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Executive Summary

Background
This Strategic Review of Neurology services in Ireland was undertaken during 2006 and 2007. In Ireland neurological services have not yet received the same high profile as other conditions e.g. heart health or cancer. Yet neurological conditions are common, life-changing and disabling. They exert major work loads on many parts of the health service. The main reasons for conducting the Review include, the HSE priority to transform the health service so as to ensure integration between all its parts and to achieve optimum patient outcomes, the recognition that demand for neurology services is increasing but our current service arrangement can no longer meet the level of need, the realisation that the rapid pace of technological advances in neurology, that can lead to successful treatment, will fundamentally change the way the service is delivered.

In Ireland it is estimated that over 700,000 people have a neurological condition which account for one in eight consultations in primary care and one in five emergency medical admissions to hospital. They can be difficult to diagnose. They are often long term and disabling. As the population grows and ages prevalence increases. There are a large number of neurological diseases ranging from the relatively common conditions of migraine and epilepsy, Parkinson’s disease and multiple sclerosis to rare conditions such as myasthenia gravis and motor neurone disease. They affect all age groups from the young, economically active adults and older people who are more likely to have neurodegenerative diseases.

Aim and Methodology
The Review was overseen by a multidisciplinary Steering Group whose aim was to identify the current provision and future requirements for neurology and neurophysiology services in Ireland. The specific objectives were to:

1. Describe the epidemiology of neurological conditions in Ireland.
2. Evaluate current neurology services, including paediatrics and neurophysiology.
3. Review the evidence in relation to models of service delivery and make a recommendation on the preferred model for the Irish health system.
4. Identify requirements for the development of neurology and neurophysiology services nationally and prioritise service requirements.
5. Report to the Director of the National Hospitals Office.

The work was undertaken by four Working Groups which reported to the Steering Group. The Working Groups examined:

1. Health Information and Epidemiology
2. Description and Assessment of Current Services and Proposed Model of Care
3. Technology, Training and Research and Development (R&D)
An examination of the epidemiology of neurological conditions including the projection of prevalence as the population ages was undertaken. The current neurological service was thoroughly assessed. Personnel who provide neurology services in all hospitals were consulted. Hospital utilisation statistics were compiled and examined. Patient pathways were mapped. Research was undertaken with GPs and patient representative groups. Best-practice in the provision of a modern neurology service was investigated as were the impact of technology, research and development and the need for training in the specialty.

Recurring themes that emerged include:

- The service is based on a sound footing in that it has committed high quality personnel - many being international leaders in their area of expertise
- Patients with neurological conditions require specialist multidisciplinary care on a long term basis
- There are major weaknesses in the way the service is delivered e.g. poor integration between different parts of the service
- Demand for care outstrips supply. There are long waits and access is inequitable
- The service is largely hospital based and it is overloaded
- There is huge potential to change the landscape of neurology services in Ireland. These include the wish for neurology personnel to change in the interest of patient care and to embrace the opportunities that technology, research and specialist training can create in providing better patient outcomes.

Assessment of the Current Approach to Providing Neurology Services

i. Epidemiology

Chapter 2 describes the epidemiology of neurological conditions. Approximately 44,000 people are diagnosed with a neurological condition in Ireland every year. At least 110,000 people with a neurological condition are significantly disabled by their condition and approximately 1.5% of the population are caring for a person with a neurological condition.

Migraine is the commonest neurological condition affecting over 500,000 people and the commonest neurological condition presenting to primary care. Epilepsy is the second most common condition affecting over 30,000. More than 6,000 people have Parkinson’s disease and up to 7,000 have multiple sclerosis. In the population as a whole a prevalence rate of 10 per 1,000 for dementia is estimated and this increases to 70 per 1,000 among people over the age of 65 years.

People with neurological conditions frequently attend their GP. It is estimated that every year all patients with epilepsy and multiple sclerosis attend their GP, two-thirds of patients with Parkinson’s disease attend and one in twenty migraine patients attend their GP. Overall neurological conditions account for one in every eight GP consultations.
ii. Service Utilisation

Chapter 3 describes service utilisation. In Irish hospitals 83% of neurology admissions are emergency rather than elective. In addition 15-17% of all admissions from ED have a neurological condition. Approximately 8% of ED attendees present with a neurological condition. The average weekly time spent by neurologists in providing a consultation service to other hospital departments in a modern 500 bed hospital is equivalent to one whole-time neurologist - approximately 35 hours per week.

Inpatient hospital statistics do not capture the full workload of the neurology service. There are approximately 40,000 inpatient admissions every year. Patients with neurological conditions are often admitted under other specialties and do not see a neurologist.

The main reasons for admission to hospital with a neurological condition include seizures and headache (10,000 per year), cerebrovascular disease (8,500 per year) and multiple sclerosis (1,500 per year). Only 17% of admissions are day cases. Neurological conditions have long average lengths of hospital stay (ALOS) - the ALOS for acute stroke is 18 days. For neurodegenerative conditions the ALOS is 23 days yet such conditions account for only 6% of admissions.

There are 44,000 people invited to neurology outpatient clinics each year but 21% do not attend. There are long waits to access the neurology service especially as an outpatient. These delays occur at all stages of the patient pathway: referral and investigation, diagnosis, treatment and management. Community services are poorly developed from the neurology perspective.

There is a large variation in the availability of neurology services around the country with unequal access and long waiting lists for diagnosis, treatment and care. Ireland currently has eight adult neurology units and three paediatric units. There are 24 approved adult neurologist posts of which seven are unfilled. For the current population it is recommended that the current needs for Ireland is 42 adult neurologists. New neurologist posts have been approved to develop services in Waterford, Limerick and Sligo and to enhance existing services. The number of approved neurologist posts currently stands at approximately 1 per 180,000 population. A ratio of 1 per 100,000 is currently recommended. Each new consultant post requires a multi-disciplinary team of allied health professionals and specialist nursing. To meet population needs 12 paediatric neurologists are required (ratio of 1 per 100,000 childhood population. To meet international norms 12 clinical neurophysiologists are needed.

The service is predominantly hospital based. However, people with neurological conditions are frequent attendees to their GP. GPs are happy to be more involved in the care of patients with neurological conditions but, in their view, they do not receive enough support from specialists in the form of guidelines for care, continuing education
and fast access to neurological opinion. There is very little integration with Primary Care and PCCC, including AHP services.

iii. Views of stakeholders
Consultation was undertaken with personnel in all hospitals that provide a neurology service. Research with GPs was conducted. The views of patients and voluntary groups were obtained. These are described in Chapter 4.

A number of consistent themes emerged from this consultation process:

- The key strengths of the service include the dedication and expertise of its personnel, the multi-disciplinary approach (where this is established), involvement of voluntary groups, commitment to research and development and innovation.

- Many weaknesses in the current system were identified. These include the long waits for services at all levels, insufficient specialist resources in hospitals and community, poor access to diagnostics and specialist multidisciplinary care, poor integration between hospital and community services and difficulty in accessing patient equipment and aids.

- The challenges to be addressed include the management of increasing workloads, greater opportunities to treat patients successfully, integrating care between hospital and primary / community services and exploiting the role of technology. There are good examples of how neurologists are currently meeting these challenges and are being responsive to the needs of patients e.g. fast access, electronic based consultation service and tele-neurophysiology service which removes the need for unnecessary travel.

- GPs are generally unhappy with current service. This is primarily because of delays faced by patients. GPs are keen to work in a collaborative manner with the specialist service and promote a patient centred, integrated approach. There are good examples in Ireland of GP led services e.g. migraine clinics. The main proposal made by GPs that would lead to an improvement in services is that more neurologists need to be appointed.

- The scope for AHPs specialising in neurology is increasing but there is a shortage such specialists in hospitals and a greater shortage in community health settings. This leads to a combination of inappropriate hospital utilisation and inadequate access to appropriate care.

The advent of new therapies and treatment opportunities is changing neurology practice. The service in Ireland is currently challenged by these advances. The way Ireland delivers neurology care is not sustainable. It is not able to meet demands. It lacks integration and real multidisciplinary care. The structure and system need to be radically overhauled, so that most care is provided as close to the patient’s community as possible, with Primary and
Community Health services and local hospital services empowered to play key roles, while enhancing specialist and tertiary services that provide the required critical mass for rare and complicated conditions, and that will facilitate the development of a strong academic programme of clinical and translational research in the neurosciences.

**Role of the Voluntary Sector**
The role of the voluntary sector is described in Chapter 5. Neurology services engage well with voluntary organisations but there is scope for even greater collaboration, for example:

1. **Provision of specialised services**: Voluntary services provide a range of specialised services and supports focused on the wider health and social needs of people with neurological conditions and their families. They have an important role as a single uniform point of contact in a complex care pathway. Therefore voluntary organisations should be seen as a key component of the service.

2. **Advocacy and representation of the needs of people with the condition**: Voluntary organisations have an important role to play in advocating for the needs of people with neurological conditions. On an individual level, many provide specialised services to help people to identify and access the services they require. At a broader level, they perform an essential role as “gatekeepers”, identifying and promoting the needs of the people they represent on a wide range of policy issues. Increasingly, there is recognition that service users need to be more involved in the planning and delivery of health services. Voluntary organisations provide an effective forum for consultation on service needs and service provision as they represent a wide range of service users.

3. **Resource for information, service development, innovation, research and training**: Voluntary organisations act as an important hub to drive and promote research on neurological conditions. They are involved in pioneering innovative approaches and bring together a wide range of interest groups to focus on the condition. Voluntary organisations are a vital resource in terms of specialised knowledge and expertise to inform service design and delivery.

**Technology, Research and Development**
The scope of technology in neurology is described in Chapter 6. An array of new technologies is enabling more accurate neurological diagnoses, better treatments and outcomes. While Ireland has a strong neurology research community it needs to keep pace with international developments and opportunities. A wide range of complex expertise is required in this emerging field including strong academic research to enable the safe delivery of new techniques. Specialist training is an essential component in fostering a strong neurology community in Ireland including medical, technical, allied health professional and nursing.
The neurology service already uses ICT in innovative ways to provide better and more responsive services for patients e.g. web enabled services and tele-medicine. There are greater opportunities to exploit these technologies for patients e.g. in developing a national epilepsy network. The significant role of technology in the management of long term neurological conditions cannot be underestimated.

Recommended Model for Neurology Services in Ireland
Chapters 7 and 8 describe the proposed model for delivering neurology services in Ireland and the rationale for a Network Approach.

The vision of achieving a world class neurology service is achievable in Ireland but this requires that a number of changes be made to the way the service is delivered. This includes changes to the current structures and systems to enable the development of a flexible, accessible, multidisciplinary service that is appropriately resourced and where all parts of the service works together to achieve best patient outcomes.

i. A New Structure
It is recommended that neurology services in Ireland should be delivered through four Managed Clinical Networks – co-terminus with the four HSE Areas (facilitating integration with Primary and Social Care Networks in PCCC). These Networks should be supported by a National Neurology Steering Group. Developing a Managed Clinical Network for Neurology requires a structured approach and new ways of thinking and working by all participants across geographic locations and traditional institutional boundaries. Active management and genuine participation are key to achieving the potential benefits and optimal patient outcomes. This approach reflects the HSE priorities to deliver high quality, integrated and responsive care. It enables Transformation. It optimises opportunities for local input in the design of neurology services. The establishment of the Networks should ensure that the energy and resources of service providers within each region are focused to achieve clear objectives to improve services.
The diagram, above, shows the structure of the proposed Networks – each with a population of approximately one million people:

1. **Dublin-North-East**: includes Beaumont, the Mater Hospital and the North East Hospital network with outreach services to Connolly Hospital
2. **Dublin-Mid-Leinster**: includes St Vincent’s University Hospital, St James’s Hospital, AMNCH with outreach to the Midlands
3. **South**: includes Cork University Hospital, the Mercy Hospital and Waterford Regional Hospital
4. **West**: includes University Hospital, Galway, Sligo Regional Hospital and Limerick Regional Hospital.

The characteristics of each Network, its roles / functions and operating requirements are described in detail in Chapter 8. These include:

- Regional self-sufficiency for general neurology services and ongoing integrated patient management.
- Medical leadership; the availability of specialist personnel to comprise a multidisciplinary team approach; the provision of relevant support services e.g. radiology; facilities for research and education.
- Population based networking of available resources across traditional boundaries, with regional decision making and governance.
• Integration between primary, secondary and tertiary services with national leadership and agreement where complex cases are treated by implementing national protocols.

• Good communication and coordination among staff, both within hospitals and between hospital and community-based services (including GPs). Joint patient care planning and shared appointments to the Network occur.

• Consistency and quality in service development and delivery at all levels

• Better patient care, particularly in terms of quality, access and co-ordination. Service monitoring and audit are always undertaken.

Roles / Functions at National Level - The National Neurology Steering Group Role

A National Neurology Steering Group should be established with the following the roles and functions:

- The establishment of a national governance structure for neurology. This could include the provision of advice on the infrastructure capabilities to facilitate population based outcomes e.g. protocols of care, audit framework, hi-tech developments, ICT, web based services and electronic health records etc.

- Commitment to Regional implementation of the Network model of working.

- Development of an effective interface with the National Hospitals Office, PCCC and Population Health Directorates, the Regional Clinical Networks and relevant Expert Advisory Groups to facilitate ongoing planning and development of neurology services at national level.

- Ensuring an effective dialogue at all levels so that regional priorities / objectives for service development and the ongoing development of services are consistent with agreed national priorities for neurology.

- Co-ordination and agreement of management and referral protocols for neurology patients between different care settings.

- Leadership in the development of relevant disease-specific approaches to care and best-practice; promotion of high standards of care and from which a strong base of academia can be established.

- Ensuring relevant networking arrangements are put in place throughout the regions to support the delivery of agreed approaches e.g. a national epilepsy programme.

- Ensuring that neurology services are appropriately engaged with national planning and delivery of relevant education, training and research. This includes the agreement of, and provision of guidance on, appropriate monitoring and audit activities to be undertaken within the Regional Networks. It will ensure that there is a strategy for neurology research across institutions (university, institution and foundation-based), including the integration of science and medicine towards achieving best patient outcomes.

- Commitment to integration and the provision of expertise across communities as a means of minimising impacts of geography/distance.

- Ensuring that personnel act according to ethical and moral standards/principles consistent with ‘best practice’ in neurology care and optimal use of public funds for public health benefits.
An Implementation Framework needs to be put in place to ensure that the roles and functions outlined above are delivered and to ensure that the new model has a robust governance framework. Getting these mechanisms right, and managing them actively, is critical if Neurology services are to be transformed.

Recommendations of the Neurology Review and Implementation

1. Developing a Patient Centered Service
   1. People who are suspected of having a neurological condition should have prompt access to specialist neurological expertise for an accurate diagnosis and treatment as close to home as possible.

2. People with long-term complex neurological conditions should:
   i. Have a multi-disciplinary assessment of their needs.
   ii. Have an individual care plan that addresses their health and social needs. The person with the condition and their family should have an integral role in the development of this plan.
   iii. Receive multi-disciplinary care as close to home as possible.
   iv. Be assigned a named patient care coordinator and be involved in the decision as to who this person will be.
   v. Be supported in understanding and managing their condition.
   vi. Have the information they need to make informed decisions about their condition and care.
   vii. Receive timely, ongoing, high quality rehabilitation advice and support services suitable for their needs in different settings, as required.
   viii. Have access to appropriate vocational assessment and support to enable them to find, regain or remain in work and access other occupational and educational opportunities.
   ix. Receive timely, appropriate assistive technology/equipment and adaptations to support independent living.
   x. Be put in touch with the relevant patient support organisations as a formal part of their treatment pathway.

3. A support plan for the carer should be an integral part of the care plan.
2. Service Structure

1. A National Neurology Steering Group should be established to provide clinical and managerial leadership, set standards and performance targets – *Target to establish the National Steering Group - June 2008.*

2. Neurology services should be delivered in a Managed Clinical Network Approach which includes all aspects of the service including voluntary services, as described above. *Target to establish the Network Approach - June 2008.*

   i. The four Clinical Networks will be accountable (reporting on a quarterly and yearly basis) on all aspects of their service including funding utilisation.

   ii. New neurologist appointments should be to the Network rather than to an institution. A multidisciplinary team of allied health professionals (the number and type of AHPs required will depend the type of neurology service being provided) and specialist nursing are needed for each neurologist. These will also be appointed to the Network to ensure real integration between hospital, community, disability and other services.

   iii. Facilities for the delivery of neurology services outside the acute hospital setting should be identified in each Network. This is especially important for patients who need on-going AHP services and rehabilitation.

   iv. All neurology units should have links to local academic and research facilities.

   v. The Networks should develop outreach services with hospitals in the region that do not have a neurology service – on a needs basis e.g. outpatient services.

   vi. A greater focus should be placed on enabling ambulatory day care and in providing care as close as possible to the patient / family through structured services with Primary Health Care and Community Services.

3. Neurology Personnel

1. The current required number of adult consultant neurology posts needs to be increased to a ratio of 1/100,000 population in accordance with Comhairle na nOspideal recommendations. This requires a minimum of 42 adult posts nationally. Priorities for additional adult neurologists are:

   - The West (which currently has the lowest number per 100,000 population).
   - Additional neurologist posts should be allocated to Limerick, Sligo and Waterford so that no neurologist operates single handed and to enable regional self-sufficiency.
   - The two National Centres should be resourced in accordance with Comhairle recommendations.
   - Thereafter existing neurology centres in the four networks should be staffed to appropriate recommended levels.
2. The neurology centres in the four Regional Networks should be staffed with multidisciplinary teams. The type and number of AHP and specialist nursing input should be determined on the basis of what is essential for the multi-disciplinary team to operate effectively.

3. While it is recommended that AHP/ Specialist Nurse appointments should to the Network, rather than to an institution, it will be necessary for a number of AHPs in each discipline to be located, perhaps on a rotational basis, to the community service so as to foster integration and enhance neurology skills in the community services.

4. Specialist nurses with expertise in neurological conditions e.g. movement disorders, multiple sclerosis, epilepsy should be available to work across all parts of the network.

5. All externally funded clinical AHP posts should be mainstreamed.

4. **Paediatric Neurology**

1. Paediatric neurology services should be provided by a Clinical Managed Network from Dublin and Cork with outreach services nationally, as described in Chapter 7.

2. A ratio of one paediatric neurologist per 100,000 childhood population is required i.e. 12 paediatric neurologists for the current population.

3. Allied Health Professionals should be appointed at the same time as paediatric neurologist appointments in accordance with the needs of the service.

4. The need for dieticians to be appointed to each of the paediatric neurology centres for the management of the ketogenic diet for children with epilepsy is a priority.

5. The need for the appointment of clinical neuro-psychologists in each of the paediatric neurology centres is a priority.

6. In relation to consultant (and team) staffing:
   i. Three consultant paediatric neurologists (including an academic post) should be appointed to the tertiary-quaternary hospital in Dublin within the next three years. Within five years there will be a need for two additional whole-time consultant paediatric neurologists to Dublin bringing the total complement to nine.
ii. The post in Cork (CUH) should be restructured making it a whole-time post. In addition a second whole-time consultant paediatric neurologist without commitment to general paediatrics should be appointed to CUH as a priority. Within the next five years a third whole-time consultant paediatric neurologist to CUH.

7. Two clinical neurophysiologists with a special interest in paediatrics should be appointed - one at each of the Dublin Children’s Hospitals and ultimately working together at the new tertiary Children’s hospital. They should have links to an adult hospital and have specialist expertise e.g. spinal monitoring.

8. Consideration should be given to establishing a Specialist Training Programme in paediatric neurology.

5. **Clinical Neurophysiology**
   1. Each academic teaching hospital that has a neurology service should also have a clinical neurophysiology service which is led by a clinical director, who is on the Specialist Register, and who will set clinical governance and performance criteria and undertake audit. Smaller neurology units should be linked electronically with clinical neurophysiology units.

2. Clinical Neurophysiology centres should conform to best-practice in terms of space and equipment.

3. A higher specialist medical training programme for clinical neurophysiology should be developed. This should be linked to European centres for curriculum development and training planning.

4. The training of clinical measurement technologists is central to the provision of a clinical neurophysiology service. The training programme should be linked to the clinical neurophysiology service to ensure that new technologists meet the requirements of the service. Clinical neurophysiologists should collaborate with the training centres and contribute to the teaching programme.

5. Ireland’s current population requires 12 clinical neurophysiologists. Each major clinical neurophysiology department requires four senior technology personnel and two basic grade technologists.

6. Teaching, research and audit are essential components of the service.

6. **Service Integration**
   1. The development of a sustainable approach to chronic illness management rests on ensuring that there is real integration between all parts of the service and the voluntary sector including:
   i. Developing plans and protocols to link hospital, community services and other relevant services
   ii. Developing PCTs and social care networks to facilitate patients to have multidisciplinary treatment in the community with access to specialists as required. This will bring care closer to the patient and is a key
step toward providing a more equitable, accessible service for patients while reducing the burden on hospital services.

iii. A joint approach to the management of patients with long term neurological conditions by AHPs in hospital and community settings. Therapists with expertise in neurology will be available at social care network level in each of the disciplines.

iv. Hospitals in the network will facilitate the transfer of specialist neurology skills to AHPs and nursing personnel in the community through joint training, joint continuing professional development, joint appointments etc.

v. Guidelines of care and support for GPs in managing patients with long term neurological conditions will be developed. This will be initiated by neurologists in the Network in association with GPs in the region.

vi. Enhanced training for GPs who will be encouraged to be more involved in the neurology service e.g. GP managed and run migraine clinics under leadership of consultant are successful in Ireland.

vii. Research with GPs will be encouraged and facilitated.

7. Voluntary sector

1. The services provided by voluntary organisations should be recognised as a core component of the Network.

2. Voluntary organisations should be integrated with all other neurology services in the network.

3. Funding requirements for voluntary organisations needs to be examined.

8. Technology

1. The significant role of technology in the management of long term neurological conditions cannot be underestimated. Major developments in this area are in the interest of patients, GPs and specialist neurology services. Substantial investment in dedicated facilities and in technological research are required on a national basis. The National Steering Group should provide advice in this regard. In addition a wide range of complex expertise is required in this emerging field including strong academic research to enable the safe delivery of new techniques and the assessment of specialist training requirements to deliver hi-tech neurological care. In this way the rapid dissemination and utilisation of technology on a Network basis will be facilitated.

2. ICT projects of proven efficiency and effectiveness should be developed, in particular the use of telemedicine for neurophysiology services and remote video assessment of patients.

3. The development of the National Electronic Patient Record should be prioritised. This will have benefits for many services.

4. The possibility of developing electronic referrals to neurology units on a national basis should be explored.
5. In the context of developing a national Movement Disorder Programme the establishment of a Deep Brain Stimulation Service in Ireland should be considered. This should meet the same standards as defined by National Specialised Services Commissioning Group (NSSCG) in the UK. (see Appendix 6.1)

6. In relation to the use of Natalizumab (Tysabri), this new treatment should be provided under strict neurologist control as outlined in Section 6 of the main report and in Appendix 6.2.

7. A national epilepsy network should be established.

8. The neurology community should link with HIQA in the context of Health Technology Assessment.

9. **Academic Developments and Research**
   1. Neurological research should be fostered and promoted so as to enhance patient outcomes and quality of life.
   2. Neurological epidemiological information systems need to be developed. These systems should also reflect service utilisation, support performance management and facilitate research / audit including the role of technology across all disciplines.
   3. Collaborative ventures in neurology between academic, clinical and industry sectors should be encouraged so as to develop programmes to improved care and outcomes for neurology patients.
   4. Consideration should be given to developing an Irish Neurology Bio-bank to support the planned neuroscience clinical database.
   5. There is a need to increase the number of academic clinicians in Irish Medical Schools in line with the recommendations of the Fottrell & Buttimer Reports. Consideration should be given to increasing the number of Neuroscience Chairs at the Universities.
   6. Research posts for AHPs and specialist nursing should be supported.
   7. Increases in academic funding of clinical and basic neuroscience research studies including new technologies should be in collaboration with Science Foundation Ireland, Health Research Board and Forfas.

