

The National Clinical Programme for Epilepsy: model of care

Item Type	Guideline
Authors	National Clinical Programme for Epilepsy
Publisher	Health Service Executive (HSE)
Download date	04/03/2021 10:53:55
Link to Item	http://hdl.handle.net/10147/622772

The National Clinical Programme for Epilepsy

MODEL OF CARE



EPILEPSY

Clinical Strategy and Programmes Division

National Clinical & Integrated
Care Programmes
Person-centred, co-ordinated care



 ROYAL COLLEGE OF
PHYSICIANS OF IRELAND



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

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Document Management

Document Info

Document Number:	
Created By:	National Clinical Programme for Epilepsy
Version Number:	20
Last Saved On:	21.9.16
Document Status	Final draft approved by HSE Leadership
Date Effective:	To be confirmed
Approval Date:	
Approved By:	NCP Epilepsy Working Group NCP Epilepsy Consultants' Clinical Advisory Group
Responsible for Implementation:	Acute Hospitals Division
Responsible for Audit and Monitoring:	Acute Hospitals Division
Revision Date:	

Version Control

Version 20 June 2016	Approved by HSE Leadership
Version 19 June 2015	Post review by CSPD
Version 18 April 2015	Amendments by Clinical Lead
Version 17 March 2015	Amendments following 2nd external consultation
Version 16 (2nd Substantive Draft) Nov 2014	External Consultation Approved by CAG
Version 15 Sept 2014	Amendments made by working group in preparation for CAG
Version 14 August 2014	Amendments including Health Promotion
Version 13 June 2014	Amendments including Patient Safety & Transition
Version 12 April 2014	Working group amendments
Version 11 March 2014	Working group amendments including glossary of terms
Version 10 Feb 2014	Amendments/editing Clinical Lead
Version 9 Nov 2013	Feedback collated and agreed by working group
Version 8 Oct 2013	Executive Summary agreed by CAG
Version 7 July 2013	Review of MOC by working group
Version 6 Dec 2012	Clinical Lead & Lead Nurse review feedback
Version 5 Sept 2012	Feedback from consultation reviewed and version amended
Version 4 April 2012	1st Substantive Draft for Consultation
Version 3 March 2012	Amendments in advance of consultation
Version 2	Review of draft by working group
Version 1	Initial draft by working group

Foreward

In 2010, at the advent of the National Clinical Programmes, the HSE sought expressions of interest from groups of clinical teams, community clinicians, carers and patients who were interested in new ways of delivering safe effective care in a resource constrained environment with the explicit goal of delivering 'better care with better use of resources'. Those of us working in the field of Epilepsy in Ireland had been awaiting such a call since 2007 when the first of a number of national meetings to develop a standardised, evidence based, approach to care took place. The National Epilepsy Service of Ireland or NESI, as it was then, was merely a plan; a proposal to develop an accessible, safe and quality service for all citizens from cradle to grave, organized around an integrating principle that put the patient at the centre of our concerns and valued information access and sharing, in the right place at the right time, as the key to proper care delivery.

After the financial collapse of 2008, it was clear that investment in the care system would be under the most significant downward pressure since the founding of the state. Added to this was the emerging environment of patient safety and quality improvement which saw regulation outstripping process change to such a degree that one might be forgiven for thinking that the health system was in a state of chaos and near collapse.

The emergence of the National Clinical Programmes was a lifeline for those ready and willing to develop a national service under challenging conditions. In May 2010, the Clinical Advisory Group of the National Clinical Programme for Epilepsy, under the umbrella of the Royal College of Physicians (RCPI) was inaugurated. What follows is a vision document developed by the National Clinical Programme for Epilepsy and the CAG in determining the best way to deliver epilepsy care in Ireland. The document also provides an outline, supported by evidence from the international literature, of the building blocks that are required to create the conditions to realise the vision. The document is the work of many people, not least Irish people with Epilepsy who contributed to the model during a public consultation that was held in 2012 and again in 2014 with the help of Epilepsy Ireland.

We have done our best to address the comments of all contributors large and small. The Model of Care, as a vision for the service over the next decade is now complete. We anticipate with changing demographics, service requirements and new advances in the treatment of the disease that a peer review process may see the need for development of a new vision for service beyond that. For now, this document carries the hope for the most important standardization in epilepsy care in the history of the state but it is only words on a page and it is up to us all to implement and sustain its ideas.

Colin P Doherty MD
National Clinical Lead for the National Clinical Programme for Epilepsy

Executive Summary

This document, developed by the National Clinical Programme for Epilepsy (NCPE) and the associated Clinical Advisory Group (CAG) of experts outlines a vision for the design and delivery of epilepsy care for Ireland.

Epilepsy is a chronic disease characterized by unpredictable, sometimes lifelong, often dangerous seizures which result in involuntary alterations in behaviour and consciousness. The condition affects about one in every 100 people and is second only to stroke as the commonest chronic neurological disorder in Europe. Of the 40,000 sufferers in Ireland (10,000 of whom are under 16 years), only about 70% are well controlled on medication, leaving about 12-15,000 people who have breakthrough seizures, and are in regular contact with secondary and tertiary hospital services. There are 130 epilepsy deaths per year. Many patients with epilepsy suffer from mental health problems, and the condition has significant implications for social, vocational and occupational aspirations.

Driven by the competing imperatives of delivering better, safer care within a sustainable cost framework and under the direction of the office of Clinical Strategy and Programmes, the National Clinical Programme for Epilepsy (NCPE) has been charged with addressing the historic deficiencies in epilepsy care through a comprehensive change programme that delivers care from cradle to grave in epilepsy. This will be achieved by addressing three core objectives:

1. Improving access to expert care and information.

2. improving the quality of care across the healthcare spectrum from prevention, through managed primary care to complex surgical care for difficult epilepsy

3. Improving value conscious care by shifting care where possible from expensive hospital based care to the community

Fig 1; core objectives of the National Clinical Programme for Epilepsy

Recommendations

The core of the plan to deliver these objectives is to address each aspect of care with a specified care pathway, delivered by specified experts.

- a. **Managed primary care** will be delivered by General Practitioners (GP) working with practice nurses and other community health workers with the support of Registered Advanced Nurse Practitioners (RANP) across the country, who will help manage patients with stable disease in the community, and will guide others less well-controlled through the health system providing them with the resources for self-management, point of contact and referral information for expert care in the epilepsy centres.
- b. **Group Based Epilepsy Centres** nationally will be staffed by a new cohort of epilepsy experts from a nursing background (RANP's) who will be population based and be the main contact within the group for expert services (see Fig 4). Working in tandem with medical consultants and epilepsy Non-Consultant Hospital Doctors (NCHD's), they will provide routine epilepsy care in the epilepsy centres including in and outpatient care, begin providing rapid access service for community and emergency department (ED) referrals, telephone, email and virtual advice.. In time they will provide outreach services to secondary care hospitals, maternity hospitals, intellectual disability services and primary care centres. They will act as a resource for non-specialist epilepsy services in each centre for both medical and nursing staff. The delivery of care will necessarily be slightly different between the paediatric services and adult ones, with more of an emphasis on co-managing with local paediatricians in the former. The paediatric services will also benefit from transition clinics, to introduce adolescent patients with epilepsy to the staff on the adult service.
- c. Through the use of an **integrated care pathway** (section 12.5), administered through Emergency Departments (ED) and the AMAUs (Acute Medical Admissions Units), front-line physicians will use an intelligent, evidence-based algorithm to help with management and disposition of patients who come to hospital with first seizures or breakthrough events. International evidence suggests that there is significant variance in care for patients presenting with seizures at the emergency interface and that too many patients are being admitted when often they could safely receive care, advice and rapid follow-up as an outpatient.
- d. The 15% or so of **highly complex epilepsy** patients who need to be assessed for possible epilepsy surgery will be dealt with by expanding the pre-surgical evaluation beds in Ireland from 4 (2 paediatric and 2 adult) to 8 (2 paediatric and 6 adult). These beds will be spread over 3 sites - 2 paediatric beds in the new national paediatric hospital, 4 adult beds in Beaumont Hospital, Dublin and 2 in Cork University Hospital (CUH).

Key Messages of the Model of Care

The epilepsy care programme has a vision for the transformation of epilepsy care in Ireland:

To provide the best value care for all people with epilepsy in the right place, at the right time, sharing the best available information

By then a whole cohort of new experts in nursing will be helping to manage the requirements of good quality care in this chronic disorder. Care will be centralized in epilepsy centres when necessary and decentralized in a structured primary care programme where possible. A sophisticated and robust means of electronic information management will be developed to become a defacto disease registry within which the important evidence-based metrics underlying good clinical practice will be gathered. Front-line physicians delivering care at the emergency department interface will be provided with an integrated seizure care pathway that will reduce admissions and length of stay, whilst improving patient safety by eliminating treatment variability. Finally, for the 15% or so of very difficult to control epilepsies, the national epilepsy surgery programme, will be enhanced and expanded over 2 sites to provide world-class access to complex but potentially curative surgery.

The National Clinical Programme for Epilepsy describes an integrated service which achieves positive outcomes for patients by enabling clinicians to work together across boundaries and different sectors to deliver safe, effective and person centred care.

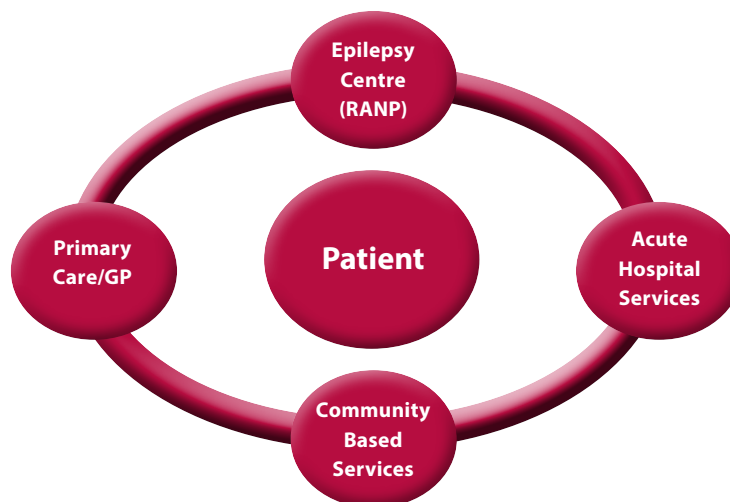


Fig 2; Patient centred care across epilepsy services

The benefits of such a service to patients include;

- More efficient integrated care
- Care which is consistent and meets best practice standards regardless of geographic location
- Improved access to appropriate services
- Care delivered in the most appropriate setting

The benefits of such a service to staff include;

- Coherent approach to the local implementation of National Standards, guidelines and care pathways regardless of care setting
- Service designed in line with international best practice
- Using the skills, knowledge and expertise of a range of healthcare professions in various settings in new ways.

1.0 Background

1.1 Introduction

Epilepsy is the most common serious neurological disorder of young people and affects an estimated 50 million people worldwide [6]. Societal costs are considerable as individuals with medically intractable seizures make up a third of the epilepsy population [6]. More than EU15 billion is spent annually on the treatment of epilepsy in Europe, which amounts to about 0.2% of the regions total GNP, a financial burden comparable to that of lung and breast cancer combined [7, 8]. Approximately 3.4 million individuals in Europe suffer from epilepsy; whilst up to 2% of the population will suffer from epilepsy at some stage in their lives [6]. An Irish prevalence study in 2005 estimated that up to 37,000 people in Ireland (who are over the age of 5) have the disorder, which gives a point prevalence of about 0.8%, in line with other industrialised nations [9].

After a century of unprecedented innovation in clinical medicine and public health, the last 20 years has seen modern medicine assailed by a continuous stream of data pointing to the harm caused by therapeutic and procedural error leading to failures both of omission and commission. Unlike other high reliability organisations such as the airline industry and the nuclear industry, the notion that safe practice (and not just the aspiration but demonstrably safe practice) needs to be at the heart of the healthcare industry has had a difficult time in sticking. Recent data has shown up to 25% of patients suffer some form of avoidable harm after hospital admission and up to 1% either die or suffer permanent disability as a result of mistakes [10]. Irish medicine has been relatively slow to recognise the significance of this data although in recent times a number of government sponsored reports have begun to lay out a framework for safety and quality with regulations designed to drive improvement [11, 12 & 13]

The National Clinical Programmes under the governance of the Division of Clinical Strategy and Programmes at the Health Service Executive (HSE) in Ireland is at the heart of a new paradigm that seeks to systematise complex healthcare needs in order to address the safety and quality deficits until recently hidden in Irish healthcare. The NCPE is one of a number of chronic disease programmes whose goal is to use international evidence and expert consensus to create a programme of improvement in the quality of, access to and value of, epilepsy care in Ireland.

The key innovation of the Programme is the creation of a cohort of registered advanced nurse practitioners (RANPs) to compliment the current medical expertise that can help in the chronic disease management of epilepsy and integrate it with care in the community. Central to this integration is that it will provide timely access, intelligent support to general practitioners and outreach clinics in the community. It is anticipated and evidence would suggest that these services will demonstrate true value by reducing admissions to the acute hospitals and reducing the length of stay in those admitted. Admissions to acute hospitals and length of stay have been identified as key performance indicators for the National Clinical Programme for Epilepsy and are monitored quarterly.

The availability of relevant clinical information to clinicians when and where it is needed is a critical success factor for the programme. A secure web-based electronic patient record (EPR) will facilitate this by supporting the sharing and exchange of standardised patient information. EPR access to authorised clinicians at any geographical location throughout Ireland will improve integration of Irish health services and enhance continuity of care for people with epilepsy. The EPR will also support high quality performance management for the epilepsy programme as it makes possible efficient interrogation and analysis of large volumes of individual or populations of integrated, harmonised and consistent patient data.

1.2 Context

The NCPE recognises the need for a collaborative approach to service enhancement and delivery. The development of this MOC draws from key policy developments and reforms within the Irish health services. The implementation of these policies and reforms are key to the successful implementation of the recommendations within the NCPE model of care.

- ❑ Department of Health and Children's Value for Money Review of Disability Services, 2012 [1] has resulted in significant restructuring of disability services following the recommendations of the review. There are also recommendations for further restructuring and policy development in the areas of reconfiguration of therapy services (recommendation 5.10), formal outcome measurement based on the assessment of person centered plans (recommendation 6.6); establishment of a primary care network (recommendation 7.12) and cross sectoral working (recommendation 7.17)
- ❑ The Reform of Primary Care, 2012-2015 [2]. The objectives of this report include building the capacity of primary care teams. A network of primary care centers would be integral in chronic disease management programmes.
- ❑ HSE Chronic illness framework, July 2008 [3]. The key goals of this framework is to provide individuals, groups and carers with early diagnosis, education, optimum clinical and social care in the most appropriate setting, stable control of their condition, self-management support, avoidance of complications and improved outcomes
- ❑ National Healthcare Charter, National Advocacy Unit, Quality and Patient Safety Directorate, HSE 2012 [4]. This Charter was developed with input from many parties including patient advocacy groups and individual advocates. It is designed to involve service users in influencing the quality of healthcare in Ireland. It the Charter and principles within it will be used to support the implementation of the National Standards for Safer Better Healthcare.
- ❑ National Standards for Safer Better Healthcare [5]: by incorporating national and international best available evidence, these standards promote healthcare that is up to date, effective and consistent. These standards were approved by the Minister for Health on 16th May 2012. In addition to providing a sound basis for anyone planning, funding or providing healthcare services to work towards achieving and maintaining high quality, safe and reliable care, it is hoped that service users will use the National Standards to understand what high quality and safe healthcare should be and what they should expect from a well-run service.

1.3 Current utilization of acute hospital care in epilepsy

Studies in the last decade have shown that the majority of patients with epilepsy will be urgently admitted to secondary and tertiary care institutions (mostly through the Emergency Department) at some point in the history of their illness and a significant proportion will require multiple visits [7]. Furthermore, symptomatic seizures secondary to acute medical or surgical illness, alcohol and drug intoxication, brain trauma and stroke add to the burden of seizure pathology presenting to all sectors of the Irish health system. Finally, a range of mimic disorders from psychogenic non-epileptic seizures (PNES), to blackouts caused by impaired vascular responsiveness contribute to the diagnostic and therapeutic challenges.

Despite the heavy burden of seizures in the Emergency Department, international studies suggest that the majority of patients are referred unnecessarily for admission to hospital and that the acute treatment of seizures is often ineffective and highly variable [14, <http://www.nashstudy.org.uk>]. Furthermore, audits from Irish hospitals have shown that patients are often left as inpatients without specialist opinion and awaiting diagnostic tests. All of this evidence suggests that seizure admissions to hospitals are a cause of unnecessary medical intervention, variable care, delayed diagnosis and prolonged length of stay [15, 16 & 17].

In Ireland, composite data from the Hospital In-Patient Enquiry system (HIPE) revealed that in 2008 before the programme came into being, there were 6,982 discharges from acute Irish hospitals with a principal diagnosis of epilepsy; the total number of bed days used was 31,532 with an average (mean) length of stay (LOS) of 4.5 days (median 3.3 days) per discharge. The creation of a new model of care in Ireland using a seizure care pathway with early follow-up and prioritized diagnostics shows average length of stay has been reduced to 3.5 days by 2013

This demonstrates the massive efficiencies which can be achieved across acute hospitals. If the full economic rate (FER) of a bed day is costed at approximately €840 per night, in 2008, the admissions of 6,982 patients cost the health service €26,391,960. In 2013 the admissions of an additional 941 patients i.e. 7923 cost the health service €23,293,620 demonstrating a significant gain in value to the service.

Year	Discharges	Bed days	AvLOS	Cost €
2008	6982	31,532	4.5 days	26,391,960
2013	7923 ¹	27,974	3.5 days	23,293,620
2015	6009	27372	3.4 days	22,992,480

Table 1; reduction in bed days achieved

Average cost per discharge (Appendix 12.1). Appendix 12.2 shows summary figures and costs over 3 years.

1.4 Mortality

Adults and children with epilepsy have an increased rate of mortality about 2-3 times that of the general population [20]. This increase is highest in the first two to three years after diagnosis and generally related to the underlying cause of the disease. In those with long-standing refractory epilepsy, increased mortality is related to epilepsy and is mainly due to Sudden Unexplained Death in Epilepsy (SUDEP), death due to complications of prolonged uncontrolled convulsive activity also known as Status Epilepticus (SE), and accidents and injuries related to unpredictable seizure activity [20]. The National Sentinel Audit of Epilepsy Related Death in the UK found that epilepsy related death particularly SUDEP is underestimated by healthcare professionals [21]. The audit demonstrated that 38% of deaths that were sudden and unwitnessed did not have a post mortem. They conclude that is difficult to estimate the number of epilepsy deaths from national data. Recent epidemiological data suggests that the biggest risk factor for SUDEP is uncontrolled seizure activity [22].

The picture in Ireland is probably similar and therefore the figures given below are a conservative estimate of deaths related to SUDEP and SE in Ireland [23, 24 & 25]. In addition deaths due to non-convulsive status epilepticus (NCSE) and accidents are not included in the figures below. Data from Jawad and colleagues in Ireland has shown that in an elderly hospitalized population, the mortality from NCSE was 50% over a five-year period [25]. It is an aim of this programme to reduce the number of lives lost to epilepsy primarily through improvements in seizure control and standardized pathways for the treatment of status epilepticus in the ED.

1 Beaumont, GUH and Portlaoise almost doubled total discharges which accounted for 600 of the extra 1000. (this anomaly could be attributed to a number of factors i.e. change in local coding practice etc)
Population growth rate for Ireland was 1.2% and as such could account for 400 patients to the discharges

Epilepsy Prevalence estimates ¹	Estimated no of PWE ³	Rate of SUDEP cases / yr ²	Estimated no SUDEP cases /yr ³	Incidence & no of deaths from status epilepticus ⁴ based on 2010 Irish population	Estimated range of deaths per year from SE & SUDEP
8.3/1000 $\geq$ 5 years	34,171 PWE	0.6-1.3/1000 PWE	21-44 cases /year	Incidence; 706 cases Deaths from SE; 67 deaths/year	88-111
9.0/1000 $\geq$ 5 years	37,052 PWE	0.4-1.1/1000 PWE	15-41 cases /year	Incidence; 706 cases Deaths from SE; 67 deaths/year	82-108

Table 2. Morality figures from Irish Studies (Donohue et al 2013)

1 From Linehan et al 2010

2 Based on work by Langan et al 1998

3 Based on 2010 population estimates from www.cso.ie

4 Based on work by Knake et al 2001 with incidence rate of 15.9/100,000 and Case Fatality Rate of 9.3% for SE

1.5 Current Models of Care: National and international evidence

Responding to the challenge of maximising the benefits of medical advances for patients while minimising the burgeoning demand on healthcare systems, there is an international change in the chronic conditions like epilepsy are managed. Chronic disease management (CDM) aim to move from episodic reactive health care delivery to one that prevents the occurrence of disease, and improves the quality of life of those who already have a chronic illness by averting or delaying further deterioration [12]. In the case of epilepsy, the focus of chronic disease management is on seizure management and health promotion.

