

The National Epilepsy Care Programme in Ireland

Health Service Executive,
Clinical Strategy and Programmes Directorate

DRAFT

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Executive Summary

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. The condition kills about 130 people per year. Many patients with epilepsy suffer from mental health problems, and the condition has significant implications for social, vocational and occupational aspirations.

Under the direction of the office of Clinical Strategy and Programmes, the national epilepsy care programme 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. To improve value conscious care by shifting care where possible from expensive hospital based care to the community.

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 an Advanced Nurse Practitioner (ANP) in every region in the country (defined on proposed Integrated Service Area (ISA) Boundaries, who will manage patients with stable disease in the community, who will guide others less well controlled through the health system providing them with the resources for self-management, and contact and referral information for expert care in the regional centers.

b. Six Regional Epilepsy Centres nationally (4 adult and 2 paediatric) will be staffed by a new cohort of epilepsy experts from a nursing background who will be population based and be the main contact within the region for expert services. Working in tandem with medical consultants and epilepsy trainees, they will 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 (defined as Level 2 hospitals in the Acute Medicine Programme), primary care centres and residential intellectual disability services. By virtue of the plan for regional centres, 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**, administered through ED and the AMAU (Acute Medical Admissions Unit), 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 too many patients are being admitted when often they could safely receive care and 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 and 2 in Cork University Hospital (CUH).

The epilepsy care programme has a five-year 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 6 regional 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 epilepsy, the national epilepsy surgery programme, will be enhanced and expanded over 2 sites to provide world-class access to complex but potentially curative surgery.

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1. Background

1.1 Introduction

Epilepsy is the most common serious neurological disorder of young people and affects an estimated 50 million people worldwide [1]. Societal costs are considerable as individuals with medically intractable seizures make up a third of the epilepsy population [1]. More than EU15 billion is spent annually on the treatment of epilepsy in Europe, a financial burden comparable to that of lung and breast cancer combined [2, 3]. Approximately 6 million individuals in Europe suffer from epilepsy; whilst up to 2% of the population will suffer from epilepsy at some stage in their lives [1]. A Recent Irish prevalence study estimated that up to 37,000 people in Ireland have the disorder, which gives a point prevalence of about 0.8% in line with other industrialized nations [4].

The thrust of the new Clinical Programme in Epilepsy Care from the Directorate of Clinical Strategy and Programmes at the Health Service Executive (HSE) is to use international evidence and expert consensus to create a programme of improvement in quality of, access to and value of, epilepsy care in Ireland. The long-term vision for the programme is ***to provide the best value care for all people with epilepsy in the right place, at the right time, sharing the best available information.*** The kernel of the project is to create a cohort of Advanced Nurse Practitioners (ANPs) to complement the current medical expertise that can take over the chronic disease management of epilepsy from more general services and integrate it with their care in the community. Central to this integration is that it will provide timely access, intelligent support and outreach clinics for general practitioners in the community which will demonstrate true value by reducing admission to the acute hospitals and reducing the length of stay in those admitted.

The availability of relevant clinical information to clinicians when and where 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 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 [2]. 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 Non Epileptic Attack Disorder (NEAD), 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. Furthermore, audits from Irish hospitals have shown that patients are often languishing as inpatients without specialist opinion, awaiting diagnostic tests. All of this evidence suggests that seizure admissions to Irish hospitals are a cause of unnecessary medical intervention, delayed diagnosis and prolonged length of stay [6, 7, and 8].

In Ireland, composite data from the Hospital In-Patient Enquiry system (HIPE) reveals that in 2008 before the programme came into being, there were 6,982 discharges from acute Irish hospitals with a principal diagnosis of epilepsy in that year; 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 one of the large urban teaching hospitals in Ireland using a seizure care pathway with early follow-up and prioritized diagnostics, showed that over 30% of admissions could be avoided

and the average length of stay could be reduced to 10 to 6 days and the median length of stay to 4 day to 2 [9]. Table 1 below summarizes potential bed savings by introducing a new model of care.

Table 1: Acute Hospital Discharges 2008 for Principal Diagnoses of Epilepsy, Status Epilepticus and Convulsions not otherwise specified – potential bed days avoided and savings generated using number of discharges and averaged median LOS from Appendix 1

	No. discharges	Potential bed days saved	#Amount saved (€) (bed days * 700)
Total no. discharges in 2008	6,982		
Admissions avoided by discharge from ED of formerly admitted patients (30%)	2,095	6,914(2095*3.3)	
Of remainder reduction of median LOS from 3.3 to 2 days	4,887	6,353 (4,887*1.3)	
Total	6,982	13,267	
In addition:			
Potential savings on admissions from previously undiagnosed patients who are potentially admitted with at least one seizure per year and who are now seizure free within structured primary care service.	2000	4,000	
Reduction of *mean LOS for SE from 10 days in 2008 to median 5 days) from better treatment of SE	230**	1,150 (230*5)	
Total	2,300	5,150	
ALL		18,417	€12,891,900

*Mean LOS used here as SE patients tend to be those with longer than average LOS

Average cost per discharge (Appendix 1). Appendix 2 shows summary figures and costs over 3 years.

1.3 Mortality

Adults and Children with epilepsy have an increased rate of mortality about 2-3 times that of the general population [10]. 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

[10]. The National Sentinel Audit of Epilepsy Related Death in the UK found that epilepsy related death particularly SUDEP is underestimated by healthcare professionals [11]. The audit demonstrated that 38% of deaths that were sudden and unwitnessed did not have a post mortem and that the cause of death was inadequately stated in 41% of deaths where a post mortem was carried out. 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 [12].

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 [13]. In addition deaths due to non-convulsive status epilepticus (NCSE) and accidents are not included in the figures below. Data from Jawad et al in Ireland has shown that in an elderly hospitalized population, the mortality from NCSE was 50% over a five-year period [14]. It is a stated aim of this programme to save at least 1/3 of lives lost to epilepsy primarily through improvements in seizure control and standardized pathways for the treatment of status epilepticus in the ED.

Table 2. Morality figures from Irish Studies

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 ≥ 5 years	34,171 PWE	0.6-1.3/1000 PWE	21-44 cases	Incidence; 706 cases/year Deaths from SE; 67 deaths/year	88-111
9.0/1000 ≥ 5 years	37,052 PWE	0.4-1.1/1000 PWE	15-41 cases	Incidence; 706 cases/year Deaths from SE; 67 deaths/year	82-108

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

1.4 Models of care: National and international evidence

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 [15]. 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 Drug Toxicity (AED) toxicity and share the responsibility of taking care of epilepsy patients [16, 17].

Investigations on 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 [18, 19, and 20]. Nurse run 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 run 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 [21]. 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. Epilepsy Nurse Specialists employed in hospital epilepsy clinics can play a key role in supporting doctors and helping patients manage their condition for optimal outcomes [22].

A trial by the UK's National Institute for Clinical Excellence [NICE] found that people supported by an epilepsy nurse had significantly lower depression scores [23]. Trial participants commented on nurses' ability to reduce their fears and anxieties. NICE and Scottish Intercollegiate Guidelines Network SIGN [24] recommend that epilepsy nurse specialists should be an integral part of the network of care of individuals with epilepsy.

In terms of case load per nurse, the experience in St James's Hospital shows that one epilepsy nurse specialist 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 [9]. The ENS can successfully operate telephone advice lines and provide electronic support [9]. Experience of the Clinical Nurse Specialist (CNS) in Epilepsy 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 [25]. Recently, research has shown that patients attending specialist services in Ireland and receiving information and education on epilepsy related matters from a CNS, compare favourably, in terms of quality of life, drug compliance and knowledge of their condition with European and US epilepsy centres [26, 27]. Despite the clear evidence in favour of epilepsy nurse involvement, in terms of care delivery, the environment of the specialist epilepsy clinic remains to be validated.

