisational, local and national). An essential element of this transformation will be the optimum management and communication of relevant, clinical information. Within chapter VIII opportunities where improved information management and communication can enable service reform will be recommended. Irrespective of the approach adopted by policy makers in managing a chronic disease like epilepsy, the essential collection and communication of robust information must become and remain a priority.

Chapter VIII: The research contribution

8.0 Introduction

Throughout the world there is a drive to improve the quality, safety and efficiency of chronic disease management (CDM). Using epilepsy as an exemplar of chronic disease this research and development programme aimed to optimise the use of information and communication (via the epilepsy-specific EPR) to improve the quality, safety and efficiency of epilepsy care within Beaumont Hospital and nationally throughout Ireland. In addition, it was proposed that lessons learnt in this project would inform the wider CDM debate, by demonstrating the role of information and communication technology enabling the integration of key components of CDM reform policy. Adoption of this research and development approach would realise the full potential of the epilepsy-specific EPR in reconfiguring the strategic delivery of epilepsy care nationally and to identify the opportunities where optimum information management and communication within healthcare processes of care could support key components of CDM reform policy.

As discussed in chapter I (section 1.1) the potential benefits of this research and development project were to be demonstrated through formative and summative research evaluation projects, both technical and social. This would allow clinicians, health managers and health policy makers to appreciate, understand and document the value added to care processes in respect of not only epilepsy care and management but the wider context of CDM reform. It was proposed from the beginning that iterative socio-technical evaluation lessons learned from the model applied in this programme, i.e. clinician led eHealth development and strong clinical, IT expert and organisation stakeholder collaboration would benefit others who undertake similar projects in the future. Appropriate research evaluation of ICT initiatives in healthcare is essential as it informs similar related healthcare projects and guides future ICT decision making in the context of CDM reform (Moehr, 2002; Westbrook et al, 2009).

However as reported in chapter 1 (section 1.3) a widely reported obstacle to successful ICT implementation in healthcare is an under appreciation of existing service deficits and an under appreciation of the paradigm shift that occurs between pioneer work in local development sites and subsequent general application of the information technology to a wider organisation. It was in this context that social research evaluation was conducted in this project in tandem with technical evaluation (Appendix 1). Inappropriate integration of the epilepsy-specific EPR could have exposed clinicians, patients and healthcare organisations to significant avoidable risks. It was in this context that pre-implementation evaluation of existing epilepsy services in Ireland was conducted. Documenting the structure and process of pre-existing epilepsy services in Ireland formed the basis of this proposed PhD thesis and identified objectively the opportunities where optimum information management in the care process could support and inform the development of a model of shared-care for PWE underpinned by the essential elements of effective CDM. Lessons learnt could subsequently inform a template to guide the management and reform of similar complex, chronic diseases.

The hypothesis of this PhD (Chapter I – section 1.4) argued that existing structures and process of epilepsy care in Ireland were undocumented and must be must be fully explored and understood prior to implementing a potential enabler of reform such as the epilepsy-specific EPR. This thesis formed an integral component of the overall research component of the project and was conducted in conjunction with technical research evaluation studies. The thesis captured the essence of current structure and process of epilepsy care services in Ireland and identifies the opportunities where better information management and communication could inform the transformation of healthcare services.

The structure and process of epilepsy care in Ireland was examined from the unique perspective of patients with epilepsy (Chapter IV), primary care services (Chapter V; VI; VII) and specialist care services (Chapter VI) reporting on the current standards of epilepsy care, its management and the gaps in services that exist in the Irish healthcare system. Within each study was an emphasis on information and its management and how it is currently utilised to inform and manage patient care. Similarly, gaps in existing

structures and processes of care were identified to highlight the opportunities where improved information management could enable the transformation of services. In this concluding chapter the findings of the research are presented (Chapter IV; V; VI; VII), summarised and contextualised within the international research evidence pertaining to epilepsy care and the wider debate of CDM reform.

8.1 The Scope of the Thesis and the Research Outcomes

This thesis was part of a larger research project (Chapter I) aiming to transform the care and management of people with epilepsy (PWE) in Ireland by improving the quality and availability of clinical information within and between various healthcare settings using information technology (epilepsy-specific EPR). The objective of this research thesis was not to evaluate the technology but rather to more clearly understand when and where improved information management and communication could enable the reorganisation and integration of care for a chronic disease like epilepsy.

As discussed earlier, the evaluation component of the overall research project contains dimensions of both technical and social research evaluation (Chapter I – section 1.0; 1.3; 1;4). Specific to this PhD was pre-implementation research that examined the current structure and process of epilepsy care in Ireland prior to implementing the epilepsy-specific EPR project. The emphasis of this research was to identify the challenges and opportunities for the EPR to be utilised to improve the quality, consistency and reliability of epilepsy care locally (epilepsy service at Beaumont Hospital) and nationally (epilepsy services in Ireland) through optimum information management.

In addition this pre-implementation evaluation identified the critical interphases of care processes where improved information management could improve and enable service reconfiguration; informed the technical aspect of the EPR project regarding design and implementation; informed the development of an innovative model of shared care for epilepsy care in Ireland and contributes to the knowledge base regarding the development and integration of similar projects.

This PhD thesis did not and could not include implementation and post implementation research evaluation in relation to the EPR project. Such research is essential and is proposed within the project. It is required to scientifically demonstrate the actual impact of the epilepsy-specific EPR on patients, healthcare workers and healthcare organisations post integration of the technology. Future evaluation research projects are suggested at the conclusion of this chapter (section 8.7).

8.2 Summary of the Research Findings

8.2.1 Primary care and epilepsy services in Ireland

8.2.1.1 Structure and process of epilepsy care

- The process of epilepsy care in the primary care setting is reactive and unplanned and is not strategically integrated or coordinated.
- Primary care services in Ireland do not play a central, active role in managing the care of PWE.
- Referral pathways from primary to specialist neurology care for people with epilepsy (PWE) are inconsistent, unstructured, and geographically inequitable.
- Protracted time intervals in accessing specialist epilepsy services results in PWE being referred to local emergency departments to circumvent the delay.
- Roles and responsibilities specific to epilepsy management within primary care services are not operationally or strategically defined.
- Epilepsy specific information recorded in the primary care records of PWE is inconsistent and unreliable.
- Primary care services are not obliged to provide a minimum data set of clinical information to initiate the referral from primary to specialist care.
- Primary care services experience significant communication barriers when attempting to access specialist neurology advice and information.
- Irish general practitioners (GPs) have self-reported significant epilepsy-specific knowledge deficits and perceive their role primarily as educationalists in managing the care of PWE.

- Patient care in the primary care setting could benefit from identifying and adequately resourcing GPs with a specialist interest in epilepsy.

8.2.1.2 Outcomes of epilepsy care

- A significant gap exists in the quality and consistency of epilepsy care in Ireland that has serious implication for the safety and well being of PWE.
- Service inadequacies and inequality are perceived by clinicians and patients regarding access to specialist tests, investigations and neurology expertise.
- Primary care services in Ireland do not strategically maintain a minimum data set of performance indicators that allows on-going monitoring of the quality of epilepsy care.
- The primary care management of PWE does not incorporate decision support (e.g. clinical guidelines) or proactively manage populations of PWE using information technology (e.g. epilepsy registers, epilepsy recall registers).