Nationally and internationally, effective models of practice in epilepsy include the following components;

- Epilepsy Nurse Specialists
- Supported Self-Management
- Integration with Primary Care
- Effective Clinical Information Systems

Supporting evidence for all of the above are described in detail in the following sections including reference to how these could be adapted to the Irish Health Service.

1.5.1 A nurse led model of care

A Cochrane review of models of epilepsy care found strong evidence for positive outcomes by the involvement of epilepsy nurse specialists and self-management strategies alone [26]. Outcomes measured included morbidity, mortality, seizure freedom, quality of life and knowledge of epilepsy and its treatment. Epilepsy Nurse Specialists (ENS) have become an integral part of the epilepsy care team. They identify and document seizure activity, perform appropriate interventions, recognize signs of anti-epileptic drugs (AED) toxicity and share the responsibility of managing the care of epilepsy patients [27, 28].

Investigations into the effectiveness of Epilepsy Nurses in primary care and from clinical trials suggest that Epilepsy Nurse Interventions are highly useful and that epilepsy patients cared for by a nurse are well informed and have a high degree of satisfaction [29, 30 & 31]. Nurse led Epilepsy Clinics and Services have become a leading light for all nurse led services. A randomized controlled

trial to test the feasibility and effect of nurse led Epilepsy Clinics in primary care has shown that such clinics for patients with epilepsy are feasible, well attended and significantly improve the level of advice and drug management [32]. While relatively few adults have seen an epilepsy nurse, 74% of those who have thought that nurses helped them to cope better by providing information, advice and support. Clinical Nurse Specialists (CNS) in Epilepsy employed in hospital epilepsy clinics can play a key role in supporting doctors and helping patients manage their condition for optimal outcomes [33].

A trial by the UK's National Institute for Clinical Excellence (NICE) [34] found that people supported by an epilepsy nurse had significantly lower depression scores. Trial participants commented on nurses' ability to reduce their fears and anxieties. NICE [34] and the Scottish Intercollegiate Guidelines (SIGN) [35] recommend that epilepsy nurse specialists should be an integral part of the network of care of individuals with epilepsy.

Within the Irish context and considering the configuration of neurology and epilepsy services, the role of the clinical nurse specialist in epilepsy would not wholly support the network model proposed which incorporates outreach from hub centres.

While the role of clinical nurse specialist is highly valued, the epilepsy programme is proposing a more integrated service, establishing strong working links with primary care and community based services. To achieve this vision, the role of advance nurse practitioner is required.

1.5.2 Supported Self-Management

Health promotion is the process of enabling people to increase control over and improve their health. A shift from medical paternalism is discouraging dependency and promoting individual patient/carer responsibility. Internationally, self-management in many chronic diseases is receiving increased attention. Empowering patients to take a more active role in their care improves their understanding of their condition, increases compliance with treatment and encourages adoption of healthier lifestyles. In epilepsy, this leads to individuals having a better awareness of and management of stressors that trigger seizures, reduced seizure frequency, less inappropriate use of health services and reduced medical costs [59]. Patient education is the first step in achieving self-management and the supporting the "knowledgeable patient" (59).

Even for those with longstanding epilepsy, knowledge and understanding of their condition have been shown to be lacking [37]. Passivity and general acquiescence among people with epilepsy often leads to poor expectation of treatment outcomes and a reluctance to raise important issues, such as the incidence of adverse events, with their clinicians [44, 60]. This abdication can result in clinicians planning treatment without fully understanding the patient's healthcare goals or the barriers they face in achieving them. Better partnership between the patient and clinician is required to ensure that decisions respect patients' wants, needs and preferences and that patients have the education and support they need to make decisions and participate in their own care [61]. For people with epilepsy, such patient-centered care can lead to improved seizure control, better quality of life and reduced inappropriate use of scarce health resources (e.g. emergency services, hospital admissions, redundant investigations).

A number of studies have examined a variety of different education programmes and have illustrated that these can impact positively on patients' knowledge, coping with their epilepsy, and possibly seizure frequency [26, 64, 66, 67, 68 & 69]. The education programmes cover topics such as Living with Epilepsy, Epidemiology, Basic Knowledge, Diagnostics, Therapy, Self-control, Prognosis, Psychological aspects. The various education programmes employ a range of different formats and methods of delivery. For example, some are delivered as one-hour weekly sessions over a

3 month period, some are delivered as a 2-day or weekend course. Face to face, telephone or Internet have all been employed. Holistic epilepsy care includes both medical and social (lifestyle, employment, safety, etc.) dimensions. Patient support and education is an important component to addressing all of these dimensions.

1.5.3 Primary care

International experience of the delivery of epilepsy care has been growing since the late 1990's. In addition to the deficiencies in hospital care, primary care has also come under scrutiny. In 1997 in the British Journal of General Practice, Thapar noted that patients in the NHS with epilepsy were not being managed in a structured or systematic way in primary care [39]. He highlighted the overall poor control of the condition, inappropriate prescribing and poor communication with patients with epilepsy. In the same issue, Ridsdale and colleagues show that both General Practitioners (GPs) and patients hoped for a frequency of review and depth of communication that were not being achieved. They concluded that new skills and resources were needed [40]. In an editorial of that issue, the author warned that improvements would make demands on already stretched general practice resources but that the success of structured programmes in diabetes, asthma and heart disease suggested that it would be possible to delivery care successfully [41].

To build a picture of the GP perception of their role in the management of epilepsy in Ireland a recent survey was conducted by Varley and colleagues. A questionnaire was sent to a sample of 700 Irish GPs [42]. Of 247 respondents 96% supported the concept of shared care for epilepsy. However, they were very dissatisfied with existing neurology services, including pathways of referral (84%) and access to specialist neurology advice and investigations (94%). Because of delays GPs often referred to the emergency department for assessment and treatment (73%). A deficit in epilepsy care expertise among GPs was acknowledged (35%). This survey identified significant opportunities for improved epilepsy management within the primary care sector.

A study of the interface between primary care and specialist services in Ireland demonstrated the challenges perceived by healthcare professionals to delivering a consistent high standard of epilepsy care [43]. For example, a continuing stigma contributes to epilepsy and its care not being spoken about and consequently not receiving the social or political attention it deserves.

Geographic variation in availability of and access to epilepsy services leads to considerable inequalities for people with epilepsy and their families as does the public or private status of a patient (i.e. with or without private health insurance). Furthermore, a lack of knowledge and confidence to manage epilepsy among practitioners at the primary care level together with poor communication between primary and specialist services was considered a significant barrier to enhancing continuity of care.

While a model of shared epilepsy care between the primary and specialist sectors was considered the way forward, it was advised that this would require clearly defined roles, formalised clinical pathways, enhanced and continuing medical education, and support of information and communication technology. All of these attributes are addressed in the new model of care described in this document.

More recently, using a phenomenological approach, Varley's group conducted one-to-one interviews with 20 people with epilepsy to learn about their healthcare journey from onset of symptoms through to their first interaction with specialist epilepsy services [44]. Five major themes emerged including;

- ▲ Delayed access to specialist review
- ▲ Disorganisation of existing services
- ▲ Uncertainty regarding the competency and role of primary care services

- ▲ Significant unmet needs for females with epilepsy
- ▲ Unmet patient information needs.

The findings reveal important insights into the challenges experienced by people with epilepsy in Ireland and identify the opportunities embodied in the new programme of care where service reconfiguration could improve the quality and efficiency of care provided. Finally, an audit carried out on records of patients in the community with a documented diagnosis of epilepsy revealed a large number of patients (75%) with the diagnosis who had no evidence of recent specialist review and nearly 40% who had not been seen by their GP in the previous 2 years [45].

The epilepsy programme takes account of the significant reconfiguration of resources occurring across all hospital sectors and the increasing demands being brought to bear on GPs. Nevertheless the programme envisages GPs and other community health workers in each community healthcare organisation having a key role in delivery of epilepsy care within the community. The focus of the programme is to;

- ▲ Develop a model for the shared management of epilepsy patients in primary care with GPs
- ▲ Individualized care plans for each patient
- ▲ Generic protocols and checklists for acute seizure treatment and chronic disease management in the community
- ▲ Close links with epilepsy centres through the RANP epilepsy who will provide advice, rapid referral pathways back to the specialist service and eventually outreach clinics at primary care centres and secondary care hospitals.

1.5.4 Clinical Information Systems

Timely sharing and exchange of standardised clinical information both within and across organisational boundaries is fundamental to the realisation of effective chronic disease management [59]. However, this is limited by a lack of shareable patient medical records. Medical records are still often paper-based with healthcare organisations keeping their own exclusive record. Although electronic patient records (EPR) exist, their adoption into clinical practice has been slow.

EPRs have the potential to;

- ▲ Improve standardisation of medical vocabulary and record keeping
- ▲ Allow services to be delivered in the most appropriate setting for the patient
- ▲ Advance health services monitoring and planning
- ▲ Enhance health service co-ordination and continuity of care
- ▲ Facilitate clinical research data mining requirements.

Unlike paper-based records, multiple users at any location can have simultaneous access to a centrally stored record via the internet thus improving availability of important clinical information at the point of patient care. The continuum and cost effectiveness of epilepsy care can benefit from a secure web-based EPR which is accessible to all authorised clinicians [62]. This enabling technology can support the delivery of shared care networks that ensure patients receive appropriate care when and where needed.

2.0 The National Clinical Programme for Epilepsy: A new Model of Care for Epilepsy patients in Ireland

Using the national and international evidence reviewed in chapter one the National Clinical Programme for Epilepsy has developed a model of care delivery that is national, population-based,, multidisciplinary and collaborative and predominantly nurse led. It is designed to improve the safe and effective utility of healthcare services for people with epilepsy. As well as improving services for those already identified in the system it will bring a significant number of patients with epilepsy into the care sphere. There are 3 distinct elements of the care pathway that evidence suggests will improve outcomes:

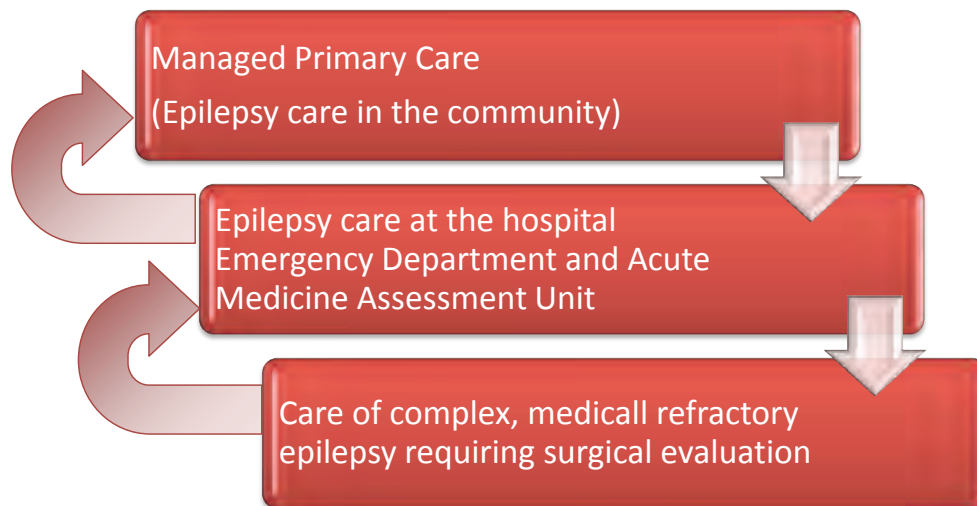


Fig 3; 3 elements of the care pathway for people with Epilepsy

2.1 Overarching Aims

The National Clinical Programme in Epilepsy Care, in line with all of the clinical programmes from the Directorate of Clinical Strategy and Programmes has 3 main goals:

- ▲ The delivery of improved quality of care
- ▲ Improved access to specialist care for patients with epilepsy
- ▲ Delivering value for money through best use of health care resources. This will ensure the sustainability of the programme into the future.

2.2 Objectives of the National Clinical Programme for Epilepsy

Quality:

- ▲ To improve the management of acute seizures at primary, community and hospital level using an integrated care pathway for seizure management (ICP).
- ▲ To reduce the number of hospital admissions, length of stay and readmission rates.
- ▲ To improve seizure control and quality of life for patients (See all 8 criteria for quality care in epilepsy from the American Academy of Neurology [47]).
- ▲ Improve patient experience

Access:

- ▲ To reduce waiting time for epilepsy care.
- ▲ To provide access to specialist direction.
- ▲ To ensure all epilepsy patients have timely access to a structured primary care programme.
- ▲ To reduce wait time for epilepsy surgery.

Value:

- ▲ To reduce average hospital Length of Stay (LOS) (19,000 bed days nationally).
- ▲ Avoid unnecessary hospital admissions
- ▲ To reduce unnecessary investigation and treatment.

2.3 Targets of the National Clinical Programme for Epilepsy

Establishment of network of Epilepsy Centres (fig. 4).

Epilepsy Centres staffed by a new cohort of epilepsy experts from a nursing background (RANP's) who will be the main contact within the group for expert services (see Fig 4). Working in tandem with medical consultants and epilepsy Non-Consultant Hospital Doctors (NCHD's), they will provide routine epilepsy care in the epilepsy centres in outpatient care, begin providing rapid access service for community and emergency department (ED) referrals, telephone, email and web-based advice. In time they will provide outreach services to secondary care hospitals, maternity hospitals, intellectual disability services and primary care centres.

Population based nurse-led service. 1 nurse per 140,000 pop.

In terms of case load per nurse, the experience in St James's Hospital Dublin shows that one nurse specialist in epilepsy) with a case load of about 1,500 patients can, in conjunction with the consultant epilepsy specialist and a neurology registrar, deliver on median length of stay reductions, is effective in admission avoidance and reduces time to first seizure evaluation and follow-up [19]. The nurse specialist in Epilepsy can successfully deliver an advice service by telephone and/or by email [19]. Experience of the nurse phone advice line in Beaumont hospital on the north side of Dublin has shown that telephone support has had a significant impact on presentations to the Emergency Department [36]. Recently, research has shown that patients attending specialist services in Ireland and receiving information and education on epilepsy related matters from a specialist nurse compare favourably, in terms of quality of life, drug compliance and knowledge of their condition with European and US epilepsy centres [37, 38].

Structured primary care programme led by GPs in association with the PCT and the RANP epilepsy.

The epilepsy programme takes account of the significant reconfiguration of resources occurring across all hospital sectors and the increasing demands being brought to bear on GPs. Nevertheless the programme envisages GPs and other community health workers in each community healthcare organisation having a key role in delivery of epilepsy care within the community

Seizure Care Pathway for acute hospital based seizure management in ED/AMAU and wards.

Through the use of an integrated care pathway (appendix 12. 6), administered through Emergency Departments (ED) and the AMAUs (Acute Medical Admissions Units), front-line physicians will be supported in the use of an intelligent, evidence-based algorithm to help with management and disposition of patients who come to hospital with first seizures or breakthrough events

Expanded, appropriately resourced, pre-surgical evaluation programme in two centres.

Patients with complex epilepsy requiring presurgical work-up and evaluation for possible device implantation will be referred to Beaumont and CUH. There will be a 4-bedded video telemetry unit

in Beaumont Hospital, and a 2-bedded video telemetry unit in CUH fully staffed with staff nurses. The staffing requirements for the highly specialist services are detailed in section 8.

Delivery of care in the most appropriate setting through access to clinical information when and where needed via an electronic patient record (EPR) (e.g. for community outreach, primary care and hospital-based).

Standardized clinical documentation, sharing and exchange of patient information between clinicians as well as performance monitoring and evaluation are all key to the success of the new model of epilepsy care. This will be facilitated by a secure web-based electronic patient record (EPR) which will provide authorized clinicians, regardless of geographical location, with access to complete and accurate patient records when and where needed.

Development of patient-centeredness through patient education with links to Epilepsy Ireland (EI) and other informational resources for self-management.

The Epilepsy programme has a strong working relationship with Epilepsy Ireland, the national advocacy service for people with epilepsy. The programme has engaged with Epilepsy Ireland and their members with respect to educational requirements with a view to developing information and educational supports. Like Epilepsy Ireland, the programme advocates for a patient centred service built on principles of respect, choice, patient involvement, access and information.

Countrywide telephone direction for health professional

A lack of knowledge and confidence to manage epilepsy among practitioners at the primary care level together with poor communication between primary and specialist services is considered a significant barrier to enhancing continuity of care. The epilepsy programme aims to begin to address this perceived barrier through the development of telephone access to guiding information.

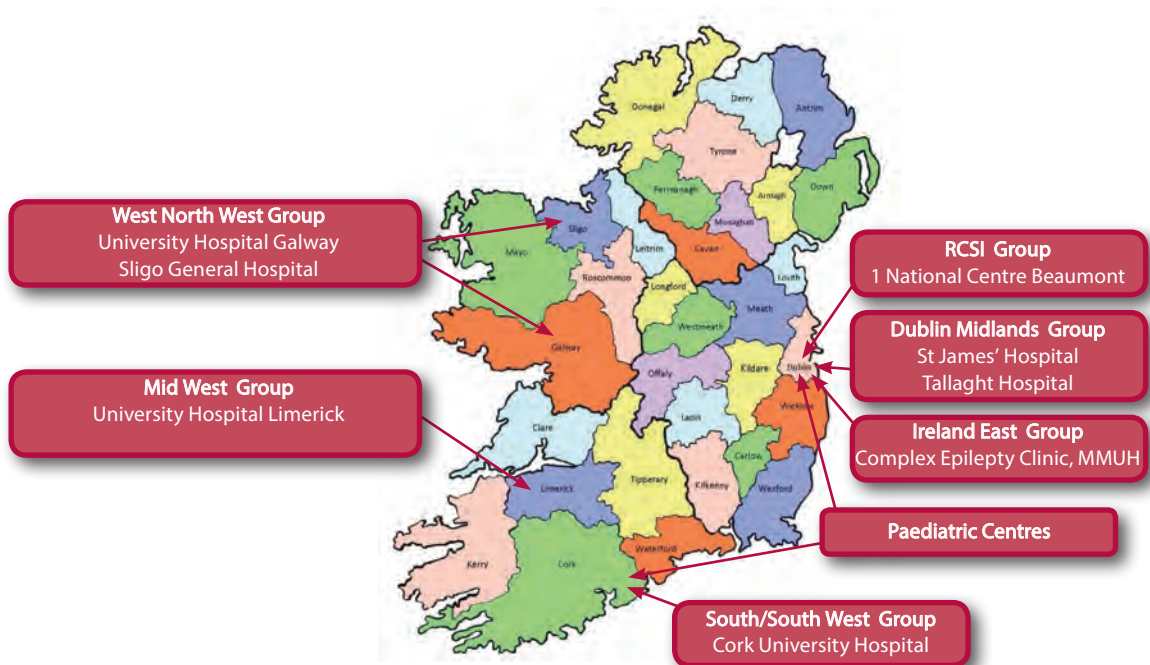


Fig 4. Location of Epilepsy Centres Nationally

3.0 The New Epilepsy Care Pathway

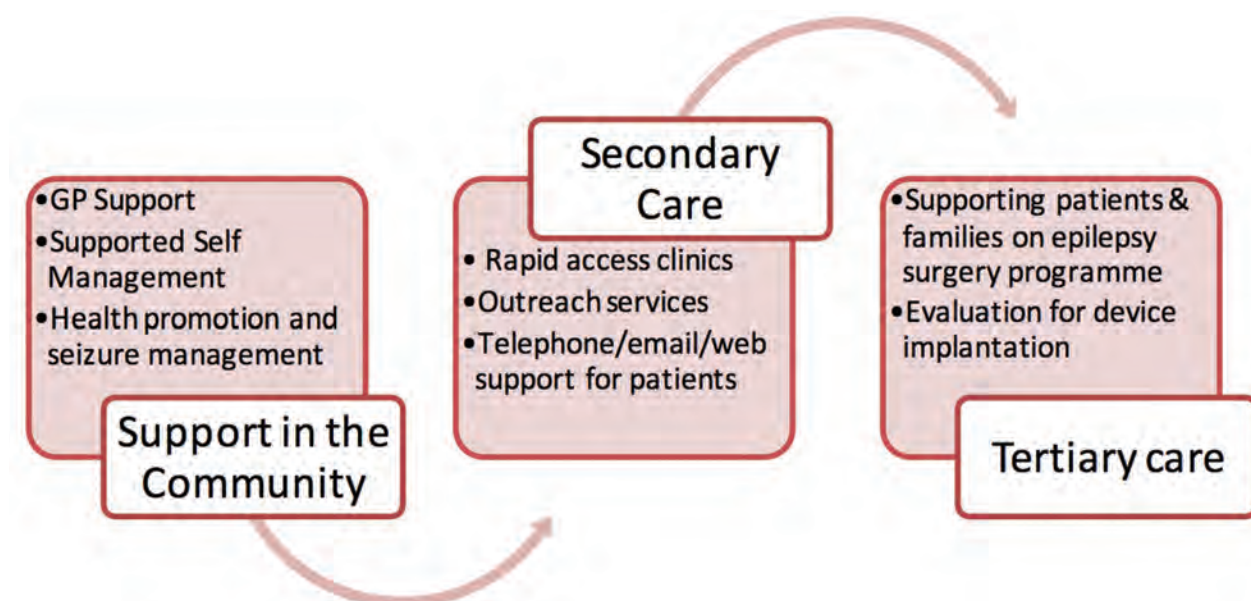


Fig 5; the proposed Epilepsy Care Pathway

3.1. Managed Primary Care (epilepsy care in the community)

Health Promotion and Prevention

The traditional continuum of care is a system that guides and tracks patients over time through a comprehensive array of health services spanning all levels of care intensity across 3 categories as identified in Figure 6 below. It is predicated on the fact that there is an underlying illness, injury or disease and does not appear to support the supported self-management of chronic conditions such as epilepsy.