1.5 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 National Health Service [NHS] with epilepsy were not being managed in a structured or systematic way in primary care [28]. 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 [29]. 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 [30].

To assist with building a picture of GP role perception 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 [31]. 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 [32]. 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, Varlay'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 [32]. 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; and 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 [33].

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 in each region having a key role in community delivery of epilepsy care. The focus of the programme is to develop the management of epilepsy patients in primary care with GPs; individualized care plans for each patient; generic protocols for acute seizure treatment and chronic disease management in the community; close links with regional centres through the ANP epilepsy who will provide advice, rapid referral pathways back to the specialist service and eventually outreach clinics at primary care centres and model 2 hospitals.

2. A new mode of care for Epilepsy patients in Ireland: The National Epilepsy Care Programme

Using the national and international data above and in line with other chronic disease programmes the National Epilepsy Programme has devised a model of care delivery that is national, population-based, predominantly nurse led and designed to improve the safe and effective utility of healthcare services for adults and children 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 programmes that evidence suggests will improve outcomes:

1. Managed Primary Care (Epilepsy care in the community)
2. Epilepsy care at the acute hospital interface
3. Care of complex, medically refractory epilepsy requiring surgical evaluation

3. Overarching Aim

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 and, improved **access** to specialist care for patients with epilepsy while at the same time delivering on **value** (cost) which will ensure the sustainability of the programme into the future. These goals will be realized

over the first 3-5 years of the programme.

Quality:

1. To reduce mortality from SUDEP, Status Epilepticus and injuries (100-150 per year; reduce by 1/3).
2. To increase the prevalence of patients who are seizure free (by approx 2000 patients).
3. To reduce no. of hospital admissions, length of stay and readmission rates. (Reduce median length of stay by 1.1 days in each hospital).

Access

1. To eliminate the waiting lists for epilepsy care.
2. To provide 24/7 access to specialist opinion.
3. To ensure all epilepsy patients have timely access to a structured primary care programme.
4. To reduce wait time for epilepsy surgery.

Value

1. To investigate opportunities to make drug cost related savings.
2. To reduce average Length of Stay [LOS] (19,000 bed days nationally).
3. To reduce unnecessary investigation and treatment.

4. Outline of the National Epilepsy Service of Ireland (NESI)

1. Establishment of network of Regional Epilepsy Centres 4 adult, 2 paediatric (fig. 1).
2. Population based nurse-led ambulatory service. 1 nurse per 140,000 pop.
3. Structured primary care programme led by GPs in association with the Primary Care Team [PCT] and the ANP epilepsy.
4. Seizure Care Pathway for acute hospital based seizure management in ED/AMAU and wards.
5. Expanded pre-surgical evaluation programme in two centres.
6. Centralized administration with nationwide electronic patient record (EPR) access for community outreach.
7. Links to Brainwave and other informational resources for self-management.
8. 24 - 7 countrywide telephone advice for health professionals

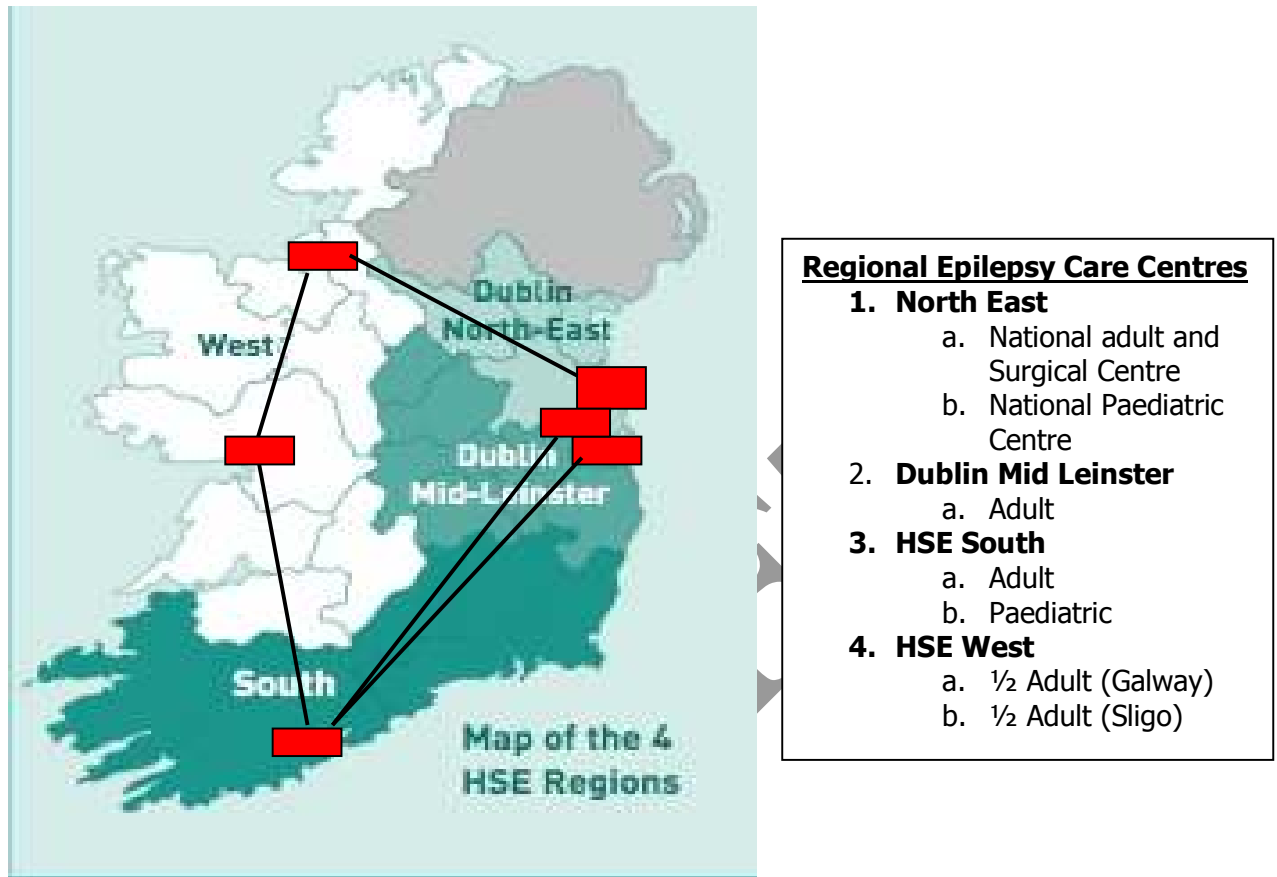


Fig 1. HSE Administrative Map (each region approx 1 million)

5. Three distinct but related parts embodied in the Epilepsy Care Pathway

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

a) General practitioner

GPs will be supplied with an intelligent support toolkit in paper form and via web-based interface. 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 utilized in general practice with any red flags triggering rapid referral back to the regional epilepsy centre. Standard Operating Procedures (SOPs) have been developed for all relevant activities. Electronic access to Regional Epilepsy Centres for rapid electronic referrals will be facilitated via neurolink www.healthlink.ie or

other national electronic referral system. The GP will be the clinical leader for epilepsy care delivery in the community. The number of GPs with a register of epilepsy patients will be a key performance indicator (KPI) for the programme (see 8.5 for other KPIs). The GP will work with the population-based ANPs to provide annual assessment for stable patients and will coordinate care with the hospital and eventually at the primary care centre and residential intellectual disability sites for local ANP led-clinics for those with refractory disease requiring chronic disease management. A structured programme of continuous audit will be developed with 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.

b) Advanced Nurse Practitioners– ambulatory and community role

The programme envisages the recruitment of 20 new nurses nationally to bring the number of paediatric and adult epilepsy nurse specialists to approximately 30. The ANPs will be assigned a population base of patients. The adult assignments will be 4-5 nurses for each region (Dublin North East/Dublin Mid-Leinster/ HSE South and HSE west) and within each region the ANP will be responsible for an area, mirroring the planned HSE integrated service areas (ISA) (see appendix 3 for proposed ISA's nationally). The Paediatric Nurses (CNS and ANP) will cover under 16 year old patients nationally (appendix 4). The Paediatric centre in Dublin (following the amalgamation of neurology services in Dublin) will have 6 epilepsy nurse specialists and will cover 3 HSE regions (Dublin North East, Dublin Mid Leinster and HSE West). The nurses at the Paediatric Centre in Cork will cover HSE south.