10. **Training**
    1. Training of medical, nursing, technology and allied health professional staff needs to be enhanced at undergraduate and post graduate levels. The numbers of specialist training posts should be determined at a
national level so that future population demands can be met. This assessment of specialist training needs should be a role for the National Steering Group.

2. Training priorities should address the present and future skill mix in neurology – presently there is a lack of senior/clinical specialist therapy posts throughout the neurology sector and the role of the therapy assistant needs to be promoted.

3. GP Education and Training Schemes are responding to the growing prevalence of neurological conditions by providing training in neurology. Established GPs should be facilitated with ongoing training and greater integration with neurology services.

11. Rehabilitation
1. Each Neurology Network should have neuro-rehabilitation services to address acute, transitional and long-term rehabilitation needs of patients including residential facilities. This will reduce bed occupancy in acute hospitals and lead to better outcomes for those with neurological illnesses.

2. A National Rehabilitation Strategy is required which would address neuro-rehabilitation needs including the needs of people with acquired brain injury.

3. The specific service and rehabilitation requirements for those who have sustained a stroke are to be identified in the Stroke Strategy.

4. Rehabilitation facilities for chronic long term care of the under-65 age group in particular need to be developed.

5. The health needs of patients / families with Alzheimer’s disease requires specific strategic consideration. This should also take account of the requirements of younger Alzheimer’s patients.

Implementation
The above recommendations are multiple and challenging. They can not all be implemented in the short-term. The main priority is to establish the National and the Regional Clinical Network structures. This will serve as the basis for prioritising national and regional developments including staff numbers, training and research but most importantly it will get the Network in to action so that national and regional leadership develops, continuity of patient care becomes easier to achieve and patient needs are met.
1. Context

1.1 What are Neurology and the Neurosciences?
Clinical neurology is the medical specialty concerned with the prevention, diagnosis, treatment, continuous assessment and care of patients with diseases of the central and peripheral nervous system including disorders of the muscles. Specialist care is provided by consultant neurologists in collaboration with a multidisciplinary team that includes specialist nurses, members of the professions allied to medicine and primary care physicians.

In Ireland it is estimated that over 700,000 people have a neurological condition. It is estimated that neurology conditions account for one in eight consultations in primary care and for one in five emergency medical admissions to hospital. They can be difficult to diagnose. They are often long term and disabling. As the population grows and ages the incidence increases. There are a large number of neurological diseases ranging from the relatively common conditions of migraine and epilepsy to rare conditions such as myasthenia gravis and motor neurone disease. They affect all age groups from the young, economically active adults and older people who are more likely to have neurodegenerative diseases.

The Neurosciences include both medical and surgical specialities as well as diagnostic support services and rehabilitation. All these services are interdependent and the care pathway for many patients spans several of the neuroscience specialties.

1.2 Opportunities and Challenges for Neurology Services
The scope and nature of neurological practice is developing rapidly as new, effective and complex therapies for many disorders including multiple sclerosis, epilepsy and Parkinson’s disease emerge. These technological advances together with increasing disease prevalence, changing demography and greater patient expectations all contribute to the growth in demand for services that are multidisciplinary and specialist.

The complex needs of patients with long term neurological conditions involves, not only prompt medical assessment and treatment but also, early rehabilitation, personal, family and carer support, timely access to assistive technologies, where relevant, and above all a patient centred service. These challenges mean that organisational infrastructures and systems must be flexible and integrated to provide the best quality of care in the context of financial realities.

1.2.1 The Need to Transform Health Care
Prior to the establishment of the HSE in 2005, health services in Ireland were delivered through a complex structure of ten regional Health Boards, the Eastern Regional Health Authority and a number of other different agencies and organisations. The HSE replaces all of these organisations and it is now the single body responsible
for ensuring that every one can access cost effective and consistently high quality health and personal social services. To date, there has been considerable regional variation in the development of neurology services, with the development of five adult and two paediatric neurology units in Dublin, an integrated adult (CUH and Mercy Hospital) and a paediatric unit in Cork and an adult unit in Galway.

Ireland’s health service over-relies on its acute hospital sector for the management long-term conditions. This is not sustainable as it leads to long waiting times for diagnosis and specialist treatment. It causes inconvenience for patients who travel long distances for care of conditions that have complicated management pathways. It creates bottle-necks at many stages of the care pathway. It can lead to work overload, inefficiencies, insufficient multidisciplinary care and poor integration with other aspects of the service especially Primary Care and Community Services. The role of Primary Care in the Neurosciences has not received particular attention.

A number of strategic / policy developments provide a focus for this Review. These Include:
1. The HSE Transformation Programme
2. Neurological Alliance of Ireland – Standards of Care
3. Comhairle na nOspideal Review of Neurology & Neurophysiology Services 2003
4. The Disability Act, 2005

1.2.2 The HSE Transformation Programme
The HSE Transformation Programme aims to shape the health service so that people are enabled to live healthier and more fulfilled lives. It is set in the realisation that the health care system is under increasing pressure for many reasons including our ageing population, increasing prevalence of chronic diseases and escalating health care costs. Improving chronic disease management, including neurology, is a priority for the Transformation Programme.

Its challenge is to maximise the impact of limited resources to provide more integrated and better quality services, to re-orientate health services to support patients in managing their conditions and to provide more of their care through Primary Care Teams in the community. The successful implementation of these Programmes will transform the way in which neurological disease is managed in Ireland. This will enhance the quality of life of patients with a neurological condition, in that they will be central to the care process and receive the highest quality service that is properly integrated in meeting their needs.

1.2.3 Neurological Alliance of Ireland – Standards of Care
Traditionally, in Ireland the voluntary sector has played a critical role in developing advocacy, treatment and support services for neurological patients. The HSE is anxious to build on the strong partnerships which already exist within the health system. For this reason, the input of the voluntary sector has been a central part of this
Review. Between 2000 and 2002 The Neurological Alliance of Ireland (NAI) published three reports on recommended Standards of Care for:
1. People with disabling (progressive and static) neurological conditions in the hospital and community (2000)
2. People with non-physically disabling neurological (and associated psychiatric) conditions (2001)
3. For people with disabling neurological conditions where cognitive decline is a major feature (2002).

These documents provide an insight to the complex, specialist needs of patients at referral, diagnosis and management. They show that health and social service requirements (including transport, education, employment, access to new treatments and devices) can vary at different stages of the person’s illness. They highlight that proper management requires integrated care and support networks from a wide range of services reflecting the long-term and complex nature of many neurological disorders.

1.2.4 Comhairle na nOspideal Review of Neurology & Neurophysiology Services 2003
A review of Neurology and Neurophysiology Services was undertaken by Comhairle na nOspideal in 2003. A summary of the report is provided in Appendix 1.1. Its main recommendations were that neurological services should be linked to the two neuroscience centres in Beaumont Hospital and Cork University Hospital. Further development of services was recommended for Dublin, Cork and Galway. Services should be established in Limerick, Sligo and Waterford. The report also recommended the numbers of neurologists in these hospitals. A Comhairle report on Neurosurgery was also published in 2006. The implementation of recommendations arising from each of these reports will be integrated.

1.2.5 The Disability Act 2005
The 2005 Disability Act has particular relevance for patients with long-term neurological conditions. It states that assessment officers (employees of the HSE) will carry out needs assessments of applicants which will indicate whether the person has a disability and, if so, the nature of the disability. Where there is a disability they will provide a statement of health and education needs and the time ideally required by the person(s) for the provision of those services.

1.3 Review of Neurological Services
A comprehensive strategic review of the neurosciences has not been undertaken in Ireland. In the context of new opportunities and demands for neuroscience services it is expected that all parts of the service will be strategically reviewed on a phased basis. There are many components to the neurosciences and they have different organisational structures, personnel and priorities, for example, neurology priorities are different to those of neurosurgery. Each of these neuroscience specialties deserves a review in their own right. Medical neurology and clinical neurophysiology is the focus of this first Review. The recommendations of this Review will be fully integrated with future developments in Neurosurgery and the implementation of the Comhairle Report on
Neurosurgery. It will also be integrated the Rehabilitation Strategy which is currently being planned. While it is acknowledged that Stroke Care is an integral part of neurology work, the Department of Health and Children (DOHC) has recently established a Cardiovascular Policy Group which will also focus on Stroke. A specific HSE Stroke Plan is currently being prepared to reflect the importance of this service. This Plan will be integrated with the DOHC Policy Group and with developments in neurology in general.

1.3.1 Aims and Objectives

The aim of this Strategic Review is to identify the current provision and future requirements for neurology and clinical neurophysiology services in Ireland. The specific objectives are to:

1. Describe the epidemiology of neurological conditions in Ireland
2. Evaluate current neurology services, including paediatric neurology and clinical neurophysiology.
3. Review the evidence in relation to models of service delivery and make a recommendation on the preferred model for the Irish health system.
4. Identify requirements for the development of neurology and neurophysiology services nationally and prioritise service requirements into short, medium and long-term.
5. Report to the Director of the National Hospitals Office.

Four working groups were established on:

6. Health Information and Epidemiology
7. Description and Assessment of Current Services and Proposed Model of Care
8. Technology, Training and Research and Development (R&D)

Their terms of reference outlined in Appendix 1.2.

References

1. Transformation Programme, 2007-2010, Health Service Executive, Ireland
2. Standards of Care, Neurological Alliance of Ireland 2000, 2001, 2002
3. Comhairle na n Ospideal, Review of Neurology and Neurophysiology Services, 2003
SECTION A – THE CURRENT SERVICE

2. Assessment of Need

KEY POINTS

- Neurological disease is common in Ireland (estimated to affect approximately 700,000 persons).
- The prevalence will increase in the coming years as the population ages. It is estimated that approximately 44,000 people are diagnosed with a neurological condition every year.
- At least 110,000 people with a neurological condition are significantly disabled by their condition and approximately 1.5% of the population are caring for a person with a neurological condition.
- Migraine is the commonest neurological condition and the commonest neurological condition presenting to primary care.
- Epilepsy, dementia, stroke, Parkinson’s disease, brain injury and multiple sclerosis are amongst the other prevalent neurological conditions.

2.1 Introduction

Neurology has the highest number of conditions listed in the International Classification of Diseases (ICD). These conditions include headache, migraine, epilepsy, stroke, brain injury, Parkinson’s disease, multiple sclerosis and rare conditions such as myasthenia gravis and motor neurone disease.

An assessment of neurological need in Ireland is presented below, using the available international and Irish prevalence, incidence, and health service utilisation data. (Appendix 2.1 gives a detailed discussion of the issues surrounding the use of the available health information to estimate neurology need).

Ireland’s population will increase to 5.5 million by 2031. It is projected that there will be an upward bulge shift in the population pyramid, with a major expansion in the numbers aged 50 years of age and over, figure 2.1.1

As many neurological conditions have a higher prevalence in older persons, Ireland’s projected ageing population will result in a greater prevalence of neurological conditions.

Figure 2.1 Projected Population Pyramid for Ireland Numbers 2002 to 2031 (in thousands) by age group and gender1
2.2 Estimating the Overall Burden of Neurological Conditions in Ireland

In the absence of data on the number of Irish residents living a neurological condition, UK figures have been applied to the Irish population to provide an estimate of burden of neurological disease.

Table 2.1 applies the rates published by the Neurological Alliance (UK) to the Irish Population now and into the future. 2, 3, 4, 5, 6

<table>
<thead>
<tr>
<th>Persons living with neurological condition</th>
<th>2006 IRISH CENSUS: 4,234,925</th>
<th>CSO POPULATION PROJECTIONS FOR IRELAND</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>UK NEURO-NUMBERS REPORT</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Persons living with neurological condition</td>
<td>17%</td>
<td>725,987</td>
</tr>
<tr>
<td>2006 IRISH CENSUS: 4,234,925</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2011 Year: 4,488,000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2016 Year: 4,811,000</td>
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<td></td>
</tr>
<tr>
<td>2021 Year: 5,070,000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Help with daily activities</td>
<td>0.6%</td>
<td>25,410</td>
</tr>
<tr>
<td>2. Disabled by neurological conditions</td>
<td>2%</td>
<td>84,699</td>
</tr>
<tr>
<td>3. Neurological condition but able to manage lives on daily basis</td>
<td>14.5%</td>
<td>615,879</td>
</tr>
<tr>
<td>2006 IRISH CENSUS: 4,234,925</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Each year number newly diagnosed with neurological condition</td>
<td>1%</td>
<td>43,559</td>
</tr>
<tr>
<td>Number caring for person with neurological condition</td>
<td>1.5%</td>
<td>61,709</td>
</tr>
<tr>
<td>CSO POPULATION PROJECTIONS FOR IRELAND</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number caring for person with neurological condition</td>
<td>1.5%</td>
<td>61,709</td>
</tr>
<tr>
<td>2011 Year: 4,488,000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2016 Year: 4,811,000</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2021 Year: 5,070,000</td>
<td></td>
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</tr>
</tbody>
</table>

*A definition of neurological conditions is not given in the Neuro-numbers report but the text indicates that stroke and brain injuries are included in the statistics.

**The Central Statistics Office population projections (M1F2 assumptions) are likely to be conservative estimates. Ireland has an aging population and the prevalence of neurological conditions increase with age.

It is estimated that:

- Nearly three quarters of a million people in Ireland have a neurological condition. This will increase by approximately 37,000 in five years, by 99,000 in ten years and by 143,000 in fifteen years to an estimated 869,143 by the year 2021.

- 2.6% of the current Irish population (110,109) are significantly disabled by their neurological condition. This will increase by 6,500 in five years, by 15,000 in ten years and by almost 22,000 in fifteen years to an estimated 131,820 by the year 2021.

- Approximately 44,000 persons were diagnosed with a neurological condition in 2006. This will rise to 45,000 in 2011, 48,000 in 2016 rising to over 50,000 in 2021.
• Approximately 62,000 persons are caring for a person with a neurological condition in 2006. This will increase to 66,000 in five years time, to 71,000 in 2016 and to 75,000 in 2021.

Considering the young age profile of the current Irish population, it is likely that employing UK prevalence rates will currently over estimate neurological diseases that are prevalent in older persons.

Nonetheless, the current and projected number of people in Ireland affected by neurological conditions either as cases or as carers is very large and increasing. These people will have multiple needs likely to have a significant impact on the health services, on other services and on society in general.

2.3 Estimating the Irish Prevalence of Common Neurological Conditions

In the absence of comprehensive Irish data, prevalence rates in the published worldwide literature are used to estimate the prevalence of neurological conditions in Ireland (table 2.2):

• Approximately 580,185 Irish persons suffer from migraine. This is expected to increase by about 40,000 by the year 2011. Thus, migraine is the commonest neurological condition with an expected prevalence of 137 per 1,000 persons. ², ⁷, ⁸

• Currently, between 22,000 persons (0.52% prevalence rate) and 33,000 persons (0.71%) suffer from epilepsy in Ireland. This is expected to increase by almost three thousand by 2016. ², ⁹, ¹⁰, ¹¹

• Over 6,000 persons age 60 years of age and over, have Parkinson’s disease (1% prevalence rate). This will increase to over 9,000 persons by the year 2021.¹²

• Currently there are between 3,515 (0.83% prevalence) and 7,792 (1.84% prevalence) persons with multiple sclerosis in Ireland. ¹³, ¹⁴

• Dementia, stroke and brain injury contribute significantly to the neurology workload (table 2.2)

Neurological disease is common and the prevalence will significantly increase in the coming years.
Table 2.2: Estimates of numbers in Irish Population with particular neurological conditions

<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>Migraine</td>
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<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>European</td>
<td>137</td>
<td>580185</td>
<td>614856</td>
<td>659107</td>
<td>694590</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>World-wide</td>
<td>121</td>
<td>512426</td>
<td>543048</td>
<td>582131</td>
<td>613470</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Dementia</td>
<td>10</td>
<td>42349</td>
<td>44880</td>
<td>48110</td>
<td>50700</td>
<td></td>
<td></td>
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<tr>
<td>65 years of age and older</td>
<td>70</td>
<td>28560</td>
<td>31780</td>
<td>37100</td>
<td>42910</td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Epilepsy</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>European</td>
<td>22022</td>
<td>23338</td>
<td>25017</td>
<td>26364</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>World-wide</td>
<td>33068</td>
<td>31865</td>
<td>34158</td>
<td>35997</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Stroke</td>
<td>5</td>
<td>21175</td>
<td>22440</td>
<td>24055</td>
<td>25350</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>65 years of age and older</td>
<td>9</td>
<td>38114</td>
<td>40392</td>
<td>43299</td>
<td>45630</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Parkinson's disease</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Over 60 years of age</td>
<td>10</td>
<td>6340</td>
<td>7230</td>
<td>8220</td>
<td>9280</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;= 65 years of age</td>
<td>9.5</td>
<td>4304</td>
<td>4788</td>
<td>5558</td>
<td>6394</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Brain Injury</td>
<td>2.28</td>
<td>9656</td>
<td>10233</td>
<td>10969</td>
<td>11560</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Long term problems</td>
<td></td>
<td></td>
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<td></td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>Working Age Adults</td>
<td>12</td>
<td>30550</td>
<td>32926</td>
<td>34602</td>
<td>35842</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Multiple Sclerosis</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Conservative estimate</td>
<td>1</td>
<td>4235</td>
<td>4488</td>
<td>4811</td>
<td>5070</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>European Average</td>
<td>0.83</td>
<td>3515</td>
<td>3725</td>
<td>3993</td>
<td>4208</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Ireland – Wexford</td>
<td>1.21</td>
<td>5124</td>
<td>5430</td>
<td>5821</td>
<td>6135</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Ireland – Donegal</td>
<td>1.84</td>
<td>7792</td>
<td>8258</td>
<td>8852</td>
<td>9329</td>
<td></td>
<td></td>
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<tr>
<td>Motor Neurone disease</td>
<td></td>
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<tr>
<td>Irish prevalence figure</td>
<td>0.07</td>
<td>296</td>
<td>314</td>
<td>337</td>
<td>355</td>
<td></td>
<td></td>
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<tr>
<td>Muscle dystrophy</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Huntington’s disease</td>
<td>0.14</td>
<td>593</td>
<td>628</td>
<td>674</td>
<td>710</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Myasthenia Gravis</td>
<td>0.3</td>
<td>1270</td>
<td>1346</td>
<td>1443</td>
<td>1521</td>
<td></td>
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<td></td>
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<td></td>
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<tr>
<td>Trigeminal neuralgia</td>
<td>0.7</td>
<td>2964</td>
<td>3142</td>
<td>3368</td>
<td>3549</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*M1F2 assumptions**QNHS- Quarterly National Household Survey: Health Module attached to QNHS – Q3 2007. 29
2.4 Neurological Conditions in Primary Care

There is no routine collection of primary care activity data in Ireland. The UK Royal College of General Practitioners collects data on a weekly basis from some practices – Weekly Returns Service (WRS). These data shows that:

- Migraine is the commonest neurological problem presenting to primary care in the UK.
- Epilepsy is the second commonest.
- Stroke and dementia account for a significant amount of neurological disease in primary care.
- Parkinson’s disease is also a common reason for presenting to primary care with a neurological condition.

The likely number of patients presenting to primary in Ireland is estimated by applying UK person consultation rates to the estimated Irish prevalence figures for neurological conditions (table 2.3):

- **Approximately one in twenty migraine sufferers attend their GP in a year.** Thus by the year 2011, it is estimated that almost 31,000 persons with migraine will present at least once in the year for primary care. This is likely to increase to 33,000 in 2016; and to 35,000 in 2021 (prevalence 137/1,000, table 2.2).

- **Almost all persons with epilepsy attend their GP in a year.** Thus by the year 2011, it is estimated that approximately twenty-two and a half thousand persons with epilepsy will attend their GP; increasing to over 24,000 in 2016; and to over 25,000 in 2021 (prevalence 5/1000, table 2.2).

- **Approximately two thirds of persons with Parkinson’s disease attend their GP in a year.** Thus by the year 2011 almost 9,000 persons with Parkinson’s disease will attend the GP; increasing to over 9,600 in 2016; and to over 10,000 in 2021 (prevalence 3/1000, table 2.2).

- **All persons with multiple sclerosis attend the GP in a year.** Thus by the year 2011, Four and a half thousand persons with multiple sclerosis will attend for primary care. This will increase to almost 5,000 in 2016; and to over 5,000 in 2021 (conservative estimate of prevalence 1/1000, table 2.2).
Table 2.3: A Rough Comparison; Estimated Population Prevalence (based on worldwide literature as detailed in Table 2.2)* Versus General Practice Prevalence *** (based on WRS UK GP consultation rates over a period of one year22)

<table>
<thead>
<tr>
<th>Condition***</th>
<th>Population non-standardised prevalence (based on worldwide literature)*</th>
<th>UK General Practice Age standardised prevalence rates per persons registered in the practices (WRS) 2005**</th>
<th>Implications</th>
</tr>
</thead>
<tbody>
<tr>
<td>Migraine</td>
<td>121 - 137/1,000</td>
<td>7.4/1,000</td>
<td>Approximately 1/20 migraine suffers attend General Practice in a year</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>5 - 7/1,000</td>
<td>4.4/1,000</td>
<td>Approximately 60-90% of persons with epilepsy attend General Practice in a year</td>
</tr>
<tr>
<td>Parkinson's disease</td>
<td>2-3/1,000</td>
<td>1.3/1,000</td>
<td>Approximately two-thirds of patients with Parkinson's disease attend General Practice in a year</td>
</tr>
<tr>
<td>Multiple Sclerosis</td>
<td>0.83 - 1/1,000</td>
<td>0.8/ 1,000</td>
<td>Almost all persons with multiple sclerosis attend General Practice in a year</td>
</tr>
</tbody>
</table>

* This is not the Irish prevalence. It is a conservative estimate of the average worldwide prevalence. See Table 2.2 for references.

**This is not the Irish general practice prevalence. The general practice prevalence figures are from RCGP Weekly Returns Service (UK).22

***The available data only allows comparisons for some of the neurological conditions presenting to primary care.

2.6 National Physical and Sensory Disability Database

The number of people registered with neurological conditions on the National Physical and Sensory Disability Database (NPSDD) was examined. Numbers registered with a neurological condition as the primary disability are listed in Appendix 2.3. As can be seen, the figures are substantially lower than would be estimated when applying the prevalence rates from other countries to the Irish population (see Sections 2.2, 2.3, 2.4).

The NPSDD is a voluntary register of people currently in receipt of a service in relation to their disability and agreeing to be included on the database. The NPSDD provides valuable information in relation to the service needs of distinct groups within physical and sensory disability. It also provides a useful guide to determining the future service needs of this group. It has been estimated that 59% of the target group are registered. Over one third of those registered have neurological conditions (38%).
It is not the primary purpose of the NPSDD to accurately measure of the prevalence of neurological conditions in Ireland. Inclusion on the database is entirely voluntary, meaning that people who do not wish to participate will not be included. Those awaiting diagnosis, or not in receipt of services for their condition, are likewise excluded. It would be misleading to use the database as an indication of the prevalence of the various conditions identified.

2.7 Irish Prevalence Data - Neurological Alliance of Ireland

Through the Neurological Alliance of Ireland (NAI), voluntary organisations provided information they had on the prevalence of neurological conditions in Ireland.