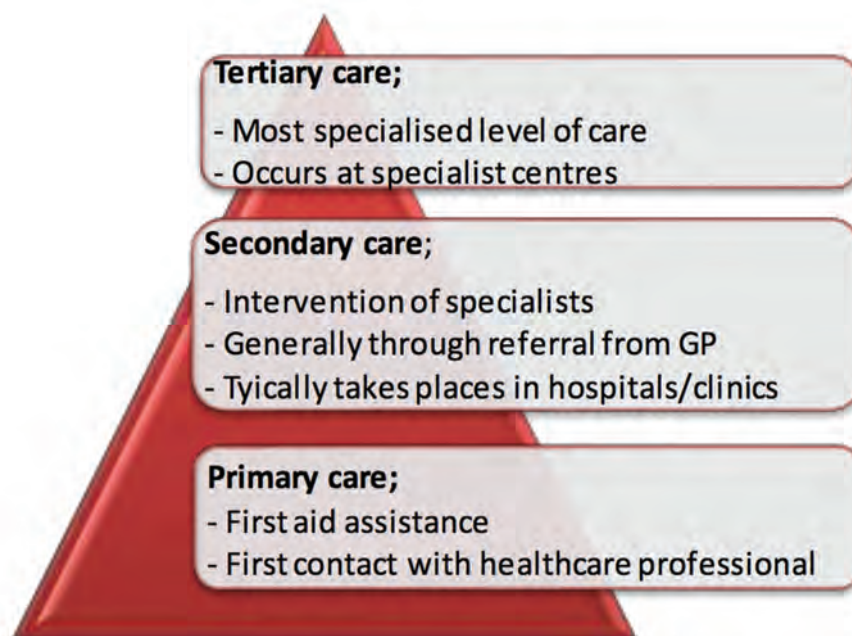


Figure 6; Traditional Health Care Continuum

The proposed new healthcare continuum includes the concept of health promotion and preventative care as outlined below in Figure 7.

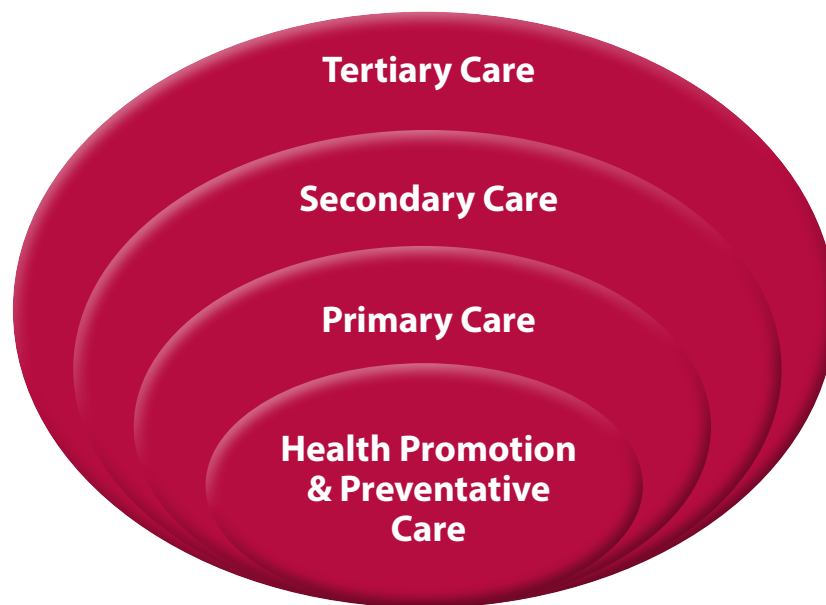


Figure 7; Proposed new model of continuum of health care

All services have a responsibility for health promotion and prevention. Within the health system, primary care services are the first and ongoing points of contact for the majority of health service users, so a significant proportion of health promotion will reside at this level. The local basis of primary care services should facilitate the delivery of national health promotion initiatives and campaigns.

Over the past two decades, the role of self-management in chronic diseases has gained momentum. Self-management programmes are now acknowledged as a key element of quality care.

Self-management education for people with epilepsy should fit into the patient journey and pathway. Generic self-management programmes will equip service users with the knowledge they need to manage themselves and become an 'expert patient'. In addition, Epilepsy specific self-management programmes, such as Epilepsy Ireland's STEPS programme (Support & Training in Epilepsy Self-management) will address more condition specific issues such as;

- ▲ Living with Epilepsy
- ▲ Managing seizure triggers
- ▲ Lifestyle and safety
- ▲ Understanding the impact of diet, exercise and sleep.

Likelihood of success in this regard can be maximised by facilitating access to psychological and neuropsychological support for the building of coping skills, increasing self-efficacy and avoiding acquiescence and poor expectations of treatment outcomes, knowledge and understanding when dealing with the transient effects of seizures and permanent damage to the brain.

In summary, supported self-management should provide individuals with chronic conditions with the information and skills they need to manage their own condition confidently and to make daily decisions which improve their health and wellbeing and improve clinical, emotional and social outcomes.

An implementation plan needs to be developed to ensure self-management programmes are planned and delivered in an integrated manner and that patients can access the most appropriate self-management programme. This implementation plan should review the efficacy of various models, outline the staffing requirements and training needs etc.

General practitioner and care in the community

Within the vision of the NCPE GPs will be supported to provide care for stable patients in the community. Information on referral, acute seizure management, monitoring epilepsy treatment and essential patient information will be provided. A standard checklist for good epilepsy care will be developed which can be used in general practice with any red flags triggering rapid referral back to the regional epilepsy centre. Standard Operating Procedures (SOPs) have been developed to support the management of patients with epilepsy in the primary care setting.

Electronic access to Epilepsy Centres for rapid electronic referrals will be facilitated via neurolink www.healthlink.ie or other national electronic referral systems. The GP would be considered the clinical leader for epilepsy care delivery in the community but aspects of care such as the checklist could be administered by practice nurses with appropriate training.

The RANPs will work with GPs to provide assessment for stable patients. Together they will coordinate care with the hospital and eventually at the Primary Care Centre and with services for people with intellectual disability for local RANP led-clinics for those with refractory disease requiring chronic disease management. Once in place, a structured programme of continuous audit would be recommended. Any such audit tool would be developed with all relevant key stakeholders including the Irish College of General Practitioners (ICGP) to monitor outcomes and patient and GP satisfaction with the service with the aim of delivering continuous improvement.

Clearly, there are many dependencies that need to be realised before the full spectrum of managed primary care can be implemented. Nevertheless, we believe that such developments are crucial not only for treatment of epilepsy but for chronic disease management in general.

Advanced Nurse Practitioners– ambulatory and community role

The programme envisages the recruitment on adequate numbers of RANPs to allow for the achievement of the recommended ratio of 1:140,000 population. This equates to 32 posts across the country. Currently there are 17.25 WTE CANPs/RANPs & CNS in post in adult epilepsy services. The Paediatric Nurses (CNS and RANP) will cover paediatric patients nationally (appendix 12.3). The number of epilepsy nurse specialists for paediatrics will be increased to 9. Currently there are 6WTE RANP/CNS in post in paediatric epilepsy services nationally.

Every patient with epilepsy in Ireland should have access to the epilepsy RANP service attached to one of the adult or paediatric centres. Patients attending services outside of their locality will be encouraged to transfer care back to the centre in their local area so as to avail of the RANP service. The nurse led service will be a protocol driven, chronic disease model of care covering the following responsibilities:

- ▲ Rapid access clinics in acute hospitals providing acute neurological care.
- ▲ Outreach clinics. – Intellectual disability services and non-acute hospitals.
- ▲ GP and community practice nurse support.
- ▲ Liaison with physicians in hospitals without neurology services, and with paediatricians.
- ▲ Telephone/e-mail/web support for patients.
- ▲ Links to Epilepsy Ireland and the Irish Branch of the International League Against Epilepsy (ILAE).

- ▲ Ensure complete, accurate and up-to-date documentation of clinical encounters using an Electronic Patient Record (EPR).
- ▲ Implementation of Standard Operating Procedures (SOPs) and management operating procedures (MOPs).
- ▲ Use of Electronic Patient Record and Standard Operating Procedures (SOPs) and Management Operating Procedures (MOPs).
- ▲ Registration and measurement of Key Performance Indicators, quality outcomes and clinical audit.
- ▲ Health Services Research, population health and clinical and translational research.

Role of not for profit organisations

The Epilepsy Programme considers it important to highlight the vital role of not for profit organisations, in particular Epilepsy Ireland, as part of the overall infrastructure of epilepsy care in this country and therefore as a key support for epilepsy service delivery.

Not for profit organisations, which serve as direct service providers also support people with epilepsy and their families and act as a vital bridge between services and the rest of the healthcare system. They also play a key role in supporting healthcare staff in non-specialist settings in identifying and meeting the needs of people with epilepsy.

- ▲ Other services provided include;
- ▲ Community Resource Officers
- ▲ Supported self-management programmes
- ▲ Outreach
- ▲ Online support services
- ▲ Support groups
- ▲ Aids & Appliances
- ▲ Advocacy

3.2 Secondary and tertiary care

The focus of the acute care in epilepsy is to implement SOPs linked to evidence based guidelines around managing seizures outside of hospital (i.e. GP surgery or residential intellectual disability centre) in the ED/AMAU and on hospital wards (see proposed Integrated Care Pathway for seizure management in the ED/AMAU - appendix 12.5). Each of the epilepsy centres will be led by a consultant neurologist with specific training in epilepsy care. This group/regional lead will be the responsible and accountable clinician for the delivery of the Epilepsy Programmes' goals.

The programme has been working with key stakeholders to define unambiguous guidelines for initial seizure management and subsequent referral onwards for specialist opinion follow-up. The programme will define best practice around existing international guidelines [30,31]. However, it is envisaged that Irish national evidence-based standards for specific aspects of care will be developed and submitted to the Irish National Clinical Effectiveness Committee for sanction (NCEC).

The role of Registered Advanced Nurse Practitioners in the acute services

- ▲ Provide routine follow up care to people with epilepsy attending the epilepsy outpatient services along with medical colleagues.
- ▲ Act in a consultancy capacity in reviewing patients with an established diagnosis of epilepsy who attend the ED or are admitted.

- ▲ Provide ongoing support to inpatients, families and parents of children admitted with seizures
- ▲ Provide rapid access clinics in acute hospitals providing acute neurological care for ED discharges and first seizures.
- ▲ Supporting patients and families on the epilepsy surgery programme.
- ▲ Develop outreach clinics. – Intellectual disability services and non-acute hospitals.
- ▲ Provide GP and community practice nurse support.
- ▲ Liaise with regional physicians in hospitals without neurology services, and with paediatricians.
- ▲ Provide telephone/e-mail/web support for patients and families
- ▲ Establish links to Epilepsy Ireland and The Irish Branch of the International League Against Epilepsy (ILAE).

The consultant epileptologist or paediatric neurologist will provide oversight and clinical governance, and be responsible for RANP clinical training. Professional governance for the nurses will be to the Director of Nursing at each regional centre (see section 7 for detailed governance arrangements). Detailed -memorandums of understanding (MOU's), Standard operating procedures (SOPs) and management operating procedures (MOPs) on outreach have been developed and are available to any service developing outreach clinics and the service where the outreach clinic is provided can review and agree on any amendments to the generic documents for outreach.

Neurophysiology and Radiology at the regional centre will provide routine EEG, ambulatory and prolonged video-EEG and MRI and CT services. It is likely that process improvement and new resources will be required in neurophysiology and radiology, which is envisaged in new diagnostic support programmes.

3.3 Highly Specialised Care

Beaumont Hospital and Cork University Hospital (CUH) will house its own nurse led group service but in addition, patients with complex epilepsy, requiring presurgical work-up and evaluation for possible device implantation will be referred to Beaumont and CUH. There is a 4-bedded video telemetry unit in Beaumont Hospital, and a 2-bedded video telemetry unit in CUH. On the paediatric side, the model of the single bedded units in Temple Street and OLCHC will continue until the amalgamation as the national paediatric hospital, when a new two bedded unit will be created.

Requirements in terms of staffing for the highly specialised centres are detailed in section 8. They include access to neurophysiology, radiology, health and social care professionals including neuropsychology, neuropsychiatry and pharmacy.

The national centre will be housed in Beaumont hospital and will provide a hub for the national EPR and tele-support rollout. The consultant epileptologist /paediatric neurologist and programme clinical lead will provide oversight and governance and will have a role in epilepsy fellow and RANP training.



Figure 8: Video EEG monitoring unit in CUH

3.4 Considerations for special groups

3.4.1 Paediatrics

As stated in the executive summary, the programme is committed to access, quality and value across the spectrum of ages from paediatrics to the elderly. There is recognition that it is difficult to capture the particular concerns of special groups like children in one document. On the other hand, the programme is conscious of the historical resourcing problems when paediatrics has not been included in population-based service developments. This is why the ethos of this programme has been to include paediatrics whilst recognising the special requirements of this group in the areas of pharmacology, psychosocial development, rights and responsibilities of parents and carers and service development. The delivery of paediatric epilepsy care will be part of the wider plan for all paediatric neurology care as will be detailed in the Model of Care for Paediatrics.

Service delivery across the country.

There are approximately 1 million citizens under 16 years of age. This gives an approximate prevalence of epilepsy of 8,000 paediatric patients. The allocation of paediatric nursing will be improved by 33% bringing the total to 9. This gives a maximum nurse to patient ratio of approximately 1:880. There are 2 centres with one centre larger than the other. Nursing ratios will however be maintained as much as possible.

Appendix 12.3 shows a map of the county by county population under 16 years. The current population of under 16 year olds in the south of the country is approximately 270,000. The Paediatric centre in CUH will provide service to the south/south east hospital groups and corresponding Community Healthcare Organisations bearing in mind that 15% will end up being referred to the Dublin centres for consideration of epilepsy surgery.

Ketogenic Diet

Approx. 30% of children with epilepsy have drug resistant epilepsy. 2008 Recommendations of International Ketogenic Diet Study Group (Kossoff et al [70]) recommend that Ketogenic Diet should be strongly considered for in a child who has failed 2-3 AEDs regardless of age or gender.

Efficacy of the ketogenic diet for the management of paediatric refractory epilepsy has been demonstrated in a number of randomised controlled studies, systematic reviews and meta-analysis.

The findings have been very consistent, with approximately 50-60% of responsive patients having a >50% reduction in seizures, 30% having a >90% seizure reduction and 10% becoming seizure free [71]. Cochrane Review 2012 reported that those with medically intractable epilepsy or those in whom surgery is unsuitable, a ketogenic diet could improve seizure control, but tolerability is poor [72].

Ideally, within the specialist paediatric epilepsy centers, there should be a ketogenic team. In addition to the paediatric neurologist, input from dietitians and nurse specialist would be required in a ketogenic team. Access to similar teams should be considered in adult centers as there is increasing evidence that Ketogenic Diet or a modified version of Ketogenic diet can be as effective on seizure control in adults as seen in children. Also with increasing diagnosis of Glut 1 deficiency, where at present the diet is to be used as the lifelong treatment of choice, there are increasing numbers of patients transferring to adult services [73].

We envisage over the next 5 years that there will be a requirement of 2 WTE dietitians, with nursing and admin support within the New National Children's hospital; this will allow for caseload of 30-40 children on the diet at any one time. There is a need for a 0.5 WTE at CUH and 1 WTE Dietitian at 2 of the adult centers and 0.5 at the remaining 2 adult centers. This gives a total requirement of trained Dietitians across the paediatric and adult epilepsy services of 5.5 WTEs (currently there is the equivalent 1 WTE). Nursing and admin support will managed within existing resources of the centres.

Managed Care in the Community for Paediatrics.

A network of care based on lead community paediatricians using standard operating procedures in conjunction with nursing expertise, which will use phone, email and web based support and the epilepsy EPR. In time outreach clinics may be developed. Current resources for these networks are listed below.

Dublin	OLCHC	2 Paediatric Neurologists Community Paediatrician
	CUH Temple Street	2 Paediatric Neurologists 3 Community Paediatricians
	AMNCH	3 Community Paediatricians
Cork	CUH/ Mercy Hospital	2 Paediatric Neurologists 9.5 wte Paediatricians 4.7 Neonatologists
Peripheral Paediatric Units	Limerick	8 Paediatricians
	Tralee	3 Paediatricians
	Portlaoise	3 Paediatricians
	Kilkenny	3 Paediatricians
	Clonmel	3 Paediatricians
	Waterford	3 Paediatricians
	Wexford	3 Paediatricians
	Drogheda	8 Paediatricians
	Cavan	3 Paediatricians
	Mullingar	3 Paediatricians
	Ballinasloe	3 Paediatricians
	Galway	4 Paediatricians
	Castlebar	4 Paediatricians
	Sligo	3 Paediatricians
	Letterkenny	3 Paediatricians

*Table 3 Current Resources for Paediatric Network
Information correct as of March 2014*

In urban areas where general paediatricians are scarce, some community care for stable epilepsy patients in the older child category could be provided by GPs under guidance and RANPs in a similar fashion to adults. The Paediatric Emergency Services manage childhood seizures and status epilepticus according to International Guidelines. Currently children with new onset epilepsy are usually seen by a Consultant Paediatrician within 4–6 weeks. Children referred for EEG by a Consultant Paediatrician usually have their EEG undertaken within 2–5 months. Paediatricians in Peripheral Paediatric Units have access to Consultant Paediatric Neurology advice 24/7. There is no delay in access to Paediatric Epilepsy Surgery if this is deemed appropriate. The British Paediatric Neurology Association has instituted Paediatric Epilepsy Training programmes (PET courses – for GPs, Paediatricians and Paediatric Neurologists) and 2 courses have been held in Ireland.

Transition to adult services

Transition is the planned move of a patient's care from a paediatric to an adult health care provider. Transition is a step necessary to achieve the best outcomes possible for patients and their families in areas of health, independence and adulthood. Transition can be defined as 'a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-orientated healthcare systems' [49]

Preparing for this transition is essential as paediatric services which are generally family centred and developmentally focused differ significantly from adult medical services which attempt to acknowledge patient autonomy.