8.2.2 Specialist Care and Epilepsy Services in Ireland

- Specialist epilepsy services for PWE provide care in isolation without the integration of a strategic, coordinated approach to care that promotes better continuity through the sharing of care between healthcare sectors.
- Human resource deficits are reported by clinicians providing epilepsy specialist care in Ireland.
- Current specialist epilepsy services for PWE may result in patients having unrealistic expectations of service available.
- Geographical diversity and inequality in Irish epilepsy care impacts negatively on the outputs of existing specialist services.
- The public versus private two tier system of Irish healthcare provision is perceived as inequitable by clinicians who provided specialist care to PWE.
- Poor communication between various healthcare sectors obstructs the expedient transfer of information between specialist and primary care sectors.
- Specialist care services for PWE in Ireland lack confidence in the clinical competency of GPs to manage the care of PWE.

- Reluctance to discharge stable PWE from specialist services may result in patients not receiving continuous, proactive care in the primary care setting.
- Improved patient information management and communication via information technology should be used to enable the transformation of epilepsy care.

8.2.3 The Perspective of People with Epilepsy

- Delayed access to specialist care impacts detrimentally on the healthcare experiences of PWE in Ireland.
- In the current structure of healthcare delivery, PWE feel isolated and are not empowered to participate in their self-management.
- There are no agreed treatment endpoints between PWE and their clinicians.
- PWE are insecure regarding the function and clinical competency of their GP.
- Women with epilepsy in Ireland encounter significant unmet needs.
- PWE in Ireland experience significant unmet information and communication needs that contribute to the non-integration of their care.
- PWE in Ireland view their health journey linearly and view specialist care services as the ultimate arbitrator of their care irrespective of their clinical status.
- PWE in Ireland do not have minimal expectations of the health service.
- Management plans are not agreed with PWE and an environment to promote self-management and self-efficacy are not available.

8.3 The research contribution to epilepsy care in Ireland

8.3.1 *Access to Quality Epilepsy Care in Ireland*

The international evidence reporting on the delivery of epilepsy care in the primary setting over the past twenty years suggests that PWE are not managed in a structured or systematic way (Thaper, 1996: Minshall and Smith, 2006). The primary care deficits demonstrated in this thesis support many of the challenges previously reported in the literature regarding the inadequacy of epilepsy services (Thaper et al, 1998; Montouris, 2000; Thom et al, 2002; Bishop and Allen, 2003; Prinjha et al, 2005; Minshall and Smith, 2006; Sample et al, 2006; McCorry, Marson and Jacoby, 2009).

Irrespective of the chronic disease the effectiveness of primary care is dependent on its structure and interaction with other health services. In Ireland, primary care for PWE is primarily delivered by GPs who also are charged with acting as "gatekeepers" to secondary and specialist care. For PWE or suspected epilepsy their first point of care therefore is with their GP who refers the patient to appropriate secondary/specialist services based on the clinical presentation. The Primary Care Strategy for Ireland (Department of Health and Children, Ireland, 2001) had proposed to strengthen the primary care system by allowing it to play a more central role as the first and ongoing point of contact for patients and to provide an integrated, multi-disciplinary, high-quality health service for consumers.

Many aspects of the Primary Care Strategy for Ireland have not been delivered to date and as a result major structural challenges now exist within the primary care setting. For example the financing of primary care gives rise to particular concerns over equity of access to GP services. While 30 per cent of the Irish population on low incomes are entitled to free primary care (medical card patients), the remaining 70 per cent must carry the full financial cost (Nolan, 2008a). Such co-payments may be leading to significant barriers and inequalities while medical card patients face no such constraints on use (Nolan, 2008a).

Increasingly, healthcare systems have instigated programmes of disease management and reform that link standards of primary care to quality outcome measures (Minshall and Smith, 2006). For example, the GP contract scheme in the UK links performance targets (quality indicators) with fiscal remuneration in the care and management of many chronic diseases including epilepsy (Williams et al, 2007). In the Irish context no such programme exists for epilepsy care. For example, while Irish GPs agree that epilepsy care should be shared between primary and specialist neurology services (Chapter V) the inconsistency and unreliability of data recorded in the primary care records of patients (Chapter VII) suggests that the majority of interaction between Irish GPs and PWE are reactive and unplanned.

While access to primary care services via the GP was not a significant finding in this study, the subsequent referral of patients to specialist neurology services was widely reported by PWE and GPs as difficult and protracted. Difficulty in accessing specialist care was widely reported by clinicians (Chapter V: VI) and patients (Chapter IV). Specialist care for PWE in Ireland is delivered in isolation without the integration of a strategic, coordinated approach to care that promotes better continuity through the sharing of care between healthcare sectors. The development of dedicated epilepsy specialist services has occurred locally within the larger hospital-based neurology services (Beaumont Hospital; University Hospital of Cork). This development is unstructured, has evolved non-strategically over time and is delivered within the fiscal constraints of general neurology services. Access to such services is undefined and as a result the referral and management of PWE within such services is inconsistent and unclear. As a consequence long waiting lists have developed for specialist epilepsy review with patients attempting to access services that are struggling to cope with demand.

Improving access to any healthcare service requires a state of equilibrium to exist between supply and demand (Nolte and McKee, 2008). This minimises the development of delayed appointments and delays between service requirement and service delivery (Nolte and McKee, 2008). The development of significant gaps between supply and demand not only contributes to a delay in meeting patients' needs, but it can also be expensive and generate waste within healthcare systems (Von Korff, Glasgow and Sharpe, 2002).

In modern healthcare systems, health policy makers and healthcare organisations have demonstrated that demands for health services are not insatiable, but actually predictable (Department of Health and Children, 2008; Nolte and McKee, 2008). Such predictions should be population-based and fully understand the requirements and scope of the services provided. Over demand can be accurately anticipated and should be based on the analysis and interrogation of appropriate data collected on all requests coming into the system (Busse et al, 2010). These predictions can then be used to improve access to systems of care and inform a framework of care for any specific condition.

Specific to access and epilepsy care in Ireland, there is a need to objectively assimilate appropriate data to inform the reconfiguration of care services. The ad-hoc system of referral that currently exists between primary and specialist care services does not facilitate measurement of the demand for epilepsy services. The quality, safety and efficiency of epilepsy care in Ireland were largely unknown prior to the findings of this research thesis with unsupported assumptions reported regarding existing services. This evidence demonstrates that the current service provided to PWE in Ireland is fragmented, inconsistent and delivered within a system that does not fully appreciate the requirements and needs of the wider population.