Every patient with epilepsy in Ireland will have a named ANP attached to one of the adult or paediatric centres. Patients attending services outside of their regions will be encouraged to transfer care back to the regional centre so as to avail of the ANP service. The nurse led service will be a protocol driven, chronic disease model of care (see appendix 5 for example of Telephone support SOP) covering the following responsibilities:

1. Rapid access clinics in acute hospitals providing acute neurological care.
2. Outreach clinics. – Intellectual disability services and non-acute hospitals.
3. GP support.

4. Liaison with regional physicians in hospitals without neurology services, and with paediatricians.
5. Telephone/e-mail/web support for patients.
6. Links to Brainwave (Irish Epilepsy Association) and Irish Branch of the International League Against Epilepsy (ILAE).
7. Ensure complete, accurate and up-to-date documentation of clinical encounters using an Electronic Patient Record (EPR).
8. Implementation and use of Standard Operating Procedures (SOPs)
9. Registration and measurement of Key Performance Indicators, quality outcomes and clinical audit.
10. Health Services Research, population health and clinical and translational research.

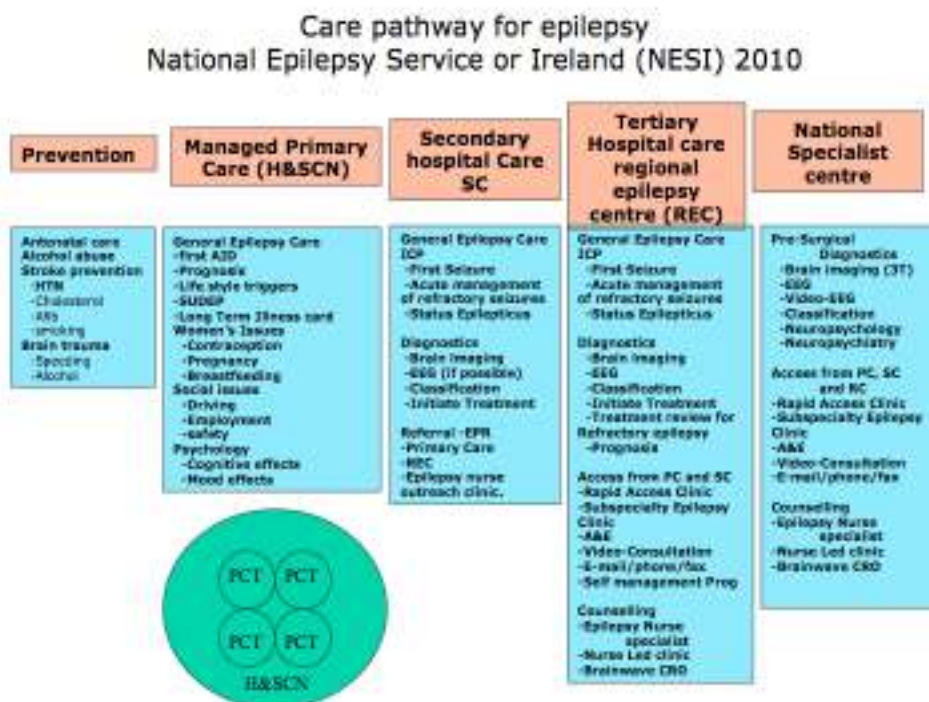


Figure 2. Care pathway for Epilepsy

5.2 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/AMU and on hospital wards (see examples of pathways for seizure management in the ED/AMU – appendix 6 and 7). Each of the regional centres will be led by a consultant neurologist with specific training in epilepsy care. This regional lead will be the responsible and accountable clinician for the delivery of the programmes' goals. The programme has been working with the pre-hospital care services, National Emergency Care Programme and the National Acute Medicine Programme to define unambiguous guidelines for initial seizure management and subsequent referral onwards for specialist opinion follow-up. The programme will currently define best practice around existing international guidelines [23, 24]. However, it is envisaged that Irish national evidence-based guidelines for specific aspects of care will be developed and submitted to the Irish National Clinical Effectiveness Committee for sanction (NCEC).

Advanced Nurse Practitioners, The acute hospital role:

1. Chronic disease management for refractory disease.
2. Rapid access clinics (for ED discharges and first seizure).
3. Telephone advice and e-mail support for patients and families (Appendix 5).
4. Ongoing support of inpatients, families and parents of children admitted with seizures.
5. Supporting patients and families on the epilepsy surgery programme.

The Consultant epileptologist or paediatric neurologist will provide oversight and clinical governance, and be responsible for ANP clinical training. Professional governance for the nurses will be to the Director of Nursing at each regional centre (see section 8 for detailed governance arrangements).

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.

5.3 Highly Specialized Care (National Epilepsy Centre)

Beaumont hospital will house its own nurse led regional service but in addition, patients with complex epilepsy, requiring presurgical work-up and evaluation for possible device implantation will be referred there. There will be a 4-bedded video telemetry unit in Dublin, and a 2-bedded video telemetry unit in Cork fully staffed with staff nurses (Fig 4). On the paediatric side, the model of the single bedded units in the Children's University Hospital (CUH) Temple Street and Our Lady's Children's Hospital, Crumlin (OLCHC) will continue until their amalgamation as the national paediatric hospital, when a new two bedded unit will be created. The staff nurses in the adult units will also provide 24/7 nationwide out of hours telephone advice for hospitals and primary care sites with EPR access and remote management (this includes directing physicians to intelligent support services regarding management of uncontrolled seizures in adults and children). The national centre will be housed in Beaumont Hospital and will provide a hub for the national EPR and telesupport rollout. The Consultant Epileptologist /Paediatric Neurologist and Programme Clinical Lead will provide oversight and governance and will be responsible for epilepsy fellow and ENS training.



Figure 3: Modern Video EEG monitoring unit

5.4 Considerations for special groups

a) 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 recognizing the special requirements of this group in the areas of pharmacology, psychosocial development, rights and responsibilities of parents and carers and service development.

Within this document several key areas of difference need to be highlighted:

1. Regional service delivery. There are approximately 1 million citizens under 16 years of age (appendix 4). This gives an approximate prevalence of epilepsy of 8,000 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. Since there are only 2 centres and one of those is necessarily larger, the regional delivery model will be uneven but will maintain the nursing ratios as much as possible. Appendix 4 shows a Map of the county by county population under 16 years. The current population of under 16 year olds in HSE South along with old HSE Mid-western region is approximately 270,000. It makes logistical sense given the resource allocation nationally for the Paediatric regional epilepsy centre in CUH to take responsibility for this cohort, bearing in mind that 15% will end up being referred to the Dublin centres for consideration of epilepsy surgery.

2.0 Managed Care in Community for Paediatrics. A network of care based on lead community paediatricians using standard operating protocols in conjunction with nursing expertise, which will use phone, email and web based support. 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
	Tallaght Hospital (AMNCH)	3 Community Paediatricians
Cork	CUH/ Mercy Hospital	2 Paediatric Neurologists 10.5 wte Paediatricians 4 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

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 ANPs in a similar fashion to adults. The Paediatric Emergency Services manage childhood seizures and status epilepticus according to International Guidelines. At present, most children with newly onset epilepsy are 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.