Transferring care to adult physicians should be 'a guided educational and therapeutic process, rather than an administrative event' [50]. It should also recognise that transition in health care is only one element of the wider transition from dependent child to independent adult and that in moving from 'child centred to adult health services, young people undergo a change that is systemic and cultural, as well as clinical' [50]. Encouraging young people to develop as much independence as possible, both from their families and health care staff will help bridge the gap to adult service.

Transition should be a planned, phased process, ideally one that is delivered in phases. Irrespective of age or number of phases, it is widely agreed that the concept of transition should be introduced in early adolescence, with the young person becoming aware of their own health and care needs, and the full implications of their medical condition. Progression through phases should be based on the assessment of the young persons' understanding and their confidence in their own autonomy. Six key areas should be addressed in all phases of transition and these are;



Fig 9; 6 key areas to be addressed during transition to adult services

By the final phase, the young person should have a considerable degree of autonomy over their care. They should be aware of their own health care needs and how best to access support or seek advice and further information/education if needed. With respect to clinical governance, the patient remains under the care of the clinician from the paediatric service until they are formally reviewed at the adult service.

For transition to be successful there are a number of key elements which needs to be considered;

- ▲ Effective communications between hospitals for transfer of medical records and imaging results. Within the NCPE, it is anticipated that the EPR will address this issue, allowing for a more seamless transfer of care.
- ▲ Flexibility with respect to timing of transition. Not all young people will be ready to make the transfer to adult services at the same time. Issues such as cognitive and physical development, emotional maturity and the status of their health should be taken into account when planning transition. This is particularly relevant for children/young adults with comorbid difficulties which could include learning difficulties.
- ▲ Appropriate educational interventions are necessary to assist the adolescent understand the disease, treatment rationale, recognising triggers, taking appropriate action and learning how to seek help from health professionals and navigate the health system. Within the NCPE, it is hoped that the role of the RANP, both from paediatric and adult services, will assist the patient through this process. Having the RANP as key contact person will also be beneficial as they key person will be 'gate-keeper' for other ancillary services and will assist the patient in terms of how to access same.
- ▲ Concerns about equivalency of service are highlighted as potential challenges for successful transition. The NCPE would anticipate that transferring from one predominantly nurse led service to another equivalent nurse led service should ensure that expectations with regard to quality and intensity are met.

The NCPE have developed a standard operating procedure (SOP) to guide transition from paediatric to adult services. It is anticipated that agreement on same will lead to coordinated transfer process which will include paediatric service, adult epilepsy service, transition nurse and primary care physician.

The NCPE recommends that each site serving paediatric patients with Epilepsy refer to the SOP even when paediatric and adult services are in the same hospital as evidence would suggest that geographic collocation does not always translate into smooth transition services.

The SOP is based on the following recommendations for best practise;

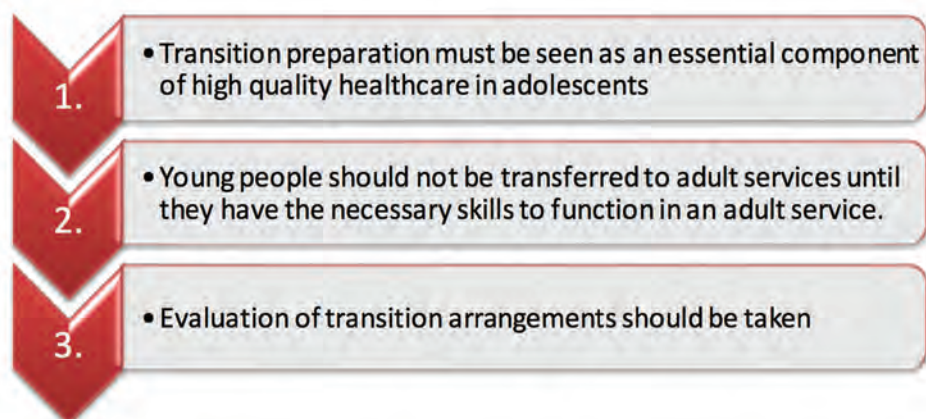


Fig 10; best practice recommendations for transition

3.4.2 Intellectual disability

People with Intellectual disability frequently have the most difficult to control forms of epilepsy. The frequency of epilepsy amongst this group of people is approximately 20-25%. There are, as with paediatrics, particular needs in this group that need to have special consideration. The primary concern is the development of a coherent and expert outreach service, which will vastly improve the experience of those with Intellectual Disability (ID) who attend hospital outpatient clinics. It is envisaged that the regional nurse-led service will provide this outreach with a lead nurse within the ID service acting as a lead and liaison with the regional RANP.

Similar to the above there will be a toolkit of pathways and protocols for the specific intellectual disability sector. A memorandum of understanding will be agreed between the centres providing the outreach and the ID organisation hosting the outreach clinic prior to the outreach clinic commencing. It is envisaged that the MSc Advanced Practice (epilepsy) programme or specific education modules from it will be extended to nurses in the intellectual disability sector with the explicit aim of the intellectual disability services developing the role of CNS and RANP in epilepsy.

There is also a significant role for neuropsychology with respect to the management of this group of service users. This role can be described as both direct and indirect;

- ▲ supporting individuals with ID directly (e.g. cognitive assessment (monitoring cognition over time); support with emotional, psychiatric or behavioural presentations; medication management; promoting independence; providing education)
- ▲ supporting individuals with intellectual disability indirectly (e.g. supporting staff/families in recognising and recording seizure activity; promoting least restrictive practices; providing staff training and education)

3.4.3 Older People

Older people comprise the fastest growing group of patients being diagnosed with epilepsy. They often have epilepsy as a result of an underlying neurological or metabolic disease (such as head trauma, stroke, dementia, diabetes, and thyroid disease). As such there is a higher representation of older people as inpatients, and a significantly higher proportion who suffered from potentially life threatening prolonged seizures i.e. status epilepticus. The main considerations in a population of older people include the following;

- ▲ consideration the possibility of co-morbid conditions;
- ▲ awareness of the sometimes subtle presentation of dangerous prolonged seizures in the hospitalized patient
- ▲ To make sure that at the Care Pathway and the protocol for management of seizures in the hospitalized patient includes consideration of subtle confusion or delirium as presentations of epileptic seizures.

3.4.4 Women with epilepsy

A very detailed SOP on the management of women with epilepsy has been developed. It covers the pathways of care associated with all aspects of pregnancy, contraception and menopause and includes detailed intelligent support for the obstetrics service in the management of seizures and guidance for ante-natal care including specific information covering the known extra risks of epilepsy associated with pregnancy to both the mother and foetus.

3.4.5 Psychogenic Non-Epileptic Seizures

It is thought up to 15% of regular attendees at epilepsy clinics world-wide are suffering from seizures that are not due to epilepsy but may be caused by a variety of other disorders that cause transient neurological dysfunction. Clinical pathway to exclude cardiac and other vascular reactivity disorders have been developed by far the most common cause of non-epileptic seizures

are psychogenic and often related to chronic long-term psychological difficulties that are now manifesting as physical disorders. The treatment of this group of patients in epilepsy clinics is recognized as a significant cause of inappropriate therapy.

This group requires a highly specialized multidisciplinary team that will only be available at the epilepsy centres and currently is only available at one centre in Ireland. Significant further investment will be required to properly manage this group of patients and it will require new psychology and psychiatric resources which have not yet been realized by the programme (see section 8 Requirements).

4.0 National Guidelines for epilepsy care, Standard Operating procedures (SOPs) and Management Operating Procedures (MOPs)

The epilepsy programme has reviewed and assessed all internationally recognized guidelines of care. The broad general principles of epilepsy care are embodied in Commission on European Affairs: Appropriate Standards of Epilepsy Care Across Europe document, first published in 1997 [46]. In time it is envisaged that definitive guidelines for specific area care that have high impact and are exclusive to the Irish health system will be developed and subsequently sent for sign-off by the clinical effectiveness committee. End to end guidelines along the lines of SIGN and NICE [34, 35] will not be completed in the short term, rather, single focused guidelines be drawn up through the governance of the Clinical Advisory Group.

In the meantime the National Epilepsy Care Programme began a process of wide consultation (patient, medical, nursing, patient advocacy and HSCP) for the development of a book of standard operating procedures (SOPs) and management operating procedures (MOPs) (to date forty two SOPs have been created). In line with policies and procedures outlined by the HSE, this programme will seek to marry evidence based clinical decision making with process improvements that will reduce variability across the health system in epilepsy care. Currently there are 13 SOPs in wide usage throughout the services not including the SOPs being used in the EMUs.



Figure 11; Practice Iceberg

5.0 The Electronic Patient Record

Standardized clinical documentation, sharing and exchange of patient information between clinicians as well as performance monitoring and evaluation are all key to the success of the new model of epilepsy care. This will be facilitated by a secure web-based electronic patient record (EPR) which will provide authorized clinicians, regardless of geographical location, with access to complete and accurate patient records when and where needed. The EPR will support prompt interrogation of integrated, harmonized and consistent patient data thus supporting patient management. For the past 8 years a programme of research and development undertaken by the epilepsy team in Beaumont hospital has resulted in the design, development and implementation of such an EPR [42, 43 & 54]. Adoption of EPRs is part of world-wide efforts to manage the increasingly complex needs of patients with chronic illnesses such as epilepsy. A recent survey of clinical directors and programme leads in the Irish health Service shows that the development of integrated electronic solutions is considered to be of the highest priority amongst health professionals.

The EPR is a web-based application and contains functionality appropriate to the delivery of epilepsy care. System modules include: clinic administration, demographics, social history, epilepsy history, anti-epileptic medication, allergies, clinical investigations, VNS clinic, OPD plan, multidisciplinary team meeting template, nurse telephone advice line (TAL) template. The EPR has a comprehensive audit trail that tracks system use and changes to records made by users. The system incorporates clinical archetypes for representing a patient's clinical description within the EPR. It also provides the flexibility to capture patient specific nuances. The epilepsy EPR architecture was designed to improve standardisation of medical vocabulary and record keeping, to support the delivery of clinical services as well as clinical research and health services monitoring and planning. A reporting tool allows efficient interrogation and analysis of data about individuals or populations of patients. This functionality holds all of the quality indicators recently published by the American Academy of Neurology for good care [43].

The EPR has been in daily use at Beaumont Hospital since 2008 and in St James's Hospital, Galway University Hospital and Limerick University Hospital since 2012. In 2014 it was rolled out to Sligo Regional Hospital, the Mater University Hospital Dublin, and Cavan Monaghan Hospital Group. The EPR is also supporting outreach clinics in the intellectual disability sector (e.g. Daughters of Charity Clonsilla, St Mary's Drumcar, Cheeverstown, and in maternity care (e.g. National Maternity Hospital Holles Street, Rotunda Hospital, Our Lady's Hospital Drogheda). As the NCPE continues to evolve, the EPR implementation will expand further. For example, there are plans to roll it out to support paediatric care and transition clinics. Furthermore, the EPR will be enhanced to support patient-self management by developing relevant patient portals to the system.

The epilepsy EPR is having a positive effect on how epilepsy care and clinical research is delivered. It is improving quality, safety and value in epilepsy services. Clinicians say it is promoting a service that is more responsive to the needs of the patients. Information is available in a more timely fashion and more clinicians have access to the same information thus promoting a model of shared epilepsy care. To date more than 6, 500 individual epilepsy patients have a validated electronic record. There are almost 60 users of the EPR including consultant epileptologists, non-consultant hospital doctors, clinical nurse specialists, community epilepsy nurses, researchers and clinical management personnel. The success of this EPR was acknowledged when it was awarded a Taoiseach's Excellence in Public Service Award in 2012.



Figure 12; Potential benefits of EPR

The epilepsy EPR has become a national information system that is accessed using web-based secure portal at all regional sites. The system allows for rapid retrieval of patient information anywhere in the country, synthesis of results and easy and instantaneous communication with primary care and other centres. Patient registration on the EPR is a key performance indicator for the NCPE. The EPR project anticipates the development of a national unique health identifier over time which will be incorporated into the system.

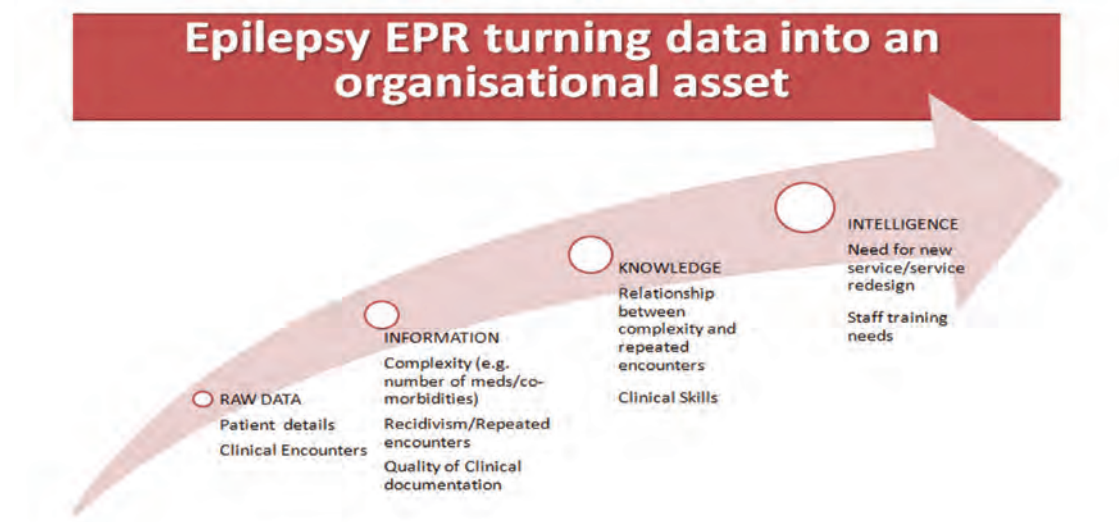


Figure 13; EPR as organisational asset

6.0 Research

One of the most important quality indicators for any health service is the quality of research performed by the multi-disciplinary team. Such research should be directed towards improving the quality and safety of care for the beneficiaries of the service locally, regionally and nationally. It should also contribute to the international efforts to improve understanding of the basic mechanisms of the disorder and its treatment.

The epilepsy care domain in Ireland has a long tradition of driving and participating in basic science, clinical trials and health services research to drive continuous quality improvement. In this regard, strong national and international collaborations have been formed. A goal of the NCPE is to ensure that this research tradition continues to grow and is aligned with wider health research strategies (e.g. Science Foundation Ireland, Health Research Board, European Union). The NCPE will work to build research capacity by developing relationships between healthcare practitioners and academia, and promote integration along the research continuum from bench to bedside and bedside to bench. The desired outcome is that the epilepsy domain is seen as a priority and strong contender for national and EU research funding.

As has been demonstrated in other conditions all patients attending regional centres or outreach clinics should be offered the opportunity to be enrolled in research projects with the above aims. The NCPE encourages participation in research of various forms including phenomenological and qualitative research, health service delivery research using both formative and summative research methodologies, population based research, translational research and basic mechanisms of epilepsy. Joint programmes for clinical trials with industry are also encouraged to develop and test new treatments.



Figure 14; academic and clinical research

The NCPE programme has developed an SOP for research enrolment that is offered to all new and existing patients. As has been demonstrated in other area, Ireland has the unique potential for the delivery of national population based data with cooperation across institutional and geographic boundaries which are embedded in the governance structure of the care delivery service and which can be replicated for research purposes.

7.0 Governance

7.1 Introduction

The approach to clinical governance for the epilepsy care programme will be in line with the Code of Governance for The Health Service Executive [51]. Clinical governance means corporate governance for clinical performance, built on the model of the Chief Executive Office, working in partnership with the clinical directors, directors of nursing/midwifery and service/professional leads.

Clinical governance is about people receiving the right care, at the right time, from the right person in a safe, honest, open and caring environment [41] (see Appendix 7 for guiding principles). Effective governance arrangements recognize the interdependencies between corporate, financial and clinical governance across the service and integrates them to deliver high quality, safe and effective healthcare. Effective governance and accountability can be achieved by embedding leadership and operational management at a corporate and clinical level. This is underpinned by 6 key steps (summary figure 9):

1. Agree the measurable safety, quality, access and cost objectives you want to achieve which are in line with HSE national priorities.
2. Ensure there is a documented standardised pathway in place, which is supported by standard clinical decision making and regulatory requirements.
3. Ensure that all parties involved in the pathway have total clarity of their accountability roles, responsibilities and governance arrangements.
4. Ensure there is a balanced set of metrics in place to track the performance of the pathway.
5. Ensure there is an effective clinical meeting held regularly, where those who are managing the pathway identify variance in its operational performance and log actions to be taken to improve the outcome for the patient.
6. Where the reason for the variance is unclear or the action to address variance is significant then ideally there should be some skilled local project and process improvement resource available to guide the clinicians through the change process [may need external support or oversight].

THE EMBEDDING OF CLINICAL OPERATIONAL MANAGEMENT

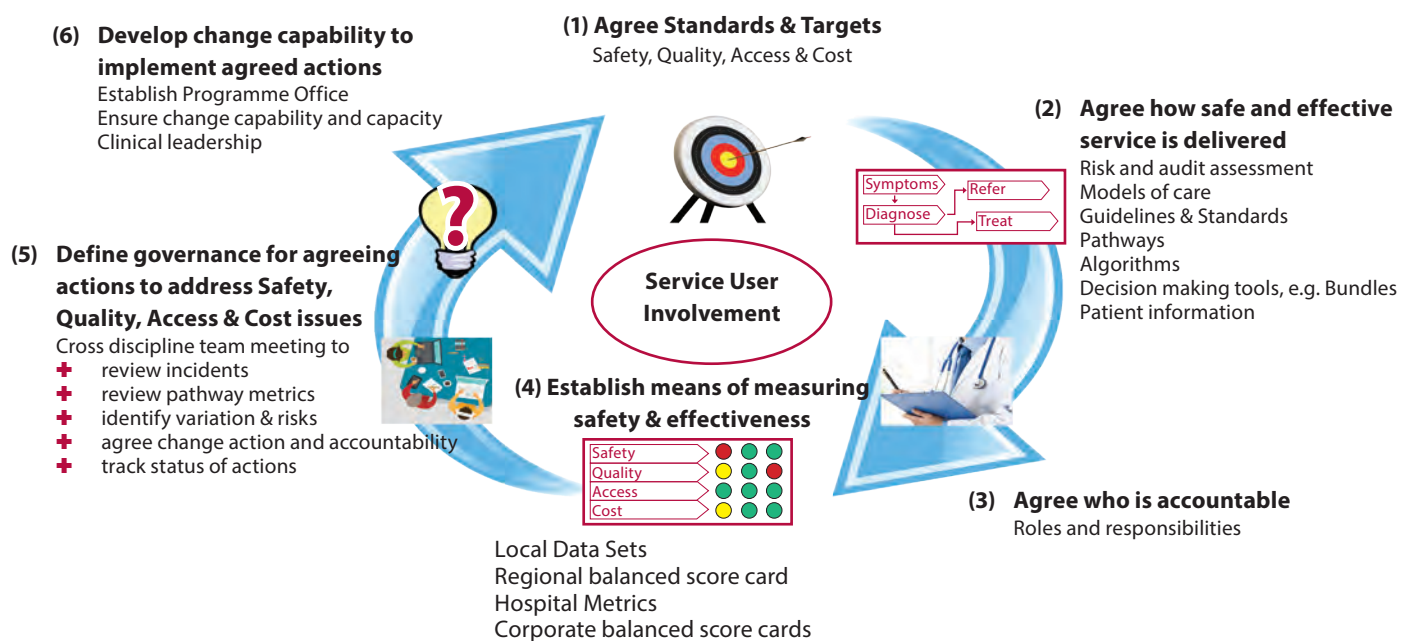


Fig 15; key steps to effective clinical governance

The National Clinical Programme for Epilepsy has embedded these principles by adopting a leadership and accountability framework that envisages every clinician and administrator working in the programme having clear roles and responsibilities. The structure of the programme is summarized in Fig 10. It embraces clinical effectiveness, clinical audit, research and development, clinical indicators, integrated pathways, risk management, and organisational development.