What constitutes high quality epilepsy care remains contentious and difficult to define which makes the reform and improvement of epilepsy care challenging. (Pugh et al, 2007). While there may be a lack of research consensus to support any one model of care for PWE (Bradley and Lindsey, 2008) two models of service provision have been suggested by researchers over routine care; specialist epilepsy out-patient clinics and nurse-specialist services that coordinate care between primary and secondary/tertiary (hospital-based) care. Adopting this evidence, the Department of Health and Children in Ireland have set out a national framework targeting the reconfiguration and reform of chronic disease care and management (Department of Health and Children, Ireland, 2008a). A core component of this strategy is the establishment of disease specific national clinical directorates by the Health Service Executive (HSE) of Ireland with responsibility for defining how health services are delivered, measured and resourced for individual chronic diseases (HSE Transformation Programme, 2007-2010).

One such programme, the National Epilepsy Programme is now responsible for devising a model of care specific to epilepsy that is national, population-based, predominantly nurse-led and designed to improve the safe and effective use of healthcare resources for PWE (HSE Transformation Programme, 2007-2010). An overarching aim of the National Epilepsy Programme is to improve and reform the quality of epilepsy care, improve access to care for PWE while at the same time delivering on value which will ensure the sustainability of the programme. The five year vision of this programme aims to transform epilepsy care by providing the best value care for all PWE in the right place, at

the right time, sharing the best available information. Critical to the success of this programme is the timely and appropriate availability of relevant clinical information to clinicians when and where needed. A web-based information and communication technology (ICT) like the epilepsy-specific EPR is proposed to support this essential element of effective CDM by facilitating and supporting the sharing and exchange of standardised patient information. Irrespective of their geographical location an authorised clinician at any geographical location throughout Ireland can utilise the EPR to improve integration of epilepsy services in respect of quality, access and value. Optimum information management through the epilepsy-specific EPR will efficiently interrogate and analyse large volumes of individual or populations of integrated patient data.

Research studies have reported that PWE may actively self-manage their condition, proactively seek epilepsy-specific information and engage the support of patient advocacy groups (Sample et al, 2006). In this thesis however, PWE in Ireland had little or no insight into the constituents of effective CDM and did not engage or were not aware of self-help or patient advocacy groups. They tended to view their healthcare journey linearly which may reinforce their passive role in respect of self-managing their care. It has been suggested that PWE are fearful of their condition and the potential for increased seizure activity (McCorry, Marson and Jacoby, 2009). Therefore patients with more intractable forms of the disease may not fit the profile of patients who can be autonomous and self-managing of their condition. It is possible that such patients become conditioned to a passive role from which clinicians take their cue. This must be carefully considered in any healthcare reform strategy attempting to "shoehorn" all PWE into a structure of care that requires all patients to take responsibility to actively self-manage their disease.

8.4 The Research Contribution to Chronic Disease Management Reform

The trend towards transforming chronic disease management (CDM) is reflected in more recent health policy in Ireland (Department of Health and Children, Ireland, 2008a: HSE Transformation Programme, 2007-2010). The aim is to improve the quality of and access to healthcare services while maximising the benefit of medical science advances for patients and minimising the fiscal burden on the health care service. Chronic disease

management policy recommends the strategic introduction of healthcare initiatives that promote the health of the population and advocates for structured, integrated care across organisational boundaries that is supported by appropriate information and communication technologies (Department of Health and Children, Ireland, 2008a). The desired goal is chronic disease care that is safe, of high quality, efficient and delivered in the appropriate health care setting.

The primary objective of the overall project was to use epilepsy as an exemplar of a chronic disease and demonstrate the opportunities where improved information management and its communication via the epilepsy-specific EPR could enable and support systemic, long-lasting reform. Within this project, social research evaluation was conducted to examine the structure and process of existing epilepsy care in Ireland. This mixed methods approach to evaluation examined epilepsy care from the perspective of key stakeholders and forms the basis of this PhD thesis. The approach and design of each study captured various perspectives and interphases of epilepsy care and contributed to a better understanding of existing epilepsy care in Ireland.

The argument supporting this research approach was highlighted earlier (Chapter I). Unsuccessful adoption into healthcare of technology like the EPR often occurs because of a failure to recognise deficits and challenges within the structure and process of existing services (Dorr et al, 2007). Documenting the structure and process of pre-existing epilepsy services in Ireland identified objectively and methodically the opportunities where optimum information management in the care process could support and inform the development of a model of shared-care for PWE underpinned by the essential elements of effective CDM. It is propose in the overall project that lessons learnt could inform a template to guide the management and reform of similar complex, chronic diseases. Epilepsy is considered a good exemplar of chronic disease as patient outcomes are recognised to be sensitive to the quality of service provided and is associated with comorbidities which makes appropriate care planning complex (Chapter III).

CDM is a way of coordinating care and ensuring that people gain the healthcare support they require at appropriate times that should result in a better quality of life and improved

health outcomes for patients. The assimilated evidence reported in this thesis identifies the opportunities where better information management and communication via the epilepsy-specific EPR could support strategic improvements to existing services and contribute to a new model of innovative epilepsy care. While the probe condition in this project is epilepsy, the findings maybe generalisable to other similarly complex chronic conditions. Having first described the implications of the research findings in the context of epilepsy research knowledge, the findings are now discussed in the context of CDM reform and the use of improved information management to enable the transition. In the next section the essential elements of chronic disease health policy are used to interpret the findings of the studies presented in this thesis and a proposed action to initiate the change for epilepsy care is proposed.

Keeping in mind the objectives of the overall epilepsy-specific EPR project and the research objectives of the PhD thesis, the findings of the research studies are discussed and contextualised using the essential elements that underpin the Irish policy framework strategy for CDM (Department of Health and Children, Ireland, 2008a). At the micro-level, the research contributes to the knowledge base seeking to define the optimum care and management of PWE. At a macro-level the research identifies the opportunities where improved information management and communication can be used to inform the development and integration of a strategic model of care for PWE, and more widely the reform of CDM.

8.5 How Improved Information Management enables Chronic Disease Management reform

In this section the essential elements of CDM health policy in Ireland (Department of Health and Children, Ireland, 2008a) are used to interpret the research findings of the studies (Chapters IV; V; VI; VII). Using epilepsy as an exemplar of chronic disease and the epilepsy-specific EPR as the enabler of CDM reform through optimum information management and communication, a proposed action is highlighted for each essential element of CDM. Each proposed action recommends potential improvements where deficits exist in epilepsy services however difficulty exists when attempting to prioritise

their importance as it can be argued that all elements of optimum CDM must be prioritised as the whole is greater than the sum of the parts. For example, prioritising access to specialist epilepsy care may not improve the quality of care for the wider population if the primary/specialist interphase remains incongruent with shared care principles.

The relationship between the essential elements of CDM is interdependent in that good CDM results from the different elements being present and working in harmony. As the effect of these essential elements increase, the quality, consistency, reliability, safety and cost effectiveness of the overall system is likely to improve. While some elements may individually make more of a difference the combined effect of all elements are mutually reinforcing and add greater value when all are present. The adoption and integration of the epilepsy-specific EPR for example into the clinical environment assimilates and collates patient information however its widespread availability at any geographical remote location can enable the transformation of how and where the services are delivered. While this research thesis does not reflect a complete model of shared care for PWE in Ireland, the work has been acknowledged within and has contributed to this new proposed model of care for PWE in Ireland proposed by the National Clinical Programme for Epilepsy Care.