Table 2.4 shows the Irish prevalence figures (numbers) for specific neurological conditions as supplied by the individual patient organisations to the NAI.
<table>
<thead>
<tr>
<th>NEUROLOGICAL CONDITION</th>
<th>NUMBER WITH THE CONDITION IN IRELAND</th>
<th>SOURCE OF PREVALENCE FIGURE SUPPLIED BY NAI MEMBER ORGANISATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Migraine</td>
<td>Based on a prevalence rate of 14.3%, up to 500,000.</td>
<td>Steiner, T.J., Scher, A.I., Stewart, W.F., Kolodner, K., Liberman, J. and Lipton, R.B. (2003).&quot;The prevalence and disability burden of adult migraine in England and their relationships to age, gender and ethnicity&quot;. Cephalalgia, 23, pp 519-527.</td>
</tr>
<tr>
<td>Syringomyelia</td>
<td>Approx 400 (1/10,000)</td>
<td>Numbers supplied by the Syringomyelia Self Help Group</td>
</tr>
<tr>
<td>Parkinson’s Disease</td>
<td>Approx 6,000-7,000 Based on 2-3/ 1000, over 60 years of age, 10/ 1000, over 80 20-30/ 1000</td>
<td>Hauser, R. and Zesiewicz, T. (2006) &quot;Parkinson's disease questions and answers&quot; Published by Merit Publishing International</td>
</tr>
<tr>
<td>Progressive Supranuclear Palsy</td>
<td>100 known cases</td>
<td>Dr. Tim Lynch, Consultant Neurologist, Mater Hospital Dublin, supplied information to the Progressive Supranuclear Palsy support group</td>
</tr>
<tr>
<td>Myasthenia Gravis</td>
<td>400 known cases</td>
<td>Numbers supplied by the Myasthenia Gravis association</td>
</tr>
<tr>
<td>Muscular Dystrophy</td>
<td>The most common type, Duchenne Muscular Dystrophy, affects 1 in 3500 male births- approx 200 affected in Ireland</td>
<td>Numbers supplied by the Muscular Dystrophy association</td>
</tr>
<tr>
<td>Motor Neurone Disease</td>
<td>250, 78 new cases/ year</td>
<td>Numbers supplied by the Motor Neurone Disease Association</td>
</tr>
</tbody>
</table>
Assessment of Services References


3. Current Neurology Services

Key Points

- People with chronic neurological conditions need multidisciplinary, neurologist directed care in a variety of care settings.
- Ireland currently has eight adult neurology units and three paediatric units. Three additional neurological units are currently being established in Waterford, Limerick and Sligo which will enhance existing services.
- As of October 2007 there are 24 approved neurologist posts of which seven are currently unfilled. For the current population 42 neurologists with multidisciplinary teams are needed (based on Comhairle recommendations).
- Inpatient admissions do not reflect the neurology workload:
  - The main reason for admission to hospital with a neurological condition is convulsions / epilepsy (7,000 per year).
  - There are approximately 1,500 admissions due to Multiple Sclerosis.
  - Only 17% of admissions are day cases.
  - Neurological conditions have long average lengths of hospital stay (ALOS) - the ALOS for acute stroke is 18 days. For neurodegenerative conditions it is 23 days yet these conditions account for only 6% of admissions.
  - 83% of neurology admissions are emergency rather than elective.
  - 15-17% of admissions from A&E have a neurological problem.
  - There are 44,000 people invited to neurology OPD clinics each year but 21% do not attend.
  - The inpatient consultation service in the average tertiary hospital takes approximately 35 hours per week.
  - There are long waits for the service especially as on outpatient. These delays occur at all stages: referral and investigation, diagnosis, treatment and management.
  - Community neurology services are poorly developed.

3.1 Service Structure

Neurological conditions are common. Patients with these conditions are treated in primary, secondary and tertiary care. Most neurological conditions are chronic in nature. Many are complex and require the services of a variety of professionals in a variety of settings. There are currently eight adult neurology units in the Ireland of which two are designated national centres (Beaumont Hospital and Cork University Hospital). There are three units delivering paediatric neurology services: Our Lady’s Hospital for Sick Children, Crumlin, Children’s University Hospital, Temple Street, and Cork University Hospital. Funding has been allocated to establish new adult neurology units in Limerick, Sligo, Waterford and Drogheda/North East. These units are expected to be operational in 2008.
Neurology services are currently delivered / planned in the following hospitals:

<table>
<thead>
<tr>
<th>HSE Region</th>
<th>Adult Services</th>
<th>Pediatric Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>HSE Dublin North East</td>
<td>Beaumont Hospital Tertiary Service – neurosurgery on site</td>
<td>Children’s University Hospital, Temple St.</td>
</tr>
<tr>
<td></td>
<td>Mater Hospital</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Our Lady of Lourdes – Drogheda – service funded in 2008 but post not yet in place</td>
<td></td>
</tr>
<tr>
<td>HSE Dublin Mid Leinster</td>
<td>St. James’ Hospital</td>
<td>Our Lady’s Hospital for Sick Children, Crumlin</td>
</tr>
<tr>
<td></td>
<td>St. Vincent’s University Hospital</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Adelaide &amp; Meath Tallaght Hospital</td>
<td></td>
</tr>
<tr>
<td>HSE West</td>
<td>University College Hospital, Galway</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mid West Regional Hospital Limerick - Service recently established. Consultant to start in January 2008.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sligo General Hospital - Service recently established. Consultant to start in January 2008.</td>
<td></td>
</tr>
<tr>
<td>HSE South</td>
<td>Cork University Hospital Tertiary Service – neurosurgery on site</td>
<td>Cork University Hospital</td>
</tr>
<tr>
<td></td>
<td>Mercy Hospital,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Waterford Regional - Service recently established. Locum in post.</td>
<td></td>
</tr>
</tbody>
</table>
3.1.1 Tertiary Neuroscience Centres

Beaumont Hospital
Beaumont Hospital is the national centre for complex epilepsy, complex stroke, motor neurone disease, post polio syndrome and adult muscular dystrophy. It is the supraregional centre for all other forms of neurological illness. The catchment area is national for many conditions and it also provides services on a regional basis. There are currently four approved consultant Neurologist posts in Beaumont of which three are currently filled. There are 30 dedicated neurology beds and of these, 28 are general neurology beds and 2 are epilepsy telemetry beds. The department provides a 24 hour in-house on call service to Beaumont Hospital and, as a result, 65% of all admissions to the department come through emergency department. The neurology unit accepts transfers from all other hospitals in the country.

Cork University Hospital (CUH)
There are currently four approved consultant neurology posts in CUH of which one is vacant. In addition there is also a further 0.5 WTE dedicated to paediatric neurology, 0.25 WTE to the Dystonia/Botox clinic and 0.35 to neuro-otology service. CUH is one of two tertiary referral centres for Neurology in Ireland (Beaumont being the...
other). There are 20 designated neurology beds at CUH for a geographic catchment area of approximately 1.5 million.

3.1.2 Secondary Care Adult Neurology Services

The West
A Neurology Unit, based at UCHG, serves a population of over one million. It accepts patients from all acute hospitals in the region. Three posts are approved but one post is currently vacant. There is one dedicated 5-day bed for video-telemetry EEG monitoring. Prior to 2007 this was the only neurology unit west of the Shannon. New neurology services were funded during 2006 in Sligo and Limerick. The recruitment process is underway and both units are expected to be operational by 2008. Sligo has a neurophysiology telemetry links with Beaumont.

The South
In addition to the service at CUH there is a neurology service at the Mercy Hospital Cork with one WTE consultant neurologist. A neurology service Waterford was approved in 2006 and the service is expected to be operational by 2008. A locum consultant neurologist is currently in place.

The East

Mater Hospital
The Mater Hospital currently has two WTE consultant neurologists. It provides services at local, regional and national level. It has a 6-bedded Stroke unit, a 6-bedded stroke rehabilitation unit shared with old age medicine and 4 acute neurology beds. There are no "protected" inpatient beds.

St James’s Hospital
There are two WTE consultant neurologists at St James’s. St James’s Hospital provides local (South Dublin), Regional (greater Dublin area and Leinster) and national neurology services. At present there is one dedicated neurology bed in St James’s.

St. Vincent’s University Hospital
There are two WTE Consultant Neurologists at St Vincent’s University Hospital. It provides services to the south eastern area of Dublin and south east Ireland. There are 11 designated beds for neurology.

Adelaide and Meath Hospitals, incorporating the National Children’s Hospital, Tallaght (AMNCH)
Currently there is 1.6 WTE consultant Neurologists in AMNCH. The AMNCH serves a regional population of approximately 500,000 and services are also provided at national level. See tables 3.3, 3.4 and 3.5.
**The North East**

A new post of consultant neurologist and support staff were funded and approved during 2007 for the North East. This post is expected to be in place in 2008.

### 3.1.3 Paediatric Neurology Services

Hospitals that provide a paediatric neurology service are:

- Children’s University Hospital, Temple Street
- Our Ladies Hospital for Sick Children, Crumlin.
- Cork University Hospital (CUH)

There are 4.5 WTE Consultant Neurologists dedicated to paediatric neurology in Ireland. The National Hospital’s Office has identified funding for a new post of Clinical Neurophysiologist with a special interest in paediatrics— the structure of this post is currently under consideration. The post is expected to be put in place in 2008 and will link with an adult hospital. A detailed account of Paediatric neurology services is given in Chapter 7.

### 3.2 Staffing of Neurology Units

Although a number of neurology units have specialist nursing and allied health professional staff who are dedicated to neurology services, in many hospitals staff are shared with other specialties, and so it is difficult to quantify the number of whole time equivalent staff working within each neurology department.

Where services are delivered to neurology patients in the community setting, this is part of the caseload of generalist community staff or in some cases, specialist staff working with voluntary agencies. It is recognised that the number of community allied health professionals who work with neurology patients is inadequate and the new PCCC social care network model is designed to address the current deficiencies in the service.

Arising from the specialist nature of neurological services there will be a need to ensure that community posts remain linked to main neurology units and have access to the full range of expertise e.g. by developing rotational posts, joint appointments etc.

### Neurologist Staffing

In 2006 €3m development funding was allocated to develop neurology and neurophysiology services throughout the country. As a result new neurology services were funded in Waterford, Limerick and Sligo. Up to then there were no consultant led neurology services in these areas. The funding allowed for the recruitment of one neurologist with a multidisciplinary team in each area e.g. clinical nurse specialist, physiotherapist, occupational therapist, speech and language therapist. That year additional neurology posts were also approved for Beaumont and Cork University Hospital.
In 2007 the HSE was allocated an additional €4m to enable it to continue to implement the Comhairle report on neurology and for Phase 1 Implementation of the Comhairle report on Neurosurgery. The neurology funding for 2007 allows for the appointment of three additional consultant neurologists – Cork (a post with a special interest in paediatrics), Galway and Our Lady of Lourdes, Drogheda. The funding also allowed for the appointment of two new consultant clinical neurophysiology posts in Dublin (AMNCH and St. James Hospital).

There are currently 24 approved posts of consultant neurologist in Ireland (7 of the newly approved posts are currently vacant), an increase of 10 posts since the publication of the Comhairle Report, giving a ratio of one consultant neurologist per 180,000 population. There is a long lag period from the approval to the filling of a post. This needs to be addressed. The location of the posts is shown in table 3.1.

### Table 3.1 Approved Consultant Neurologist Posts October 2007

<table>
<thead>
<tr>
<th>HOSPITAL / HSE REGION</th>
<th>POPULATION 2006</th>
<th>FILLED</th>
<th>APPROVED VACANT POSTS</th>
<th>CONSULTANT ESTABLISHMENT IN 2007</th>
</tr>
</thead>
<tbody>
<tr>
<td>St. Vincent's</td>
<td>202</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>St. James’s Hospital</td>
<td>202</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Tallaght Hospital</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td><strong>Dublin Mid Leinster Total</strong></td>
<td><strong>1,215,711</strong></td>
<td><strong>6</strong></td>
<td><strong>0</strong></td>
<td><strong>6</strong></td>
</tr>
<tr>
<td>Beaumont Hospital</td>
<td>3</td>
<td>3</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Mater</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Beaumont / Drogheda</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Dublin North East</strong></td>
<td><strong>927,525</strong></td>
<td><strong>5</strong></td>
<td><strong>2</strong></td>
<td><strong>7</strong></td>
</tr>
<tr>
<td>Galway Regional Hospitals</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Sligo General Hospital</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Limerick</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>West</strong></td>
<td><strong>1,010,690</strong></td>
<td><strong>2</strong></td>
<td><strong>3</strong></td>
<td><strong>5</strong></td>
</tr>
<tr>
<td>CUH</td>
<td>3</td>
<td>3</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Mercy</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Waterford Regional Hospital</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>South</strong></td>
<td><strong>1,080,999</strong></td>
<td><strong>4</strong></td>
<td><strong>2</strong></td>
<td><strong>6</strong></td>
</tr>
<tr>
<td><strong>Overall Total</strong></td>
<td><strong>4,234,925</strong></td>
<td><strong>17</strong></td>
<td><strong>7</strong></td>
<td><strong>24</strong></td>
</tr>
</tbody>
</table>

In September 2007 the HSE announced the approval of two additional neurology posts under the 100+ scheme in St. Vincent’s University Hospital, Dublin. These posts have not yet been processed through the Consultants Applications Committee. They have not been reflected in the above table.
Clinical Neurophysiology Staffing

In 2007 the HSE approved the appointment of two additional consultants in clinical neurophysiology allied to the restructuring of two existing posts all based in Dublin. The net result is that each of the Dublin Academic Teaching Hospitals (DATHs) would then have a dedicated consultant with a sessional link to Beaumont Hospital. This structure was based on discussions with the hospitals and submissions from the Neuroscience Cogwheel based in Beaumont. In 2007 the HSE also announced its intention to progress the appointment of an additional a clinical neurophysiology post with a special interest in paediatrics based in Dublin and linked to an adult hospital. However this post had not progressed by November. These new appointments and restructured posts should result in the following posts being approved by the end of 2007, table 3.2.

Table 3.2  Clinical Neurophysiology Staffing Levels – September 2007

<table>
<thead>
<tr>
<th>Location</th>
<th>Filled</th>
<th>Approved Vacant Posts</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>St. James’s – 10&lt;br&gt;Beaumont – 1</td>
<td></td>
<td>X</td>
<td>New post approved 2007</td>
</tr>
<tr>
<td>Tallaght – 10&lt;br&gt;Beaumont – 1</td>
<td></td>
<td>X</td>
<td>New post approved 2007</td>
</tr>
<tr>
<td>St. Vincent’s – 10&lt;br&gt;Beaumont – 1</td>
<td></td>
<td>X</td>
<td>Restructured of existing post holders contract</td>
</tr>
<tr>
<td>Beaumont – 9&lt;br&gt;Blanchardstown – 2</td>
<td></td>
<td>X</td>
<td>No change – person in post</td>
</tr>
<tr>
<td>Beaumont – 13</td>
<td></td>
<td>X</td>
<td>New post approved 2007</td>
</tr>
<tr>
<td>Mater – 10&lt;br&gt;Beaumont – 1</td>
<td></td>
<td>X</td>
<td>Restructured of existing post holders contract</td>
</tr>
<tr>
<td>C.U.H. – 8&lt;br&gt;Mercy – 3</td>
<td></td>
<td>X</td>
<td>No change – person in post</td>
</tr>
<tr>
<td>Tertiary Paediatric Hospital with sessional commitment to adult hospital</td>
<td></td>
<td>Not processed</td>
<td>Post with special interest in paediatric neurophysiology to be progressed in 2007 – structure of this post under discussion</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td></td>
<td>5 Unchanged&lt;br&gt;2 Restructured&lt;br&gt;1 Additional</td>
</tr>
</tbody>
</table>

Table 3.3 provides information subspecialties and numbers of designated neurology beds per unit
Table 3.4. provides information on staffing levels at each of the neurology units
Table 3.5 provides information on specialist neurology outpatient clinics.
<table>
<thead>
<tr>
<th>Hospital</th>
<th>Subspecialties</th>
<th>Designated beds</th>
</tr>
</thead>
<tbody>
<tr>
<td>AMNCH</td>
<td>MS</td>
<td>No designated beds (average occupied beds 20-30)</td>
</tr>
<tr>
<td></td>
<td>Parkinson's Disease</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Acute general neurology</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Stroke</td>
<td></td>
</tr>
<tr>
<td>Beaumont</td>
<td>Complex Epilepsy</td>
<td>28 general neurology beds and 2 epilepsy telemetry beds</td>
</tr>
<tr>
<td></td>
<td>Complex Stroke</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Motor Neurone Disease</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Post Polio Syndrome</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Adult Muscular Dystrophy</td>
<td></td>
</tr>
<tr>
<td>CUH</td>
<td>Epilepsy</td>
<td>20 designated beds</td>
</tr>
<tr>
<td></td>
<td>Headache / Migraine</td>
<td></td>
</tr>
<tr>
<td>Mater</td>
<td>Movement Disorder</td>
<td>A 6-bedded Stroke unit, and a 6-bedded stroke rehabilitation unit shared with</td>
</tr>
<tr>
<td></td>
<td>Stroke</td>
<td>old age medicine, 4 acute neurology beds. There are no &quot;protected&quot; inpatient beds.</td>
</tr>
<tr>
<td>St Vincent’s</td>
<td>Dystonia</td>
<td>11 designated beds</td>
</tr>
<tr>
<td></td>
<td>Multiple Sclerosis</td>
<td></td>
</tr>
<tr>
<td>St James’s</td>
<td>Epilepsy</td>
<td>One dedicated bed</td>
</tr>
<tr>
<td></td>
<td>Multiple Sclerosis</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Inflammatory neuropathies</td>
<td></td>
</tr>
<tr>
<td>UCHG</td>
<td>Movement disorder</td>
<td>One dedicated 5-day bed for video-telemetry EEG monitoring</td>
</tr>
<tr>
<td></td>
<td>Epilepsy</td>
<td></td>
</tr>
<tr>
<td>Mercy, Cork</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>AMNCH</td>
<td>Beaumont</td>
</tr>
<tr>
<td>--------------------------</td>
<td>-------</td>
<td>----------</td>
</tr>
<tr>
<td><strong>WTE</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consultant Neurologist</td>
<td>1.6</td>
<td>3</td>
</tr>
<tr>
<td>Consultant Neurophysiologist</td>
<td>3</td>
<td>16 sessions</td>
</tr>
<tr>
<td>Paediatric Neurologist</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Registrars (inc. SpRs)</td>
<td>2 HSE funded registrars</td>
<td>4</td>
</tr>
<tr>
<td>SHOs / Interns</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Clinical Nurse Specialist – HSE funded</td>
<td>1 HSE funded through brainwave (HSE)</td>
<td>4</td>
</tr>
<tr>
<td>Clinical Nurse Specialist – non-HSE-funded</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Physiotherapy</td>
<td>3 (I/P+O/P)</td>
<td>6.5</td>
</tr>
<tr>
<td>Occupational Therapy</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Speech &amp; Language Therapy</td>
<td>1</td>
<td>0.5</td>
</tr>
<tr>
<td>Clinical Nutritionist</td>
<td>0.2</td>
<td>0.5</td>
</tr>
<tr>
<td>Clinical Neuro - Psychologist</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Social Worker</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Secretarial support</td>
<td>2</td>
<td>?</td>
</tr>
<tr>
<td>Hospital</td>
<td>Specialist Outpatient Clinics</td>
<td></td>
</tr>
<tr>
<td>----------</td>
<td>-------------------------------</td>
<td></td>
</tr>
<tr>
<td>AMNCH</td>
<td>- MS Clinic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Neuroinflammation clinic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Rapid access clinic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Parkinson’s disease clinic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Movement disorder &amp; Botox clinic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Stroke Prevention clinic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- TIA clinic</td>
<td></td>
</tr>
<tr>
<td>Beaumont</td>
<td>- Rapid access stroke clinics</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Epilepsy clinic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Neuromuscular clinic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Migraine clinic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Motor Neurone Disease</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- MS multidisciplinary clinic</td>
<td></td>
</tr>
<tr>
<td>CUH</td>
<td>- Neurophysiology clinic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Epilepsy clinic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Neuro-otology clinic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Headache / Migraine clinic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Dystonia / Botox Clinic</td>
<td></td>
</tr>
<tr>
<td>Mater</td>
<td>- Stroke / TIA Rapid access clinic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Parkinson’s Disease clinic</td>
<td></td>
</tr>
<tr>
<td>St Vincent’s</td>
<td>- MS clinic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Neuro-inflammation clinic (for suspected MS and other inflammatory conditions)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Rapid access clinic New patient referrals</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Return(review General Neurology clinics</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Parkinson’s Disease clinic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Botox clinic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- MS &amp; CIPD clinic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- MS neuro-rehabilitation clinic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- General rehabilitation clinic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Neurovascular clinic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Neurolink - internet based referrals for GPs (checked daily)</td>
<td></td>
</tr>
<tr>
<td>St James’s</td>
<td>- Cognitive behavioural neurology</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Epilepsy clinic*</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Parkinson’s Disease clinic*</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- MS clinic*</td>
<td></td>
</tr>
<tr>
<td>UCHG</td>
<td>- Neurophysiology clinic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Epilepsy clinic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- Movement disorder clinic</td>
<td></td>
</tr>
<tr>
<td></td>
<td>- MS research clinic</td>
<td></td>
</tr>
</tbody>
</table>

* being established
3.3 Dedicated Services

Neurology is increasingly becoming an ambulatory specialty, where care may be delivered on an out-patient or day-case basis. Improved access to day-case and community facilities is required as this could reduce the need for inpatient treatment. However, currently inpatient beds are often required to co-ordinate multidisciplinary care for patients with complex chronic neurological disease. For example patients with Parkinson’s disease often need a series of investigations, a series of medication adjustment and rehabilitation measures including physiotherapy, occupational therapy, speech and language therapy, dietetics and neuro-psychology services. Currently it is difficult to co-ordinate this on an outpatient setting in the absence of a one-stop-shop for patients with neurological disorders.

While a number of centres have dedicated inpatient beds for neurology patients, this is not always the case. Where beds are available, they may be subject to local pressures from the Emergency Department, thus limiting the provision of care for non-emergency cases and curtailing the provision of services at a regional and national level. Also, where neurology beds exist they are frequently on general wards rather than neurology wards, where greater nursing expertise in the care of patients with complex needs would be available.

3.4 Hospital Utilisation - Hospital Inpatient Enquiry system (HIPE)¹

3.4.1 Limitations of HIPE Data

The HIPE database records inpatient and day case hospital activity. There are some limitations to obtaining comprehensive information on neurological hospital activity from the HIPE database as a significant proportion of hospital activity for neurology patients is not recorded in HIPE.

- Neurology has the highest number of conditions listed in the International Classification of Diseases (ICD9). There is no one-disease group code in the HIPE database for neurological conditions. It is not possible to conduct a search of the HIPE database that will identify all episodes of neurological care.

- Consultation requests from a non-neurology consultant to a neurologist (within hospital neurological consultations when the patient is under a different consultant) are not recorded in HIPE.

- Emergency Department (ED) and Outpatient activity are not recorded in HIPE.

- Specialist Nursing and Allied Health Professional activity is not recorded in HIPE.

3.4.2 HIPE Search Strategy

For the purposes of this Review hospital neurological activity data for 2004 was examined using the Major Diagnostic Category grouping in HIPE (MDC). Each HIPE record relates to one episode of care. The principal
diagnosis is the main reason for the episode of care. If the principal diagnosis is a medical neurological diagnosis, the record is classified under Diseases and Disorders of Nervous System Major Diagnostic Category (MDC). Within this MDC category, there are 15 sub-groups of neurological conditions. Within these sub-groups there are many Principal Diagnoses.

3.4.3 Major Neurological Conditions
Overall, neurological conditions account for approximately 4% (40187 / 984137) of all HIPE episodes. Detailed results for the Diseases and Disorders of Nervous System Major Diagnostic Category are given in Appendix 3.1 and 3.2. The results are summarised below.

- The biggest neurological sub-group in HIPE is Seizure & Headache, accounting for almost 30% of the neurological HIPE episodes.

- Cerebrovascular disorders combined with TIA and Pre-cerebral Occlusions account for 23% of medical neurological episodes.

- Degenerative nervous system disorders accounted for 6% of medical neurological episodes.

- The majority of episodes were inpatient episodes with only 17% day cases.

- Cranial & peripheral nerve disorders (accounting for 10% of medical neurological conditions) were the only neurological sub-group where the majority of HIPE episodes were day-cases rather than inpatients.