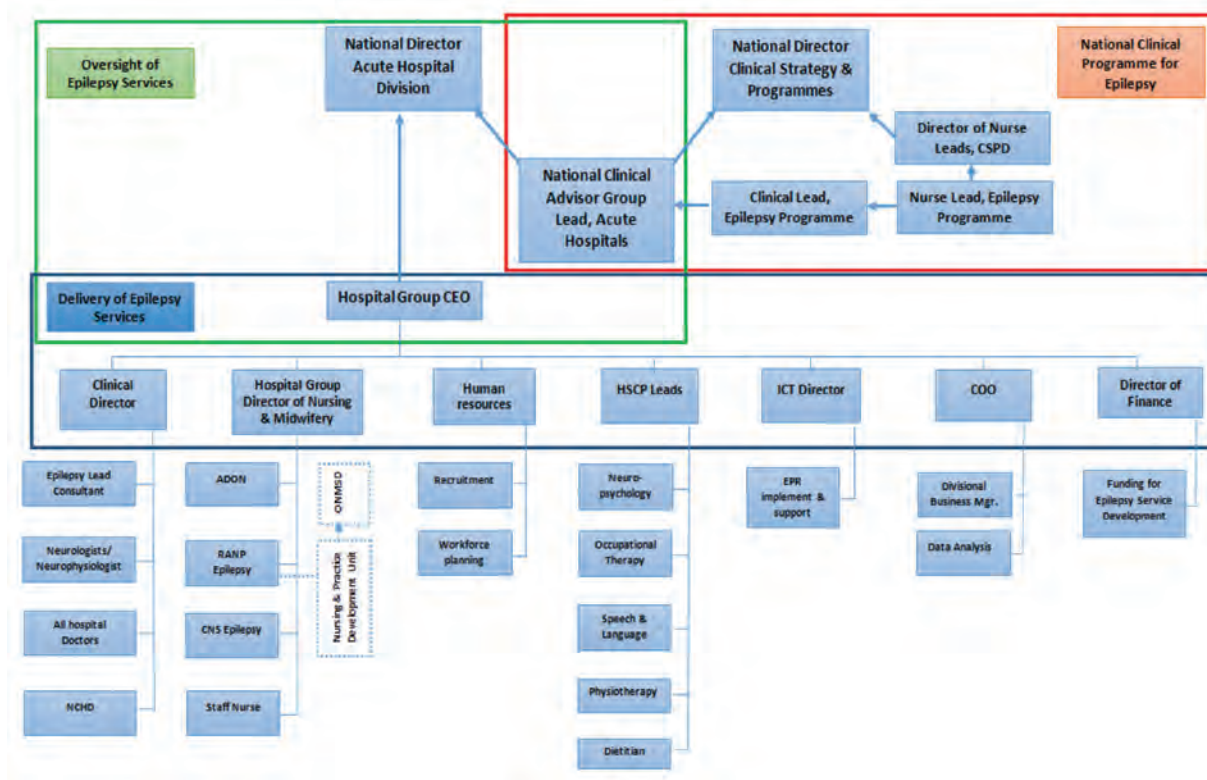


Fig 16; Governance of Epilepsy Service

7.2 The Governance structure of the programme

The governance consists of two supervisory groups:

1. A working group

The working group was convened in April 2010. The project group consists of: A National Clinical Lead who is a consultant neurologist with special training in epilepsy, a National Lead Advanced Nurse Practitioner (RANP) in epilepsy care, an assistant Director of Nursing (workforce planning), a Public Health Consultant, General Practitioner and a Programme Manager. This group meets weekly to plan, implement and continuously evaluate the programme.

2. A Clinical Advisory Group (CAG)

The clinical advisory group was first convened in May 2010. This group consists of all members of the project group in addition to: all consultant neurologists with specific training in epilepsy care, two consultant neurophysiologists, a neuropsychologist, a chief clinical measurement scientist and a representative of the national patient organization (Epilepsy Ireland), a physician with special training in intellectual disability and a medical physicist / health informatics specialist. It is envisaged that this group will be the main conduit of information and the dissemination of detail in relation to programme development, rollout, research, audit and performance in the medium to long-term.

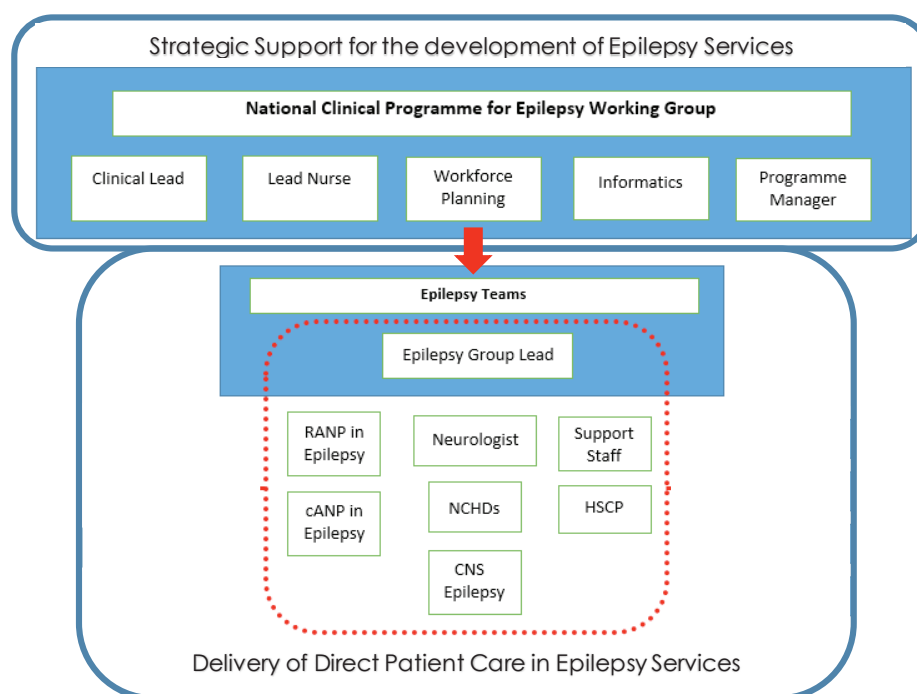


Figure 17; National Epilepsy teams

7.3 Roles and Responsibilities

With respect to roles and responsibilities, it should be noted that responsibilities outlined below are in addition to local and professional accountability pathways.

National Clinical Lead for Epilepsy

The National Clinical Lead for the epilepsy programme will be a consultant Neurologist with specialist training in Epilepsy care working in one of the regional centres. He or she will be accountable to the National Director, Clinical Strategy & Programmes Division, the clinical advisory group for the national epilepsy programme, the CEO and board of the HSE. It is envisaged that this role will rotate regularly amongst the regional leads in an attempt to provide both clinical leadership and project management opportunities amongst the epilepsy consultant cohort.

Epilepsy Group Clinical Leads

Group Epilepsy Leads are the lead clinicians for the realisation of the vision, aims and objectives of the NCPE in each of the hospital groups. He or she is accountable to the National Lead with respect to the quarterly reporting of KPIs and Audit outcomes. In relation to epilepsy care, he or she has responsibility for the co-ordination of standardized care within the resources available within the region including supporting the training of nurses (to RANP level), Epilepsy fellows, other neurology trainees and medical students.

National Nursing Lead

The National Nursing lead is the lead RANP. He or she is accountable to the National Clinical Lead and to the Office of Nursing and Midwifery director within the clinical programmes division. He or she will act as a mentor for epilepsy CNS and RANPs, be responsible for developing RANP and CNS competencies and will work closely with the RCSI in the development of the curriculum and the course evaluation for the MSc Advanced Practice (Epilepsy). It is envisaged that this role is rotated regularly (every 2-3 years) to provide leadership opportunities to the RANP cohort.

Consultant Neurologists

Consultant neurologists (with or without special training in neurology) will work in collaboration with group epilepsy leads in the delivery of NCPE aims and objectives.

The Epilepsy RANPs and CNSs

RANP's & CNS's in epilepsy are clinically accountable to the patient's named consultant neurologist and to the group epilepsy lead. They are professionally accountable to the Director of Nursing (DON) in which the epilepsy centre is hosted and the national programme lead RANP (epilepsy). Nurses working away from the epilepsy centre in another hospital or health care setting will have professional accountability and responsibility to the DON in these outreach hospital or health care settings. He or she will be responsible for the local delivery of high quality epilepsy care in the hospital, and in the community at outreach clinics. He or she will be responsible for the safe, efficient and effective management of patient information both paper and electronic.

Health & Social Care Professionals

Health & social care professionals (HSCP) are professionally accountable to their department manager and/or existing local line management arrangements. With the roll-out of CORU, HSCP's will have to maintain their own registration/continued professional development with the support of their manager. When working with patients with Epilepsy, HSCP's should work in a multidisciplinary fashion with other clinicians, supporting the person with epilepsy in identifying and achieving their identified goals.

General Practitioner

The General Practitioner is accountable to the Irish College of General Practitioners and the HSE. The GP has responsibilities for the general management of epilepsy patients in the community, and for maintaining contact with their epilepsy centre.

Administrators

The administrators will be accountable to the administrative supervisor in the epilepsy centre. He or she will be responsible for registration of all patients on the EPR and the management of the administrative functions to support the work of the group epilepsy lead and RANP/CNS in Epilepsy within the centre.

7.4 Training

Nursing

This programme has planned and is currently supporting the creation of a new cohort of expertise at registered advanced nurse practitioner (RANP) level. Nurses currently working at Epilepsy CNS level may opt to stay at this level and the programme acknowledges their contribution. The Professional accountability of nurses and midwives is clearly defined by the Scope of Nursing and Midwifery Practice Framework. Each nurse and midwife is individually accountable for his/her professional practice including appropriate delegation. [47]. It is expected that new staff will be recruited as 'candidate ANPs'. Defined competencies using a competency framework will allow these newly appointed candidates to move towards Registered Advanced Nurse Practice over a predetermined period of time through a combination of education, experience, supervision and clinical practice competency development. Education will commence with a post-registration module/programme, which will cover basic physiological, pharmacological, psychological and social issues to do with epilepsy. A Personal Development Plan, the competency framework with supported mentorship; benchmarking and extensive clinical experience will enable the novice epilepsy nurse over time to practice at an advanced level.

The Royal College of Surgeons have collaborated with the programme/leads and have developed an MSc advanced practice (epilepsy) (inclusive of nurse prescribing), which provides the educational components required to allow nurses to achieve the competencies necessary for registration as a RANP. This commenced in January 2012.

Medical

Neurology departments nationally currently employ just two junior doctors in a fellowship capacity, but without formal recognition of training by the medical colleges. Furthermore, there are no agreed training, service and research requirements. A formal process will be put in place with the Irish Committee on Higher Medical Training (ICHMT) the Irish Institute of Clinical Neuroscience (IICN) and the National Epilepsy Care Programme envisages, to create two, 2-year fellowship training programmes in Epileptology suitable for doctors either at SPR level or eligible for SPR training. Centres in Beaumont Hospital and St James's Hospital will run these fellowships. A curriculum will be developed with training in Clinical epileptology/EEG/ Epilepsy surgery multidisciplinary decision making/ neuropsychiatry and neuropsychology. It is envisaged that over the lifetime of the programme, four fellowships will be developed nationally one in each region.

In addition to the fellowship programme, there will be an ongoing programme of education for the following groups:

- ▲ SPRs and Non- SPR registrars Neurology
- ▲ Acute Medicine Physicians, AMAU Staff and Neurology ward nurses
- ▲ Medical Students
- ▲ General Practitioners

Clinical Neurophysiological Science

Clinical Neurophysiological Scientists (CNPS) have an important role in the timely access to high quality diagnostic neurophysiological techniques such as routine and emergency (including portable EEG) and more specialized studies such as ambulatory EEG and Prolonged Video-EEG.

Currently clinical neurophysiological scientists (formerly known as EEG technicians) are required to attain a BSc Hons in Clinical Measurement Science (Neurophysiology) at the Dublin Institute of Technology (DIT) Kevin Street, School of Physics and Health Sciences in Dublin or an equivalent international degree.

Developments in this area include a voluntary state register for clinical measurement scientists beginning in 2012 and recognition of the Irish Institute of Clinical Measurement Science (IICMS) as the regulatory professional body. With the expansion of the Epilepsy Monitoring units the establishment of a national training centre for EMU monitoring for CNPS should be considered: professional competency exams are currently only available via the American Society for EEG and EP Technologists e.g. ABRET CLTM.

7.5 Key Performance Indicators and Audit.

Regular prospective audit will be central to the programme in order to justify funding and demonstrate improved outcomes in quality and access. The epilepsy EPR, which will be updated at every clinical encounter, will contain the data required for generating key performance indicators. Special arrangements for audit of telephone and electronic communication will be made and the HIPE data base will be used to understand outcomes in hospitalized patients. Draft Key performance Indicators have been submitted to the division which include:

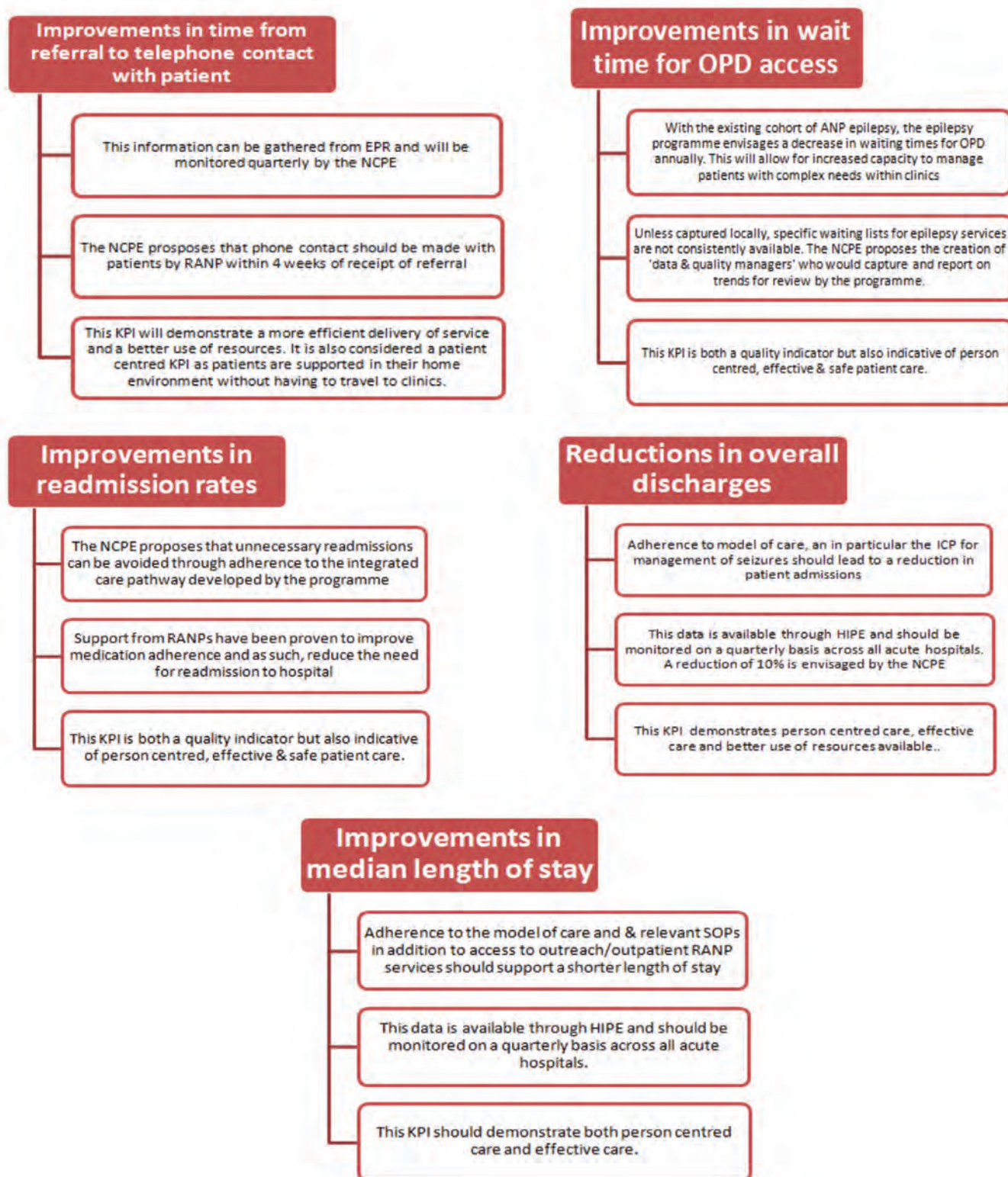


Figure 17; Key Performance Indicators

The KPIs chosen are specific, measurable and feasible in that for the most part they use existing data. They have considered the domains of 'structure, process and outcome' with particular emphasis on quality and access. It is not possible to measure individual patient level costs at this time but it is expected that reduced bed days will result in cost savings. The process will involve establishing a baseline, tracking changes and reporting on improvements or areas which require intervention. The KPIs also provide criteria and standards for clinical and organisational audit.

Governance will be addressed at two levels to ensure an effective performance monitoring system:

- ▲ Scientific governance of the KPIs within the overall Clinical programmes with technical oversight of the selection of indicators; updating based on evidence; agreement of data definitions; ensuring robust analysis; etc. and
- ▲ Management structure for sign off on KPIs and for implementing processes for data collection, analysis and reporting.

The National KPIs will be reviewed in the context of the Corporate and Service Plan with Department of Health. Data collation, analysis and reporting processes will be developed with the Directorate of Corporate Planning and Control Processes (CPCP). The KPIs will also be reported in conjunction with current monitoring HSE frameworks i.e. Healthstat. In September 2010 HIQA published 'Guidance on developing key performance indicators and minimum data sets to monitor health care quality' based on an analysis of evidence from an extensive literature review. This document has been used to inform the epilepsy programme on indicator development.

7.6 Patient Safety and Quality Improvement.

In the last 15 years since the publication of 'To err is human' in 1999, international health systems have begun to address the phenomenon of avoidable harm. Many studies since the early 1990's have shown that the percentage of patients harmed by the healthcare system is anything from 10-25% and this figure remains stubbornly high despite multiple interventions and safety system changes. A number of factors contribute to this scenario including the rising complexity of medical care, the increased longevity of citizens leading to living with multiple chronic illnesses and explosion in medical and scientific knowledge; but by far the most important factor is the failure to reduce the variation in medical care.

According to the International Ergonomics Association (IEA) "Ergonomics (or human factors ergonomics HFE) is the scientific discipline concerned with the understanding of the interactions among humans and other elements of a system, and the profession that applies theoretical principles, data and methods to design in order to optimize human well-being and overall system performance." It then goes on to state:

HFE contributes to five domains of patient safety:

1. Usability of medical devices and health information technology
2. Focus on human error and its role in patient safety
3. Role of health care worker performance in patient safety
4. System resilience and its role in patient safety
5. HFE systems approach to patient safety.

All of these are pertinent to the NCPE. The programme has been orienting itself towards measuring these outcomes. ***In our view what we are about in healthcare reform is safety of our patients and our staff;*** all else flows from that statement; all quality, all performance, all satisfaction; is really a debate about how safe a practice is, not how good or efficient, or effective or value added it is but if we first and foremost concern ourselves with how safe it is...we have at least a common aim!

The HSE has in place structured systems to identify, report, investigate and address incidents that arise in the delivery of healthcare services. Protocols are in place that are adhered to nationally, to ensure that any incidents of harm are investigated locally so that any issues are identified and actions taken to ensure any risk is minimized. Staffs employed by the HSE have been trained to ensure that all local investigations follow the agreed HSE's Investigation Procedure.

For the delivery of epilepsy care, systems will be in place to ensure adherence to good standards, including ethical standards and systems for making and dealing with complaints in line with existing HSE guidance documents/policy. Clinical decision-making support tools in the form of Integrated Care Pathways, SOP's and MOP's have been developed by the epilepsy programme to ensure that the care given is standardised with minimum variation and is wholly evidence based.

Information governance including how data will be protected and how information is to be disseminated throughout the system will be developed in line with the overall information strategy for the Clinical programme. It is anticipated that the forthcoming Health Information Bill will address many of the issues around data and information governance.