Specific Paediatric Proposals on Model of Care

Quality

- Improvement in the accuracy of diagnosis in childhood epilepsy by hosting further PET courses and access to Paediatric Neurology.
- Improvement in seizure freedom through more accurate diagnosis and more rational drug use.
- Reduction in bed days in Paediatric Epilepsy Care

Access

- Programme aimed at improving support to General Paediatricians rather than GPs as the way forward in improving Paediatric Epilepsy Care.
- This support will be based on:
 1. Guidelines for management of common Epilepsy Syndromes
 2. Improved web based access to Regional Epilepsy Centres
 3. Improved access to Regional ANPs in Epilepsy
- Managed clinical networks anchored by General Paediatricians in the 15 “peripheral” Paediatric Units around the country will be developed
 - This clinical network would be centered around two Epilepsy Centres in Dublin and Cork and work on a hub and spoke model
 - Pending the appointment of additional Paediatric Neurologists to Dublin and Cork we would endorse a programme of outreach clinics to Peripheral Units run by a visiting Paediatric Neurologist, Advanced Nurse Practitioner and EEG clinical measurement scientist.
 - The Regional distribution should vary somewhat from the Plan for Adult Services in anticipation of possible future alliances between existing small Paediatric Units.

- 4 Units in the South East of the country for example are within a 30 mile radius of each other. 3 of the 4 are in South Leinster and for the purpose of this Model they should be considered a unit.

b) Intellectual disability

Patients with Intellectual disability frequently have the most difficult to control forms of epilepsy. The frequency of epilepsy amongst this group of patients 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 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 ANP. It is hoped that this outreach service will begin very soon after the programme launches in the larger residential centres. Similar to the above there will be a toolkit of pathways and protocols for the specific intellectual disability sector.

c) Elderly

The elderly 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 elderly patients as inpatients, and a significantly higher proportion who suffered from potentially life threatening prolonged seizures called status epilepticus. The main considerations in the elderly, therefore are; to consider the possibility of co-morbid conditions; to be alert to the sometimes subtle presentation of dangerous prolonged seizures in the hospitalized patient and 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. In this, liaison must be established with the ED, Acute Medicine and Care of the Elderly programmes. This engagement has begun.

d) Allied Health Professional Role

Access to Dietetic, Occupational Therapy (OT), Physiotherapy (PT) and Speech and Language Therapy 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 (10) and stroke. The integration of therapy services across the hospital service, primary care and ID services will be facilitated by the GP.

OT's 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.

Children with intractable epilepsy can be considered for specialised dietary treatment which involves a ketogenic or very low carbohydrate diet. This diet is complex and requires the input of a specialised dietician working with highly motivated parents.

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.

6.0 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 The ILAE Commission on European Affairs: Appropriate Standards of Epilepsy Care Across Europe document, first published in 1997 [35]. 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 line of SIGN and NICE [23, 24] will not be completed in the short term, rather, single focused guidelines be drawn up through the governance of the National Clinical Effectiveness Committee.

In the mean time the National Epilepsy Care Programme has begun a process of wide consultation with patients and patient advocacy, medical, nursing, and allied health professionals for the development of a book of standard operating procedures (SOPs). To date, forty five SOPs have been created by the various working groups. 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.

7.0 The Electronic Patient Record

Standardized clinical documentation, the 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) that will provide authorized clinicians, regardless of geographical location, with access to complete an accurate patient record 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 [31, 34, and 40]. 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, Vagus Nerve Stimulator (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 [36].

The EPR has been in daily use at Beaumont Hospital for the last 4 years and 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 2000 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 Epilepsy Care programme envisages this EPR becoming a national information system that will be accessed using web-based secure portal at all regional sites. The system will allow for rapid retrieval of patient information anywhere in the country,

synthesis of results and easy and instantaneous communication with primary care and other centers. It is envisaged that registration on the EPR will be another KPI for the programme. The EPR number will be the patients' national epilepsy number, which anticipates the development of a national unique health identifier over time.

8.0 Governance

8.1 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 [37]. 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 [37] (see Appendix 6 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 4):

- Agree the measurable safety, quality, access and cost objectives you want to achieve which are in line with HSE national priorities.
- Ensure there is a documented standardised pathway in place, which is supported by standard clinical decision-making and regulatory requirements.
- Ensure that all parties involved in the pathway have total clarity of their accountability roles, responsibilities and governance arrangements.
- Ensure there is a balanced set of metrics in place to track the performance of the pathway.
- Ensure there is an effective 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.
- 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].

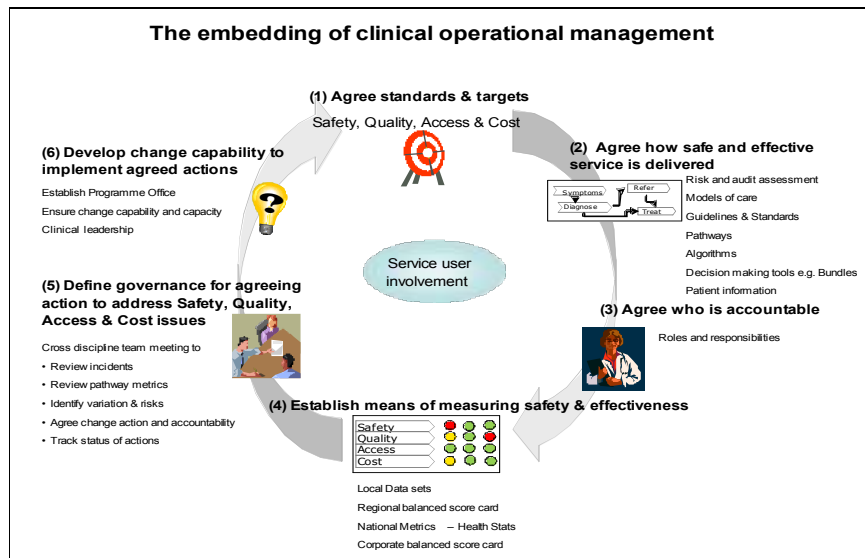


Figure 4

The National Epilepsy care programme 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 5 where the patient is pivotal to clinical and corporate governance strategy development. It embraces clinical effectiveness, clinical audit, research and development, clinical indicators, integrated pathways, risk management, and organisational development.