3.4.4 Principal Diagnoses
- Examination of the number of HIPE episodes associated with each principal diagnosis within the neurology MDC shows that ten principal diagnoses account for 58% of all neurological activity recorded in HIPE in 2004 (Table 3.6)

- Excluding cerebro-vascular disease (occlusions of cerebral artery, transient cerebral ischaemia), the biggest number of HIPE episodes were for discharges with a principal diagnosis of convulsions, epilepsy, migraine or dizziness & giddiness.
Table 3.6: Top Ten Principal Diagnoses in the top nine Neurology Groups within the Disease and Disorders of the Nervous System MDC; HIPE 2004

<table>
<thead>
<tr>
<th>Top 10 Principal diagnosis</th>
<th>No. of HIPE episodes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Convulsions</td>
<td>3595</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>3464</td>
</tr>
<tr>
<td>Occlusions cerebral artery</td>
<td>3392</td>
</tr>
<tr>
<td>Dizziness &amp; Giddiness</td>
<td>3222</td>
</tr>
<tr>
<td>Transient Cerebral Ischaemia</td>
<td>2557</td>
</tr>
<tr>
<td>Mononeuritis of upper limb &amp; multiplex</td>
<td>1724</td>
</tr>
<tr>
<td>Multiple Sclerosis</td>
<td>1496</td>
</tr>
<tr>
<td>Malignant Neoplasms of the Brain</td>
<td>1047</td>
</tr>
<tr>
<td>Migraine</td>
<td>1018</td>
</tr>
<tr>
<td>Intracranial Injury</td>
<td>949</td>
</tr>
<tr>
<td>Sleep disturbances</td>
<td>905</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>23369</strong></td>
</tr>
</tbody>
</table>

*(58% of all medical neurology)*

*Data source: HIPE & NPRS Unit, ESRI*

3.4.5 Length of Hospital Stay

Detailed results on length of stay and bed days used are given in Appendix 3.2 and summarised as follows:

- Cerebro-vascular disorders used the greatest number of beds in 2004 with an average length of stay of 18 days.

- After cerebro-vascular disease, Degenerative Neurological Conditions were responsible for the highest number of bed days, although only responsible for 6% of medical neurological admissions but with an average length of stay of 23 days.

- Degenerative Neurological Conditions is a group term including Parkinson’s disease, Alzheimer’s disease, other cerebral degenerations and Motor Neurone disease.

- Seizures & Headaches were the third commonest use of beds. Although the average length of stay was only 4 days, the large number of admissions with this diagnosis led to significant bed day usage.
3.4.6 Area of Residence & Hospital of Treatment

HIPE data were examined to explore the relationship between the Area of Residence of the patient and the location of the hospital providing the treatment. The HSE has four administrative areas, West, South, Dublin Mid-Leinster and Dublin North East. Two hospital networks exist in each of the administrative areas.

Each HIPE case is assigned to a HSE administration area based on the county of residence. The patient may receive treatment in a hospital located in a hospital network in a different HSE administrative area to that within which the patient resides. The detailed results are provided in Appendix 3.3 and Appendix 3.4. The results are summarised below:

- In general, patients receive inpatient treatment in a hospital located in their own HSE Administrative Area.

- 12.4% of episodes with a principal diagnosis of a medical neurological condition were treated in a hospital outside of the HSE Administrative Area of residence of the case.

- Patients with ‘Spinal Disorders & Injuries’ and ‘Nervous System Neoplasms’ were the most likely to receive their treatment outside of their HSE Administrative Area, unless they live in Dublin Mid-Leinster.

3.5 Attendance at Neurology Outpatient Departments

The Performance Management Unit (PMU) of the National Hospitals Office (NHO) has been collecting national outpatient data since January 2006. While these data are not condition or patient specific they give an indication of the demand for neurology outpatient services (Table 3.7).

<table>
<thead>
<tr>
<th>OUTPATIENT CLINICS</th>
<th>TOTAL INVITED</th>
<th>NON-ATTENDERS</th>
<th>PERCENTAGE NON-ATTENDANCE</th>
</tr>
</thead>
<tbody>
<tr>
<td>All OPD Clinics Nationally</td>
<td>3,501,299</td>
<td>497,029</td>
<td>14.2%</td>
</tr>
<tr>
<td>Neurology OPD Clinics Nationally</td>
<td>44,030</td>
<td>9,323</td>
<td>21.2%</td>
</tr>
<tr>
<td>All OPD Clinics In Hospitals With Neurology Clinics</td>
<td>1,749,571</td>
<td>294,694</td>
<td>16.3%</td>
</tr>
</tbody>
</table>

*Source: Performance Management Unit, National Hospitals Office, HSE.*
3.6 Neurology at Emergency Departments

There is limited Irish information on the presentation of patients with neurological problems to Emergency Departments (ED). The recently published HSE survey of patient experiences in ED in 2006 found that neurological problems were a common reported reason for attendance. Pain in the head/eyes was the third commonest presenting complaint (9%) after injuries and abdominal pain.

In the Royal Victoria Hospital in Belfast, it was noted that in one week, 75 out of 972 (8%) new patient attendances at ED had a neurological illness. In the UK, the Neurological Alliance Neuro-Numbers report states that 10% of visits to Accident and Emergency Departments are for a neurological problem.

Chronic illness is one of the factors associated with frequent ED users. A French study, prospectively over a year, looked at patients who presented to ED and for whom a neurological assessment was requested. The ED Team was not aware that the study was ongoing. The study found that a neurologist was asked to examine 14.7% of the patients (1,679 / 11,421).

In the UK a number of studies have recorded the reason for attendance at a paediatric emergency departments. Seizures were the presenting problem in 5% of those who had a medical problem in one year long study. A second study in five different hospitals found that seizures accounted for 16% of medical presentations at ED.

In conclusion, the evidence suggests that neurological problems are a frequent reason for attendance at both adult and child EDs.

3.7 Emergency Admissions of Patients with Neurological Conditions

- National figures provided by the PMU for 2006 show that 62% (2,567/ 4,175) of inpatients under the care of a neurologist were emergency admissions (Data is missing from one major hospital where the returns to the Performance Management Unit do not distinguish between patients admitted under a neurologist and other medical admissions).

- HIPE data (2004) show that 83% (27,703 / 33,552) of neurology patients were emergency rather than elective admissions. In this instance, the definition of a neurology inpatient was not confined to patients who were under the care of a neurologist.

- HIPE data (2004) show that 68% (382,082 / 562,276) of all acute hospital inpatients were emergency admissions.
• Table 3.8 shows the breakdown of neurology admissions (emergency and elective). Two conditions cerebro-vascular disease and Seizure & Headache, account for most of the emergency admissions. Seizures and Headaches were responsible for more than 10,000 emergency admissions in 2004. Many of these patients were admitted for three days or less.

• Information from other countries supports the hypothesis that neurological conditions are responsible for a significant number of emergency admissions. The Strategic Review of Neurosciences in Wales quoted a figure of 20% of all acute emergency admissions to medical wards have a significant neurological problem, half of them with stroke.9

• This figure is supported by an Irish study in a major Dublin hospital. This study found that 15% to 17% of all admissions from ED had a neurological problem (unpublished data –presentation by the hospital as part of the consultation process for this Review).

Table 3.8: Acute Hospitals Inpatient cases by DRG and Type of admission
HIPE Principle diagnosis of a neurological nature 2004

<table>
<thead>
<tr>
<th>DRG</th>
<th>Emergency admission</th>
<th>Elective admission</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Seizure &amp; Headache</td>
<td>10,043 (93%)</td>
<td>740</td>
<td>10,783</td>
</tr>
<tr>
<td>Cerebro-vascular disease*</td>
<td>8,492 (89%)</td>
<td>958</td>
<td>9,458</td>
</tr>
<tr>
<td>Traumatic Stupor &amp; coma</td>
<td>1,931 (91%)</td>
<td>180</td>
<td>2111</td>
</tr>
<tr>
<td>Other disorders of nervous system***</td>
<td>1889 (57%)</td>
<td>1415</td>
<td>3304</td>
</tr>
<tr>
<td>Degenerative nervous system disorders</td>
<td>1,283 (65%)</td>
<td>702</td>
<td>1985</td>
</tr>
<tr>
<td>Cranial &amp; peripheral nerve disorders</td>
<td>1,093 (62%)</td>
<td>668</td>
<td>1761</td>
</tr>
<tr>
<td>Concussion</td>
<td>948 (100%)</td>
<td>0</td>
<td>948</td>
</tr>
<tr>
<td>NS neoplasms</td>
<td>729 (65%)</td>
<td>389</td>
<td>1118</td>
</tr>
<tr>
<td>Multiple Sclerosis &amp; cerebellar Ataxia</td>
<td>492 (48%)</td>
<td>525</td>
<td>1017</td>
</tr>
<tr>
<td>NS infection**</td>
<td>623 (88%)</td>
<td>86</td>
<td>709</td>
</tr>
<tr>
<td>Spinal disorders &amp; injuries</td>
<td>180 (49%)</td>
<td>186</td>
<td>366</td>
</tr>
<tr>
<td>Total</td>
<td>27,703 (83%)</td>
<td>5,849</td>
<td>33,552</td>
</tr>
</tbody>
</table>

Data source: HIPE & NPRS Unit, ESRI
*Three DRGs - /specific Cerebrovascular Disorders except TIA, TIA & Preerebral occlusions, Non-specific Cerebrovascular disorders.
**Two DRGS: NS Infection excluding Viral Meningitis, Viral meningitis
***Three DRGS: Other Disorders of nervous system, Hypertensive encephalopathy, Non-traumatic stupor & coma

3.8 Inpatient Neurology Consultation Service

As part of this Strategic Review a consultation exercise with the hospitals that currently provide a neurology service was undertaken (Chapter 4). It was apparent at all hospitals that inpatient referrals to the neurology service are an important and significant part of the work of a consultant neurologist and other allied staff.
Costello et al. (2005) monitored the neurology consultation service over a twelve-month period in a 575 bed tertiary referral centre in Dublin. A total of 577 patients were referred for in-house consultation. On average, 11 new consultations and many follow-up reviews were evaluated each week. The authors reported that this constituted 35 man-hours per week and was a significant workload issue for the neurology service. This consultation exercise established a de novo diagnosis in patients admitted with active neurological symptoms (40.7% of referrals), a significant alteration in the diagnosis where the referring consultant had already established a working diagnosis (11.1% of referrals), and gave advice in the ongoing management of active neurological symptoms when the diagnosis was historically established and secure (48.2%).

In order of frequency the most common reasons for consultation were stroke, seizures unrelated to alcohol, alcohol related seizures, movement disorders, neuromuscular disease, and disorders of cognition, acute headache and functional neurological syndromes.

The research made reference to the fact that some hospitals do not provide an acute on-call neurology service thereby placing an extra burden on non-neurologist consultants. Many neurological problems present in an ill-defined manner, which can lead to inappropriate use of expensive investigative tools and resources. This research suggests that neurological consultation or admission directly into the care of a neurologist is likely to lead to a more tailored diagnostic workup, possibly reducing cost and improving outcomes for the patient.

3.9 Waiting for Services
Long waiting lists for access to neurology services are common and are a concern. While some hospitals provided detailed information on waiting times for neurology services, these were not externally validated. However, from the information received, a number of interesting observations can be made:

- **Out patient waiting times:** Although there was variation between hospitals, in general the waiting times for OPD appointments ranged from six months to more than a year (depending on the type of clinic and the nature of the neurological condition). The considerable variation in the provision of services by patient status (inpatients versus outpatients) often leads to the admission of a patient who might otherwise have received services as an outpatient.

  "Recently a patient arrived at my clinic one year early. They didn’t realise that the appointment was for 18 months rather than 6 months”  [Dublin Neurologist]

- **Access to diagnostic services:** Access to diagnostic services varied considerably depending on whether clients were being treated on an inpatient or out-patient basis. In general, inpatients received prompt
appointments for diagnostic services such as MRI or EEGs. Out patients were likely to wait many months for diagnostic tests e.g. a nine to ten month wait for a MRI, or a 90-day wait for an EEG.

“Some patients travel to other countries to see a neurologist because of the delays here – I know of one patient who was seen in Stuttgart and another who was seen in Scotland” [Dublin Neurologist]

- **Access to Allied Health Professional Services**: There is considerable variation between in-patient and out-patient access to the services of AHPs. Depending on the service, hospital inpatients may receive these services within a few days or wait up to two weeks, thereby prolonging their length of hospital stay. Out-patient services were considerably less accessible with many patients waiting between 3-6 months for a minimal service and in some cases, no services at all. Access to AHPs services in the community is difficult.

- **Access to Medical Social Workers, Dieticians and Psychologists** are most limited. Very few hospitals report reasonable access or waiting times. Where available, services were often restricted to high priority in-patient cases only. Ongoing care in the community is rarely possible.

**Current Neurology Service References**

1. Hospital In-Patient Enquiry & National Perinatal Reporting Scheme Unit, Economic and Social Research Institute Dublin.
2. HSE Emergency Departments. Patient profiles, experiences and perceptions.
4. Consultation Process

Key Points

- The key strengths of the Irish neurology service include the dedication and expertise of its personnel, multi-disciplinary approach and involvement of voluntary groups.

- The main weaknesses include the long waits for services, insufficient resources at specialist and community levels, limited access to diagnostics and specialist multidisciplinary care, poor integration between hospital and community services.

- The challenges include the management of increasing workloads, greater opportunity to treat patients successfully, integrating care between hospital and primary / community services, exploiting the role of technology.

- GPs are generally unhappy with current service. This is primarily because of delays faced by patients. GPs are keen to work in a collaborative manner with the specialist service and promote a patient centred, integrated approach.

An integral part of this Review was to identify the views of stakeholders. There were two parts to the consultation process:

1. Consultation with hospital, community and voluntary services
2. A separate GP focus group and a GP survey that was facilitated by the ICGP.

Meetings were held with the Neurological Alliance of Ireland, Alzheimer’s Society, Social Work Association, Dieticians and Peter Bradley Foundation.

4.1 Consultation with Hospital, Community and Voluntary sector

This part of the consultation process consisted of:

- Structured ‘site visits’ / meetings in eight adult hospitals that provide specialist neurology services
- A structured meeting with the paediatric neurology group; and
- A structured meeting with the National Neurological Alliance (NAI).

This consultation process worked well. The meetings were well attended (an average attendance of 19 people, representing all disciplines involved in neurology, plus occasional other interested parties in some sites) and the level of participation was good at the meetings.

The consultation meetings invited participants to name what was working well in their neurology service/in neurology in Ireland, and to identify what was not working so well in neurology (in their site/across the country). Many of the meetings also included an invitation to those present to map the path through the health service of people with one or two neurological conditions, from onset through to treatment and on to life
with the condition. The meetings concluded with an invitation to participants to identify what they believed to be priorities for attention within neurology services.

4.2 Overview of Findings

A synopsis of the state of neurology services in Ireland, as described by the stakeholders in this exercise, is as follows:

Strengths of Neurology Services

- There is enormous dedication and commitment from staff across the board in neurology services.
- The service is increasingly a multi-disciplinary one. There is a widespread recognition that neurology conditions are best managed by a wide range of disciplines in both acute hospitals and in the community. Whilst the medical model continues to predominate, there is an increasing recognition of the need to help people live well with their condition.
- The involvement of voluntary organisations is a key part of the service. There is scope for even greater collaboration.
- There are great examples of innovative approaches in managing neurological conditions. These could have a much greater potential application than has yet been realised e.g. telemedicine.

Weaknesses of Neurology Services

- Ireland today may not a great place to have a neurological condition. In general, a person could expect to wait quite a while for consultation, then for diagnosis, then for multi-disciplinary attention and for care, especially continuing care at home.
- The scope of Neurology and the ability to manage patients with long term neurological conditions has greatly improved in recent years but the responsiveness of the service has not kept pace. Therefore there are resource deficits across the spectrum of hospital, primary and community services.
- Staff working in neurology services are in danger of becoming demoralised and dejected because they are under significant service pressure.
- There is insufficient integration between community and hospital services for people with neurological conditions, and there is a need to address the emerging clinical governance issues (for example, what is the optimum role of GPs and acute hospitals with regard to referral and management of conditions; is it a good use of resources to have separate assessments by the same professionals in hospital and in the community; consistency of approach, etc).
- Access to services is inconsistent across the country and even between postal districts in Dublin.
- Medical card ineligibility can present a serious barrier to accessing services in the community and to being able to live well with a neurological condition.
- There are concerns about the level of investment in clinical neurophysiology.

4.3 Main Themes
A number of consistent themes emerged in the meetings with the ten groups and the points made at the meetings tended to fall, in the main, under the following heading:

- Resource levels
- Integration, primary care / community services, voluntary services
- Multi-Disciplinary Team-working, coordination, skill mix and interpersonal relations
- Access to service / waiting times / eligibility
- Access to diagnostics
- Patient-centredness and family support
- Specialisation and sub-specialisation
- Discharge planning
- Education, training & research
- Equipment for patients
- Written protocols / guidelines / care pathways
- Dedicated in-patient beds / bed management / hospital space
- Paediatric-specific
- Acute hospital (episodic care) vs. chronic disease management
- Equity/consistency
- Innovation

Participants at the consultation meetings looked at the ‘good news’ with regard to the above headings, and the ‘not-so-good news’. On the basis of this, plus mapping the journey of ‘typical’ neurology patients through the health service, they identified a number of priorities. Section 4.4 gives the stakeholders’ views of what is needed.

4.4 Priorities for Attention - Views of personnel who provide the service

4.4.1 Staffing
The neurology service requires more specialist multidisciplinary staff to meet health needs and provide a timely neurology service to people on a population basis. Shortages of neurology personnel (in both hospitals and in the community) result in delayed admissions and delayed discharges (because of the level of service in the community). Communication and coordination, of the service amongst staff, both within hospitals and between hospital and community-based services (including GPs), needs to be enhanced.
4.4.2 Clinical Neurophysiology
The neurophysiology service is need of development and expansion. Each academic teaching hospital that has a neurology department also needs a neurophysiology service.

4.4.3 Hospital-Community Integration / Coordination
There is a need for greater integration and coordination between hospital and community services (e.g. more joint appointments). There should be joint, realistic care planning between the hospital and the community, so that people are can be discharged with an expectation of service continuity in the community. There needs to be better communication and collaboration with primary care staff so that people get better, more coordinated care. The links/interface between hospitals and the community need to be enhanced together with more community-based care. The outreach role is one which the Group endorses particularly for therapy and nursing roles.

“One of us has spent years trying to source entitlements and was told by a hospital social worker to contact the Citizen’s Information centre which, in turn, said to contact a social worker. Social work support is not available to someone who is not in hospital”. [member of a patient support group]

4.4.4 Eligibility and Equity
Eligibility issues are a problem for people with chronic conditions in terms of continuity of care, cost and access to multi-disciplinary care outside the hospital setting. In relation to equipment some parts of the country are reasonably well-served by neurological services but other parts are not. The service is inequitably distributed across the country because of different staffing levels in different hospitals. Services should be provided on the basis of clinical need and these should be standardised throughout the country. In particular aids and appliances need to be provided in a timely manner so that people can be enabled to manage as independently as possible at home.

4.4.5 Specialist Expertise
It was the consensus of the Review Group that more (general) neurologists and neurologists with specialist expertise are needed. Neurological conditions will not be diagnosed in a timely manner if people cannot get to see the right consultants and treatments may be delayed. People are generally happy to travel to see the specialist neurologist for assessment and diagnosis, and for complex care or treatment, but it is important that there is regional self-sufficiency for general neurology services and ongoing multi-disciplinary review and management. We need more specialist therapists and nurses and greater opportunities for GPs to develop an interest in neurology.

“I have been waiting for three years to see a neurologist with regard to my epilepsy diagnosis; as a result it as severely affected my life with regards my job, my family and my health”.
4.4.6 Models of Care

There were many options and ideas suggested as to how to model neurology services in Ireland, of which the most common included:

- The focus should be on more ambulatory day care and in providing care as close as possible to the patient / family.
- Neurology is quickly moving towards being a day care/out patient service: with more space, hospitals could have more clinics including one-stop clinics, rapid access clinics and pre-assessment clinics.
- The value of the Rapid Access Clinic model for all neurology (not just stroke) needs to be considered.
- Protection of some acute beds for neurology patients in one area within the hospital would mean that all the neurology ‘experts’ could work in the one area (and patients would receive better care).
- The option of developing national disease management models, e.g. for epilepsy, needs to be considered. Facilities for chronic long term care of the under-65 age group are not adequate. More long-stay/step-down facilities for care for people with chronic neurological conditions is needed.
- Specialist neurology community services are needed, for example, an extension of the First Patient pilot project which empowers patients, helps them to live well with their conditions, and improves their quality of life.
- The management of younger Alzheimer’s patients needs to be prioritised.

4.4.7 Paediatric-Specific Priorities

Multi-disciplinary paediatric services need to be accessible on a regional basis.

4.4.8 Allied Health Professionals and the Neurology Service

The consultation exercise conducted, as part of this Strategic Review, highlighted the central role of Allied Health Professionals (AHPs) in the care of patients with neurological conditions. A number of issues for these specialties were identified by the consultation process, at steering group meetings and in submissions to the steering group:

- Accurate Statistics on Neurological Conditions

There is no single and/or uniform database dedicated to any of the AHP services for patients with neurological disorders. Hence, it is difficult to estimate accurately the number of neurological patients in Ireland who currently receive and/or have received AHP services (either within hospital or community settings) or those who require AHP services.
• **Expansion of roles and duties of AHPs**
  There is increased recognition and expansion of the role of a range of AHPs including audiology, dietetics, occupational therapy, orthoptics, physiotherapy, clinical psychology and clinical neuropsychology, social work and speech and language therapy in the management of patients with neurological conditions and their families (See Appendix 3.6 for further details on the disciplines involved in neurology).

• **Increasing Workloads**
  Current service provision for neurology patients is restricted, both in hospital but particularly in the community. Many AHPs treat neurology patients alongside a general and excessive caseload leading to long waiting lists for outpatient services and restricting the input that can be given to patients and their families. Many patients with neurological conditions may require more than one therapist to treat a patient, due to their dependency level. A shortage of assistants nationally results in two therapists (rather than one therapist and one assistant) treating a patient. This reduces number of patients that can be treated by the therapist.

• **Space, Facilities and Equipment**
  Managing with limited space is a challenge. Limitations in space are a feature in all settings, acute, rehabilitation and primary, community and continuing care. This applies to treatment for individual patients and for group interventions.

  Facilities for clinical work and ICT to support data collection / audit are in short supply. Equipment is often funded through voluntary agencies and various forms of fundraising and prompt access to equipment for patients with neurological conditions is a difficulty. There is also a lack of access to specialised facilities such as hydrotherapy which is very limited nationally.

  The current low numbers of AHPs specialising in neurological conditions means that priority has to be given to patients with higher levels of disability over those with lower levels of disability. This means that the majority of neurological patients in early stages of disability or with minimum disability do not consistently access many of the AHP services. This results in few patients being assessed early in their illness and this tends to lead to urgent crisis referrals to the service at a later date. Limited access to transport is also a factor for many patients who need to access AHP and other services. Many services are inaccessible to patients who cannot arrange their own transport. The availability of AHP services is often determined by the geographical area where the patient is living and what AHP services have been funded in these areas. In addition, there is often an age based criteria for access to many services with very poor service provision for people over 16 and under 65 years. Children with neurological conditions who enter mainstream schooling have limited access to AHPs including paediatric clinical neuropsychologists. Private extended care facilities are exceptionally limited in their access to AHPs. Many of these facilities are private in nature although often funded to a greater or lesser extent by the
HSE. It is essential that patients who reside in these facilities receive the prompt care from AHPs as their condition requires. There should be no difference between a patient living at home and one in a care facility, public or private, in terms of access to appropriate intervention.

- **Evidence Based Practice and Research and Development**
  Current workloads mean that there is very little research being undertaken in the AHP field other than research that is based in the universities. AHP clinical research is essential for the development of services to patients with neurological conditions and urgently needs to be resourced at the clinical/care delivery level. Development of models of best practice and innovation are constrained by work pressures.