Reference to the National Standards for safer better healthcare is also essential when addressing issues around quality patient services. The standards provide for the first time, a strategic approach to improving safety, quality and reliability in our health services. They will form the basis for future licensing of all healthcare facilities in Ireland.

In particular, the standards will:

- ▲ make sure that service providers are accountable to the public, service users and those who fund them
- ▲ help the people in charge of services identify what they are doing well, and where they need to improve
- ▲ help make sure that the quality and safety of services is the same no matter where people live in Ireland or what health service they use – no matter where the service is, it should be safe
- ▲ describe what should be in place for day-to-day services to be safe and effective.

The Epilepsy Programme is confident that when implemented, the recommendations within this model of care are in line with the safer better healthcare standards.



Figure 18; Epilepsy Programme & Standards for Safer Better Health Care

7.7 Performance Management

The epilepsy programme recommends team based performance management (TBPM) as a mechanism for managing performance across the programme sites. TBPM:

- ▲ Provides greater clarity on roles and purposes
- ▲ Enables better communication and participation within and among teams
- ▲ Increases motivation by providing a structure within which staff can contribute to the service goals
- ▲ Provides a means for identifying and addressing learning and development needs
- ▲ Each of the regional sites will be expected to perform and function as a team with the regional lead taking the position of Team Leader. Each of the teams will review its progress under the leadership of the regional lead.

Personal Development Planning is a continuous development process that enables people to make the best use of their skills and helps advance both the individuals plans and the goals of the organization. The Epilepsy teams are expected to develop PDP's and to discuss them with their line managers and regional lead on a regular basis.

The epilepsy programme teams are expected to comply with local and national disciplinary and grievance policies when poor performance requires review.

8.0 Requirements

As referred to previously and repeatedly throughout this vision document, the realisation of many of the aims of the NCPE is reliant on additional resources. Quantification of some of these resources is a challenge, as the model proposed, in particular the role of the Advanced Nurse Practitioners in Epilepsy. As a new service, there are no equivalent services for which appropriate ratios can be benchmarked. The proposed ratio of 1:140,000 population is roughly based on current population, prevalence of epilepsy and an anticipated cohort of 30 RANPs. These figures are based on current levels of service provision and would not be reflective of any potential increase in demand in the service which is likely as knowledge and awareness of the service increases. Any changes in demographics/prevalence will also need to be reflected in workforce planning for sustainability of the nurse led model proposed in this model of care.

Neurologists

Ideal ratios of neurologists are easier to anticipate. Currently there are 34 approved Consultant Neurologist posts in the country. Of these, 33 are currently filled. With a population of approximately 4.5 million, our current ratio stands at 1:132,352. The Association of British Neurologists (ABN) would recommend a ratio of 1:70,000 population, or a minimum of 64.3 neurologists for Ireland. Currently there is a shortfall of 30 consultants nationally, in line with ABN recommendations.

While specific recommendations are referenced below, it should be noted that the follow also need to be considered;

- ▲ Access; access to services should be equitable across the country and not variant depending on staffing levels in different hospitals/primary care. Access to services includes initial access to Consultant Neurologist, access to diagnostic services and access to treatments either as an inpatient, day patient or out-patient.
- ▲ Specialist Expertise; additional neurologists, with specialist expertise in Epilepsy are needed to support the timely diagnosis of patients with epilepsy. There is a need also for more specialist Health & Social Care professionals and greater opportunities for GP's to develop an interest in Epilepsy.
- ▲ Health & Social Care Professionals enable people with epilepsy to achieve their maximum independence within the limits of their condition and so help to reduce the burden of disease and improve quality of life. Many people are enabled to remain in the workforce. Challenges arise around the fact that there are no internationally recognised staffing ratios for HSCPs treating people with neurological conditions, including epilepsy. It is important that resource requirements are patient needs based into the future.
- ▲ Dedicated administrative support is an essential requirement of all epilepsy services. Not only does this support the efficient management of OPD clinics, it also ensures that time meant for direct patient care is not spent on administrative tasks as this is not considered the best use of available resources.
- ▲ Space, facilities & equipment; Sufficient resources in terms of space, facilities and equipment are required in all settings. Investment in additional staff is of little benefit if they do not have the space to see patients.
- ▲ Engagement with all stakeholders; this applies to all service providers from in-patient services, nurse-led services, primary care (self-management), non-statutory/voluntary agencies and GP's. Care for patients with all chronic diseases including Epilepsy should cross institutional boundaries.

Neurophysiology (Routine EEG and Long Term Monitoring)

Approximately 6,000 patients are discharged from Irish hospitals each year with a primary or secondary diagnosis of epilepsy. Assuming each one of these will require at least one EEG (acknowledging that some may require more than one, or some form of Long Term Monitoring) that means that the national EEG requirement for inpatient evaluation is above 6,000. Outpatient EEG testing requires about 1750 EEGs for new diagnoses of epilepsy and at least one EEG/year for the difficult to control group of refractory epilepsy (approximately 10,000 patients). This gives a conservative estimate of 15-17,000 EEGs per annum nationally for inpatients and outpatients. Assuming 5-7% will undergo surgical or diagnostic evaluation this will yield approximately 600 overnight telemetry, ambulatory or prolonged recordings. The academic group of neurophysiologists in Ireland has begun a process of engagement with the office of Clinical Strategy and Programmes to make sure that resources are aligned to deliver the neurophysiological need and have produced a document for manpower planning.

Issues under consideration:

- ▲ Space and consultant requirements to deliver on prioritized EEGs for admitted patients to facilitate delivery of reduced LOS and admission avoidance.
- ▲ Possible applications of tele-neurophysiology for areas without designated cover [53, 54, 55, 56 & 57]
- ▲ Requirements for Clinical Neurophysiological Scientist numbers for national delivery on goals including expanded Presurgical Centres.
- ▲ The impact on non-EEG neurophysiology services.

Radiology

In the last two decades, brain imaging has emerged as a key diagnostic test in the evaluation of seizures. Cranial Computerized Tomography (CT) given its ease of delivery, general ease of access both during regular hours and on-call and its sensitivity to major intracranial pathology that might be at the route of a symptomatic seizure is generally the first study performed in the acute or ED environment. However, the International League Against Epilepsy (ILAE) [46] as well as other national and international guidelines SIGN [34] and NICE [35] all agree that MRI is the modality of choice for imaging seizures with focal onset. MRI has increased sensitivity for causative lesions of epilepsy even when the CT is negative. [47]. It has been suggested that recurrent presentations to ED of refractory epilepsy cases results in over utilization of CT imaging and it is envisaged that the epilepsy programme will save on needless CT procedures.

With this in mind the epilepsy programme has forged links with the National Radiology Programme to:

- ▲ Configure radiology such that timely and appropriate CT can be acquired in the emergency situation with MRI being obtained within a reasonable time scale
- ▲ Develop the notion of 'one stop shops' during first assessment for epilepsy which would include the concept of protected slots for epilepsy imaging

Neuropsychology, neuropsychiatry and psychology services

Among the most significant co-morbidities for patients with epilepsy are cognitive and emotional difficulties associated with the diagnosis. It is thought that more than 50% of patients may suffer from depression, 10% psychosis and at least the same amount with cognitive impairment which is related either to transient effects of seizures and medication or the more permanent effects of damage to the brain as a consequences of, or underlying causes of, seizures. In addition there are large group of patients with non-epileptic seizures (often referred to as PNES –psychogenic Non-Epilepsy Seizures or NEAD – Non-Epileptic Attack Disorder). The most common cause of PNES is psychological difficulties and managing this disorder requires highly specialised skills.

The number of Clinical Psychologists and Clinical Neuropsychologists in Ireland falls well below international guidelines, which recommend that Clinical Neuropsychologists should be linked with all neurology / neurosurgery services, representing a core neuroscience discipline in acute, community and rehabilitation teams.

Clinical Neuropsychologists are the experts in psychology as applied to neurological conditions. Core functions the Clinical Neuropsychologist contributes within Neurology services are as follows;

- ▲ Neuropsychological Assessment
- ▲ Psychological Therapies and Interventions
- ▲ Training
- ▲ Research

Clinical Neuropsychologists also have a key role to play in supporting patients with intellectual disability; individuals with ID and epilepsy often have difficulty self-reporting. There is a need then for those supporting them to be skilled in observing and interpreting their behaviour and their communication in relation to seizure activity and medication effects.

Patients presenting with psychogenic NES represent one area for highly effective intervention by neuropsychology. While many of these clients are open to an account of their experience as having been other than an epileptic seizure, in many more complex cases the advanced therapeutic skills of the experienced neuropsychologist are required to support clients to reach satisfactory reformulations of their experiences, enabling them to learn to manage their difficulty, avoiding recurrence and the attendant distress and costs to the individual, healthcare providers and the broader society

The NCPE envisages the delivery of mental health services by specified individuals trained in the delivery of care for patients with epilepsy. At this point significant investment will be required to expand the specialised neuropsychiatric and psychology services across the epilepsy centres but it is expected that community psychology will be enabled to provide some of the screening and counselling of these patients to relieve the burden on these centres.

Health & Social Care Professionals

Access to dietetic, occupational therapy (OT), physiotherapy (PT) and speech and language therapy (SLT) services will be needed as appropriate to patient need particularly for those with complex epilepsy who may have significant co-morbidities. Epilepsy may be a part of many conditions such as acquired brain injury, brain tumours, intellectual disability (ID) and stroke. The integration of therapy services across the hospital service, primary care and ID services will be facilitated by the GP.

OTs have a key role in discharge planning and rehabilitation of patients with complex epilepsy and in the management of cognitive and safety issues including provision of advice and equipment for home adaptations. Physiotherapy management of clients with epilepsy is focused on the physical disabilities of that client e.g. injury as a direct result of a seizure, brain damage as a secondary consequence of epilepsy, management of vertigo, headache, dizziness, falls prevention and respiratory intervention in the acute phase.

Patients, particularly those with complex epilepsy may require speech and language therapy (SLT) for communication issues which may be quite subtle, but can have a significant impact on participation and on well-being. Examples would include difficulties in non-propositional language type skills such as topic management, sensitivity to conversation partner's needs and literal interpretation.

The ketogenic diet for the treatment of Epilepsy in childhood has been the focus of renewed interest. The NICE guidelines 2012 [69] in the UK recommend that all children & young people with epilepsy whose seizures have not responded to appropriate AEDs are referred to a tertiary paediatric epilepsy specialist for consideration of the use of a ketogenic diet (Recommendation 1.12.1). Dietitians play a vital role in the education, supervision and treatment of patients on this intensive diet. The dietetic treatment complements & in some case replaces the pharmacological treatment to improve quality of life for some patients with Epilepsy.

Finally, Clinical Neurophysiological Scientists (CNPS) have an important role in the timely access to high quality diagnostic neurophysiological techniques such as routine and emergency (including portable EEG) and more specialized studies such as ambulatory EEG and Prolonged Video-EEG.

Pharmacy

The chronic nature of the condition and the drugs employed in the treatment of epilepsy means that there is a need for access to pharmacy services. These services can provide on-going support, advice and guidance for both healthcare professionals involved in their care and for the patients themselves with regard to their medical management.

Pharmacy in Primary Care

The following services can be easily implemented at this level in a relatively efficient budget neutral process:

- ▲ Medication Usage reviews (MUR's): whereby the pharmacist's consults with the patient, and on the basis of an assessment of the patient's understanding of their medication use, formulate a mutually agreed plan to optimise the patient adherence to their treatment program. With the patient's consent this process allows the pharmacist to make recommendations to the prescriber to enhance patient adherence/concordance. As patient adherence is critical in Epilepsy care community pharmacy is ideally positioned to support the patient.
- ▲ Compliance Aids/Monitoring: The majority of pharmacy practices offer some access to compliance aids for patients who have difficulty with complicated treatment regimens, in collaboration with their GP. Compliance aids such as Monitored Dosing Systems (MDS) – commonly referred to as "Blister packs" are also used to physically check the patient's adherence to the treatment regimen.
- ▲ Drug Information Service: As part of the current Community Pharmacy Contract 1996 (CPC) the pharmacist is obliged under Clause 9 to conduct a full clinical review of the patients medication profile on each occasion a prescription is presented. This level of holistic assessment is especially critical when it comes to managing hospital discharge prescriptions. The pharmacist will review any departmental discharge prescription in light of other co-existing treatment regimens – and work with the local GP and/or the Secondary care medical team to ensure that any new treatment is appropriate relative to potential for Drug Interactions and Side Effect profile. Each pharmacy has access to comprehensive Drug Information packages as standard practice.

It is important to highlight the position of community pharmacies in terms of managing the patient transition between interfaces. Community pharmacy practice records provide the most up to date record of medications dispensed to the patient in the community – anecdotally the pharmacy PMR has been shown to be more accurate than the primary Care GP record [65].

Pharmacy in Secondary care

At present, where clinical pharmacy services are available in secondary care, pharmacists advise the specialist team on medication related issues on an individual patient basis, in response to

specific queries and in the development of evidence-based guidance for the medical management of patients with epilepsy. The clinical pharmacy service aims to ensure continuity of care between healthcare settings in medication-related issues.

Where available, Pharmacy Medicines Information services provide quality, evidence-based information to support all healthcare professionals with medication-related queries about the care of patient with epilepsy e.g. review of new drug treatments, development of patient information about AEDs, advice on therapeutic drug monitoring. This service may be particularly beneficial to the new Advanced Nurse Practitioner and Nurse Prescribers in regard to medication related issues.

Pharmacists can also provide pharmaceutical input into integrated care pathways, protocols involving drug therapy, medication management, patient education, and review of patient compliance. The integration and continuity of pharmaceutical care is an important consideration in medication safety management. The roles and responsibilities of clinical pharmacists have been outlined in the Report of the National Clinical Programme for Acute Medicine 2010 and will be the same for the care of patients with epilepsy.

Considerations for Special groups in Primary and Secondary Care within Pharmacy

Women of child bearing age, pregnant and nursing mothers

There are important pharmaceutical care considerations in this group due to the potential teratogenic nature of many AEDs and the challenges in managing AED therapy in pregnancy and lactation. There are also clinically significant drug-drug interactions between the AEDs and some contraceptive agents which can be problematic for the management of both indications. Community Pharmacy can form a critical support structure to manage the patient throughout maternity care.

Older People

The Pharmaceutical Care of these groups is significant in terms of polypharmacy and the complex nature of regimens used in the treatment of Epilepsy. Factors such as altered drug handling, the risk of drug-drug interactions and drug-disease interactions due to other co-morbidities require significant pharmacy input. The clinical Pharmacist has an important part to play in highlighting drug-related problems and liaising with Epilepsy specialists in the care of this patient population.

Paediatrics

Review by a clinical pharmacist with particular reference to dose calculation and formulation, therapeutic drug monitoring, interactions and administration via enteral feeding tubes is essential in this patient group. Any procurement issues around unlicensed and specially manufactured extemporaneous preparations may also be addressed and communicated to primary care services.

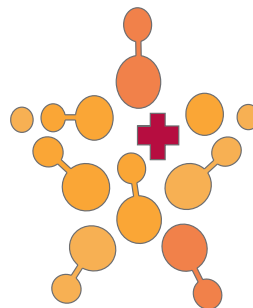
Intellectual disability

Clinical pharmacists are available to identify the pharmaceutical care needs of individual people and to support enquires from the community in the medication –related management of these individuals.

9.0 Concluding Comments

As one of the national clinical programmes under the clinical programmes and strategy division, the Epilepsy Programme is considered one of the outpatient initiatives. The programme has concluded the first phase of planning and implementation which included:

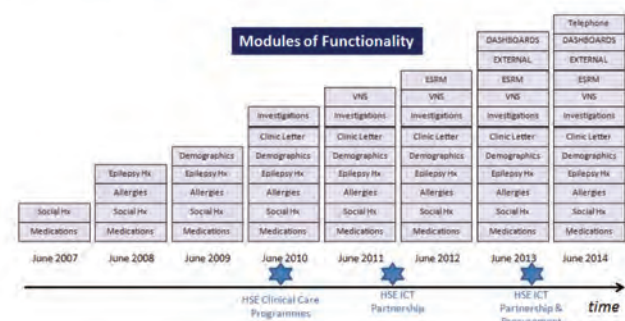
- ▲ Appointment of clinical leads, programme manager, workforce planning, and public health expertise commenced in April/May 2010
- ▲ A Clinical Advisory Group (CAG) under the auspices of the Royal College of Physicians in Ireland has been convened quarterly since May 2010.
- ▲ Engagement with clinicians at stakeholder institutions has been conducted for all epilepsy centres.
- ▲ Implementation plans have been delivered to all centres and will be signed off in advance of service provision beginning.
- ▲ A system-wide consultation for the development of standard operating procedures has been undertaken and the first 12 priority Standard Operative Procedures have been signed off on at the Clinical Advisory Group on the 12th of December 2012.
- ▲ In 2012 the first MSc Advanced Practice (Epilepsy) to fulfil the academic requirements for advanced nurse practitioner commenced in conjunction with the Royal College of Surgeons in Ireland. An international prize for nursing was awarded to the programme in 2012.
- ▲ The initial Draft model of care document has been signed off by the CAG and RCPI and the ICGP (Irish College of General Practitioners) and was posted on the Epilepsy Ireland website in December 2012. Feedback this generated was incorporated into the document.
- ▲ All centres are utilizing SOPs and MOPs to one extent or the other.
- ▲ All of the centres are actively using the Epilepsy EPR and the further development of the system and its amortization has been guaranteed for the next 3 years through a CMOD grant.
- ▲ 2 centres are actively using the Integrated Care Pathway for Seizure in the Emergency Room and have participated in the second UK National Audit for seizure management in hospitals (2013).
- ▲ 9 outreach clinics have been established; 3 in the intellectual disability sector, 2 in maternity hospitals in Dublin and 4 in general hospitals.
- ▲ RASC in number of Centers (SJH, Beaumont, CUH, GUH and LUH)
- ▲ 3 Nurses graduated from RCSI with MSC Advanced practice (epilepsy)
- ▲ Collaboration with National Medicines Information Centre to produce Pharmacological Management of adults with epilepsy Bulletin (Volume 20 number 4 and 5)
- ▲ Nursing services have seen a significant expansion across all service delivery sites, i.e. ED/AMAU, in-patient, Out-patient, Outreach. The table below identifies the broad scope of practice for these Advanced Nurse Practitioners, both registered and candidates.



**care
challenge**

EPR Trajectory

Exploratory, Technical Development, Adaptation, Evolution



Epilepsy Nursing Services (Adults)	Beaumont	Mater	SiH	Tallaght	Limerick	Galway	Sligo	Cork
Electronic Patient Record Implementation	✓	✓	✓		✓	✓	✓	✓
Outpatient Services								
Nurse Led out-patient clinics	✓	✓	✓	✓	✓	✓	✓	
Rapid Access Clinics	✓		✓					
OPD referral triage	✓		✓			✓		✓
Combined OPD clinics	✓		✓					
Group information OPD			✓	✓				
Regional Outreach	✓		✓					
Vagus nerve stimulation clinic OPD	✓		✓	✓	✓	✓		✓
In patient Services								
Video EEG waiting list validation	✓							✓
Acute in-patient referral	✓	✓	✓	✓	✓	✓	✓	✓
Ambulatory Services								
Ambulatory phone service	✓	✓	✓	✓	✓	✓	✓	✓
Ambulatory email support			✓					
Education								
Irish Nurse Epilepsy Group Conference	✓	✓	✓	✓	✓	✓	✓	✓
Education to Nurses both undergraduate & post grad	✓	✓	✓	✓	✓	✓	✓	✓
Education to other Allied Healthcare Professions	✓	✓	✓	✓	✓	✓	✓	✓
Research								
Clinical Audit	✓	✓	✓	✓	✓	✓	✓	✓

Fig 19; Breadth of Epilepsy Nurse Services

10.0 Contributors & Stakeholders

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The working group and the clinical advisory group would like to acknowledge the large contribution made by patients, their families and carer's in the development of this plan.