8.5.1 Informing a Model of Epilepsy Care in Ireland

8.5.1.1 Essential element 1

Healthcare services should provide structured and integrated care for patients with long-term chronic diseases

On an individual basis some PWE in Ireland may be satisfied with the epilepsy care received. The research presented in this thesis suggests however that the current structure and process of epilepsy care in Ireland is not strategically delivered or coordinated across the various healthcare settings. Epilepsy services in the primary and specialist care setting are provided in isolation with little evidence of structured or integrated care. As a result,

the quality and consistency of epilepsy care is sub-optimal resulting in significant challenges for PWE and clinicians.

Action required:

The inequality and disorganisation of epilepsy care services in Ireland requires urgent reform and reconfiguration as significant clinical risks for PWE and clinicians may exist. The coordination of care for PWE can be improved by establishing structured networks of shared care between key healthcare sectors that are supported by health information management systems. There is currently a national strategy targeting the reform of CDM in Ireland which includes the reconfiguration of (Department of Health and Children, Ireland, 2008a: HSE Transformation Programme, 2007-2010). Improving access to epilepsy services requires a state of equilibrium to exist between supply and demand which prevents the development of delayed service delivery. This is significant for PWE as early correct diagnosis and treatment intervention decreases the impact of the disease on their physical, psychological, physiological and social well being. Appreciating and measuring objectively the requirements of PWE reduces the gap between supply and demand and quantifies the resource requirements for the wider population. A new model of care for PWE in Ireland supported by the general principles of CDM policy is required so that care can be structured, integrated and strategically coordinated for the wider population.

8.5.1.2 Essential element 2

Programmes should be developed for the major disease groups in the form of disease management programmes (DMPs)

Such a programme specific to the care and management of PWE should strategically set out the organisation of care and how resources should be structured to follow the patient. In the current healthcare system, fiscal resources do not follow the care pathway of PWE. For example a general practitioner in Ireland will receive the same fiscal payment irrespective of the quality of care delivered while a specialist neurology service continues to accept newly referred patients even though intractable delays already exist in the scheduling of appointments.

Healthcare providers in primary care and specialist hospital-based services should be appropriately recognised, incentivised and contracted to deliver modern, fit for purpose services through a formalised DMP. As demonstrated in this thesis, the current structure and process of epilepsy care in Ireland does not identify or legislate for individual and organisational roles and responsibilities in delivering care to PWE using a population-based approach. The quality of a persons care is defined by their ability to negotiate individual care journeys through a healthcare system that is not strategically incentivised or performance monitored.

Action required:

Health policy makers in Ireland are currently developing DMP's for individual chronic diseases, including epilepsy (Department of Health and Children, Ireland, 2008a: HSE Transformation Programme, 2007-2010). The findings in this thesis can inform this process of epilepsy care reform by having identified the challenges and the opportunities where action is required. For example the demarcation of the epilepsy specialist service and role is undefined and as a consequence their impact may be diminished. It is likely that epilepsy services under the Epilepsy Programme proposed in the new model of care will advocate and outline how care is to be structured through a process of reconfiguration.

8.5.1.3 Essential element 3

Models of shared care should be developed within DMPs that describe the nature of roles and responsibilities between primary care and specialist services.

The aim of such an epilepsy care model is not be to make all clinicians expert in epilepsy care; rather it is about developing their role in on-going epilepsy management. Ideally, optimum CDM should be shared between primary and specialist services. However, the definition of "shared care" must be clearly defined and understood between the key stakeholders. A model of shared care should be collaboratively defined among the disease specific primary and specialist key stakeholders. Roles and responsibilities should be formalised and care pathways should be evidence-based. For the majority of patients with chronic disease, once a diagnosis is made and appropriate treatment is in place, their on-going management can be provided in the primary care setting. Collaboration with

some levels of specialised care will be required to amend diagnosis, update treatment plans or manage subsequent complications.

Action required:

The research presented in this thesis supports the urgent need to develop and integrate a model of care for PWE in Ireland that integrates and coordinates "shared care" between primary and specialist services. The notion that epilepsy care in Ireland is currently "shared" is not accurate as evidenced by this thesis. Instead care processes for PWE tends to be polarised between clinicians or multidisciplinary care teams in individual healthcare settings. The extent of the fragmentation between healthcare settings is significant and should not be underestimated in any strategy attempting to reform epilepsy services. While no one model of epilepsy care is superior, a shared care model developed within a strategic DMP will clearly identify roles and responsibilities and should be supported by the optimum use of patient information.

8.5.1.4 Essential element 4

The primary care sector should be central in delivering chronic disease management

The complexity and prevalence of chronic diseases has placed a significant responsibility on heavily burdened and under-resourced primary care services. This has been added to by the significant reconfiguration of healthcare delivery to the primary care setting (Department of Health and Children, Ireland, 2008a: HSE Transformation Programme, 2007-2010). In more recent times Irish health policy has targeted certain high profile diseases such as hypertension and diabetes through a number of primary care initiatives (Department of Health and Children, 1999; Department of Health and Children, 2001). Equally debilitating common, chronic illnesses however such as epilepsy have largely been ignored despite the international evidence highlighting significant deficits in service provision and patient outcomes.

The research findings presented in this thesis have revealed the extent of the challenge facing policy makers and clinicians in Ireland attempting to reform the quality and integration of epilepsy care in the primary care setting. In its current structure the population of PWE in Ireland is not receiving timely, high quality care. The fragmented

and episodic delivery of epilepsy care may often be delivered ad-hoc within an environment that is neither resourced nor coordinated to meet the modern day requirements of patients with a chronic disease like epilepsy. Government policy is committed to ensuring equity of access to health care on the basis of need for care rather than other considerations such as the ability to pay. The current public/private two tier system of healthcare delivery in Ireland is exacerbating and complicating the reform agenda in Ireland and is a considerable obstacle for primary care services. In addition the move to free primary care for all citizens in the future suggests that turbulent times lie ahead for primary care services.

Action required:

Lessons learned from previous chronic disease initiatives can contribute to the development of a primary care strategy specific to epilepsy care that must be implemented in conjunction with the general framework of CDM. The primary care strategy (Department of Health and Children, 2001) had proposed the development of multi-disciplinary primary care teams that are resourced and incentivised to meet pre determined objectives. However the implementation of this strategy has decelerated due to the constraints imposed by the world-wide recession with the primary care sector encountering adverse conditions which has contributed to an environment of uncertainty. It must be considered during any reconfiguration process that the methodology employed to finance primary care in Ireland influences access and utilisation of services which has implications for equity across groups.