- **Lack of Clear Staffing Ratios for AHPs**
  There is little published in the literature in terms of the number and type of AHPs required for each type of neurological patient. The UK National Service Framework for Long-Term Conditions (which confined its brief to neurological conditions) detailed the importance of the AHP in the management of neurological conditions. AHPs enable clients with these conditions to achieve their optimum independence within the limits of their condition and so help to reduce the burden of disease and improve quality of life. Many clients are enabled to remain in the workforce. Challenges arise around the fact that there are no internationally recognised staffing ratios for AHPs treating people with neurological conditions. It is important that resource requirements are patient-needs based into the future.

- **Integration and Co-ordination of Services**
  There are examples of service integration between different services but opportunities to enhance these with the development of PCTs are needed. Examples of integration include:
  - Links between hospital based AHPs and community colleagues
  - Standardisation of referral procedures
  - Shared care protocols
  - Specialist out-reach nursing services e.g. MS, Epilepsy, MND to hospitals, community and voluntary groups
  - GP led Migraine clinics
  - Telephone advice to GPs and patients
  - Fast access OPD services
  - Web based interaction with Consultants and email consultations
  - Weekly specialist clinics
  - Consultant led training for AHPs and GPs
  - Telemedicine developments
Coordination and integration between different parts of the service and with the voluntary sector would ensure a more effective use of resources and improved delivery of care.

4.4.9 Conclusions
Neurology as a speciality is in a very dynamic phase. Assessment is improving, new treatments are emerging, more multi-disciplinary approaches are becoming the norm, and it is becoming more and more an out-patient and community-oriented service. So, whilst additional staff would be welcomed by both providers and service users, there is also scope for continuing to look at the way services are configured and provided, and there is already evidence of existing services flexing around new ways of working and bringing in prize-winning innovations. What also seems clear, especially when competition for resources is so keen, is that there is a need for a national view about how best to organise and deploy resources, to look at the whole picture for people with neurological conditions across the country in primary, intermediate and tertiary services.

4.5 GP Consultation

4.5.1 Background
The aim of the consultation was to obtain opinions of the neurology service and suggestions for developments.

4.5.2 Method
The consultation process was facilitated by the Irish College of General Practitioners (ICGP) through its representative on the Steering Group. There were two parts to the consultation:

- **A Focus Group** involving a small number of Dublin based GPs was held to discuss what works well / not so well, to hear their suggestions for improvements in the service including the role of technology.

- **A GP Questionnaire** was sent to a random sample of 400 GPs (from the 2000 whose email contact details are registered with the ICGP). The questionnaire built on the themes that were identified in the focus group. The questionnaire was hosted online by the ICGP from a link on their internet homepage. The survey was conducted over a 10-week period. Two email reminders sent to the GPs and a third reminder sent by conventional mail. Of the 400 GPs contacted, there were 85 respondents (21.5%). While the response was disappointingly low, the results provide useful information. Some reasons for the low response may include:
  - the use of email to contact GPs
  - the impersonal online nature of the survey
  - survey fatigue among GPs
  - interest in neurology as a medical discipline
  - busy GP schedules.
4.5.3 Results

A. Focus Group Consultation
A group of Dublin GPs from different parts of the city discussed three aspects of neurology services:

- What is working well in neurology
- What is not working so well
- What are the priorities for service development and opportunities for innovation.

1. What is working well in Neurology?
*Commitment of neurology personnel:* Despite their high workload, the commitment of neurologists and their team to see urgent cases quickly, to provide the highest possible quality service and to outreach to patients was acknowledged.

*GP led migraine clinics* – Specialist primary care clinics for some conditions have been established and are working well e.g. migraine clinics. These services have close links with neurologists. This approach facilitates patients to be treated outside hospital sector. It is a good example of how services can be integrated.

*Introduction of PCTs* – Primary Care Teams will also allow patients to have multidisciplinary treatment in the community with access to specialists as required. This service will bring care closer to the patient and is a key step toward providing a more equitable, accessible service while reducing the burden on hospital services.

*Neuro-Telelink* – GPs consider Tele-neurology a valuable development. There are successful pilots in place where GPs have access to neurologist guidance within 48 hours, thereby providing a responsive service to patients, providing reassurance to GPs and streamlining referrals to hospital. Tele-neurophysiology is also viewed as an important development that reduces patient inconvenience in relation to travelling, reduces waiting times and is responsive to patient needs.

*Training and Development* – GP Education and Training Schemes are responding to the growing prevalence of neurological conditions by facilitating training in neurology.

2. Deficiencies within the current service framework
From a GP’s perspective a number of aspects of the Neurology Service need to be improved.
Access to Diagnostics – Timely access to diagnostics is a serious problem for GPs especially for radiology. There is a view among some GPs that radiology is becoming increasingly privatised. Poor diagnostic access, especially for patients with 'red flag' symptoms is serious and can lead to inappropriate hospital admissions and ED referrals.

Long waiting lists – Long waiting lists, even for patients with worrying symptoms are a concern.

Deficiency in Community Services – The multi-disciplinary approach and integration with Primary Care is very underdeveloped.

Professional Links between primary and secondary care - GPs worry that their referral letters to neurologists might not be prioritised and they become increasingly frustrated in relation to accessing services. Hospital discharge letters often contain a lot of technical information but GPs need guidance on the patient’s management plan.

GP interest and knowledge of neurology- In the past not many GPs worked in the neurology service. As a result they may need to refer to neurologists more than may be necessary. Neurologist developed guidelines for GPs would help in this regard.

“I noticed changes in my partner and complained to the GP for at least 4 years before diagnosis. I had to insist as the GP did not find anything wrong. Finally we were referred to a neurologist. The brain scan showed frontal lobe atrophy”.

Clinical Neurophysiology – GPs cannot usually refer directly to neurophysiology. Access to this service is generally via a neurologist.

3. Potential improvements in services required
GPs made suggestions regarding some developments they believe could improve services:

Guidelines – GPs want guidelines on the management of common conditions. The also want referral guidelines and awareness of patient pathways.

Access - Greater access to diagnostic imaging is required for GPs. This would reduce the burden on consultant services and improve community care.

Improved links – GPs want better service integration including better links with rehabilitation services. At present neurology is mainly a hospital specialty.
**Chronic disease management** – Chronic disease management in Primary Care needs to be developed. In particular the roll-out of Primary Care Teams is a priority.

**Specialist Clinics** – Specialist clinics in the community for common conditions should be developed. In addition GP led migraine clinics using Consultant developed Guidelines have been shown to work well.

**Information Technology** – GPs need to improve their IT capability and electronic communication with neurologists e.g. the national development of neuro-telelink type service and other ICT based services (e.g. electronic referrals) should be a priority.

### B. Survey Questionnaire

#### General Information on GP Respondents

Of the 85 GP respondents, 51 were male and 34 were female. In relation to the location of their Practice, half (41) were city based, 25 were town based and 19 were rural.

Distances from the GP Practice to acute hospital neurology services ranged from less than a mile to 150 miles. More than half of the respondents (45) lived within 10 miles of acute hospital neurology services, two-thirds of these lived within 5 miles of a service. However, a third of respondents reported that their patients travel distances greater than 50 miles to acute hospital neurology services. Half of the GPs reported being in General Practice for more than 15 years. Only 10 respondents had less than five years service.

#### Access and Referral

- 70 of the GPs said that they considered access to specialist neurology services as ‘poor’.
- More than half of the GPs said that the usual waiting time to see a neurologist was one year and one-third said that their patients usually wait between 6-12 months to be seen.
- While the majority of GPs (49) said that in the past they were able to acquire at least one urgent referral to a neurologist for a patient, 32 felt they had not been able to do this. Of this later group, however, more than half had their urgent patient seen within two weeks.

Fig 4.1 shows the action that the GPs use to improve access to a neurologist.
Fig 4.1 Actions taken by GPs to speed up referrals to Consultant Neurologists

Neurologist - GP Links
When asked to rate the links between GPs and Neurologists for patients with neurological conditions e.g. MS, Epilepsy, Parkinson's, most respondents felt that the links were either fair (39) or poor (32). Only 14 respondents rated links between GPs and Neurologist as good.

When asked if a patient's discharge letter from a Neurologist typically included a management or follow-up protocol half of the respondents indicated this would occur either always or frequently while half indicated only occasionally. Only two respondents indicated never receiving a management or follow up protocol.

Neuro-telelink
An email service enabling direct communication between GPs and Consultant Neurologists, for advice on patient management and for fast-tracking of patients to a Neurologist is being piloted in one hospital. Respondents were asked to rate the potential usefulness of such a service; 52 felt that this service would be very useful or useful (18). Only 4 GPs felt that this service would not be useful.

Services Relating to Specific Neurological Conditions
The GPs were asked to give their views in relation to named adult neurological conditions (epilepsy, Parkinson's disease, multiple sclerosis, migraine, headache motor neuron disease and any neurological condition. Fig 4.2 shows that services were generally perceived as being fair or poor.
GPs were asked to rate services for paediatric neurological conditions and for paediatric epilepsy. Figure 4.3 shows a lower level of dissatisfaction than for the adult service.

Access to Allied Health Professional Services
The GPs gave their opinion on access to AHPs services for neurology. There were high rates of non-referral to these services and dissatisfaction. Both of these responses may be linked with non-availability of Allied Health Services for neurology patients in Primary Care, figure 4.4. In particular neuropsychology services were rated as poor and this is most likely associated with the lack of availability of the service.
View of current services

The GPs were asked two open ended questions:

1. “Are there any neurology services that you are were aware of which could be useful for the improvement of services if replicated nationally”:

Of those who responded the two main suggestions were:

- Primary Care Team roll-out with availability of Allied Health Professionals for patients with neurological conditions in the community and
- Specialist GP Clinics (with neurologist overview) for headache and Migraine.

2. “State one action that the HSE could take to improve neurology services nationally”

Of the 79 GPs answer this question, 59 said that the appointment of more consultant neurologists as the most important step that could be taken to improve neurology services in Ireland.

Other suggestions included:

- Establishing shared care services for chronic conditions
- Urgent assessment clinics for GP referrals
- Timely access to out patient clinics
- Dedicated multimedia services for GPs to access medical opinion
- Increased access to diagnostics MRI/CT for primary care.
5. Role of the Voluntary Sector

5.1 Introduction
The Neurological Alliance of Ireland (NAI) is made up of voluntary organisations that provide a range of services and supports to people with neurological conditions. The services provided by these groups should be seen as an integral part of the multidisciplinary, integrated approach to the management of these conditions. Voluntary organisations are in a unique position to provide a single point of contact and support in complex, long-term care pathways.

5.2 Background and Policy Context
A number of initiatives have focused on describing and defining the voluntary sector in Ireland. The White Paper on a Framework for Supporting Voluntary Activity (2000) outlined a set of principles to govern the relationship between the State and community and voluntary organisations. This report recognises the non-profit sector as core component of a vibrant civil society and the need to consult non-profit service providers about service design and delivery. Also included are recognition of the role of the voluntary sector in contributing to policy and relevant legislation and the diversity and autonomy of the sector. The establishment of voluntary activity units in relevant Government departments is also recommended.

The White paper made a number of specific recommendations focused on strengthening and developing the voluntary sector including the development of a legal and regulatory framework, training support and fostering and supporting volunteering. In relation to funding, it was recognised that statutory funding would be made available for mutually agreed programmes of activities consistent with government policies and objectives and steps would be taken to provide greater clarity around funding procedures and subsequent roles and responsibilities with State funders.

The value of volunteering has been identified and supported through the Taskforce on Active Citizenship. In its first report, (2007) the Taskforce outlines the vital role of volunteering in Irish society and the need to put in place structures and supports to encourage and facilitate people to offer their skills and experience in a volunteer role. The report notes the need “to promote awareness and understanding amongst public service organisations about how to engage more effectively with community and voluntary organisations”. It refers also to funding constraints for the voluntary sector, noting that “funding schemes need to be strengthened to support capacity development amongst community and voluntary organisations”

The National Economic and Social Council Strategy (2006) points to the need for more formal definition of the relationships between Government agencies and community and voluntary organisations. This strategy argues for a system of accountable autonomy in defining this relationship, allowing the voluntary sector to preserve its
ability to respond flexibly and creatively while recognising responsibility for organisation building and maximising their potential.

The most recent *Programme for Government (2007)* recognises the need to support voluntary activity, outlining a commitment to “strengthening further the relationship between Government and community and voluntary organisations.

The importance of non-profit organisations in the delivery of health care services in Ireland has been recognised in a number of documents on health policy. The *Report of the Commission on Health Funding (1989)* noted the lack of clear relationships between the Department and voluntary service providers and recommended the introduction of agreements around service provision. This was developed further in *Shaping a Healthier Future* which provided for more formal funding agreements between non-profit organisations and local health boards. The Health Strategy document, *Quality and Fairness (2000)* noted that cooperation between statutory and voluntary providers allows for a more responsive and dynamic approach to meeting needs and that there continues to be a very strong and diverse role for the community/voluntary sector in the health system. The document recognised the need to build on models of good practice in partnerships with the voluntary sector agencies and made a commitment to supporting community and voluntary activity in maintaining health.

There is still some way to go to achieve genuine partnership between the State and non-profit groups in the health sector which allows recognition of the unique capacity of the sector and provides sufficient resources to allow voluntary organisations to meet the needs of the people they serve.

The 2005 *Report of the Comptroller and Auditor General on the Provision of Disability Services by Non-profit Organisations* noted that systemic thinking about the relationship between the State and non-profit disability organisations is still underdeveloped. The report points to the failure in successive health policy documents to integrate the extent and nature of voluntary service provision. This report also acknowledged the multiple roles performed by non-profit organisations including mainstreaming delivery, innovative and flexible responses to new and ongoing needs, interacting with and supporting policy development on service design and providing feedback on service provision.

Current policy developments in health and disability recognise the requirement for partnership and genuine collaboration between all service providers. The *HSE Transformation Programme* outlines the need for a seamless integration of care across all parts of the health service and the need for programmes for the management of chronic long term conditions. Voluntary organisations are frequently to be found at the centre of the person’s transition through complex service pathways, providing a single point of contact. Their focus has always been on helping the person adapt to and manage their condition by putting in place supports at each stage of coping with the condition.
The Assessment of Need under Part 2 of the Disability Act (2005) will require positive collaborative relationships between voluntary service providers and statutory health services for the successful development and implementation of the assessment process.

The Neurological Alliance, an umbrella group of voluntary service providers, has been centrally involved in this Strategic Review. In this section an outline of the value and strength of the principles underlying the services provided by members of the Neurological Alliance is given. Examples of innovative practices by these organisations are described. Health service provision is increasingly moving towards an approach based on the individual needs of the person and integrated delivery of care. The importance of the voluntary sector in informing and supporting this needs-based approach is outlined.

It should be noted that, although, a large proportion of services, including disability services, are delivered through non-profit organisations, the legal obligation to provide these services clearly rests with the State under Section 65 of the Health Act (1953). The need to resource and develop the sector should not remove this responsibility.

5.3 The Neurological Alliance of Ireland

The NAI is made up of 24 voluntary organisations working directly to provide services and support to people with neurological conditions and their families. The range of organisations represented varies from small groups run entirely by volunteers to larger organisations with paid staff and regional offices throughout the country. The type of services provided by these organisations also varies, depending on their size and on the resources available to them. Some are involved in the provision of on-site residential, respite or training and rehabilitative programmes. Smaller groups provide advice and information and regular support meetings. All of the organisations are actively involved in promoting greater awareness of the conditions they represent and engaging in an informative and consultative role within health service and the wider community.

5.4 The Activities of NAI member groups

(a) Direct Service Provision

- Residential, home care and respite services and carer support programmes
- Rehabilitation assessment and structured training and education support programmes
- Supported employment and back to work training and assistance
- Provision of neuropsychological assessment and rehabilitation
- Casework and key worker roles (the person with the condition and their family are linked to services and supports in a structured and evaluated approach)
- Direct employment of social workers, nurse specialists, occupational, speech and language and physiotherapists and neuropsychologists
• Providing a wide range of social supports including access to social activities, breaks and respite care for families
• Access to and provision of personal assistant services
• Specialist nurse-led helpline services.
• Improving accessibility through provision of transport services and social activities and groups.

(b) Support and Advocacy

• Specialised education and counselling in relation to diagnosis and management of a neurological condition
• Specialised support, education and counselling for family members
• Support groups, seminars, conferences and other meetings
• One to one support services for people with neurological conditions around the impact of their diagnosis and ongoing management of their condition. Many organisations have specialised programmes for symptom management, adjustment to the condition, family support and information and social inclusion. These supports are designed around the specific stages in the condition, from diagnosis through early onset and progression depending on the type of neurological condition
• Provision of trained advocates working directly with people to identify and access the services they require
• Peer support for people with the condition and their families.

(c) Information provision, research, awareness, health promotion and training

• A wide range of education programmes aimed at employers, health professionals, schools and community services aimed at promoting greater awareness of neurological conditions.
• Promoting, commissioning and funding research on neurological conditions and keeping up to date with developments in research and treatment.
• Preparation and regular updating of publications such as websites, newsletters, leaflets and information booklets and manuals, videos, CDs, press releases etc.
• Training programmes and partnerships with health professionals to develop initiatives.

(d) Consultation and policy development

• Consultation at policy and planning level in all areas of health and social services around the needs of people with specific conditions.
• Development and pioneering of innovative approaches to the needs of their client group.
• Voluntary organisations play a key role in identifying needs and existing gaps in services for the people they represent.
5.5 Strengths of Voluntary Sector Service Provision for people with neurological conditions

The following are aspects of service provision in the voluntary sector that can be of particular benefit to the person living with a neurological condition and their family.

1. Services centred on the quality of life of the person with the condition
Voluntary organisations are committed to making their services centred on the overall quality of life of the person with the condition and their families. This means that they are concerned not only with access to health services but also access to a wide range of other services and supports to enable them and their families to adjust to their condition and engage in educational, work and social activities.

2. Services are Accessible and User Friendly
Voluntary organisations prioritise the need to be accessible to all those affected by the condition they represent. Many run helplines outside of office hours to provide advice and support on different aspects of the condition. Organisations run respite and activity breaks, support groups, transport services and home care supports at flexible times to suit the needs of their clients. The organisations work closely with community organisations, health professionals and the media to ensure awareness of their services. They have frequent routine contact with a range of health professionals in the local community who are well informed of the range of services they provide. Organisations provide fasttrack access to equipment, assessment and services which is particularly important for people with relapsing or progressive neurological conditions.

3. Navigation through complex care pathways
Many people with long term chronic conditions are required to navigate different aspects of the health services in order to meet their needs. Neurological conditions have a complex care pathway, with the person often needing to link to general as well as specialised services to meet their requirements. One example is their need to interface with disability services in terms of modifications to accommodation or access to aids and appliances. Voluntary organisations are an important source of information through their experience with the needs of people with specific conditions. Many provide case management and key worker services, directly linking people to the services they require at different stages of the condition and liaising with family members and community and hospital services.

4. Voluntary organisations facilitate people to manage transitional stages in living with a neurological condition
Many neurological conditions require long term management over a period of time. Our health service is designed to provide services within certain age groups. Children and those over 65 are managed within a different service framework and the transition between these services can be difficult for people living with long term chronic conditions. Voluntary organisations are experienced in advising people of their options and provide a single point of contact over time. People with neurological conditions often require support at critical stages of
diagnosis and treatment and particularly in the case of progressive conditions. Voluntary organisations have a range of supports and specialised programmes in place for people and their families at each of these stages.

5. Voluntary organisations provide specialised knowledge and experience
Voluntary organisations have built up expertise in providing information in a supportive and understandable format to people with neurological conditions and their families. They also provide information to a wide range of other groups. Some agencies have designed specific training programmes in cooperation with health professionals. Some organisations such as the Post Polio Support Group have produced guidelines for the treatment of neurological conditions within the health services.

6. Voluntary organisations have a key role as gatekeepers and advisors on health policy and planning
Voluntary organisations are informed by the needs of the people they represent and are responsive to developments in health policy and planning as they affect the people they represent. Voluntary organisations also provide specialist advocacy services to advise and empower people to access the services they require.

7. Voluntary organisations can develop imaginative and innovative responses to need and play an important role in research and evidence-based practice.
Voluntary organisations have been to the fore in developing initiatives that have been integrated into mainstream service provision. A key example is the personal assistant service for people with disabilities first developed by the Centres for Independent Living and now available through statutory disability services. Flexible, creative responses to need and the ability to fundraise to support vital projects allow voluntary organisations the capacity to develop new services.

Voluntary organisations provide an essential hub for interested people to come together to pioneer new approaches and research into the condition. These organisations provide vital access to volunteers for social and medical research into neurological conditions. Many voluntary organisations are involved in supporting and funding their own research projects and in facilitating research into the condition through their involvement in initiatives such as the Medical Research Charities group.

8. Added value of volunteering and peer support
The services of most NAI member groups are provided by professional staff. However, the added contribution and commitment provided by volunteers is an essential aspect of the strength of the voluntary sector. These volunteers often have direct experience of the condition to inform and empathise with those they support. This also means that organisations benefit from direct service-user involvement and advice, now recognised as a vital component of health service provision. Voluntary boards provide their experience and expertise free of charge and often bring diverse and innovative perspectives to the running of the organisation.
Peer support is an important aspect of voluntary sector service provision. For people living with neurological conditions, meeting others with the condition can be vital in overcoming isolation and helping them adjust to their situation. Contact with others with similar experiences is also important for family members. Voluntary organisations provide a unique platform for people to come together and benefit from the knowledge and experiences of people at different stages in living with the condition.

5.6 Challenges in Voluntary Sector Service Provision
NAI member organisations developed in response to unmet need in the provision of services to people affected by specific neurological conditions and their families. Many organisations are under pressure to secure funding and this results in difficulty for them in building capacity, recruiting and retaining experienced staff and developing professional structures and standards of service provision.

1. Need for recognition and genuine partnership
There is scope for greater recognition and structured engagement between statutory and voluntary services. Poor integration results in a fragmented service where needs are not being met in different regions of the country.

2. Need for capacity building in the voluntary sector
There is an issue of lack of capacity to provide some services within the voluntary sector. Some groups do not have the desire, staff or managerial capacity to grow beyond a certain size. The White paper recognises the need for professional support and training structures for the development of voluntary organisations.

3. Need for a collaborative approach to health service reform
There is a recognised need for voluntary organisations to work together in a collaborative way to support the needs of individual people with the condition and to prioritise these needs over traditional organisational work practices and relationships.

4. Resource and Training Needs within the Voluntary Sector
Voluntary organisations face a number of challenges in continuing to provide services. Expectations of standards and service delivery have risen among service users across the health services and this also applies to the voluntary sector. There is the difficulty of properly remunerating and retaining staff in a competitive economic environment. There is an increasing difficulty in retaining experienced staff over the long periods required to build up expertise within a voluntary organisation.

Voluntary organisations operate in an increasingly regulated administrative environment. Strict requirements under health and safety, company law and forthcoming charity regulation mean that voluntary organisations will
increasingly have to keep pace with a more complex and regulated operating environment. Dependence on project funds and on fund raising limits their scope and creates difficult to meet the needs of those they represent.

Voluntary organisations are committed to providing high quality services and innovative responses to the needs of their clients. They have historically done this in an unregulated and unstructured environment. This cannot continue to be the situation into the future. The reform of statutory health services in Ireland should be matched by a similar support for voluntary sector service providers so that these organisations can continue to provide high-quality support services.
SECTION B

6. Opportunities to Enhance Excellence from Innovation, Technology, Research and Development

6.1 Introduction

The practice of Clinical Neurology and Clinical Neurophysiology started as a diagnostic speciality based on phenomology, neuroanatomy and neuropathology in the 19th and early 20th century (the clinicopathological approach). The late 20th century saw it evolve into a therapeutic speciality driven by new molecular, diagnostic and therapeutic innovations (clinical-genetic-radiological-pathological approach). The 21st century will see the greatest advance in neuroscience, particularly in imaging, molecular biology, proteomics and metabolomics. The array of Clinical Information Systems (CISs) in development is a clear indication of the rapid pace of evolving routine clinical activities. However, there are recognised deficits in the provision of neurological services to the one billion people affected by neurological disease worldwide. Fifty million suffer from epilepsy and 24 million from Alzheimer’s disease and other dementias outlined in the recent WHO report Neurological disorders: Public Health Challenges (http://www.who.int/mental_health/neurology/neurological_disorders_report_web.pdf). The clinical neurology environment in Ireland is also under developed. At this important juncture, the Irish Health Service needs to put in place the structure and funding to enable growth in clinical research, the development of new treatments and the provision of CISs to support the further development of an efficient, effective patient-centred world-class neuroscience service.