11.0 References

1. Department of Health and Children's Value for Money Review of Disability Services 2012
2. Future Health: A Strategic Framework for Reform of the Health Service 2012-2015. Department of Health
3. HSE Chronic Illness Framework, July 2008
4. National Healthcare Charter, National Advocacy Unit, Quality and Patient Safety Directorate, HSE 2012
5. National Standards for Safer, Better Healthcare,
6. Shorvon SD: The treatment of epilepsy. Blackwell Publishers, Oxford, UK, 2004.
7. Pugliatti M, Beghi E, Forsgren L, et al. Estimating the cost of Epilepsy in Europe: a review with economic modelling. *Epilepsia* 2007;
8. Andlin-Sobocki P, Jonsson B, Wittchen HU, Olesen J (2005) Cost of disorders of the brain in Europe. *Eur J Neurol* 12 Suppl 1:1-27
9. Linehan C, Kerr MP, Walsh PN, Brady G, Kelleher C, Delanty N, Dawson F, Glynn M. Examining the prevalence of epilepsy and delivery of epilepsy care in Ireland. *Epilepsia*. 2010 May; 51(5):845-52. Epub 2009 Dec 1.
10. Landrigan, C. P., Parry, G. J., Bones, C. B., Hackbarth, A. D., Goldmann, D. A., & Sharek, P. J. (2010). Temporal Trends in Rates of Patient Harm Resulting from Medical Care. *New England Journal of Medicine*, 363(22), 2124–2134. doi:10.1056/NEJMsa1004404
11. Department of Health and Children (2008) Building a Culture of Patient Safety. Report of the Commission on Patient safety and Quality Assurance. (Madden Report) Dublin: Department of Health and Children.
12. Department of Health & Children, Tackling chronic disease: a policy framework for the management of chronic disease. Dublin 2008
13. Health Service Executive (2011) Code of Governance. (Version 4) Dublin: Health Service Executive.
14. Marson, T. UK epilepsy audit shows major deficiencies in care: who should respond and how? *Pract Neurol* 2013;13:1 2-3
15. Hart YM, .Shorvon SD. The nature of epilepsy in the general population. II. Medical care. *Epilepsy Research* 1995; 21:51-8.
16. Dunn MJG, Breen DP, Davenport RJ, Gray AJ. Early management of adults with an uncomplicated first generalised seizure. *Emerg Med J*. 2005;22:237-242.
17. Cascino GD, Hesdorffer D, Logroscino G, Hauser WA. Treatment of nonfebrile status epilepticus in Rochester, Minn, from 1965 through 1984. *Mayo Clin Proc*. 2001 Jan; 76(1): 39-41.
18. Smyth L, Fitzgerald M, Casey P, Plunkett PK, Doherty CP. Impact of Acute Seizure Admissions on Resources of a Large Teaching Hospital in Ireland. *Proceedings of the Irish Neurological Association Meeting Belfast May 2007*.
19. Iyer, P. M., McNamara, P. H., Fitzgerald, M., Smyth, L., Dardis, C., Jawad, T. Doherty, C. P. (2012). A seizure care pathway in the emergency department: preliminary quality and safety improvements. *Epilepsy Research and Treatment*, 2012, 273175. doi:10.1155/2012/273175
20. T, Beghi E, Sundqvist A, Johannessen SI. Medical risks in epilepsy: a review with focus on physical injuries, mortality, traffic accidents and their prevention. *Epilepsy Res*. 2004 Jun;60(1):1-16
21. Hanna N J, Black M, Sander JWS, Smithson WH, Appleton R, Brown S, Fish DR (2002) The National Sentinel Clinical Audit of Epilepsy-Related Death: Epilepsy–death in the shadows. The Stationery Office.
22. Sillanpaa, M, Shinnar, S. Long-term mortality in childhood onset epilepsy. *New England Journal of Medicine* 2010;363, 2522-9

23. Langan Y, Nolan N, Hutchinson M. The incidence of sudden unexpected death in epilepsy (SUDEP) in South Dublin and Wicklow. *Seizure*. 1998 Oct; 7(5):355-8. The incidence of sudden unexpected death in epilepsy (SUDEP) in South Dublin and Wicklow.
24. Donohue F, Doherty CP, Langan Y, White ME, White MM, Morrow S, Hayes C Mortality Due to SUDEP and Status Epilepticus *Mar*;106(3):91-2.2013.
25. Jawad T, Connolly S, Healion M, Sweeney A, Doherty CP. Outcome of non-convulsive status epilepticus (NCSE) in the elderly. Proceedings of the Irish Neurological Association Meeting Belfast May 2010.
26. Bradley, P, Lindsay, B. Care delivery and self management strategies for adults with epilepsy. Cochrane database of Systematic reviews. 2008 Issue 1 art No: CD006244; DOI: 10.1002/14651858.
27. Hosking P G, Duncan J. S. & Sander J. M. W. (2002) The epilepsy nurse specialist at a tertiary care hospital: improving the interface between primary and tertiary care. *Seizure* 11: 494–499.
28. Long L and Mc Auley (1996) Epilepsy: a review of seizure types, etiologies, diagnosis, treatment, and nursing implications. *Crit Care Nurse*. Aug; 16(4):83-92.
29. Sarkissian, Sonia, Wennberg and Richard (1999). Effects of the Acute Care Nurse Practitioner Role on Epilepsy Monitoring Outcomes. *Outcomes Management for Nursing Practice*. 3(4):161-166.
30. Scambler, A., Scambler, G., Ridsdale, L. and Roberts, D. (1996) Towards an evaluation of the effectiveness of an epilepsy nurse in primary care. *Seizure* 5 (4): 255–258.
31. Greenhill L, Betts T and Pickard N (2002). The Epilepsy Nurse Specialist--Expendable Handmaiden or Essential Colleague? *Seizure*.11 Suppl A: 615-20; quiz 623-4.
32. Ridsdale L, Robins D, Cryer C, Williams H. (1997) Feasibility and effects of nurse run clinics for patients with epilepsy in general practice: randomised controlled trial. *Epilepsy Care Evaluation Group. BMJ*. Jan 11; 314(7074):120–122.
33. Stokes, T. et al (2004) Clinical Guidelines and Evidence. Review for the Epilepsies: Diagnosis and Management in Adults and Children in Primary and Secondary Care. London: Royal College of General Practitioners.
34. National Institute for Clinical Excellence (2004) the epilepsies: diagnosis and management of the epilepsies in adults in primary and secondary care the epilepsies: diagnosis and management of the epilepsies in adults in primary and secondary care nice.org.uk/CG020childrenquickrefguide.
35. Scottish Intercollegiate Guidelines (2003) 2Guideline No. 70 Diagnosis and Management of Epilepsy in Adults. Scottish Intercollegiate Guideline Network.
36. Flynn, C. White, M, Dempsey, N Fitzgerald M, Nestor T, Crowley S, Cunningham D. A Multi Centred Audit of Nurse-Led Epilepsy Telephone Advice Services. Poster presentation at NCNM Conference 2009 (runner up prize).
37. Coker, M, Fitzgerald, M. Doherty, C. What do patients with epilepsy know about their condition: evaluation of a subspecialty clinical population. *Seizure* 2011 Jan; 20(1):55-9.
38. Gubenko, A, Parames Iyer, Tania Jawad, Margaret Fitzgerald, Yvonne Langan, Colin Doherty. Do specialist epilepsy clinics work? A retrospective review. Proceedings of Irish neurological association meeting Belfast, May 2010.
39. Thapar AK. Care of patients with epilepsy in the community: will new initiatives address old problems? *Br J Gen Pract* 1996; 46:37-42.
40. Ridsdale, Robins, D. Fitzgerald, A. The epilepsy care evaluation group. Epilepsy monitoring and advice recorded: General practitioners views, current practice and patient's preferences. *Br J Gen Pract* 1996; 46:11-14.
41. White, P. Structured management in primary care of patients with Epilepsy. *Br J Gen Pract* 1996; 46:3-4.
42. Varley J. Fitzsimons M. Epilepsy in primary care *Ir Med J*. 2009 Jun; 102(6):173-6.

43. Varley, J. Norman Delanty, Charles Normand, Imelda Coyne, Louise McQuaid, Claire Collins, Michael Boland, Jane Grimson, Mary Fitzsimons, *Epilepsy in Ireland: Towards the primary tertiary care continuum*, *Seizure*, 19, 1, 2010, 47 – 52.
44. Varley J, Delanty N, Normand C, Fitzsimons M. The health care journeys experienced by people with epilepsy in Ireland: What are the implications for future service reform and development? *Epilepsy Behav.* 2011 Feb;20(2):299-30.
45. Varley J, O'Connor R, O'Riordan D, Barry N, Normand C, Fitzsimons M. Towards the development of integrated epilepsy services: An audit of documented epilepsy care in the Mid-West region of Ireland. *Ir Med J*, 2011 Vol 104;7. pp 214-17.
46. Brodie, MJ. Shorvon, S, Canger, R. Halasz, P. Johannessen, S; Thompson, P. Wieser, HG. Wolf, P. Commission of European Affairs: Appropriate Standards of Epilepsy Care Across Europe: [ILAE Commission Report]. *Epilepsia* Nov 1997; 38(11) pp 1245-50.
47. Fountain et al. Quality improvement in Neurology. AAN quality measures in Epilepsy. *Neurology* 76, Jan 4, pp 94-99. 2010.
48. A guide to developing local strategies and good practice. Department of Health, UK, 2006
49. Blum et al, 1993, cited by DH/Child Health and Maternity Services, 2006
50. Viner, R. Transition from paediatric to adult care. Bridging the gaps or passing the buck?; *Arch Dis Child* 1999; 81:271-275
51. Heath Service Executive (2011) Code of Governance.32
52. ILAE neuroimaging commission. Recommendations for Neuroimaging of patients with epilepsy. *Epilepsia* 38 (suppl 10) 1-2 1997.
53. An Bord Altranais (2000) Scope of Nursing and Midwifery Practice Framework. An Bord Altranais: Dublin
54. Mc Quaid L, Breen P, Grimson J, Normand C, Dunne M, Delanty N, Kalra D, Fitzsimons M. Socio-technical considerations in epilepsy electronic patient record implementation. *Int J Med Inform.* 2010 May;79(5):349-60
55. Breen P, Murphy K, Browne G, Molloy F, Reid V, Doherty C, Delanty N, Connolly S, Fitzsimons M. Formative evaluation of a telemedicine model for delivering clinical neurophysiology services part I: utility, technical performance and service provider perspective. *BMC Med Inform Decis Mak.* 2010 Sep 15;10:48.
56. Breen P, Murphy K, Browne G, Molloy F, Reid V, Doherty C, Delanty N, Connolly S, Fitzsimons M. Formative evaluation of a telemedicine model for delivering clinical neurophysiology services part II: the referring clinician and patient perspective. *BMC Med Inform Decis Mak.* 2010 Sep 15;10:49.
57. Fitzsimons M, Ronan L, Murphy K, Browne G, Connolly S, McMenamin J, Delanty N. Customer needs, expectations, and satisfaction with clinical neurophysiology services in Ireland: a case for tele-neurophysiology development. *Ir Med J.* 2004 Jul-Aug;97(7):208-11.
58. Ronan L, Murphy K, Browne G, Connolly S, McMenamin J, Lynch B, Delanty N, Fitzsimons M. Needs analysis for tele-neurophysiology in the Irish North-Western Health Board. *Ir Med J.* 2004 Feb;97(2):46-9
59. Fitzsimons M, Normand C, Varley J, Delanty N. 2011 Evidence-based models of care for people with epilepsy. *Epilepsy Behav.* 2011 Nov 29
60. Ross J, Stefan H, Schäuble B, Day R, Sander JW. European survey of the level of satisfaction of patients and physicians in the management of epilepsy in general practice. *Epilepsy Behav* 2010;19:36–42
61. Institute of Medicine. *Envisioning the national healthcare quality report* Washington DC, National Academies Press 2001
62. Grimson J. Delivering the electronic healthcare record for the 21st century. *Int J Med Inform* 2001;64:111–27

63. Walker ER, Wexler B, Dilorio C, Escoffery C, McCarty F, Yeager KA. Content and characteristics of goals created during a self-management intervention for people with epilepsy. *J Neurosci Nurs* 2009;41:312–21
64. Helgeson DC, Mittan R, Tan SY, Sepulveda CS. Epilepsy education: the efficacy of a psychoeducational treatment program in treating medical and psychosocial aspects of epilepsy. *Epilepsia* 1990;31:75–82
65. Relative accuracy and availability of an Irish National Database of dispensed medication as a source of medication history information: observational study and retrospective record analysis. Grimes T, Fitzsimons M, Galvin M, Delaney T. *J Clin Pharm Ther*. 2013 Jun;38(3):219–24
66. Dilorio C, Escoffery C, McCarty F, et al. Evaluation of WebEase: an epilepsy self management web site. *Health Educ Res* 2009;24:185–97
67. May TW, Pfäfflin M. The efficacy of an educational treatment program for patients with epilepsy (MOSES): results of a controlled, randomized study. *Modular Service Package Epilepsy. Epilepsia* 2002;43:539–49
68. Dilorio C, Reisinger EL, Yeager KA, McCarty F. A telephone-based self-management program for people with epilepsy. *Epilepsy Behav* 2009;14:232–6
69. NICE guidelines for management of paediatric epilepsy 2012, <http://guidance.nice.org.uk/CG137>
70. Kossoff EH, et al. Optimal clinical management of children receiving the ketogenic diet: recommendations of the International Ketogenic Diet Study Group. *Epilepsia* 2009, 50(2):304–17
71. Kossoff EH, Wang SH. Dietary therapies for Epilepsy. *Biomed J* 2013, 36:2–8
72. Levy RG, et al. Ketogenic diet and other dietary treatments for epilepsy. *Cochrane Database Syst Rev* 2012, 14;3
73. Nei M, et al. Ketogenic diet in adolescents and adults with epilepsy. *Seizure* 2014, S1059–1311

12.0 Appendices

12.1 HIPE data: discharges from acute Irish hospitals 2008

Epilepsy principal diagnosis, ICDICM codes G40 (epilepsy), G41 (SE) and R56.8 (Convulsions NOS)

Hospital	No. discharges	No. patients	Sum bed days	Mean bed days	Median bed days	Min bed days	Max bed days	Sum DRG €	Mean DRG €
Beaumont (037)	603	517	3776	6.26	3	1	225	2,463,264	4,085
Cork University (235)	517	445	2671	5.17	2	1	137	1,550,698	2,999
Limerick Regional (303)	373	295	1381	3.7	2	1	27	1,056,650	2,833
St. James's (021)	361	313	1803	4.99	2	1	88	1,270,196	3,519
Tallaght Hospital (041)	343	293	1666	4.86	2	1	268	1,204,003	3,510
Temple Street Children's (014)	302	237	1225	4.06	2	1	59	1,154,003	3,821
Our Lady's, Crumlin (001)	259	189	1114	4.3	2	1	55	962,549	3,716
Mayo General (405)	242	173	1001	4.14	3	1	34	702,330	2,902
Letterkenny General (601)	239	201	839	3.51	2	1	63	606,975	2,540
UCH, Galway (404)	229	177	1196	5.22	3	1	77	770,472	3,365
Mater Misericordiae (005)	221	203	1494	6.76	2	1	166	652,096	2,951
St. Luke's, Kilkenny (101)	210	175	877	4.18	1	1	65	632,922	3,014
Sligo General (602)	207	166	722	3.49	2	1	21	586,119	2,831
Wexford General (103)	204	155	659	3.23	2	1	37	596,626	2,925
Mercy University, Cork (203)	194	150	824	4.25	1	1	73	635,543	3,276
Mullingar Regional (503)	186	158	492	2.65	1	1	65	470,016	2,527
South Tipperary General (105)	186	140	644	3.46	2	1	29	605,708	3,256
Tralee General (236)	184	159	835	4.54	2	1	57	615,138	3,343
Waterford Regional (100)	161	138	701	4.35	2	1	97	452,609	2,811
Naas General (004)	159	127	739	4.65	2	1	42	473,006	2,975
Connolly (022)	134	122	466	3.48	1	1	87	349,442	2,608
Portiuncula, Ballinasloe (403)	130	107	360	2.77	1	1	29	420,122	3,232
Cavan General (702)	128	100	444	3.47	3	1	15	335,828	2,624
Louth County, Dundalk (703)	126	97	403	3.2	2	1	36	338,274	2,685
Portlaoise Regional (506)	126	105	424	3.37	2	1	63	305,038	2,421
Our Lady of Lourdes, Drogheda (701)	125	100	397	3.18	2	1	49	340,191	2,722
St. Vincent's University, Elm Park (007)	122	116	1251	10.25	3	1	121	457,852	3,753
Tullamore Regional (501)	105	86	634	6.04	3	1	125	277,499	2,643
Our Lady's, Navan (705)	86	73	392	4.56	2	1	106	338,924	3,941
Nenagh Regional (308)	79	70	304	3.85	2	1	32	224,647	2,844
Merlin Park (412)	77	69	303	3.94	2	1	33	206,141	2,677
Ennis Regional (307)	74	65	235	3.18	2	1	33	192,350	2,599
Roscommon County (401)	69	57	348	5.04	4	1	29	213,275	3,091
St. Columcilles (003)	62	58	276	4.45	2	1	23	175,598	2,832
Monaghan General (704)	44	32	146	3.32	3	1	10	106,820	2,428

St. John's, Limerick (305)	42	34	161	3.83	2	1	16	116,250	2,768
Mallow General (207)	31	29	99	3.19	3	1	10	108,751	3,508
St. Michael's, Dun Laoghaire (023)	23	22	108	4.7	4	1	14	66,155	2,876
South Infirmary - Victoria, Cork (206)	16	16	70	4.38	3.5	1	19	43,288	2,706
NMH Holles Street (040)	1	1	4	4	4	4	4	2,269	2,269
Rotunda (039)	1	1	4	4	4	4	4	1,016	1,016
St. Luke's, Rathgar (015)	1	1	44	44	44	44	44	5,761	5,761
Total	6,982	5,772	31,532	4.5	3.3	1	268	22,086,414	3,163

*Averaged median

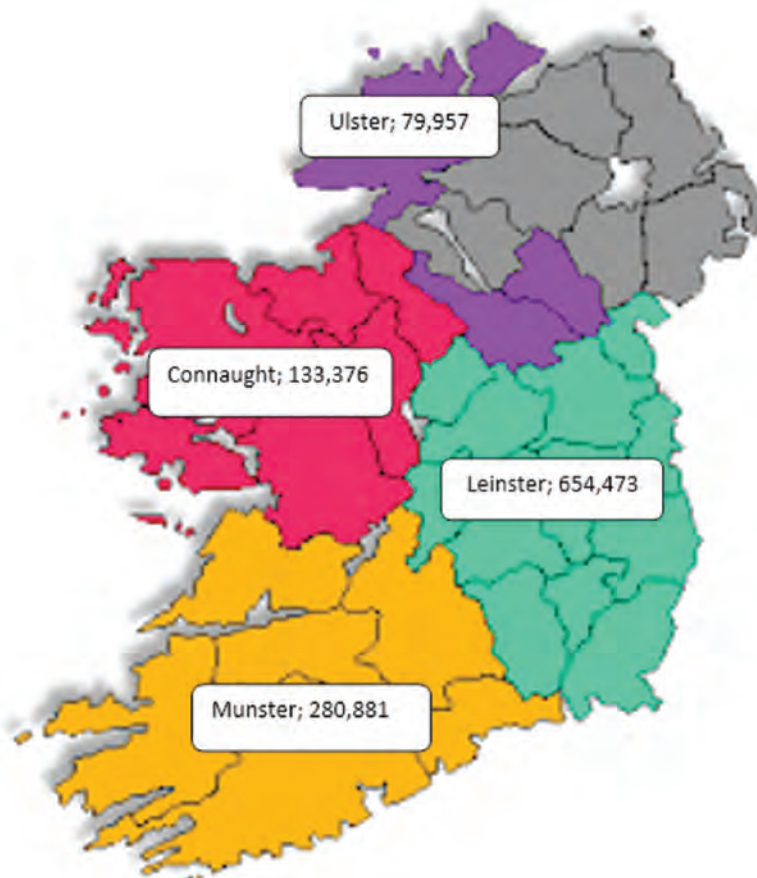
12.2 Epilepsy Principal Diagnosis All Ireland 2006, 2007, 2008 for Epilepsy, SE and convulsions NOS