8.5.1.5 Essential element 5

Clinical decision systems must be developed, implemented and integrated into shared care models targeting the reform of chronic disease management

Clinical decision systems such as clinical guidelines are considered a core element of CDM shared-care models. Clinical guidelines however do not intrinsically modify practitioner behaviour as changes to pre-existing work practices are complex and multi-factorial. Many of the challenges relate to complex change management issues. The adoption of a clinical guideline for example may be dependent on the ability of the practitioner to identify the problem and implement the appropriate changes in clinical

practice. In the United Kingdom for example GPs are financially and professionally incentivised to adopt a proactive approach to epilepsy care (Williams et al, 2007). Research in this thesis demonstrates that Irish GPs do not adopt clinical decision systems in managing PWE even though many GPs reported significant epilepsy-specific knowledge deficits.

Action required:

In Ireland, guidelines must be developed specific to epilepsy care and management in the context of the Irish healthcare system. Adopting epilepsy guidelines from the international literature in isolation is counter-productive. Such a guideline must be incorporated within a strategic model of shared care for epilepsy. A significant challenge of course for policy makers is quantifying the essential constituents of high quality epilepsy care. Developing a guideline that links healthcare delivery to quantifiable changes in outcomes for PWE requires further investigation. The potential for clinical information systems like the epilepsy-specific EPR in this context can not be overstated. Adopting appropriate information technology facilitates the longitudinal measurement of clinical information over time and evaluation of this data could identify the aspects of epilepsy care that improve or dis-improve outcomes for PWE.

8.5.1.6 Essential element 6

Clinical information systems should be developed to support CDM programmes

The consistent availability of patient information and data is required across healthcare settings and is an essential component of CDM programmes. Information technologies like the epilepsy-specific EPR in conjunction with decision support tools (e.g. clinical guidelines) improve the continuity and standardisation of care for people with chronic illness. Such templates have been developed for diabetes care in Irish general practice and have been shown to be successful in optimising data recording and automated information retrieval (Smith, Bury and O'Leary, 2004). On the other hand the evidence from this thesis has highlighted the fact that information technology is widely available in primary care, yet the majority of clinicians do not engage with electronic functionality specific to CDM. The challenge is to find ways to exploit information technologies to improve the interface and integration of care between primary, secondary and tertiary

care services. They can support the reform of CDM by empowering clinicians and patients alike in delivering evidence-based practice and identifying the gaps in care processes likely to impact on patient outcomes. Information technology and data collection systems like the epilepsy-specific EPR can support risk stratification and the timely capture of indicators or "triggers" that engages patients with appropriate services and provides the information to support subsequent interventions, and clinical decisions.

Action required:

The information and communication gaps reported in the structure and process of epilepsy care in Ireland requires a vast improvement in capturing and communicating key clinical information by and between clinicians, patients and healthcare organisations. Further research is required to better understand how information technologies like the epilepsy-specific EPR can be optimally exploited to transform CDM. It is critical that information technology systems are seen as tools or enablers of change rather than emphasising them to motivate and maintain CDM. Health policy must proactively leverage health information exchange initiatives and align incentives (individual and organisational) around the mobilisation of clinical information across various healthcare settings.

8.5.1.7 Essential element 7

Patients should actively participate in the management of their chronic disease

Chronic disease care models promoting patient self-management must target and engage meaningfully with patients. This approach improves the patient's perception of their quality of life, their satisfaction levels and their self esteem. Patients must be at the centre of the care process and clinicians must support patients in their own self-management. Patient participation in their own self-management and self-management education has improved health outcomes for certain chronic diseases (Chapter II – section 2.5). However, significant impediments to optimum self-management have been demonstrated in this thesis for PWE (Chapter IV). The current structure of epilepsy care in Ireland does not facilitate self-management education for the general population of PWE. Supporting self-management has potential but only if policies, structures and financial incentives are made available to support patient and clinicians in working together.

Action required:

Patients vary in their preference and ability to self-manage their care and the importance they place on particular health outcomes. This is especially significant for PWE as empowering patients towards self-management is complex and challenging because of the nature of the condition. However, a strategic model of care for PWE should integrate a self-management strategy that enables and facilitates as many patients as possible to manage their conditions effectively with equal emphasis on both the physical and psycho-social dimensions of life. Research is required that continues to explore patient's perceptions and understanding of their healthcare experiences so that shared expectations between the clinician and patient can be established and decisions can be made jointly in striving to achieve realistic and desired outcomes.

8.5.1.8 Essential element 8

Management care plans should be agreed for each patient; whether care is provided in primary care or a specialist setting

A shared care model that incorporates the essential elements of CDM should incorporate an agreed management plan that follows the course of the illness. The management plan should be appropriate to patients needs, agreed upon by patients and access to different levels of service should be equitable. The research conducted in this thesis revealed that PWE are not following agreed management plans in which their expectations are acknowledged. Care journeys tend to be linear with no formalised evaluation of patient outcomes or patient expectations. The reality that PWE in Ireland with private health care insurance experience more expeditious access to certain neurology services (chapter 4, 5 & 7) does not infer superior clinical outcomes but adds further complexity and is not equitable to the wider population.

Action required:

In a proposed model of shared care for epilepsy, individual disease management plans should be generated for individual patients. Each plan should outline the care objective and be agreed upon by clinician and patients to be delivered within a realist timeframe. It should reflect the impact of the interventions and be reviewed regularly.

8.6 Implications for Future Research

The research findings presented in this thesis highlight the significant challenges facing health policy makers attempting to improve the integration and coordination of CDM in Ireland. Epilepsy is a useful exemplar of chronic disease as its management is inextricably linked to the quality of care provided and the disease itself is associated with significant comorbidities. The extent of deficits and challenges within existing epilepsy services would suggest that PWE in Ireland are exposed to significant clinical risk. Future research is required to quantify the extent of this risk especially among more vulnerable groups, including patients with associated intellectual disability and patients with intractable forms of the disease. Cross-sectional population studies are required to measure the impact on patient outcomes which are likely to be significant. Health policy makers in Ireland, health care organisations, clinicians, educationalists, professional regulatory bodies (e.g. ICGP) and patient advocacy groups (e.g. Brainwave) must engage with and assume a proactive role in addressing the sustentative issues identified. A particular research emphasis relates to engaging with care providers and patients to improve services at the primary/specialist interphase.

The implementation of a new model of care for managing PWE in Ireland is imminent. The National Epilepsy Care Programme has three main goals; the delivery of improved quality of care; improved access to care for PWE and simultaneously delivering on value which will ensure the sustainability of the programme into the future. The programme must recognise the extent of the deficits in existing epilepsy care services in Ireland prior to implementing reform initiatives. The research presented in this thesis can act as a base-line against which the impact of any transformation can be measured. Repeating these studies post implementation of a new model of epilepsy care can provide evidence of its impact in the future.

Without optimimising patient information management and communication, innovative models of CDM reform for chronic diseases like epilepsy will struggle to provide the empirical evidence that demonstrates improved patient outcomes and service

performance. Information technologies like the epilepsy-specific EPR can lead the transformation of CDM and underpin models of care by providing accurate data to facilitate the measurement of service performance and patient outcomes. With the epilepsy-specific EPR proposed as a central hub in a national framework of epilepsy care, further summative evaluation research is required to evaluate its true impact on the strategic reform of epilepsy care in Ireland, which in turn informs the wider CDM reform debate. Accepting the hypothesis that improved information management and communication improves the quality, safety and efficiency of care provided then the following research questions will need to be examined:

- Does optimum information management and communication improve or provide superior outcomes of care for patients with chronic disease?
- Does optimum information management and communication improve the quality of life for patients with chronic disease?
- Does optimum information management and communication support care processes that are more cost effective?
- Does optimum information management and communication improved patient safety?
- What are the organisational issues that support or impede the optimum use of information and its communication via information technology?