The Sub-Committee on Training, Technology and Research & Development (hereafter referred to as the Sub-Committee) was established to identify areas in neuroscience that will have major impact on the future clinical practice of neurology and clinical neurophysiology. This sub-committee comprised an eclectic group of practitioners from diverse disciplines to augment clinical neuroscience specialists with researchers and practitioners from related areas. The subcommittee aimed to develop a comprehensive, multi-disciplinary and integrated approach to the development of future initiatives. It believes that clinical neuroscience is an ideal model to study in the Irish Health sector on how technology can enhance healthcare delivery practices, how the process and outcome of service re-orientation can be studied and how new healthcare information systems and ICT can be developed and assessed. The areas that the sub-committee identified as promising are described in this section including:

- A discussion on New Technologies with the potential to improve patient care,
A discussion on a number of Information and Communication Technologies with the potential to improve the administration, management and delivery of neuroscience services

A discussion on Research & Development, Academic Development and Training

6.2. New Technologies

There are a number of new technologies with the potential to radically improve the diagnosis and treatment of patients.

6.2.1 Structural and Functional Imaging

Innovations in technology over the past two decades have provided a powerful means of exploring the overall function of the brain. Brain imaging technologies provide unambiguous measures of brain structure (computerised tomography and magnetic resonance imaging (MRI) and diffusion tensor imaging) and also index complementary measures of when (electroencephalography, event related potentials, magnetoencephalography) and where (functional MRI, single photon emission computed tomography, positron emission tomography) aspects of brain activity occur. These technologies offer the means to explain the patterns of pathophysiology underlying neurological illness. The structural technologies are primarily used to exclude a biological cause in cases of a suspected neurological or psychiatric disorder. The functional technologies show considerable potential to delineate subgroups of patients (that may have different treatment outcomes), and evaluate objectively the effects of treatment on the brain as a system.

New methodologies include Diffusion Tensor Imaging (DTI). DTI is an extension of MRI that quantifies water diffusion in living tissues. DTI, like MRI, is a non-invasive method that can be performed safely and repeatedly in vivo. An important application of DTI is the ability to track nerve fibre pathways in the brain. Such information could help the diagnosis of certain diseases like multiple sclerosis, schizophrenia and autism. Therefore, DTI opens a window for understanding connectivity within the brain. Real-time brain mapping and monitoring is considered by many as one of the most exciting current developments in neurology. Magneto Encephalographic imaging devices, which measure the brain’s magnetic field in real-time, allow more accurate localisation, for example areas causing epileptic seizures. This brain imaging technology can also aid in the diagnosis and study of disorders such as Parkinson’s disease, multiple sclerosis, dementia and schizophrenia.

While brain imaging technologies show considerable utility we are only using a small fraction of this potential. In the next 10 years, the focus will be on minimising the over-interpretation of results. This will be through replication of brain imaging findings, judicious combination of complementary methodologies, use of appropriate activation tasks, analysis with respect to large normative databases, control for performance, examining the data ‘beyond averaging’, delineating clinical subtypes, exploring the severity of symptoms, specificity of findings and effects of treatment in the same patients.
6.2.1.1 Examples of Progress in Advanced Neuro-imaging in Ireland

a) Brain Morphometry Laboratory at Beaumont Hospital

The Brain Morphometry Laboratory (BML) at Beaumont Hospital has been studying and developing techniques for quantitative MRI analysis. Conventional brain MRI imaging is subjectively examined by a radiologist in two-dimensional coronal, sagittal or axial image slices. Objective morphometric analysis introduces a level of precision in the assessment of brain structure (length, area, volume) that is not available with visual inspection alone. This objective analysis leads to increased diagnostic yield and further elucidation of the pathogenesis of disease. Using computerised techniques, the BML has expertise in \textit{in-vivo} volumetric, surface area and cortical gyrification analysis of a range of brain structures including the whole brain, temporal lobe, hippocampus and entorhinal cortex. The BML provides quantitative MRI-based volumetric assessment of the mesial temporal lobe as a routine in the pre-surgical work-up for patients being considered for surgical treatment of their epilepsy at Beaumont Hospital.

There are currently three postgraduate students (2 PhD and 1 MSc) engaged in research at the BML laboratory studying:

- Improving epilepsy care with novel advanced MRI techniques. This project is funded by the Health Research Board. It aims to enhance the understanding of the aetiology of epilepsy and the pathogenesis of brain morphology under the influence recurrent seizures.

- Genotype to brain imaging phenotype: A new standard for associations. This project is funded by the Royal College of Surgeons in Ireland Research Committee. The project aims to determine if brain structure endophenotypes provide clues to the genetic basis of seizure-induced damage in temporal lobe epilepsy by correlation of genetic screening and QMRI results. The project takes advantage of the Irish Epilepsy Gene Biobank which is part of the Programme for Human Genomics (PHG) in Ireland (through the Programme for Research in Third Level Institutions (PRTLI), cycle 3) and to add neuroanatomic endophenotypic descriptors to the data series.

b) Imaging Research Infrastructure

The Trinity College Institute of Neuroscience (TCIN) in Dublin has recently established dedicated MRI facilities. This imaging research centre houses a 3 Tesla whole body scanner for human imaging research and a small-bore 7 Tesla scanner for living animal studies. In addition, the HRB has recently funded the establishment of a National Imaging Research Centre on the campus of St. James's Hospital in Dublin. This second centre will also house a whole body 3 Tesla MRI for human imaging research.

Having these imaging resources available and dedicated to the research community in Ireland offers substantial promise for neuroscience. The structural and functional imaging and brain morphometry research outlined above
require the acquisition of raw MRI data. These digital data are subjected to post-acquisition processing to extract further structural and functional detail. The image processing can be conducted at any location where the appropriate resources exist. In this way raw data acquired at TCIN might be processed at Beaumont Hospital or data acquired at St. James's hospital could be processed in University College, Galway. The establishment of dedicated imaging research facilities will enhance these activities and bring Ireland in line with international neuroscience centres by building capacity nationally and promoting multi-centre collaboration.

6.2.2 Molecular Diagnostics and Biobanking for Neurological Diseases

Lying at the heart of an integrated approach to understanding and treating neurological disease is a biobank linked to detailed clinical patient records and which has in place, protocols for sampling and storage of spinal fluid, brain tissue and DNA. Such a biobank would constitute the basis for future correlative and biomarker studies and would work in tandem with a national neurogenetics diagnostic service. The genetic input into neurologic disease, particularly neurodegenerative disease, is developing at such a rapid rate that it is virtually impossible for the existing National Genetic Service to keep abreast of developments in neuroscience. No longer is genetic testing required simply for counselling but is critical for early diagnosis. Only by making early diagnoses will it be possible to offer early therapeutic interventions likely to make a difference to the natural history of the neurodegenerative disorder.

The genetic input to neurologic disease ranges far beyond traditional familial neurological conditions and it is increasingly evident that genetic mechanisms are critically important in other equally devastating conditions such as malignant brain tumour, epilepsy and stroke. Understanding the genetic basis of neurologic disease causation has led to spectacular advances in therapies. For instance, the unfolding genetic basis for Alzheimer disease has been pivotal in the development of therapeutic strategies which strive to block the release and diffusion of soluble A-beta and so reduce synaptic and neuronal injury. Such a concept would have been inconceivable 10 years ago. Similar strategies are being developed in other neurodegenerative conditions whereby the mRNA of key offending proteins is targeted for silencing. Application of sophisticated biologic pathway analyses has led to the discovery of pathways which may be blocked or diverted in order to prevent neuronal injury. The recent dramatic improvements in survival of patients with high grade malignant brain tumours has followed on from years of laborious searching through thousands of brain tumour samples in an effort to uncover pathways for cell growth and division. Discovery of these pathways has been instrumental in the development of drugs which are capable of pathway inhibition and whose use has improved the survival prospects for patients with high grade malignant brain tumours.

Human tissues are essential to allow this research to progress. An integrated biobank stores tissues from carefully studied patients which are harvested either during life or after death and which are later made available for study to neuroscientists. The development of Biobank, which endeavours to capture diseased tissues from
patients with Alzheimer's, Parkinson's, Motor Neurone Disease, and inflammatory disorders such as MS together with rare but important conditions such as Creutzfeldt Jacob Disease, is perhaps the single most important research development required to underpin world class neuroscience research in Ireland. Ireland is one of the few countries in Europe which does not participate in the BrainNET European network of excellence (www.brainnet-europe.org/consortium). A human biobank has already been established in Ireland but does not include tissues from the nervous system [www.biobankireland.com]. Irish neuroscience researchers are disadvantaged as they do not have access to well studied and well characterised human tissue samples.

A Biobank would be pivotal in the following research scenarios. A key strategy in the treatment of Alzheimer's Disease (AD) is early recognition which must rely on a combination of biomarkers supplemented with neuropsychological, neurophysiological and imaging investigations. The validity or otherwise of biomarker based diagnosis in early AD can only be determined by comprehensive prospective studies of large populations over several years with subsequent pathologic confirmation. A similar strategy lies at the heart of Parkinson's Disease where availability of human tissues allows characterisation of protein interactions which are fundamental in selective neuronal degeneration. In epilepsy, the search for genetic and molecular basis of anti-epileptic drug resistance is crucial and readily lends itself to large scale genetic testing which is most valuable if carried out on brain tissues resected from patients whose epilepsy is resistant to drugs. Additionally, the genetic basis for epilepsy susceptibility may also be addressed using similar precious human tissue resources. Current MS research is focussing on axonal injury as an early and critically important determinant of long term outcome. Animal models offer only a limited opportunity to study this phenomenon. Ireland has played a major role in MS research over the last 20 years with much of the work based on availability of human tissues from the Northern Ireland MS brain bank. In recent years, it has proven increasingly difficult to maintain and restock the NI Brain Bank. Ireland lags far behind the rest of Europe in its approach to the investigation of patients with inherited neuromuscular disorders. Irish patients may wait several years before an accurate genetic and biochemical diagnosis is established and often this is only achieved on grace and favour basis with help from European neighbours. Biobanking of muscle tissue has been an essential element in acquisition of new knowledge of human muscle disease.

Consideration should be given to the establishment of an Irish Brain Biobank to support the planned neuroscience clinical database. Generation of genetic, proteomic and metabolomic data from human tissues obtained from patients who have been carefully studied during life will be the cornerstone of which neuroscience will prosper. Additionally, the genetic core will have a major diagnostic role in providing rapid diagnosis for clinicians caring for patients with neurodegenerative and neuromuscular disease.
6.3 Information & Communication Technologies (ICTs)

The development of Electronic Patient Record systems; Computer Physician Order Entry Systems; Systems for Tele-Medicine and a range of new and emerging devices have the potential to reduce ‘medical error’, improve the delivery of service to patients, offer electronic prescribing and streamline the management and administration of our clinical activity. There is a real opportunity to use clinical neuroscience as a model for the use of technology in Irish healthcare.

6.3.1 Technology-Enabled Organisational Change

The challenge of facilitating technology-enabled change within the health service should not be underestimated. Examples of costly and morale-sapping technology implementation failures are common.

A common error has been to assume technologies have consistently identifiable ‘effects’ or ‘impacts’, which can be anticipated. Research on the implementation and use of technology in a range of organisational contexts has demonstrated an array of outcomes where the same technologies are often associated with radically different outcomes in different organisational contexts. Consequently, it is important to make a clear distinction between ‘espoused technology’ (i.e. the claims made for a technology, particularly with respect to assumptions about how it will be used) and ‘technology-in-use’ (i.e. how it is actually used in practice). Technology-in-use is of much more importance in practice.

These points highlight the crucial role of the social/organisational context in shaping the outcomes of any attempted technology implementation. Just because a technology appears to be successful in one context does not mean that it will be so in another. To make meaningful contribution, then, technology must be successfully embedded within a given social and organisational context. It must become part of the fabric of social practices that comprises this context and herein lies one of the key challenges associated with facilitating technology-enabled organisational innovation (technological innovation).

These issues have a number of very important implications for facilitating technological innovation in the context of Neurology service delivery in Ireland. The challenge is to find ways of successfully and sensitively integrating new technology within institutionalised social practices that may have very long and important organisational heritages. In complex organisational environments like Neurology departments, work practices may require detailed and sustained study.
6.3.1.1 Examples of Health Informatics and Telemedicine Projects currently underway in clinical neuroscience in Ireland.

a) Organisational Change in DATH Hospital
Researchers from the UCD School of Business’ Centre for Innovation, Technology & Organisation (CITO) used ethnographic methods and process modelling techniques to study and attempt to map a broad range of work practices. They studied the possible convergence of organisational change by technology across the DATH hospitals. The study involved shadowing the Neurology team in the Mater Hospital, in addition to other services in other Hospitals, to determine how to specify systems to support clinical practice at a sufficient level of granularity.

b) Revolutionising chronic disease management with information and communication technology: A socio-technical project applied to epilepsy care in Ireland.
The Epilepsy Programme at Beaumont Hospital in collaboration with the hospital's IT department, the Centre for Health Informatics at Trinity College Dublin and the Department of Health Policy and Management at Trinity College Dublin are conducting research that aims to align people (patients with chronic disease, families, healthcare staff), processes (access to healthcare services, manner and location of service delivery, procedures for follow-up care, and the interface between clinical care and clinical research environments) and technology (application of information and communication technology (ICT) in health care practices to optimise chronic disease management). The project is funded by a five-year health services research and development grant from the health research board (HRB) and aims to evaluate the impact of an eHealth domain on healthcare process and outcome using epilepsy as an example of a chronic disease.

6.3.2 Electronic Patient Record Systems (EPRs)
It seems that a centrally-planned approach to technology innovation, including EPR, often fail because of a lack of flexibility, feedback and limited improvisation. (Orlikowski 1997). A “bottoms up” (addressing the clinical needs of physician, nursing, paramedical and patients) approach to EPR is more likely to succeed than a top down approach. It will take time to iron out all the problems in developing EPR for such a complex system such as medicine.

6.3.2.1 Examples of EPR underway in Clinical Neuroscience in Ireland

a) St John of Gods EPR System
A highly effective EPR system has been evolving at St John of Gods Hospital from the mid 1990s. The current system has been operational for four years and new functions are added every six months. Over 90% of outpatients are recorded the system. It provides a live Diary Function, Electronic Prescribing, Electronic Patient Record and Discharge, an Email Communication Package, Direct Laboratory Reports and Management Reporting tools. The system forces users to slow down; to record notes efficiently; to use fewer words and to be aware that
others have to read their notes. The physicians maintain the notes are more precise, accurate and readable. The psychiatrists established users groups for developing the system that meet monthly. The user group write up the user specification and feed into a project team. The project team interfaces with the IT department (director of IT and a programmer). The system is very successful because it has been built overtime overcoming many of the obstacles along the way by an open discussion and reflection. The subcommittee recommends a case study be conducted on the St. John of Gods EPR system to incorporate such a system into clinical neurology.

b) **Revolutionising chronic disease management with information and communication technology: A socio-technical project applied to epilepsy care in Ireland.**

An electronic patient record (EPR) will form the nucleus of the eHealth domain. Over the course of the five year R&D programme will be made accessible to authorised health service providers based at Beaumont Hospital (e.g. out-patient clinic, nurse-led telephone advice line, epilepsy monitoring unit) and beyond Beaumont Hospital (Neurologists, GPs and Primary Care Teams) involved in epilepsy care in Ireland. Ultimately the aim is to allow authorised patients to have access to their own record to promote their role in self-management.

The impact of the EPR on the delivery of Beaumont Hospital based out-patient clinic and in-patient epilepsy care services and clinical research will be assessed. It will also explore the role of the EPR in improving integration of epilepsy care services between hospital and community health services and in facilitating greater patient self-management of their condition. An epilepsy EPR is currently being designed, developed and implemented at Beaumont hospital, Dublin. The EPR is a web-based application which is being implemented on an incremental basis. The application is based on a systems architecture that captures both epilepsy specific information and generic patient information, providing an application that will be applicable to other similarly complex chronic diseases.

The model established in this project is re-usable and transferable to other similar projects. This evaluation research is examining the EPR implementation and its effects. This involves a three-stage process of pre-implementation review, implementation review and operational evaluation. These stages occur at specific points of the EPR project life-cycle. This formative and summative evaluation aims to determine the impact of eHealth on the continuum of care for patients with epilepsy and to inform future ICT implementations in the management of other chronic medical conditions.

c) **Computerised Physician Order Entry (CPOE) at Forrest General Hospital, Mississippi**

This is an example of how technology can be used to reduce the amount of time spent in ordering tests, ancillary services, prescribing medication and to increase functionality.
6.3.3 Telemedicine via phone, email and video link
The American Telemedicine Association defines telemedicine as ‘the use of medical information exchanged from one site to another via electronic communication for health and education of the patient or healthcare provider and for the purpose of improving healthcare. It is the use of information and communication technology to provide health care services to individuals who are some distance from the health care provider’.

6.3.3.1 Examples of Telemedicine underway in Clinical Neuroscience in Ireland

a) Teleneurology Belfast to Omagh Hospital and North Western GPs
Dr Victor Paterson, Consultant Neurologist Belfast has developed a system that broadly comes under the heading of telemedicine. The approach that utilises video conferencing technology to enable virtual consultations with patients at a number of specific locations, in addition to an email consultation service to GPs. He has published extensively in peer-reviewed journals outlining safety and patient satisfaction with the service.

b) Healthlink Neurology Referral St. Vincent’s University Hospital (SVUH) to South East Ireland
Dr Niall Tubridy consultant Neurologist SVUH and colleagues have developed a similar web-based system (Healthlink Neurology Referral) to enable a more focused examination in the GP’s office which is then assessed on-line by a consultant.

Both approaches have improved communication among the consultants and referring GPs but do not replace people. They both reduce waiting time for patients, improve access to consultant neurologists, reduce the number of unnecessary referrals attending neurology clinics, reduce the need for patients to self-refer to A&E, improve the quality of data supplied before the patient attends OPD, enable certain tests to be done prior to OPD and help prioritise patients before they arrive at the out-patient clinics.

c) Video-link at the National Rehabilitation Hospital, DunLaoghaire (NRH),
At the National Rehabilitation Hospital, DunLaoghaire (NRH), video conferencing has been used typically at out-patient clinics. The primary impetus for using this technology was to address the issue of patients arriving exhausted to the clinic because they had travelled long distances. Such high levels of fatigue often make clinical assessment difficult. Video conferencing also allows easier access of relevant personnel / carers / family members to participate and make valuable contributions to the clinic, without the time consuming and inconvenient aspects of travel. It also provides an efficient medium where relevant parties can participate in clinical discussions first hand (e.g. GPs, PHNs, family members) and if necessary in a prompt manner. Having the facility of video conferencing makes it easier for all parties to attend meetings and this in turn can promote and enhance the likelihood of establishing a better ‘continuum of care’.
d) **Teleneurology link between Mater Misericordiae University Hospital (MMUH) and Tullamore General Hospital**

Through the charitable donation of equipment a telexlink has been established between MMUH and Tullamore General Hospital to provide urgent inpatient neurology consultations and an academic link. Such a service could be expanded nationally to provide a similar service and improve access to clinical neuroscience and develop a virtual neuroscience network.

e) **Teleneurophysiology A Pilot Project: Implementation and Evaluation**

Digital technology associated with Clinical Neurophysiology (CN) is compatible with tele-medicine service development and may increase the efficiency of patient care particularly in areas remote from the main medical centres. In terms of teleneurophysiology (TNP) a technologist records CN data at a remote department (e.g. Sligo General Hospital - SGH) that is a satellite of a specialist CN department (e.g. Beaumont Hospital) to which the recorded data are communicated for interpretation by a consultant in CN. Communication of data can be conducted electronically over a telecommunication network.

For patients who live at some distance from specialist healthcare centres there is earlier access to care, improved access to expertise, a reduction in lost work-time or time in the local community, reduced anxiety associated with waiting for diagnostic tests and results, earlier diagnosis and introduction of treatment and reduced morbidity and mortality. There is reduced isolation of clinicians working in regional or remote centres with increased support from colleagues in the specialist centres, and clinicians have better access to clinical tools to improve the management of their patients. For healthcare managers there is improved integration of services, improved value for money, and shorter waiting lists.

Over a twenty week period between May and September 2006, 142 patients (over 18 years old) had EEGs recorded at SGH. The digital EEG recordings were uploaded to a file server at SGH from where they were available to be accessed electronically from Beaumont Hospital by a consultant in clinical neurophysiology for interpretation. The TNP pilot project received a 2006 Health Services Innovation Award (category: Innovations in Management, Technology and Communication).

The pilot project demonstrated:

- The practicability of a telemedicine model of CN service delivery.
- The benefits of the TNP model and its alignment with the national goals of the health service in Ireland - better health, fair access, appropriateness and responsiveness, and high performance.
- A six-fold increase in access to EEG services for the population of the NW and an improvement in waiting times for CN appointment.
Arising from the success of the project additional funding has been allocated to the North West in 2007 to ensure the sustainability of the project in the long term.

\textit{f) National Network of Care for Epilepsy (NANC-E): The whole is greater than the sum of its parts:}

There are only four neurologists with specialist epilepsy training in Ireland, one each at Beaumont Hospital Dublin, St. James’s Hospital Dublin, University College Hospital Galway and Cork University Hospital. A distance of up to 260 kilometres separates these centres. Video-conferencing infrastructure can enhance communication between experts in epilepsy care from geographically separate locations. The Epilepsy Programme aims to establish a network of care for epilepsy which will be supported the video-conferencing infrastructure. Video-conferencing technology facilitates transmission of text-based patient data, diagnostic images such as magnetic resonance imaging, electroencephalography recordings, pathology images, clinical video data. The technology can be used for clinical case conferences, multi-centre surgical planning, multi-centre R&D, distance education and training, grand rounds and seminars.

The video-conferencing infrastructure will facilitate a network of communication between experts in epilepsy care based at Beaumont Hospital, Cork University Hospital, University College Hospital Galway and St. James’s Hospital, Dublin. A number of research and development activities currently underway will benefit from the video-conferencing infrastructure and include:

- The development of an eHealth domain for epilepsy which aims to exploit information and communication technology to enhance epilepsy services in Ireland.
- Pharmacogenetics and epilepsy which aims to identify genetic factors which determine an individual's response to drug therapy.
- Epilepsy and Pregnancy register which aims to further understand the safety of anti-epileptic drugs in pregnancy and for resultant off-spring.
- Anti-Epileptic Drug associated bone disorder which aims to determine the prevalence of bone disease in a population with epilepsy.
- Magnetic resonance imaging based brain morphometry which aims to study the relationship between brain structure and function in epilepsy.

Telemedicine provides a more efficient means of communication but will require funding and the appointment of staff (neurologists, clinical nurse specialists) to develop the service. Any innovation in Technology or Telemedicine to be effective, sufficient, skilled and trained personnel were crucial to the success e.g., Clinical Nurse Specialists to perform a neurological exam at the local hospital while patient being assessed via telelink by consultant.
It can compliment the proposed Clinical Neurology Network Model for Health Care in Ireland. There is a need for proper durable robust equipment, the availability of expert backup staff and time to set up and maintain the service. Extra consultant sessions will be required to provide this service. **Funding should be provided to expand, study and implement these systems nationally.**

### 6.3.4 The Neuroscience Virtual Network

The development of a Neuroscience Virtual Network utilising increasing bandwidths and Virtual Private Network (VPN) technology could lead to a virtual clinical neuroscience network with a range of centres focusing on different clinical neuroscience sub-specialties including Movement Disorders, Epilepsy, Multiple Sclerosis, Stroke and Muscle Disease. The facility may enable a network of clinicians to collaborate on a range of related issues including difficult cases and new treatments. This service could include an extensive web-based component to direct patient and health-care providers to departments with information on; referrals to the nearest unit, latest research into conditions of interest as well as other resources for patients and GPs. Each hospital could be a hub within the virtual network, providing resources to update and manage the facility.