	No discharges	No patients	Sum bed days	Mean bed days	Min bed days	Max bed days	*Median bed days	Sum DRG €	Mean DRG €	Daily Cost
2006	6,685	5,430	29,831	4.5	1	338	2.5	21,339,814	3,192	715
2007	6,879	5,651	30,251	4.4	1	290	2.4	21,420,087	3,114	708
2008	6,982	5,772	31,532	4.5	1	268	3.3	22,086,414	3,163	700

*Averaged median

#Daily bed cost = Sum DRG / Sum bed days

12.3 Map of Ireland with numbers of under 17 years old indicated by province



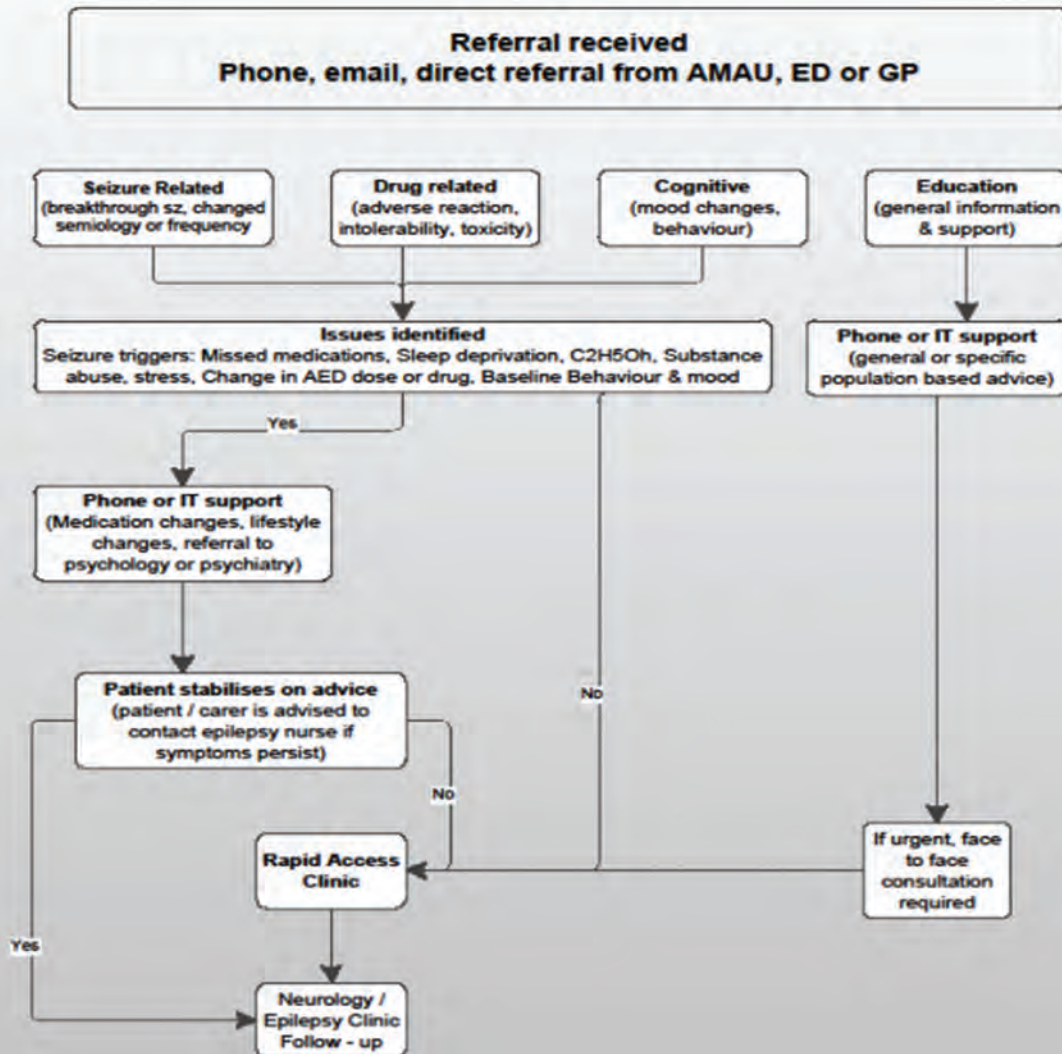
State of the nation's children; Department of Children and Youth Affairs 2012 (children = 0-17yrs)

12.4 Nurse Protocol for referrals from ED/AMAU and Community

Pathway for Referral to RASC for Patients with Diagnosis of Epilepsy known to service

December 2, 2010

Pathway for Referral to RASC for Patients with Diagnosis of Epilepsy known to Service



12.5 ED Care pathway for Seizure

Acute Seizure Management



Established Epilepsy or recurrent seizures

History of Seizure;

Date	Time
Duration/Recovery	Cyanosis
Warning	Consciousness
Altered Speech	Tongue biting
Incontinence	Tonic Clonic Activity

Seizure Investigations

FBC	U/E
ESR	LFT's
Ca Phos Mg	Glucose
Beta HCG	CRP
ECG	Chest x-ray
CT Brain	Toxicology – serum
LP	Toxicology - urine
MRI Brain	EEG
AED Levels	

Medical History;

Current Medications
Recent AED Changes
Allergies
Epilepsy Family History,
Hx Head Injury, CNS
Infection, Febrile
Convulsion

Social History;

Driver
Employment
Intellectual Disability
Habitual alcohol/illicit
substance misuse

First Seizure

Consider cause;

Tumour	Stroke
Cerebral Vein Thrombosis	Cerebral Haemorrhage
Trauma	Infection
Toxaemia	SAH
Metabolic	Intoxication
Non-epileptic seizure	

Seizure Investigations

FBC	U/E
ESR	LFT's
Ca Phos Mg	Glucose
Beta HCG	CRP
ECG	Chest x-ray
CT Brain	Toxicology – serum
LP	Toxicology - urine
MRI Brain	EEG

Consider Triggers

Illicit Substances	Missed medications
Alcohol	Stress
Sleep Deprivation	Infection
Pregnancy	Menstruation

Physical Exam

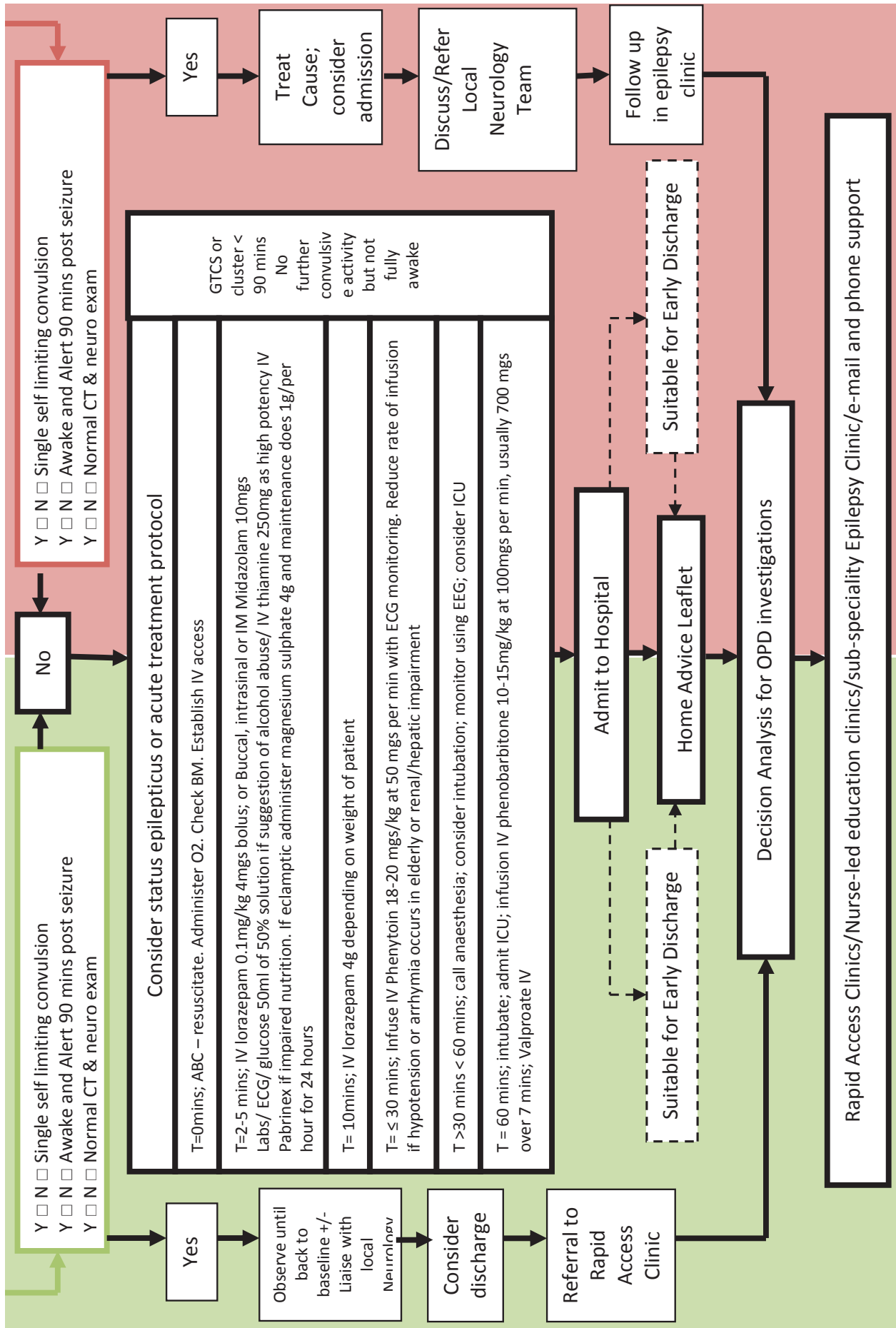
BP/Pulse/Temp/SaO2/GCS/
EWS

Screen for Injuries

Head/Neck/Chest/Cardiovascular/
Abdominal

Neurological Examination

Cranial Nerves/Pupils/Fundi/Gait/
Plantars/Mental Status



12.6 Guiding principles for clinical governance & Epilepsy Programme Clinical Governance Checklist

Prompt Questions	Y	N	Ref point in document
Accountability and Governance			
1. Does the clinical lead (s) have accountability, responsibility and authority for the development of the model of care?			Section 7.3
2. Does the model of care take account of the HSE code of governance?			Section 7.0
3. Does the model of care clearly set out the clinical and managerial leadership roles for service delivery?			Section 7
4. Does the model of care set out the accountability arrangements for safe quality patient care?			Section 7
5. Does the model of care integrate governance for quality and safety within corporate governance arrangements?			Section 7
6. Does the model of care contain an organisational chart for the relevant model?			Section 7
7. Are the lines of responsibility, accountability and authority of the following personnel clearly identified and agreed in the model of care? ▲ HSE National Directors ▲ Area managers ▲ CEO/GM (group/site specific) ▲ Clinical Directors (group /site specific) ▲ Director of Nursing/ Midwifery (group/site specific), and ▲ Members of the multidisciplinary team.			Section 7
8. Does the model of care provide for integration between: ▲ hospitals within hospital groups (HSE and voluntary)? ▲ hospital and community providers?			Section 1.4-1.6; section 3.1-3.3
9. Does the model of care outline: ▲ aims and objectives ▲ vision and core values ▲ description of services provided ▲ intended service user population ▲ location(s) or criteria for locations of service delivery, and ▲ access to services.			Section 2.1-2.2; Section 3

10.	Does the model of care contain service objectives and plans for the relevant service that take account of: ▲ existing structures and processes (e.g. committees) ▲ relevant national strategies, policies, standards and legislation ▲ current available evidence ▲ views of stakeholders (including staff, patients, public and professional/community organisations) ▲ the health and social care needs of the population served ▲ the need for ongoing staff training, development and education, and ▲ plans for the measurement of implementation.			Executive Summary, Section 1.3; Section 2; Section 5; Section 7; Section 9
11.	Does the model of care describe how the quality of clinical care is reported to the organisations' speciality/ directorate, executive and/or board quality and safety committee?			Section 7
12.	Will the model of care be publicly available and communicated to all stakeholders, in an accessible format?			Section 9
Prompt Questions		Y	N	Ref point in document
Continuous Quality Improvement				
Quality and Performance Indicators				
13.	Does the model of care identify a suite of quality of clinical care indicators which are recommended for monitoring within organisations and nationally?			Section 7.5
14.	Does the model of care recommend the measurement of patient outcome and experience through direct patient feedback?			Section 7.6; (EPR patient engagement module in planning stage)
15.	Does the model of care recommend how the quality of clinical care is benchmarked within organisations, nationally and/or internationally?			Section 4.0
16.	Does the model of care recommend public reporting of specific quality of clinical care indicators?			Section 7.5- 7.6
Risk Management				
17.	Does the model of care link with existing risk management processes in line with the HSE Code of Governance and national standards / legislation, HSE policy? E.g. ▲ risk identification, recording and reporting ▲ risk mitigation/risk reduction ▲ incident/adverse event reporting ▲ learning from mistakes			Section 7.3, Section 7.5, 7.6 & 7.7

▲ applying learning from incidents to promote a culture of patient partnership ▲ promote a culture of openness and accountability 18. Does the model of care provide a mechanism for any team member to raise concerns about the quality and safety of the service (for example Protected Disclosure, Trust in Care or Good Faith Reporting)? 19. Where the model of care includes externally provided services is there assurance that the practices of corporate and quality and safety governance are clearly implemented by the provider (i.e. in service agreements were services are externally commissioned)?			Section 7.3, Section 7.5, 7.6 & 7.7 Section 7.3, Section 5
Clinical Effectiveness and Audit			
20. Does the model of care comply with relevant legislation², National Clinical Effectiveness Committee guidelines, standards and regulatory requirements? 21. Have policies, procedures, protocols and guidelines (PPPG) that support the model of care been identified (in line with National Clinical Effectiveness Committee and existing HSE PPPG's (e.g. Code of Practice for Healthcare Records Management)? 22. Does the model of care recommend a structured programme of clinical audit?			Executive Summary; Section 1.1; Section 7.6 and Part B of MOC Section 7.5
Managing Performance			
23. Do clinical and managerial leads within services support the proposed model of care and its implementation? 24. Does the model of care clarify for interdisciplinary team members their individual and collective responsibilities for performance standards? 25. Does the model of care support a culture of performance management cycle?			Section 9 Section 7.2 Section 7.1
Record of Completion Process		Details	
Name of National Clinical Programme		National Clinical Programme for Epilepsy	
Date(s) checklist considered by National Clinical Programme Working Group		3.11.14	
Check list completed by (please include names and titles)		Colin Doherty, Maire White, Mary Fitzsimons, Edina O'Driscoll	
National Clinical Lead approval of completed checklist		Signature: Date:	

13.0 List of Abbreviations

ABN	Association of British Neurologists
AED	Anti Epileptic Drugs
RANP	Registered Advanced Nurse Practitioner
AMAU	Acute Medical Assessment Unit
CAG	Clinical Advisory Group
CRO	Community Resource Officer
CNS	Clinical Nurse Specialist
CNS	Clinical Neurophysiology Scientist
CT	Computerised Tomography
DIT	Dublin Institute of Technology
DON	Director of Nursing
EEG	Electroencephalography
ED	Emergency Department
ENS	Epilepsy Nurse Specialist
EPR	Electronic Patient Record
ELO	Epilepsy Liaison Officer
GP	General Practitioner
HIPE	Hospital In-Patient Enquiry
H & SCN	Health & Social Care Network
HSCP	Health & Social Care Professionals
HSE	Health Service Executive
ICP	Integrated Care Pathway
ID	Intellectual Disability
IICMS	Irish Institute of Clinical Measurement Science
ILAE	International League Against Epilepsy
LOS	Length of Stay
LTM	Long Term Monitoring
MDS	Monitored Dosing Systems

MOC	Model of Care
MOP	Management Operating Procedure
MRI	Magnetic Resonance Imaging
MUR	Medication Usage Review
NEAD	Non-epileptic attack disorder
NECP	National Epilepsy Clinical Programme
NCSE	Non-Convulsive Status Epilepticus
NESI	National Epilepsy Service of Ireland
NICE	National Institute for Clinical Excellence
NHS	National Health Service, UK
OT	Occupational Therapist
PEC	Professional Education Coordinator
PC	Primary Care
PCT	Primary Care Team
PDP	Personal Development Plan
PNES	Psychogenic non-epileptic seizures
PWE	People with Epilepsy
RC	Regional Care
RDO	Regional Director of Operations
REC	Regional/Group Epilepsy Centre
SC	Secondary Care
SE	Status Epilepticus
SIGN	Scottish Intercollegiate Guidelines Network
SOP	Standard Operating Procedure
SUDEP	Sudden Unexplained Death in Epilepsy
TAL	Telephone Advice Line
TBPM	Team Based Performance Management
VNS	Vagal Nerve Stimulation

14.0 Glossary of Terms

Integrated care pathway	An integrated care pathway (ICP) is a multidisciplinary outline of anticipated care, placed in an appropriate timeframe, to help a patient with a specific condition or set of symptoms move progressively through a clinical experience to positive outcomes. Variations from the pathway may occur as clinical freedom is exercised to meet the needs of the individual patient. ICP's can help to reduce unnecessary variations in patient care and outcomes. They support the development of care partnerships and empower patients and their carers. ICPs can also be used as a tool to incorporate local and national guidelines into everyday practice, manage clinical risk and meet the requirements of clinical governance. http://www.medicine.ox.ac.uk/bandolier/booth/glossary/ICP.html
Advanced Nurse Practitioners	A registered nurse who has acquired the expert knowledge base, complex decision-making skills and clinical competencies for expanded practice, the characteristics of which are shaped by the context and/or country in which s/he is credentialed to practice
Epilepsy Nurse Specialist	Specialist nurses dedicated to care of patients with epilepsy
Clinical Nurse Specialist	A RN who, through study and supervision at a graduate level, has become an expert in a defined area of knowledge and practice in a selected clinical area of nursing
Self-Management	Self-Management can simply be described as a set of skills, strategies and tactics that can be used to achieve the desired personal outcomes. Or Self-management means the interventions, training, and skills by which patients with a chronic condition, disability, or disease can effectively take care of themselves and learn how to do so
Primary care	The first - and most generalized - stop for symptoms that are new or any other acute medical problem experienced. Primary care providers may be doctors, nurse practitioners or physician assistants.
Secondary care institutions	Secondary care is where patients are treated by a physician with more specific expertise relating to particular condition. Secondary care is appropriate when the medical condition cannot be dealt with appropriately in a primary care setting.
Tertiary care institutions	Once a patient is hospitalized and needs a higher level of specialty care within the hospital, he or she may be referred to tertiary care. Tertiary care requires highly specialized equipment and expertise.

Refractory disease	Refractory epilepsy is a seizure disorder that resists drug treatment.
Managed clinical networks	A linked group of health professionals and organisations from primary, secondary and tertiary care, working in a coordinated way that is not constrained by existing organisational or professional boundaries to ensure equitable provision of high quality, clinically effective care.
Phenomenological Research	An inductive, descriptive research approach developed from phenomenological philosophy; its aim is to describe an experience as it is actually lived by the person.
Qualitative research	Research dealing with phenomena that are difficult or impossible to quantify mathematically, such as beliefs, meanings, attributes, and symbols
Formative research methodologies	Formative research looks at the community in which an agency is situated, and helps agencies understand the interests, attributes and needs of different populations and persons in their community. Formative research is research that occurs before a program is designed and implemented, or while a program is being conducted
Summative research methodologies	Measurement against predetermined competencies/standards, summative studies can show the effectiveness of a program.
Population based research	Population-based research explores questions regarding longitudinal and cohort effects of universal, targeted and clinical interventions. Research results provide new knowledge to support policy development and program planning and to determine the most effective cross-sectoral mechanisms for achieving the best possible outcomes.
Translational research	Helps to make findings from basic science useful for practical applications that enhance human health and well-being. It is practiced in fields such as environmental and agricultural science, as well as the health, behavioral, and social sciences. For example, in medicine and nursing it is used to “translate” findings in basic research quickly into medical and nursing practice and meaningful health outcomes.
Team based performance management	Designed to achieve a quality service through organizational goals, rather than to implement a performance appraisal system. The core elements will be accompanied by involving the individual in the learning, which is to be derived and in exploring what needs to happen to ensure a greater success.
Extemporaneous preparations	The mixing together of the ingredients of a prescription or drug formula and generally refers to a manual process performed for individual orders by a dispenser or pharmacist.