Governance Structure Epilepsy Programme

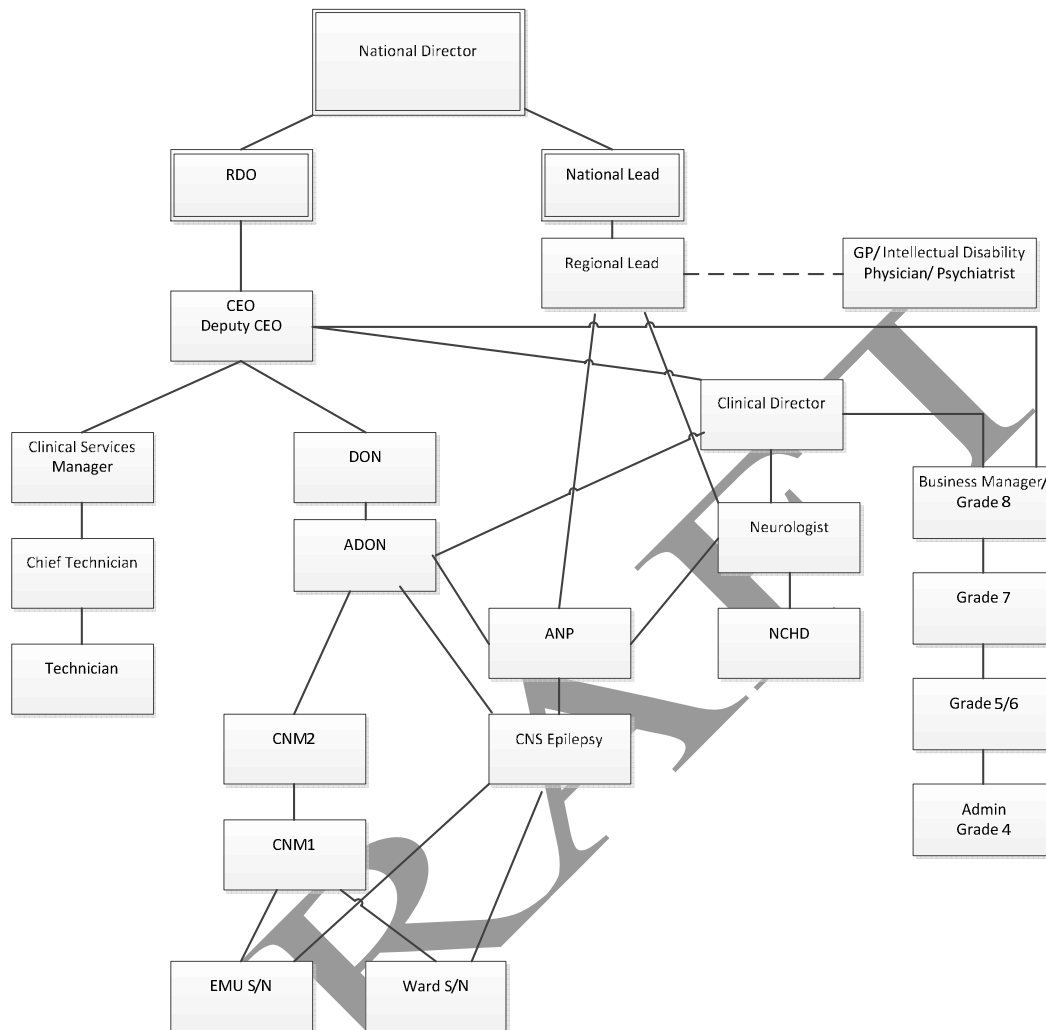


Figure 5

8.2 The Governance structure of the programme

The governance consists of two supervisory groups:

1. Project group

The project 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 (ANP) 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. It is planned that following implementation, this group will meet quarterly with the regional leads to resolve any issues which may arise, monitor and evaluate implementation and ensure a cohesive interpretation of the national strategy.

2. 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 (Brainwave), a physician with special training in intellectual disability and a medical physicist / health informatics specialist.

8.3 Roles and Responsibilities

1. 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 Programme Director in the clinical strategy and programmes directorate, the clinical advisory group for the national epilepsy programme, the Chief Executive Officer (CEO) and board of the HSE. He or she will be responsible for delivery of programme goals, quarterly reporting of national KPIs, national audit results, continuous improvement and performance management of regional leads including reporting and managing adverse events and complaints.
2. **Regional Epilepsy leads** are the lead clinicians for epilepsy in each of the 4 HSE regions. He or she is accountable to the National Lead. He or she will be responsible for quarterly reporting of KPIs and Audit outcomes, performance management of other neurologists in the region in relation to epilepsy care and training of nurses (to ANP level), Epilepsy fellows, other neurology trainees and medical students.
3. The **National Nursing lead** is the lead epilepsy ANP. He or she is accountable to the National Clinical Lead and to the National Nursing directorate. He or she will be responsible for managing ANP and CNS performance and monitoring training of CNS, ANP and other nurses in ED/AMU and medical and neurology wards.

4. **Consultant neurologists** (with or without special training in epilepsy) will be accountable to the regional lead regarding epilepsy care only. He or she will be responsible for delivery of programme goals.
5. The Epilepsy **ANPs and CNSs** are clinically accountable to the patient's named consultant neurologist and to the regional lead. They are professionally accountable to the Director of Nursing in the regional epilepsy centre and the lead epilepsy ANP. Nurses working away from the regional epilepsy centre in another hospital or health care setting will have professional accountability and responsibility to 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.
6. The **General Practitioner** is accountable to the Irish College of General Practitioners and the HSE. The GP is responsible for the general management of epilepsy patients in the community, and for maintaining contact with their regional epilepsy centre.
7. **Administrators.** The administrators will be accountable to the administrative supervisor in the regional 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 regional lead and ENS at the regional centers.

8.4 Training

A. Nursing

This programme has planned for and is supporting the creation of a new cohort of expertise at ANP level. Nurses currently working at Epilepsy CNS level may opt to stay at this level and the programme acknowledges this. Professional accountability of nurses and midwives is clearly defined by the Scope of Nursing and Midwifery Practice Framework. Each nurse and midwife is individually accountability for his/her professional practice including appropriate delegation. [39]. It is expected that new staff will be recruited at CNS or CNM 2 level. Defined competencies using a competency framework will allow these newly appointed nurses to move towards Advanced Nurse Practitioner over a predetermined period of time. The programme will commence with a

post-registration course, which will cover basic physiological, pharmacological, psychological and social issues to do with epilepsy. All new nurses recruited will be expected to become registered nurse prescribers.

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 will deliver a master's programme in epilepsy nursing (inclusive of nurse prescribing), providing educational requirements to allow nurses to achieve the competencies necessary for registration as an ANP. This will commence in January 2012.

B. 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

C. Clinical Neurophysiological Science

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: A Professional Education coordinator (PEC) similar to that role in other AHP's is due to be advertised in Early 2012 and will be based in DIT as an academic role. With the expansion of the Epilepsy Monitoring Units (EMU) 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.

8.5 Key Performance Indicators, Audit and Research

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 KPI's have been submitted to the directorate:

1. % Improvement in time from referral to telephone contact with patient
2. % Improvement in wait time for OPD access
3. % Improvement in registration on EPR and GP services
4. % Improvement in median length of stay
5. % Improvement in readmission rates
6. % Reduction in overall discharges

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 that require intervention. The KPIs also provide criteria and standards for clinical and organisational audit.

In line with other clinical programme, the KPIs will be used to monitor performance of the epilepsy programme from January 2012 with the first report in April 2012.

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 the 'Guidance on developing key performance indicators and minimum data sets to monitor health care quality' [45], based on an analysis of evidence from an extensive literature review. This document has been used to inform the epilepsy programme on indicator development.

8.6 Risk Management

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, which 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 epilepsy, systems will be in place to ensure adherence to good standards, including ethical standards and systems for making and dealing with complaints. This will happen in line with HSE's Quality and Patient Safety Directorate, which oversees the quality of services and the adherence to standards, to ensure patient safety is protected. The Directorate works to ensure robust investigation of incidents so that learning is identified and shared across the system. Clinical decision-making support tools in the form of Integrated Care Pathways, SOP's have been developed by the programme to ensure that care given is standardised and evidence based.

Information governance including how data will be protected and how information will be disseminated throughout the system will be developed in line with the overall Clinical programmes. The forthcoming Health Information Bill will address issues around data.

8.7 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 (PDP) is a continuous development process that enables people to make the best use of their skills and helps advance both the individual's 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.

9.0 Impact on Other services

9.1 Neurophysiology (Routine EEG and Long Term Monitoring)

Approximately 5,000 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 5,000. Out patient 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. Approximately 4,000 EEGs are required per region. Assuming 5-7% will undergo surgical or diagnostic evaluation this will yield approximately 600 overnight telemetry cases, ambulatory or prolonged recordings, which is approximately 120 per region. 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.

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. [41-44]
- Requirements for Clinical Neurophysiological Scientist numbers for national delivery on goals including expanded Presurgical Centres.
- The impact on non-EEG neurophysiology services.

9.2 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) [38] as well as other national and international guidelines SIGN [23] and NICE [24] 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. [38]. 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 [8,9].

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
- A guideline requiring a specified protocol and a multi-disciplinary approach to reporting of the scan requested for epilepsy at private institutions has been suggested.