Formative evaluation underpinned this thesis with an emphasis on exploratory research to inform the direction of the project. Summative evaluation will now be required to assess the impact of optimum information management (via the EPR) in supporting a strategic, innovative network of epilepsy care in the future. This research approach will require more experimental approaches such as randomised control studies that compare and contrast outcomes of care through larger population studies. These findings will have wider ramifications for the CDM reform debate and the central role of information management and communication.

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<tr><th colspan="3">Evaluating the impact of an epilepsy specific eHealth initiative in Ireland</th></tr>
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<tr><td>External projects</td><td>External Projects</td><td>External projects</td></tr>
<tr><td>The Role of the Irish General practitioner in epilepsy care (Chapter V)</td><td>Evaluate EPR impact on national structures and processes of epilepsy care</td><td>Evaluate outcomes of care for PWE in Ireland.</td></tr>
<tr><td>ICT in Irish general practice; its role in chronic disease management (Chapter V)</td><td rowspan="3">Technical development evaluation projects</td><td>Measure the quality, safety and efficiency of epilepsy care in Ireland versus best practice guidelines.</td></tr>
<tr><td>Epilepsy care in Ireland; towards the primary-tertiary care continuum (Chapter IV)</td><td rowspan="2">Evaluate the role of the EPR in supporting a model of care for PWE in Ireland</td></tr>
<tr><td>Towards the development of integrated epilepsy services; An audit of documented care in the Mid-West region of Ireland (Chapter VII)</td></tr>
<tr><td>Local Projects (Beaumont Hospital)</td><td>Local Projects (Beaumont Hospital)</td><td>Local Projects (Beaumont Hospital)</td></tr>
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Technical Research Evaluation Projects</td><td rowspan="2">To explore and document the factors that inhibit or facilitate the deployment of an Electronic Patient Record
Contributes to an evaluation framework for EPR initiatives</td></tr>
<tr><td>The Healthcare Journeys Experienced by People with Epilepsy in Ireland: What are the Implications for Future Service Reform and Development? (Chapter IV)</td></tr>
<tr><td>Social Research Evaluation Completed (PhD Thesis)</td><td>Current research in progress and proposed research</td></tr>
</table>

Appendix 2

Health Services R&D Awards 2005

1. Title of research proposal (maximum 20 words)

Revolutionising Chronic Disease Management with Information and Communication Technology:
A socio-technical project applied to epilepsy care in Ireland

2. Keywords that describe your research proposal (maximum 5 words)

1. **Chronic Disease Management**
2. **Epilepsy**
3. **Electronic Patient Record (EPR)**
4. **eHealth**
5. **ICT Evaluation**

3. Abstract/ summary of research proposal (maximum one typed page)

***Purpose*:** This is a health services research and development programme about aligning people, processes and technology to optimise chronic disease management. The *People* - patients with chronic disease, their families and healthcare providers; *Processes* - access to healthcare services, the manner and location of service delivery, procedures for follow-up care, and the interface between clinical care and clinical research environments; *Technology* - the application of information and communication technology (ICT) in healthcare practices.

***Context*:** Chronic diseases are long-term illnesses that do not resolve spontaneously and are rarely entirely cured. Their management requires participation of a diversity of healthcare disciplines (e.g. medical, nursing, psychology, physiotherapy, administration etc.) in a variety of healthcare settings (e.g. community, primary care, specialist hospital etc.) together with the active participation of the patient (and/or family/carer) in their own self-management. Timely sharing and exchange of standardised information and efficient communication both within and across organisational boundaries is key to achieving an effective management. An eHealth domain linking healthcare services to healthcare constituencies – patients and healthcare professionals at any location - facilitates information sharing and exchange and promotes a continuum of healthcare services for the benefit of the patient. eHealth is defined as the transaction of healthcare services over an electronic medium such as the Internet (including the World Wide Web, intranet, extranet).

Using epilepsy as an ideal exemplar of a chronic disease, the research proposed in this document is a socio-technical enquiry aimed at designing, developing, deploying and evaluating an eHealth domain for epilepsy care and research in Ireland. An epilepsy electronic patient record (EPR) which has been developed at Beaumont Hospital, Dublin will be the foundation upon which the eHealth domain will be established and assessed in terms of user acceptability, clinical outcomes, benefits to clinical research and cost-effectiveness. Lessons learned from the model applied in this programme, i.e. clinician led eHealth development and strong clinical, IT expert and organisation stakeholder collaboration will benefit others who undertake similar projects in the future.

Current capacity of epilepsy services in Ireland suggests significant unmet patient needs. An eHealth domain can transform epilepsy care by providing web-based EPR access to authorised patients and clinicians at any physical location. It can improve standardisation of medical vocabulary and record keeping, allow healthcare to be delivered in a more appropriate setting, advance disease monitoring, enhance shared care co-ordination and facilitate clinical research data-mining requirements. While potential benefits of eHealth are recognised, the criteria for successful implementation are less clear. Research is therefore required so that healthcare policy makers and managers can make evidence-based investment in ICT.

Specific Aims of this programme are to conduct systematic research and development to:

- Establish an Irish epilepsy eHealth domain for patients and healthcare professionals based on the epilepsy EPR infrastructure already in place at Beaumont Hospital, Dublin
- Evaluate the impact of the eHealth domain on healthcare process and outcome.

Methodology: Requirements engineering based on ethnographic analysis and Delphi interviews will establish stakeholder's needs and inform the design of the eHealth domain; software engineering of the domain will use a modular, layered and standards based architecture; iterative prototyping will provide feedback to software engineers to fine-tune the system; evaluation of the eHealth domain involving pre-implementation review, implementation review and operational evaluation will be conducted to measure its human, organisational, technical and strategic impact.

***Impact of the Research*:** The impact of this programme of research is detailed in question 15 of this proposal. It will contribute to understanding critical success factors for achieving eHealth implementation and service delivery. While the clinical field of interest is epilepsy, it will provide a good learning model that will be generalisable to other similarly complex chronic diseases.

Appendix 3

General Practitioners Management of Patients with Epilepsy Questionnaire

The aim of this national survey of GPs has two purposes. The first relates to current management of epilepsy in Ireland including the process of referral to specialist services. The second examines the extent and utilisation of computerisation in General Practice.

This survey is part of a larger study evaluating the design, implementation and impact of an Electronic Patient Record (EPR) on the care of patients with epilepsy.

The survey is being conducted by the Irish College of General Practitioners and the Epilepsy Research Programme at Beaumont Hospital, Dublin 9.