### 6.4 Research & Development, Academic Development and Training

#### 6.4.1 Research & Development (R&D)

R&D is an essential requirement for all clinical neuroscience groups to maintain and improve clinical standards, engender academic links, and further the understanding of neuroscience (“Research Infrastructure in Ireland – building for tomorrow”. “Towards Better Health: Achieving a Step Change in Health Research in Ireland”).

Most of the major scientific breakthroughs occur because of interdisciplinary collaboration. However, there remains a gap between basic science and clinical neuroscience. The Dublin-Medical-Molecular-Centre (DMMC) aims to bridge this gap. There is an opportunity for Ireland to be at the forefront of translational medicine. Large scale programs to encourage multidisciplinary neurology research and education should be integrated with the service, where impact is focused on clinical care not just on academic publications. Concentration should be placed on the combination of complementary research methodologies, analysis with respect to large normative databases, delineating clinical subtypes, exploring the severity of symptoms, specificity of findings and effects of treatment in the same patients. The HRB are actively funding a large number of research projects in Brain Diseases. The HRB structured training programme in Neuroscience involves rotation between four research laboratories providing knowledge in animal and clinical research, in addition to theoretical and didactic lectures. Moreover the HRB are interested in developing Clinical Research Centres e.g., HRB-Wellcome initiative to be build a CRC on St. James Hospital campus by 2009 including a national imaging facility. Science Foundation Ireland (SFI) has identified
translational research as a key component of the research spectrum encompassing basic (or fundamental) and applied research. Currently, approximately 25% of the SFI committed budget in the BioSciences has a human health research component. SFI is supportive of this subcommittee’s report.

The HSE has recently agreed to fund the capital costs of a new Clinical Research Facility in University College Hospital Galway. This will be a significant joint initiative with the HRB and Welcome Trust and will bring together academics, clinicians and scientists and will additionally benefit with the presence of many companies manufacturing medical devices in the region.

6.4.2 Training
The Royal College of Physicians in Ireland coordinates, supervises and monitors the training of neurologists through the Higher Specialist Training programme (Specialist Registrar-SpR scheme). There is a need to increase the number of Specialist Registrars in Neurology firstly to allow a more flexible training scheme and to provide well-trained Irish graduates for the expected increase in Consultant Neurologists. For example SpRs should spend time doing electives in neuroscience sub-specialties (e.g., neuropathology, neuroradiology, neurosurgery, neuroophthalmology, etc). Our present system does not have sufficient number of SpRs to allow this subspeciality training. Moreover, it is likely that the neurology training scheme will need significant change with the increasing array of therapeutic options in clinical neuroscience (e.g. thrombolysis in stroke, neurovascular interventions, Natalizumab in MS, DBS in Parkinson’s disease etc). An argument can be made that some of the new SpRs should be taught neurovascular intervention to staff the new stroke units around the country to provide rapid access to stroke care for all Irish citizens. There is no SpR scheme in paediatric neurology or clinical neurophysiology.

Biomedical Engineering Division of Engineers Ireland (Institute of Engineers of Ireland) provide bespoke courses on biomedical technology. A joint proposal has been submitted by Trinity College, University College Dublin, University of Limerick, National University of Ireland-Galway and the Royal College of Surgeons in Ireland to the Higher Education Authority for the creation of All-Ireland Graduate School in Biomedical Engineering in 2007. The objective here is to create an advanced framework to integrate research activities across Ireland and to develop the next generation of postgraduates that have additional research and training skills suited to the next phase of the development of Ireland’s knowledge society. It is proposed to develop a four-year programme in Biomedical Engineering and Medical Device Technology for a total of up to 40 postgraduate students across Ireland. A major component of this programme will be advanced modules Neural Engineering and Medical Imaging. Other modules include inter alia, biomedical signal processing, tissue engineering scaffold development, and constitutive laws of biological materials, implanted electronics and telemetry devices and stem cell biology etc.
There is a need to increase the training of technicians and technologists for clinical neurophysiology in view of the increasing array of diagnostic and therapeutic electrophysiology procedures e.g., DBS, spinal monitoring in spinal cord surgery, tranmagnetic stimulation for diagnostic tests and treatments, telemetry and vagal nerve stimulation in epilepsy.

With the development of academic neuro-rehabilitation in Ireland there is a need to increase the number of post graduate courses to be established and supported for allied health professionals such as physiotherapists, occupational therapists, speech and language therapists, and dieticians. There is also a need to expand and support research posts for allied health staff.

6.4.3 Infrastructure and Academic Bodies

**Trinity College Institute of Neuroscience (TCIN)** is a dedicated research institute in neuroscience, with about 40 associated PIs and their groups, as well as technical and managerial support staff. TCIN includes clinician-scientists with academic positions in Trinity College and clinical appointments in St James's Hospital, St Patrick’s Hospital and AMNCH, Tallaght. Research facilities include two high-field MR systems, which are instrumental in facilitating translational research. Interaction with PIs in Nanoscience enables the development and testing of novel contrast agents and the advancement of the technology. One of the primary objectives in TCIN is to enhance and develop translational neuroscience, using an integrative approach. Funding is being sought to study biomarkers (including neuroimaging) of Alzheimer’s disease (AD) and to study the relationship between changes in these markers and the progression from Minimal Cognitive Impairment to AD. This programme depends on the effective integration of data from animal and human studies, input from PIs in several disciplines and the support of the underpinning technologies such as brain imaging.

**The Neurological Institute, Mater Misericordiae University Hospital** is a renovated Georgian building on Eccles Street that will provide a centre of excellence in Clinical Neuroscience. In addition it will provide clinical space for assessment, treatment and study of all patients with neurological disease and a drop-in centre for patients and family members. The funding (€1.3 million raised) to renovate the building comes from fundraising.

**Irish Institute of Clinical Neuroscience (IICN)** is a society that represents the clinical neuroscientists in Ireland and advocates on their and patients behalf. It administers competitive research grants and runs an annual all-Ireland clinical neuroscience conference (Irish Neurological Association meeting). The Irish Neurological association and the Irish Consultants Neurologists’ Association are subcommittees of the IICN.
Neuroscience Ireland is a recently established society whose objective is to promote the science of neuroscience and the neurosciences in general. In addition NI will award competitive grants to neuroscientists in Ireland. At present there are 74 members and the Council comprises basic and clinical neuroscientists.

6.4.4 New Rehabilitation Models and Techniques

Neurorehabilitation is an expanding academic specialty with clear evidence that there is plasticity in the brain and spinal cord. Thus some brain regions injured can be remodelled to recover function. There is strong evidence that patients with stroke and MS do better with rehabilitation. Small levels of intervention can have powerful and specific effects. One of the main problems in acute Hospitals is the delayed discharge of patients suitable for rehabilitation or Long Term care. These delayed discharges have impacts throughout the hospital particularly in the throughput – the manifestation is most evident when it results to a backlog in the EDs. In particular patients under 65 with significant neurological disease have poor access to rehabilitation. Ideally each acute hospital should have a small acute rehabilitation unit but also access to a larger medium term facility off campus with integration of community services. Thus patients would not wait inappropriately in the acute hospital but get access to more intensive rehabilitation and hence have less disability. A national rehabilitation strategy is to be undertaken and this should recommend a programme of expansion to address the growing needs.

A number of new techniques in rehabilitation and its measurement have appeared recently including Quantitative Muscle assessment (QMA), GAITRite System and Virtual Reality (VR). VR can be defined as a ‘...a way for humans to visualise, manipulate, and interact with computers and extremely complex data’. VR can also be described as an advanced form of human-computer interface that allows the user to ‘interact’ with and become ‘immersed’ in a computer generated environment that is familiar to and/or meaningful for the user. Computer generated virtual environments (VE’s) can be created to assess and train patients to improve their cognitive, behavioural and functional abilities. This is achieved by providing interactive scenarios specifically designed for their needs by exposure to simulated ‘real world’ and/or analogue tasks.

VR offers clinical assessment and rehabilitation options that are not available using traditional methods. Advances in technology have focused on improving the level of independence and ultimately the quality of life of people living with disabilities for example, SMART Homes, voice recognition and electronic switches. VR is currently used in medical training, in particular for teaching surgical procedures, and has been applied to the clinically to with patients diagnosed with anxiety (phobias and post-traumatic stress disorder), eating and body-image disorders and pain management. VR has the potential to develop human performance testing environments that could be incorporated into traditional neuropsychological assessments. These could improve

1 Aukstkalnis & Blatner, 1992, p7
the detection, diagnosis and mapping of the deficits that occur following neurological disease. Furthermore, the possibility of linking VE assessment with brain imaging and psychophysiological technologies is emerging as a new opportunity to map brain-behaviour relationships.

Part of cognitive rehabilitation programmes often includes practicing compensatory strategies in the hope that these strategies and skills will be incorporated into the person’s day-to-day life. VR may help by providing low-cost training environments that are consistent with the user’s real world and can be repeated and increased in complexity as desired. Feedback is provided which is integral to efficient and effective learning. Creating a VR ‘office/classroom’ can allow for the assessment and re-training of relevant cognitive tasks within a controlled environment (e.g. the ability to attend to various tasks simultaneously) and this in turn can provide sufficient training / learning opportunities to enhance the patient’s return to education or work and independent living.

VR can provide opportunities to allow the patient to understand the relationship between their performance on psychometric tests and in the ‘real life’ task simulated by VR. VR can also simulate the ‘real world’ of the patient, thereby, improving the understanding and awareness of others about the limitations experienced by the patient for example, perceptual difficulties (visual field disturbances, visual neglect). Currently in Ireland the development of VR and associated technologies involves collaboration between engineering, computer science, psychology, occupational therapy and medicine, with a clinical focus on remediation of cognitive and motor deficits. The application of technology to improve the quality of life of people living with disabilities is an important area of research for clinical and social reasons and it is likely to become an important tool in future clinical practice and care.

There are some impressive examples of how rehabilitation, technology, public generosity and commitment all come together for the benefit of patients with neurological illness. One such example is the recent introduction to Ireland of the Lokomat to the National Rehabilitation Hospital in Dun Laoghaire. This is the first driven gait orthosis and is used for robotic treadmill training of neurological patients with movement disorders caused by stroke, spinal cord injury and traumatic brain injury, multiple sclerosis or Parkinson’s disease. It will result in earlier mobilisation and improved outcomes for these patients. These technological developments are an adjunct to and not a replacement for comprehensive rehabilitation.

6.4.5 Deep Brain Stimulation/Functional Neurosurgery

Functional neurosurgery and Deep Brain Stimulation (DBS) is now an internationally accepted form of treatment for Parkinson’s disease and dystonia. Ireland is the only Western European country that does not have a DBS programme. Assessment of Deep Brain Stimulation was undertaken which shows that there is need to develop a National DBS Programme utilising the Neuroscience Virtual Network. A team of neurosurgeons, neurologists, clinical nurse specialists in movement disorders, neuropsychologists, and rehabilitation staff will need to be
developed to provide this effective treatment for movement disorders. There is an increasing role for DBS in other clinical conditions including chronic pain and neuropsychiatric disorders. **In the context of developing a Movement Disorder Programme the development of an Irish DBS Programme is recommended.**

The full report on Deep Brain Stimulation is in Appendix 6.1 – Technical report No.1

### 6.4.6 Multiple Sclerosis and Natalizumab (Tysabri)

This new intravenous treatment for relapsing remitting MS is twice as effective as other immunomodulatory therapies. It requires monthly IV infusions with close monitoring of the patient for known side effects (early anaphylaxis and uncommon brain infection due to PML). MS is a common disorder in Ireland with an estimated prevalence figure of 143.4/100,000 or approximately 6075 MS patients in Ireland. Approximately 240 to 480 of these patients will be eligible for the use of natalizumab i.e., disease progression on disease modifying drugs. Therefore the use of natalizumab will increase steadily over the next few years. Neurology services and the HSE need to plan for the structural needs and extra staff required for this new effective therapy. Each neurology centre will need access to a day ward/therapy unit to infuse Tysabri in addition clinical nurse specialists/nurse practitioners to assess and monitor patients. It is strongly recommended that strict clinical and safety criteria be used for the provision of this new treatment. These criteria may need to be updated from time-to-time:

1. **Tysabri should only be given under the direction and monitoring of the neurologist.**

2. **Hospitals providing this treatment should:**

   a. Have a neurology unit with multidisciplinary team and specialist neurology nursing, and treatment should be integrated with all parts of the patients care.

   b. Have access to other specialties as required including MRI and access to specialist Neuroradiology.

   c. Have access to an infusion suite, to on-site resuscitation facilities and to on-site personnel with resuscitation skills.

   d. Have facilities to investigate complications such as PML.

   e. Mechanisms in place to record and report untoward events on a national basis.

   f. Provide patient support and counselling as required.

A comprehensive Needs Assessment of Natalizumab was undertaken (appendix 6.2 ) – Technical report No.2.
6.4.7 Stroke, Stroke Units and Thrombolysis

Stroke is a neurological condition with respect to the anatomic location of the lesion and the associated symptoms. It is the third leading cause of death and commonest cause of disability worldwide. There were 10,000 acute strokes admitted to Irish hospital in 2005 and it is estimated that over 30,000 people in Ireland are survivors of stroke. Many have significant residual disability including hemiparesis (48%), inability to walk (22%), need for help with activities of daily living (24-53%), clinical depression (32%), and cognitive impairment\(^3\) (33%).

There is overlap with the cardiovascular system in relation to the aetiology and prevention of atherothrombotic stroke. The Cardiovascular Health Strategy *Building Healthier Hearts* made recommendations for the primary prevention (reducing risk in those who are asymptomatic) of events throughout the vascular system, including stroke. The implementation of the recommendations in the *Cardiovascular Health Strategy* has been reviewed. The Department of Health and Children has established a Group to update policy on prevention and service provision for cardiovascular conditions. That review will include services for patients with stroke and the Health Service Executive is preparing plans for stroke services in the context of this national review.

Though there is substantial overlap between the primary prevention of stroke and the prevention of other cardiovascular conditions some issues are of particular importance for the prevention of stroke, such as the detection and management of atrial fibrillation. Transient ischaemic attacks (TIA) and mild strokes are associated with increased risk of recurrence. Protocols are required for the detection and management of atrial fibrillation and to fast-track access to diagnosis and treatment of suspected TIA.

Thrombolysis is an established treatment for acute myocardial infarction, though its timely delivery presents challenges, requiring public awareness of the symptoms and rapid response by the health services. There is evidence that thrombolysis also improves outcomes in thrombotic stroke. This requires rapid diagnosis, particularly to rule out haemorrhagic stroke in which thrombolytic therapy is contraindicated. The development of such a service will require protocols and training for staff in the emergency medical services and in local and regional acute hospitals. Intravenous thrombolysis given within 3 hours of acute thromboembolic stroke results in a 20% decrease in mortality and morbidity and acute stroke units decrease death and disability by 25% (Langhorne et al 1993). Half of the patients treated with TPA within 90 minutes are cured of their stroke. Moreover, intraarterial thrombolysis within 6 hours of stroke is more effective.

Protocols are required for early assessment of patients with stroke and the development and implementation of personal care and rehabilitation plans. The Irish Heart Foundation Council on Stroke has recommended the establishment of a stroke unit in each acute hospital, with designated beds, a lead physician and multidisciplinary

\(^3\) Council on Stroke, INF, 2001 and National Audit of Stroke Care, INF, 2007
team. Clarity is required on the roles of major, regional and local acute hospitals in relation to emergency diagnosis, thrombolysis, assessment, treatment and rehabilitation in the acute hospital setting.

Team meetings in the acute hospital setting and liaison with community services can smooth the transition and ensure continuation of rehabilitation and other supports when the patient leaves hospital. This process can also be assisted by counselling and information for patients, carers and family members.

In 2006 the Irish Heart Foundation and the Department of Health and Children commissioned the National Audit of Stroke Care (NASC) in Ireland. NASC is modelled on a series of quantitative reviews undertaken by the National Audit Office in the United Kingdom. It includes surveys of hospital and community care, patients and carers. The findings will provide a benchmark against which future service developments can be measured.

The Cardiovascular Policy Group established by the Department of Health and Children will utilise the findings of NASC in Ireland. It will also be informed by the up to date information on the epidemiology of stroke from the North Dublin Population Stroke Study. The Review Group will review the literature and make recommendations on prevention, treatment, rehabilitation and surveillance of stroke in Ireland. The Population Health Directorate of the HSE has consulted with stakeholders, will contribute to the national review and will support service planning to implement the recommendations of the national review.

Hospital services in Ireland are poorly prepared for the major advances in stroke care and community services are under-resourced and ill-focused to the needs of Irish people with stroke. It is recommended that stroke services be developed nationally to provide acute thrombolysis via stroke units staffed by physicians with expertise in stroke. Patients with acute stroke will need rapid access to the stroke expert, brain imaging (CT and MRI) and neurovascular laboratory cerebral angiography, thrombolysis and arterial stenting. Stroke units will need to be set up strategically around the country to provide rapid easy access to care. Future stroke physicians will not only need diagnostic training but also interventional training in cerebral angiography, intra-arterial thrombolysis, and stenting. Programmes need to be developed for primary, secondary and tertiary prevention and Health Promotion.

6.4.8 Health Information Quality Authority (HIQA)
Clinical neuroscience is an ideal model to study the re-orientation of services for the benefit of patients. There is an opportunity to test a 5-10 year strategy to re-orientate clinical neuroscience by exploiting information and communication technology but emphasising people (patients, families, carers, staff) rather than technology. Such a strategy could be done in collaboration with HIQA using the National Health Information Strategy as a template. It could lead to an understanding of how technology can enhance healthcare delivery practices whilst promoting eHealth. The neurology service is anxious to work with HIQA in relation to any of its projects or research
undertakings which will involve neurology and particularly the area of health technology assessment and quality assurance.

6.5 Academic / Clinical Neuroscience
The main challenge to the academic development remains the limited time consultant neurologists have for academic development and maintenance of international research links. The new Academic Clinician posts funded by the HSE and Higher Education Authority (HEA) as part of the programme of actions identified to implement the key recommendations in the Fottrell and Buttimer reports are very welcome. The HSE, HEA and medical schools have a joint approach to appoint 35-40 Academic Clinician position over next 4 years. A proportion of these appointments should be in neuroscience and should include Chairs of Clinical Neuroscience in all major Universities. This initiative could help to develop academic clinical neuroscience nationally. New initiatives such as a Professor of Translation Medicine (between the RCSI and Beaumont Hospital) to integrate basic research, education and clinical practice are encouraged.

In 2007 the HSE received a further €3.3m to development further initiatives in the area of medical education and training. This funding will see the appointment of an additional 17 academic clinicians as well as subsidised training abroad in specialties for which there is a shortage in Ireland and will fund research scholarships to promote research in medicine. The planned interface between University and Hospital is best supported by research facilities, including clinical skills laboratories, beside the hospital.

The lack of good epidemiological data in clinical neuroscience is a major deficit. An All Ireland Neuro-Epidemiology Centre should be developed to prospectively study and gather neuro-epidemiological data and to record accurate incidence and prevalence of neurological disease in Ireland. Collection of DNA and other biological samples should also be done at the time (Biobanking for Neurological disease).

6.5.1 Neural engineering
Neural engineering is important to Ireland’s aspirations to develop a high impact research economy. Part of this aspiration is the establishment of world class research in neural prostheses, neuromodulation devices, therapeutic electrical stimulation, and neurodiagnostics. The rationale is to build on existing successful inter-institutional collaboration in the detection, real-time monitoring and diagnostic prediction of the human physiological state. Implantable biomedical devices are becoming increasingly prevalent. There are many potential applications where the use of implantable neurostimulation can resolve or ameliorate neural deficits. These applications include Parkinson’s disease, epilepsy, tremor, blindness, sleep apnoea, facial nerve palsy, urinary incontinence, deafness, intractable pain, as well as movement of paralysed limbs. Despite recent advances a number of critical research problems remain. The neural processing approaches and devices developed in this initiative aim to provide vital information.

\footnote{Neurotech Reports, San Francisco, CA 94107, USA}
information for the control of new implantable neuroprosthetic devices. Besides providing long term vital research and core skills for the design and control of implantable neuroprosthetics, another output from this programme will be the development of specific biomedical diagnostic applications of real medical and commercial benefit.

The vision for neural engineering in Ireland is:

- To enhance algorithmic methods for analysing physiological signals and reducing the influence of signal degradation and interference.
- To develop systems for neural prostheses, neuromodulation devices, therapeutic electrical stimulation, and neurodiagnostics.
- To build core research skills, algorithms and systems for modelling the human physiological state leading to skills necessary for implanted neuroprosthetic devices.
- To produce systems in conjunction with industrial collaborators using pilot active external and implanted devices and have these clinically assessed.
7. Paediatric Services

7.1 Introduction
Paediatric Neurology has been recognised as a specific sub-speciality internationally for over four decades. Paediatric Neurology is a tertiary speciality which must be geographically distributed so as to allow all children access to Paediatric Neurology care. Each service must provide a service to a population of sufficient size to maintain the clinical, practical and academic viability of the unit. Paediatric Neurology tertiary service should be readily available to secondary general paediatrician services where uncomplicated epilepsy, migraine, neurodisability are usually managed locally.

Ireland’s population of people under the age of 19 years is 1,154,706 (27.3% of the total population) i.e. Leinster – 619,151; Munster – 319,516; Connaught – 137,050; Ulster - 78,989 (Cavan, Monaghan, Donegal). The majority of children with chronic neurological disorders are followed to late adolescence because of long waiting time for transfer to adult service. At times, patients in the mid-twenties have been seen in the Children’s Hospitals. The number of Paediatric Neurologists is in Ireland is 4.5 WTE, The ratio of Paediatric Neurologists per capita is 1:942,200 (approx). The ratio per child population (under 19 years) is 1:256,000 (approx).

7.2 Size of the Problem
It has been estimated that children with neurological disorders account for up to one-third of patients referred to a General Hospital and that a quarter of all paediatric admissions to hospital would benefit from a Paediatric Neurology opinion. With advanced information technology, improved standards of living and education, international travel (increasing expectations) families expect to see a child Neurologist if a child has a significant neurological symptom. The impact on a family of a diagnosis of a chronic neurological disorder in a child is enormous and there is a recognised high rate of marital breakdown.

7.2.1 Range of Disorders
Paediatric Neurology is a broad based speciality involving the diagnosis and treatment of:

- **Epilepsy** – prevalence 1: 200; Intractable 1:1000 children
- **Acute Encephalopathy** – prevalence 25:1000; Coma, Status Epilepticus, Stroke, Encephalomyelitis etc.
- **Acute paralysis** – Transverse Myelitis, Guillain Barré Syndrome, Spinal Cord Lesions
- **Brain Tumours** – approximately 30 per year in Ireland
- **Unexplained significant developmental delay** prevalence 1:200
- **Malformations and Syndromes**
- **Unexplained cerebral palsy**
- **Atypical Autistic Spectrum Disorder**, e.g. regression due to epilepsy (Landau-Kleffner Syndrome) or Rett Syndrome etc.
• **Neuro-muscular disorders** – prevalence 1.5 per 1000, Duchenne Muscular Dystrophy 1:3500 males
• **Neonatal Neurological disorders** *(seizures etc)*
• **Ataxia**
• **Movement Disorders**
• **Neuro-degenerative disorders**
• **Complex headache Syndromes** - Intra-cranial hypertension etc.
• **Complications of other sub-specialities** – Oncology, Metabolic, Cardiology, Renal etc.
• **Neurological Manifestations of systemic disease** – Lupus etc.
• **Severe behavioural / psychiatric disorders** which may have neurological symptoms.