10. Implementation Timeline

As one of the national programmes in clinical care, the Epilepsy Programme is considered one of the outpatient initiatives and is being developed alongside national OPD programmes in General Neurology, Dermatology, Rheumatology and Orthopedics. The programme has concluded the first phase of planning and implementation that included:

1. Appointment of clinical leads, programme manager, workforce planning, and public health expertise commenced in April/May 2010

2. A Clinical Advisory Group (CAG) under the auspices of the Royal College of Physicians in Ireland has been convened quarterly since May 2010.
3. Engagement with clinicians at stakeholder institutions has been conducted for all regional centres.
4. Implementation plans have been delivered to all centres and will be signed off in advance of service provision beginning.
5. 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 2011.
6. A master's programme in epilepsy care to fulfill the academic requirements for advanced nurse practitioner has been designed in conjunction with the Royal College of Surgeons in Ireland School of Nursing.
7. The Draft model of care document has been signed off by the CAG and RCPI and the ICGP (Irish College of General Practitioners) and will be posted on the Brainwave website for public consultation for 30 days from March 2012.

DRAFT

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12. Appendices

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

2. Hipe data 2006-2008

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

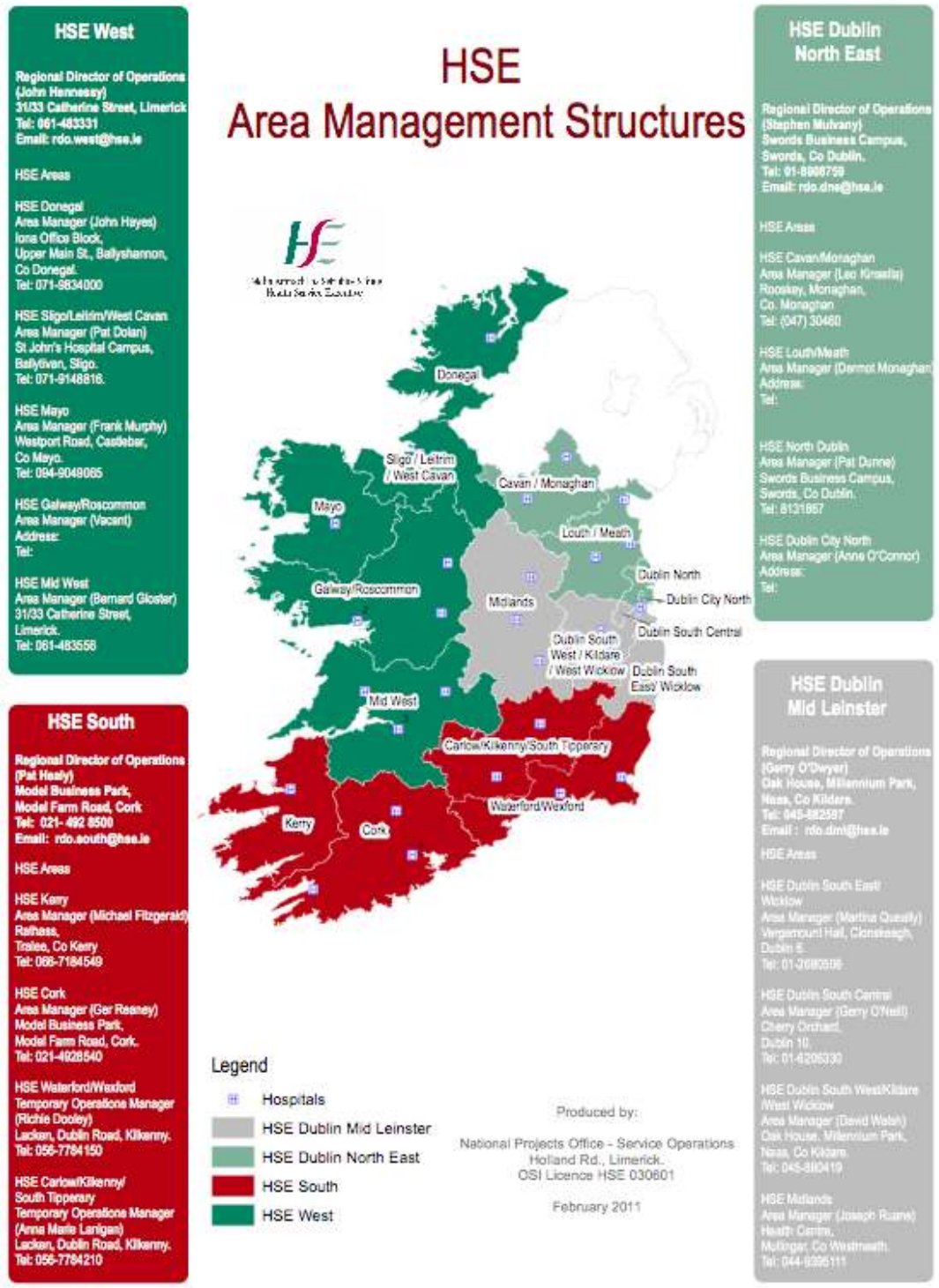
	No discharges	No patients	Sum bed days	Mean bed days	Min bed days	Max bed days	*Median bed days	Sum DRG €	Mean DRG €	#Daily bed cost
2006	6,685	5,430	29,831	4.5	1	338	2.5	21,339,814	3,192	715
2007	6,879	5,651	30,251	4.4	1	290	2.4	21,420,087	3,114	708
2008	6,982	5,772	31,532	4.5	1	268	3.3	22,086,414	3,163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

*Averaged median

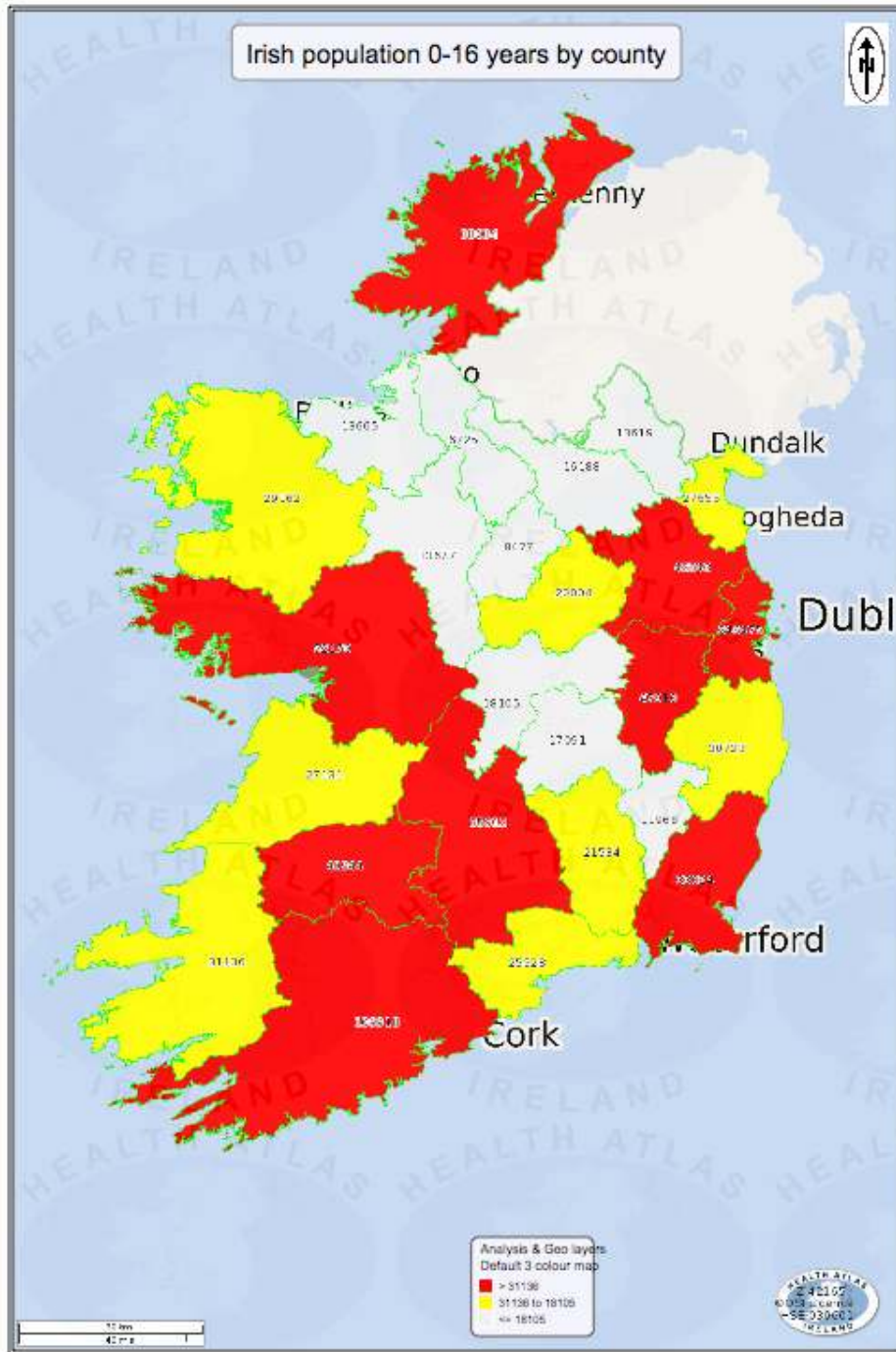
#Daily bed cost = Sum DRG / Sum bed days