If you have any further queries on this study, please contact Mr Jarlath Varley for further details on 01-8092972 or at jarlathvarley@beaumont.ie

Section 1: General Practice Details:

1] Gender: Male ☐1 Female ☐2

2] Years in General Practice: < 5 yrs ☐1 5 – 10yrs ☐2 11 – 20yrs ☐3 >20yrs ☐4

3] Total number of doctors in the practice Fulltime __1 Part-time __2

4] Area your surgery is located: Urban ☐1 Suburban ☐2 Semi-rural ☐3 Rural ☐4

5] How many patients are registered with your practice: <1000 ☐1

1000 - <2000 ☐2 2000 - <3000 ☐3 3000 - <4000 ☐4 4000 - <5000 ☐5 5000+ ☐6

6] Approximately what is your public versus private patient ratio: Public: _____ % 1

Private: _____ % 2

7] Do you employ a practice nurse: Yes ☐1 No ☐2

8] In which **county** is your surgery located: _____

9] Approximately how many miles to your local general hospital: _____

10] Approximately how many miles to the nearest hospital with neurology services:_____

11] Do you use a computer in your practice? Yes ☐1 No ☐2

*If **yes** please continue, if **no** go to section III:*

12] Is broadband available in your location? Don't Know ☐1 Yes ☐2 No ☐3

13] Which internet connection do you use? Broadband ☐1 Dial-up ☐2

14] Do you use a specific software clinical package? Yes ☐1 No ☐2

15] If yes please specify the name of the package? _____

16] Does your computer system link directly to any external system?

(e.g. Healthlink, Neurolink) Yes ☐1 No ☐2

17] If available, would you access secure electronic patient records

from your local hospital or specialist referral centre? Yes ☐1 No ☐2

Section II: Computerised Functions in your Practice

A] For which of these functions do you use your computer?	Mostly$_1$	Sometimes$_2$	Never$_3$	Function not available$_4$
1] Prescribing medications				
2] Recording reasons for prescribing				
3] Check for drug-drug interactions				
4] Checking for drug allergies				
5] Checking for drug-disease interactions				
6] Updating medication lists				

B] For which of these functions do you use your computer?	Mostly by computer$_1$	Mostly by paper$_2$	Computer & paper$_3$	Don't do this task$_4$
1] Order laboratory tests & investigations				
2] Receive test results				
3] Store test results				
4] Record progress notes				
5] Generate health summaries				
6] Write referral letters				
7] Run recall system for routine tests (e.g. Pap test, Mammogram)				
8] Create lists of patients with a specific disease				
9] Create lists of patients taking the same medication				
10] Create specific disease management plans (e.g. diabetes)				

Section III: Management of Patients with Epilepsy/Suspected Epilepsy

Approximately, how many patients with epilepsy attend your practice? _____

3A] Please indicate how strongly you agree or disagree with each of the following. The GP should …..	**Strongly disagree$_1$**	**Disagree$_2$**	**Uncertain$_3$**	**Agree$_4$**	**Strongly agree$_5$**
1] Arrange assessment & investigations following suspected seizure activity.					
2] Refer patients with acute suspected seizure activity to local Emergency Department.					
3] Refer patients with acute suspected seizure activity to a local hospital consultant.					
4] Refer patients with acute suspected seizure activity to a neurology OPD.					

3B] Please indicate how strongly you agree or disagree with each of the following statements. The GP should …..	**Strongly disagree$_1$**	**Disagree**	**Uncertain$_3$**	**Agree$_4$**	**Strongly agree$_5$**
1] Initiate drug therapy following acute suspected seizure activity prior to assessment by a neurologist.					
2] Monitor the response to such anti-epileptic drugs.					
3] Change the dose and type of anti-epileptic drugs as clinically indicated.					
4] Stop anti-epileptic drugs therapy if indicated.					
5] Educate patients about their epilepsy (e.g. work, lifestyle, driving).					
6] Manage epilepsy during pregnancy					

C] Please indicate how strongly you agree or disagree with each of the following statements.	Strongly disagree$_1$	Disagree$_2$	Uncertain$_3$	Agree$_4$	Strongly agree$_5$
1] My knowledge of epilepsy is more than adequate to deal with the day to day care of people with epilepsy.					
2] General practitioner knowledge deficits could adversely affect the care of patients with epilepsy.					
3] General practice is too busy to take responsibility for the regular follow up care of people with epilepsy.					
4] Poor communication between primary, secondary and tertiary care services contributes to the poor management of patients with epilepsy.					
5] Delayed access to a neurology specialist contributes to the poor management of patients with epilepsy.					
6] The care of people with epilepsy should primarily be based in general practice.					
7] People with epilepsy should largely be managed by neurologists with specialist training in epilepsy.					
8] Patients with epilepsy should be jointly cared for by neurologists and their GP					
9] Access to epilepsy clinical nurse specialists could greatly enhance the care of patients with epilepsy					
10] Existing referral pathways for patients with suspected epilepsy/epilepsy are satisfactory ?					

Section IV: Access to Specialty Services and Investigations for Patients with Epilepsy.

	Always$_1$	Sometimes$_2$	Occasionally$_3$	Never$_4$
1] Are you able to access an urgent CT (within 4 weeks)?				
2] Are you able to access an urgent MRI (within 12 weeks)?				
3] Are you able to access an urgent EEG (within 12 weeks)?				
4] Can you access an urgent neurology appointment for patients with suspected epilepsy (within 4 weeks)?				
5] Do you ever refer to the Emergency Department because of protracted waiting times for specialist neurology services and investigations?				
6] In your opinion do patients with private health insurance access investigations and neurology services faster than public patients?				

Thank you for completing the questionnaire.
Please return in the freepost envelope provided.

Additional comments or suggestions for improvements may be added below.

Appendix 4

Epilepsy Specific General Practice Audit Tool

1.0 Practice Demographic Profile

1.1 Surgery Location: Urban ☐ Suburban ☐ Rural ☐

1.2 Total number of doctors in the practice: Full-time ☐ Part-time ☐
If part time how many sessions per week: ☐

1.3 Practice Nurse: Yes ☐ No ☐
If yes Full-time ☐ Part-time ☐

1.4 Practice Size: < 1000 ☐ 1000 -< 2000 ☐ 2000 - <3000 ☐
3000 - < 4000 ☐ 4000 - <5000 ☐ 5000+ ☐

1.5 Public versus private ratio: Public i.e.GMS ____%
(expressed as a percent) Private ____%

1.6 How many miles to local hospital: _____ miles

1.7 How many miles to dedicated neurology services _____ miles

2.0 Practice Profile & Data Extraction

2.1 Is the practice computerised? Yes ☐ No ☐
(If no go to section 2.8)

2.2 If yes, does the practice use a specific software clinical package? Yes ☐ No ☐

2.3 If yes, please specify e.g. Healthlink1 _____

2.4 How difficult was it to retrieve electronic epilepsy specific data?

Not at all	A little	Quite a bit	Extremely difficult

2.5 Please specify reason(s) for same

2.6 Does it link to external ICT systems e.g. Healthlink; Neurolink Yes No

2.7 If yes, please specify _____

2.8 Is the practice predominantly paper based Yes ☐ No ☐

2.9 If yes, how difficult was it to retrieve written epilepsy specific data?

Not at all	A little	Quite a bit	Extremely difficult

2.10 Please specify reason(s) for same

3.0 Patient Demographic Profile

3.1 Patient ID; Initials _____ Date of Birth __/__/__

3.2 Age in years: _____

3.3 Gender: Male ☐ Female ☐

3.4 Marital Status: Single ☐ married ☐ Co-habiting ☐ Divorced ☐ Separated ☐

3.5 No of dependents: ☐

3.6 Level of education achieved: Special needs ☐ Primary school ☐ Intellectual disability ☐ Secondary school ☐ Physical disability ☐ Third level ☐ No education ☐ Unknown ☐ Not recorded ☐ Other ☐