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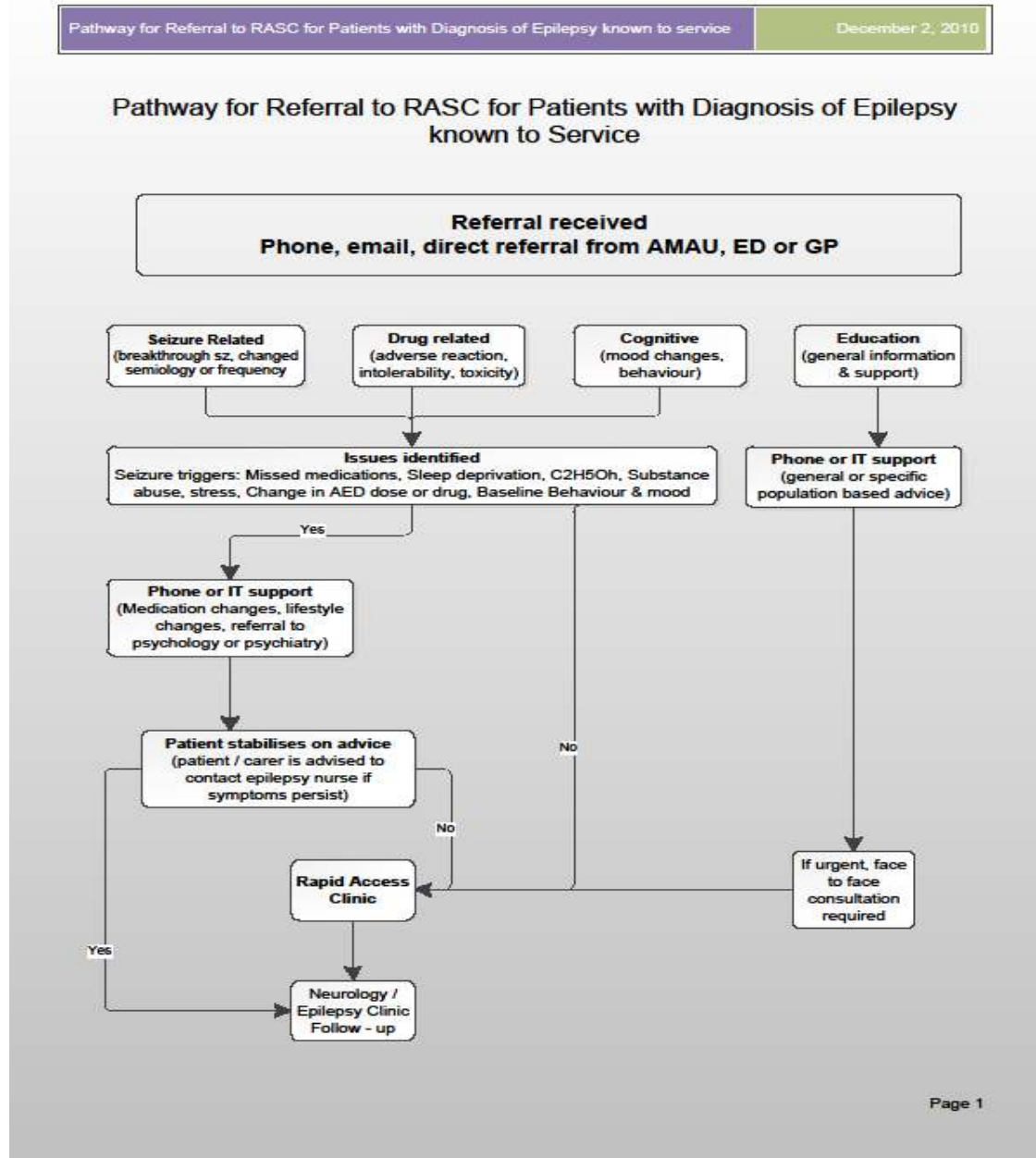
3. Proposed Integrated Service Areas



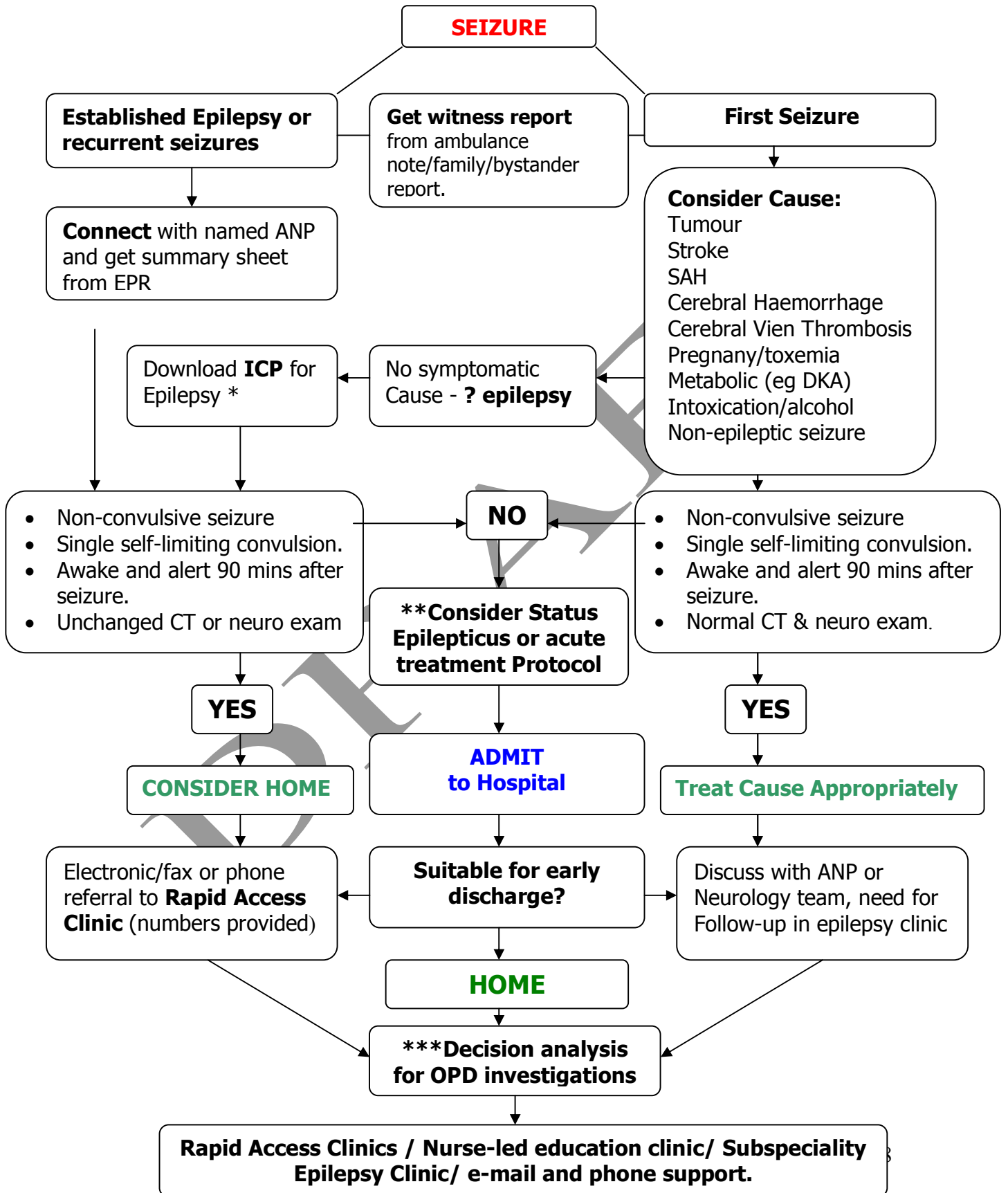
4. Map of Ireland with numbers of under 16 years old indicated by county



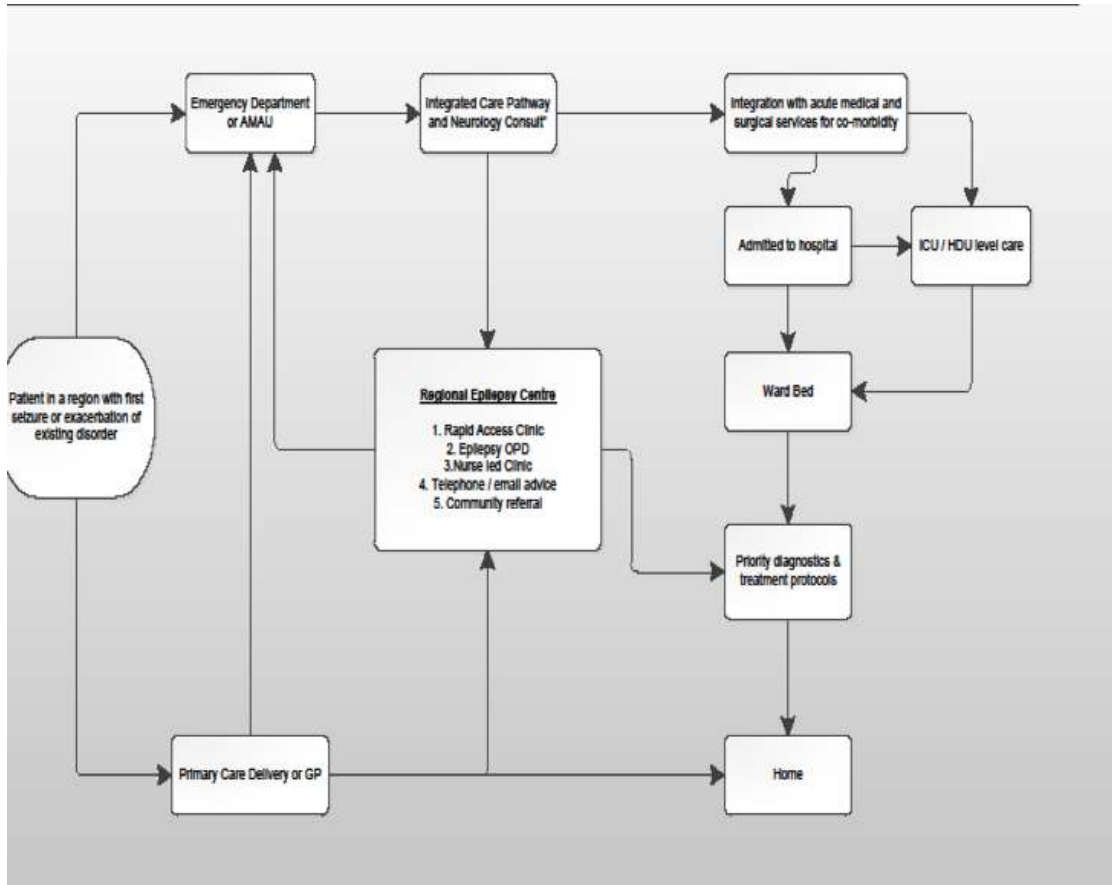
5. Nurse Protocol for referrals from ED/AMAU and Community



6. ED Care pathway for Seizure



7. Patient Pathway from Community to Hospital



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8. Guiding principles for clinical governance



National Clinical Programmes



Guiding Principles for Clinical Governance

Every decision in relation to clinical governance should be tested against the principles set out below.

Patient centeredness	The purpose of governance is to ensure safe, easily accessible, timely and high quality service for patients and the public across the continuum of care. Based on a partnership of care between patients/service users, families, carers and healthcare providers.
Single point accountability	A system whereby individuals, functions or committees agree accountability to a single individual.
Clear responsibilities	Where all employees have a current job-description setting out the purpose, responsibilities, accountabilities and standards required for the role.
Defined authority	The scope given to staff at each level of the organisation to carry out their responsibilities. The individual's authority to act, the resources available and the boundaries of the role are confirmed by their direct line manager.
Leadership	Leaders motivating people towards a common goal, making sense of change, helping colleagues to see how their work fits into the bigger picture. Professional, organisational and financial authority with responsibility to ensure that quality, efficiency and effectiveness are achieved in the delivery of clinical care.
Inter-disciplinary working	Work processes that respect and support the unique contribution of each staff member in the provision of clinical care. Inter-disciplinary working focuses on the interdependence between individuals and groups in delivering services. This requires proactive collaboration between management, administrative and clinical colleagues.
Managing performance	Managing performance in a constructive way in a continuous process (not a surprise) taking account of clinical professionalism and autonomy in the organisational setting. The performance management process develops a director/manager in managing the service and employees thereby contributing to the capability and the capacity of the individual and organisation. Measurement of the patients experience as described in the National Charter is central to how performance is measured.
Capacity and capability	Implies qualified people, adequate physical and financial resources and access to specialist expertise where necessary. Systems focused on developing the capacity and capability of inter-agency, inter-disciplinary teams and individuals to deliver effective health care services every day.
Disclosure and transparency	A culture of trust, openness, respect and caring where achievements are recognised and open discussion of error is embedded in everyday practice. Staff willingly report adverse events, because there is a focus on learning, research and improvement, and appropriate action is taken where there have been failings in the delivery of care.
Continuous quality improvement	A learning culture with a comprehensive programme of quality improvement (including clinical audit, performance management processes, supporting and applying evidence based practice, implementing clinical standards and guidelines, workforce planning and development).



9. List of Abbreviations

ANP	Advanced Nurse Practitioner
AED	Anti Epileptic Drugs
CAG	Clinical Advisory Group
CRO	Community Resource Officer
CNPS	Clinical Neurophysiology Scientist
CT	Computerised Tomography
DIT	Dublin Institute of Technology
EEG	Electroencephalography
ED	Emergency Department
ENS	Epilepsy Nurse Specialist
EPR	Electronic Patient Record
ELO	Epilepsy Liaison Officer
HIPE	Hospital In-Patient Enquiry
H & SCN	Health & Social Care Network
HSE	Health Service Executive
ID	Intellectual Disability
IICMS	Irish Institute of Clinical Measurement Science
ILAE	International League Against Epilepsy
LOS	Length of Stay
LTM	Long Term Monitoring
MRI	Magnetic Resonance Imaging
NEAD	Non-epileptic attack disorder
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
PNES	Psychogenic non-epileptic seizures
PWE	People with Epilepsy
RC	Regional Care
RDO	Regional Director of Operations
REC	Regional Epilepsy Centre
SC	Secondary Care
SIGN	Scottish Intercollegiate Guidelines Network
SUDEP	Sudden Unexplained Death in Epilepsy
SE	Status Epilepticus