3.7 Occupation: Paid employment ☐ Sick leave ☐ Supported employment ☐ Retired ☐ Unemployed ☐ Unknown ☐

3.8 Documented Hx of stigmatisation: Yes ☐ No ☐ Not documented ☐

If yes please describe: _____

3.9 Alcohol status: Non-drinker ☐ Socially ☐ Alcoholic ☐ Ex-alcoholic ☐ Unknown ☐ Not documented ☐

3.10 Smoking status: Non-smoker ☐ Ex-smoker ☐ Smoker ☐ Unknown ☐

3.11 Substance abuse: Yes ☐ No ☐
If yes please list _____

4.0 Epilepsy History

4.1 Documented Hx of Seizure: Yes ☐ No ☐
Unknown ☐ Not documented ☐

4.2 If yes age at onset of seizures: _____yrs

4.3 Aetiology of seizures documented: Yes ☐ No ☐
Unknown ☐ Not documented ☐

4.4 If yes please state aetiology _____

4.5 Classification of seizure documented: Yes ☐ No ☐
Unknown ☐ Not documented ☐

4.6 If yes please record as appropriate

Simple partial seizures ☐
Complex partial seizures ☐
Partial seizures evolving to secondary generalised seizures ☐
Generalised seizures ☐

4.7 Frequency of seizure documented in the last 2 years Yes ☐ No ☐
Unknown ☐ Not documented ☐

If yes please record as appropriate

Seizure frequency (please tick as appropriate)		**No of seizures during this period (average)**	**Duration of seizure (in secs or mins)**
Daily			
Every 1-2 days			
Every 3-4 days			
Every 4-5 days			
Weekly			
Fortnightly			
Monthly			
Moderate irregularity			
Very irregular			
Not documented			

4.8 Confirmation of a epilepsy diagnosis by a neurologist:

Yes ☐ No ☐ Unknown ☐ Not documented ☐

If yes state name of facility _____

If no diagnosis was confirmed by

	yes	no	Location/specialty
GP			
Local hospital general physician			
Neurologist			
Epileptologist			
Not recorded			
unknown			

5.0 Epilepsy History: Tests and Investigations

5.1 Record of CT Yes ☐ No ☐ Unknown ☐ Not documented ☐

If yes date of most recent CT: _____

Name/Location of institution where performed: _____

5.2 Record of MRI Yes ☐ No ☐ Unknown ☐ Not documented ☐

If yes date of most recent MRI: _____

Name/Location of institution where performed: _____

5.3 Record of standard EEG Yes ☐ No ☐ Unknown ☐ Not documented ☐

If yes date of most recent EEG: _____

Name/Location of institution where performed: _____

5.4 Record of in-patient video-monitoring Yes ☐ No ☐ Unknown ☐ Not documented ☐

If yes date of most recent EEG: _____

Name/Location of institution where performed: _____

5.5 Record of standard ECG Yes ☐ No ☐ Unknown ☐ Not documented ☐

If yes date of most recent ECG: _____

Name/Location of institution where performed: _____

6.0 Non-Epilepsy History

6.1 Document the presence or absence of co-morbid physical illness/injury

System	Illness/injury
CVS	
Resp	
GI	
GU	
CNS	
Endocrine	
Metabolic	
Rhumatology	
Other	
Undocumented	
None	

6.2 Document the presence or absence of co-morbid illness

Anxiety Disorders e.g. ocd/phobias (please tick)		*Current medications*
BPAD		
Dementia		
Depression		
Schizophrenia		
Schizoaffective disorder		
Other		

7.0 Anti-Epileptic drugs (AEDs) and PWE

7.1 Is the patient currently taking an AED Yes ☐ No ☐

Unknown ☐ Not documented ☐

If yes please complete from the following list

Carbamazepine		Lamotrigine		Primidone	
Clobazam		Myceline		Rivotril	
Clonazepam		Phenobarbitone		Sodium Valproate	
Ethosuximide		Phenytoin		Topiramate	
Gabapentin		Pregabalin		Zonisimide	
Midazolam po/pr		Diazepam		Lorazepam	
Buccal Midazolam		Other			

8.0 Epilepsy Care and Pregnancy

8.1 Is the patient a woman of child-bearing age (16 – 50 years): Yes ☐ No ☐

If yes, is the patient on Valproate?

Yes ☐ No ☐

Unknown ☐ Not documented ☐

8.2 Has the patient continued this AED through a pregnancy Yes ☐ No ☐

Unknown ☐ Not documented ☐

8.3 Has the patient being reviewed by neurology services prior and/or during a pregnancy? Yes ☐ No ☐

Unknown ☐ Not documented ☐

9.0 Current status of patient

9.1 Is there documented evidence that the patient is reviewed by their GP for their epilepsy: Yes ☐ No ☐ Unknown ☐ Not documented ☐

9.2 Date since last review by GP specific to epilepsy care (in months) _____

Unknown ☐ Not documented ☐

9.3 Review frequency by GP

< 3 months		> 3 years	
< 6 months		> 4 years	
< 9 months		> 5 years	
< 12 months		Other	
1-2 years		unknown	
> 2 years		Not documented	

9.4 Is there documented evidence that the patient is reviewed for their epilepsy by a neurologist: Yes ☐ No ☐ Unknown ☐ Not documented ☐

9.5 If yes, date of last review by neurology services (in months): _____

9.6 Review frequency by neurologist/epileptologist

< 3 months		> 3 years	
< 6 months		> 4 years	
< 9 months		> 5 years	
< 12 months		Other	
1-2 years		unknown	
> 2 years		Not documented	

9.7 Is there documented evidence of shared care between primary and neurology services: Yes ☐ No ☐ Unknown ☐ Not documented ☐

If yes describe _____

_____

9.8 If yes, is shared care documented with a

	Yes	*No*	*Location*
Private neurology service			
Public Neurology service			
Both			
Not recorded			
Unknown			

9.9 Date since last emergency admission for epilepsy (in months) _____

Unknown ☐ Not documented ☐

9.10 Date of last casualty attendance (in months) _____

Unknown ☐ Not documented ☐

9.11 is there evidence of non-compliance by the patient with epilepsy care

Yes ☐ No ☐ Unknown ☐ Not documented ☐

If yes please complete	Yes	No	Not documented	Comments
AEDs				
Appointments				
Lifestyle advice				
Risk factor reduction				