7.3 **Aims and Benefits of the Service**

7.3.1 **The aim of the service is to:**
• Provide a correct diagnosis
• Implement appropriate management
• Prevent recurrence of a condition in a child (e.g. stroke) or recurrence in another child within the family (Duchenne Muscular Dystrophy)
• Ensure a smooth **transition** of the adolescent with a chronic neurological disorder to the adult service.
• Provide ongoing education and training for all members of the Neurology Team
• Participate in audit
• Encourage and develop research
• Strengthen links with Adult Neurology where much can be learned from exposure to illnesses which are common in adults but rare in children

7.3.2 **The Benefits of an Integrated Paediatric Neurology Service are:**
• Appropriate investigation and early treatment of children with Neurological Disease with obvious implications for cost saving. In brief, these involve:
  - Investigation, diagnosis and treatment of potentially fatal disorders including coma, raised intracranial pressure etc.
  - Prevention of disability due to mismanagement e.g. early recognition of shunt obstruction preventing blindness or diagnosis of spinal cord tumour preventing permanent paralysis.
  - Prevention of recurrence of a disease in a child (stroke) or of a genetic disorder within a family (Duchenne Muscular Dystrophy etc.).
Provision of treatment without side effects; optimising the child’s development eg. appropriate drug treatment of epilepsy\textsuperscript{3,4}.

Avoiding unnecessary admission to hospital and tests which may not be indicated in certain disorders such as developmental deviations and functional disorders.

### 7.4 Composition of an Integrated Paediatric Neurology Service

An integrated Paediatric Neurology Service should have at a minimum:

- Consultant Paediatric Neurologist 1: 100,000 children
- Multi-disciplinary support team (1 per Consultant) including:
  - Administration
  - Clinical Nurse Specialist\textsuperscript{6,7}
  - Speech & Language Therapy
  - Occupational Therapy
  - Physiotherapist
  - Clinical Psychologist
  - Neuro-psychologist
  - Educational Psychologist
  - Dietician
  - Social Worker
  - Consultant Clinical Neurophysiologist, 1:2000 investigations\textsuperscript{5} (with 4 Neurophysiological Measurement Technicians and one secretary per Consultant)
  - NCHD – one SHO and one Registrar per Consultant to ensure exposure of general practice, general paediatric (and in the future) paediatric neurology trainees to Paediatric Neurology.

Specific support of:

- Neuro-surgery (Paediatric) on site
- Neuro-pathology
- Neuro-radiology (including interventional radiology embolisation etc)
- Neuro-Intensive Care

Access to general paediatrics and paediatric surgery \textbf{plus} the full range of Paediatric specialities including:

- Metabolic medicine
- Genetics
- Psychiatry
- Disability – physical (botox etc) and learning disability
- Orthopaedics
- Ophthalmology
- ENT/audiology
- Palliative care etc.
- Well developed neuro-disability service in the community.
- Adolescent friendly Transition service for example in epilepsy, advice regarding pregnancy, contraception, drug interactions and genetic counselling
- Managed clinical networks for common disorders e.g. epilepsy
- Education – e.g. in epilepsy, initial and ongoing education for all involved in childhood epilepsy is vital in order to develop and maintain expertise.
- For example, the British Paediatric Neurology Association (BPNA) has initiated a national educational programme of Paediatric Epilepsy Training (PET) at three levels. PET 1 (level 1) is aimed at helping professionals who anticipate clinical contact with children with suspected epileptic seizures. PET 2 (level 2) is for Paediatricians and specialist nurses who will provide clinical management and are developing further expertise in epilepsy. PET 3 (level 3) is for those with tertiary or quaternary level responsibilities. These standardised courses are being “rolled out” nationwide in the U.K. allowing participants to obtain appropriate and continuing training.
- Facility for research and Audit.

7.4.1 International data on Consultant Paediatric Neurology Manpower

(a) United Kingdom has a population of 59 million. The British Paediatric Neurology Association (BPNA) aims for a minimum of 120 Paediatric Neurologists in 2010, acknowledging that this number is less than required.

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of Paediatric Neurologists</th>
</tr>
</thead>
<tbody>
<tr>
<td>1995</td>
<td>37 (29 in England)</td>
</tr>
<tr>
<td>1998</td>
<td>55 (46 in England Wales, 7 in Scotland)</td>
</tr>
<tr>
<td>2002</td>
<td>63*</td>
</tr>
<tr>
<td>2005</td>
<td>81</td>
</tr>
<tr>
<td>2007</td>
<td>88</td>
</tr>
</tbody>
</table>

*Comhairle Na nOspideal Report (2003) stated that there were 34 Paediatric Neurologists in England, Wales & Northern Ireland. In Fact in 2002 there were 63 Paediatric Neurologists in the United Kingdom of whom 7 were in Scotland.

*The Report also states that figures for Scotland were n/a while the BPNA report 1998 (referred to in Comhairle Na nOspideal Report 2003) noted 7 WTE Consultant Paediatric Neurologists in Scotland.

* The Report also states that there is a whole time equivalent Consultant Paediatric Neurologist in Cork whereas in reality, this post is half time, the Consultant providing 1 in 2 on-take for general paediatrics at the Mercy Hospital.
Scotland has a population of 5 million with a geographic spread like Ireland, the population is relatively small compared to other areas of the United Kingdom but the geographic area covered is large. The current Consultant Paediatric Neurology staffing is:

- **Glasgow** – pop. 2.6 million (covers Islands & West of Scotland) – 4 Consultant Paediatric Neurologists – a fifth post about to be advertised.
- **Edinburgh** – pop. 1.2 million – 3.5 Consultant Paediatric Neurologists – (1/2 academic) - a new post about to be advertised.
- **Dundee and Aberdeen** – pop. 1.3 million – 3 Consultant Paediatric Neurologists

Yorkshire with a population of 3.2 million has 7 Consultant Paediatric Neurologists

(b) **Norway** has a population of 4.2 million and is geographic spread like Ireland. In 2006 there were 61 Consultant Paediatric Neurologists\(^\text{16}\).

(c) **Australia (2007)**\(^\text{17}\) : population 22 million, 45 Paediatric Neurologists

- **Sydney** - population 4,119,190; Childhood pop. 1,200,000 (approx.)
  - Paediatric Neurologists 12
  - Ratio 1 per 100,000 children

- **Melbourne** – pop. 3,592,591; Childhood pop. 1,000,000 (approx)
  - Ratio Paediatric Neurologist to child pop. 1:140,000
  - This figure (1: 140,000) excludes a significant number of Paediatric Neurologists in private practice bringing the ratio in Victoria to 1:115,000 children.

(d) **Canada – (2003)**\(^\text{18}\) – 1.1 Paediatric Neurologists per 100,000 children.

  - In 2001 the average age of Consultant Paediatric Neurologists was over 51\(^\text{20}\)

(e) **United States – (2003)**\(^\text{19}\)

  - The ratio in the North East is 1.46/100,000 children
  - The ratio in the West is 0.71/100,000 children

The Child Neurology Society \(^\text{19}\) has indicated that consultant Paediatric Neurology staffing level is 20% below the demand for the service. There is difficulty recruiting trainees to programmes because of perceived workload. Thus, most western countries aim for one Consultant Paediatric Neurologist for 100,000 children.

7.4.2 **RCPCH Charter (2004)**\(^\text{21}\)

- This Charter states that no Paediatrician should do more than a 1 in 5 on-call inclusive of cover for colleagues.
7.4.3 Paediatric Neurology in Ireland compared with UK and international centres.

- There are no higher specialist training posts in Paediatric Neurology in Ireland.
- In 2004 the BPNA assessed the Dublin Paediatric Neurology Service (The Children’s University Hospital, Temple Street, Our Lady’s Hospital for Sick Children plus the Neuro-disability Services) and approved the centres for training in Paediatric Neurology\textsuperscript{23}. The BPNA is keen for trainees to train in Dublin and Belfast but the Consultant commitment required to deanery and training duties\textsuperscript{24} is such that the Paediatric Neurologists are unable to join the BPNA training programme due to service workload and low level of Consultant Paediatric Neurology staffing.
- There are no middle grade posts such as clinical assistant etc.
- There are very patchy Community child health and neuro-disability services throughout the country.
- All clinical Paediatric Neurophysiology in Dublin is supervised and reported by the Paediatric Neurologist (unique in western Europe).
- There are no outreach clinics.
- There are no managed clinical networks. The recommendations\textsuperscript{3,4,10} for management of epilepsy in primary and secondary care are rarely implemented.
- There are no distance learning courses.
- There is little audit or research.
- There is no academic post in Paediatric Neurology (unique in Western Europe).
- There is no consultant presence on international speciality committees – one Paediatric Neurologist resigned from an editorial board and British and European committees because of work load.

7.4.4 Paediatric Neurology in Ireland compared with Adult Neurology in Ireland

- The paediatric neurology service is consultant delivered - there are no trainees or SpR posts in Paediatric Neurology. NCHD attachments are usually for 6 months on a GP or general Paediatric Training course. Consultant Paediatric Neurologists are the first port of call for neurological emergencies throughout the country transferred to the Childrens Hospitals (Temple Street and Crumlin in Dublin and UCH Cork).
- All clinical Paediatric Neurophysiology in Dublin is supervised and reported by the Paediatric Neurologist.
- There are no posts supported by drug companies e.g. epilepsy fellows, in part because of the ethical difficulty carrying out drug trials in children. These fellows contribute to service delivery in adult units. A

Using International standards of one Paediatric Neurologist per 100,000 children, Ireland should have twelve WTE Consultant Paediatric Neurologists.
lack of research fellows means that there is little or no research carried out in Paediatric Neurology in Ireland.

- There are no trained Consultant Paediatric Neurologists in Private Practice in Ireland.
- Investigations are often more complex in Paediatrics involving specialised metabolic and genetic studies many of which are sent to Laboratories abroad, increasing the workload.
- Many **Metabolic** disorders present with neurological symptoms (coma, seizures, delay, ataxia, hypotonia, regression etc.) and are diagnosed by Paediatric Neurologists. These disorders are rare in adults and there are few adult neurologist with expertise in neuro-metabolic disorders resulting in some patients staying with the paediatric service until the mid twenties. In contrast, conditions such as MS and Parkinsonism are rare in children.
- Consultations in Paediatrics take much longer than in adult medicine. In addition, a young couple with a child with a neurological problem will often have two sets of grandparents visit the clinic i.e. 6 adults with one child.
- The increase in birth rate has increased workload.
- The increase in non-nationals residing in Ireland, many of whom do not speak English and require Interpreters to attend clinic increases the duration of clinic consultation by at least four-fold. In addition conditions rarely seen in Ireland prior to mid 90’s such as sickle cell disease (causing stroke) some neurodegenerative disorders etc are being seen with significant workload implications.
- By comparison with the adult Neurology services, the Neuro-disability services, respite etc. are more developed in Paediatrics.

### 7.5 Current Clinical Paediatric Neurology Service in Ireland.

#### A. DUBLIN

The Dublin service serves a population under 19 years of 835,990 (Leinster, Connaught, Donegal, Cavan and Monaghan), in addition to some of Munster because of the lack of development of paediatric Neurology service there. Data on the volume and delivery of service in Dublin in 2004 is summarised in the Report of the BPNA visiting committee\textsuperscript{23}. There are four WTE Consultant Paediatric Neurologists in Dublin.

In addition to commitments at the two major children’s hospitals in Dublin, there is also a **formal** commitment to the National Children’s Hospital, Tallaght, the Rotunda Hospital and Central Remedial Clinic, Clontarf. These commitments, while necessary account for a significant commitment out of the main base hospital on the part of the three Paediatric Neurologists involved. All 4 Consultants provide an on call service to the 3 maternity hospitals in Dublin.

- The service is **consultant delivered** with **clinical nurse specialist** support.
- A 24 hour on-call 1 in 2 rota with rare cross-cover between the Children’s University Hospital, Temple Street and Our Lady’s Hospital for Sick Children, Crumlin because of the volume of work at each hospital.
• A 24 hour telephone advisory service to Paediatricians all over Ireland on a 1:2 rota.
• In-patient management and consultation including neuro-intensive care. The numbers are not reflected in the hospital HIPE data as these patients are usually admitted under other Consultants before transfer to the Paediatric Neurologists. Epilepsy, coma, investigation of delay, weakness or regression account for most hospital admissions.
• Out-patients – up to 35 patients per clinic, which is between 3 and 8 times the number seen at a Paediatric Neurology Clinic in North America (average 4-5 patients per session).
• Waiting times vary up to twelve months for some Consultant clinics.
• The Clinical Nurse Specialist participates in in-patient and outpatient management providing daytime telephone advice to families of children with chronic neurological disorders and some nurse led clinics (e.g. Epilepsy)

**Major Deficits in Dublin**

1. Multi-disciplinary support is disjointed and does not approach the required level of an integrated service. For example:

**Our Lady’s Hospital for Sick Children, Crumlin** –

• Therapist, (Speech & Language, Physiotherapist) and clinical psychology provide a service from a central pool rather than having a formal commitment to the Paediatric Neurology team.
• There is no Dietician (Ketogenic diet)
• There is inadequate NCHD support for volume of inpatient consultations.

**The Childrens University Hospital Temple Street** –

• Therapists are shared with other specialities (neonates etc.).
• There is a ½ time neuro-psychologist.
• Inadequate neuro-physiology measurement technical support for number of investigations performed.
• Part time 3-session dietician (inadequate for Ketogenic diet and feeding issues)
• The physical conditions are appalling for families and staff and there are no designated Neurology beds.

2. **Community services** (therapists, nursing etc.) are very disjointed and often not available in some counties resulting in delay in discharge of patients from hospital. Paediatric Occupational Therapy and Speech & Language Therapy have extremely long waiting lists with the result that there are unacceptable delays for treatment of sensory, coordination and language disorders which in turn lead to behavioural, school and psychosocial problems. Many of these children are inappropriately referred to hospital neurology services only to be told that the child does not qualify for a hospital based neurology programme.

3. There is long delay for patients transferring to adult service and there is no transition service.
4. There are patchy respite services for families in the community especially for children over 5 years.
5. There are no trainees or specialist Registrars or middle grades in Paediatric Neurology.

6. There is little time for:
   - Formation of **managed clinical networks, outreach clinics etc**
   - **Education** of NCHDs, AHP, Nurses, Consultant Paediatricians etc. The Neurology Teams from Dublin (Temple Street/Crumlin) and Cork meet 4-6 times / year for case presentations aimed at general Paediatric trainees. Occasionally one of the Neurologists from Belfast attends. These meetings are informal and not part of a statutory training course. The Paediatric Neurologists have formal meetings with colleagues from Belfast at the Irish Muscle Meeting and British Paediatric Neurology Association both held yearly.
   - There no training programs in paediatric neurology for Clinical Nurse Specialists
   - Audit and research are insufficient.

7. There is no on site **neurosurgery** (as exists in Cork). For example, patients referred to one of the Paediatric Neurology services in Dublin from regional units are investigated and then have to be transferred to the Neurosurgical unit in Beaumont. The most frequent reason is for head injury, a major cause of handicap and disability in children, some of which could be attributable to avoidable factors. There is need for an integrated National approach to management of head injury.

   Other disabling disorders often associated with a delay in management are shunt obstruction and acute paralysis due to spinal cord lesions requiring immediate decompression. The lack of on-site neurosurgery with tertiary Paediatric Neurology means that there may be a delay in diagnosis in management of these patients. This issue is being addressed by the HSE at present.

8. **Neonatal Neurology**

   There is need for a structured approach to evaluation (clinical and EEG) in the newborn period and to long-term follow up across the 3 maternity hospitals.

B. CORK

The Cork service has a population of 319,516 under 19 years. There is 0.5 WTE Consultant Paediatric Neurologist across 2 sites. While there is a consultant **delivered** clinical Paediatric Neurology Service it is very limited.

**Major deficiencies in Cork**

These are similar to those in Dublin. In addition:

- On-take 1:2 for general Paediatrics- not neurology– this is unacceptable
- Limited on-call for acute Neurology or Neonatal Neurology
• Delay in inpatient consultations (over 24 hours)
• Long waiting list for non-urgent referrals
• No cover when on leave, patients known to the service are covered by a Paediatric Neurologist in Dublin who will not be familiar with the patient and other new referrals to Cork are seen in Dublin.
• Significant commitment to Neurodisability (Spina Bifida, Enable Ireland, no community paediatric cover for patients outside of Cork city or for the autism services in Cork) which in Dublin and abroad is provided by Paediatricians with specific training in Neurodisability
• Lack of support services with no psychology, neuropsychology, social worker, dietitian
• Clinical nurse specialist (only 2 days per week) funding due to expire March 2008.

7.6 Clinical Paediatric Neurophysiology

DUBLIN

EEG, EMG, Evoked Potentials.
(a) In children, in contrast to adults, the major clinical work-load in clinical Paediatric Neurophysiology is EEG including:
• Routine EEG
• Sleep Deprived EEG
• EEG with sedation (difficult patients)
• Ambulatory EEG (electrodes applied and recording continues at home)
• Video EEG – in the Department for several hours
• Video EEG – Telemetry – performed over days or even weeks, which is extremely demanding on Consultant reporting time
• Pre-operative invasive recordings (where grids of electrodes are placed on the surface of the brain and monitoring continued for days)
• Intra-operative monitoring during epilepsy surgery.

Paediatric EEG is quite different to adult EEG and many normal phenomenae seen on a child’s EEG would be considered very abnormal in an adult. For this reason detailed knowledge of EEG changes with age, (birth to adulthood), of epilepsy and its management is vital to interpretation of the Paediatric EEG.

(b) Electromyography (EMG) Nerve Conduction Studies (NCV)
Visual Evoked Responses (VER) Electro-retinogram (ERG)
Sensory Evoked Potentials (SEPs)
Brain Stem Auditory Evoked Responses (BAER)
Intra-operative Spinal Cord Monitoring
The above specialised visual, auditory and motor tests account for a small proportion of the overall clinical Neurophysiological tests in children compared with adults. The Paediatric Neurologists also report on some Paediatric EEGs performed in Limerick and Galway, which are sent on CD. The volume of recordings made between the two units in Dublin more than qualify for two whole time equivalent Consultant Clinical Neurophysiologists with a special interest in paediatrics.

(c) Neonatal Neurophysiology at the Maternity Hospitals

Neonatal Continuous EEG monitoring
Amplitude Integrated EEG, Cerebral Function Analysing Monitor and Standard EEG have been used in many neonatal Intensive Care Units worldwide. The value of continuous EEG monitoring is:

- Early detection and treatment of seizures not visible on clinical observation.
- Withdrawal of care in severely brain damaged babies.
- Long term prognosis in neonatal neurological disorders.
- Early introduction of potentially helpful treatments including hypothermia and certain specific drugs.

Continuous EEG monitoring is not available on a service level at any of the children's hospitals in Dublin. There is an urgent need for an integrated approach to service such as part-time Neuro-physiology measurement technician (at the Children’s Hospitals) to provide this service as needed at each of the Maternity Hospitals in Dublin.

(d) Neonatal hearing screening
This is not widely available, the implications of early detection of hearing loss for cognitive, language, emotional and behaviour development are obvious. There are plans to develop a neonatal Hearing Screening Programme nationally.

7.6.2 CORK

(a) EEG, EMG, Evoked Potentials
EEG recordings are reported by the Consultant Clinical Neurophysiologist with a major commitment to adult Neurology. There is an urgent need for at least a half time Neurophysiologist with Paediatric experience and neurophysiology measurement technician in a suitable child friendly environment and a dedicated paediatric video telemetry bed.

(b) Neonatal Neurophysiology at the Maternity Hospital
This service is very well developed in Cork through the Cork. Maternity Services with well trained senior research technical staff of International renown. It requires part-time Neuro-physiology measurement technician to provide the clinical service.
**Purpose**
- Improve Health
- Reduce inequalities
- Be sustainable

**Values**
- Family friendly
- Pathway based
- Continually improving

**Pathway Components**
- Prevention
- Identification
- Assessment
- Management
- Long Term Support

**Practice**
- Process (evidence)
- People (competence)
- Place (environment)
- Support Services

**Needs Driven**

**Outcome Orientated**

**Figure 7.1: Managed Clinical Network**

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11Reference to Figure 7.1 for Managed Clinical Network.
7.7 Proposed Model of Care: Managed Clinical Network in Paediatric Neurology

It is proposed that paediatric neurology services be delivered via a **national network model** that integrates all parts of the service. The **tertiary** hospital based Paediatric Neurology service should be an integral part of the **managed clinical network** for children with common neurological disorders including epilepsy\(^{10}\). The recent RCPCH document “Modelling the Future”\(^{11}\) identified two essential themes that are the core foundations for the development of all children’s services. These are clarity of:

- **Purpose** (to improve health, reduce inequalities and use resources wisely and be sustainable)

- **Values** (family friendly, **pathway** based and continually improving).

  - **Pathway** based: means basing a service around a patient journey and taking a whole system approach to the commissioning, delivery and regulation of services. Groups of pathways should be delivered by teams working within a **managed clinical network** *(figure 7.1)*.

  - **Epilepsy**, with a prevalence of 0.5% is the commonest chronic neurological condition requiring tertiary paediatric neurology input. A large secondary school may have six children with epilepsy. **In Ireland at least 7,500 children under the age of 19 years** suffer from epilepsy.

Management of epilepsy in children may be difficult because of:

- Diagnostic difficulties (other disorders masquerading as epilepsy).
- Many epilepsies are age related syndromes requiring very specialised treatment
- Investigations may be normal early on
- Tests for surgical evaluation are often invasive
- Children require extensive multi-disciplinary (neuro-psychology, psychology, school support etc.) input throughout their childhood years with epilepsy.

**Managed clinical networks** have been developed elsewhere for epilepsy. These are very effective in bringing together key professionals, establishing well defined integrated care pathways and clinical guidelines for each step for the pathway. The resources required **locally** include:

- Primary care Physician
- Regional Paediatrician with responsibility for epilepsy *(Figure 7.2)*
- Clinical Nurse Specialist in the Region with expertise and responsibility for epilepsy *(Figure 7.2)*
- Access to Psychology, Speech & Language Therapy, Occupational Therapy locally
- Access to EEG and Neuroimaging – network should have guidelines\(^{10}\) for requesting these studies – NICE guidelines\(^{3}\) regarding waiting times achievable if children prioritised for “fast track” EEG etc.
• Information for families on investigations, epilepsy, syndrome diagnosis, treatment including surgery
• Neuropsychology and child psychology as needed

The stages in the pathway for a child with a seizure and possible epilepsy are outlined in Figure 7.3.

The potential impact of a managed clinical network for children with suspected epilepsy is immense:

• More direct access to specialist advice, diagnosis and treatment.
• Lower rate of misdiagnosis
• Fewer unwanted side affects from drugs
• Increased cure rate through selection for epilepsy surgery
• Earlier intervention by educational and social services
• Removal of wrong diagnosis of epilepsy from some children.

30% of children with epilepsy will have intractable epilepsy and must have good liaison between secondary, tertiary and primary care services.

<table>
<thead>
<tr>
<th>The Role of District Based Nurses</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Co-ordinate District Epilepsy working group incl. education, learning disability, social services, school nurses, mental health services, parents and children.</td>
</tr>
<tr>
<td>2. Counselling</td>
</tr>
<tr>
<td>4. Family support / Child guidance liaison.</td>
</tr>
<tr>
<td>5. GP liaison</td>
</tr>
</tbody>
</table>

Role of Paediatrician with special responsibility for epilepsy.

1. Maintain standards of diagnosis and treatment and appropriate referral patterns along the clinical pathway.
2. Liaison with district based colleagues over selection of children requiring referral to tertiary based services.
3. Attend specialist epilepsy outreach clinics
4. Regular attendance at regionally based special interest groups in epilepsy.
5. Supervision of care of children with intractable epilepsy.
6. To audit and improve local service delivery.

Figure 7.2: Roles of District Based Nurse and Paediatrician with responsibility for epilepsy in Managed Clinical Network.
Figure 7.3: Care pathway for a child with “seizure”.
7.8 Recommendations for Developing Paediatric Neurology Services

1. An integrated nationwide equitable Paediatric Neurology Service with centralised expertise leading to centres of excellence and peer review and avoiding isolation of specialists should have one Consultant Paediatric Neurologist per 100,000 children plus all the administrative, nursing and AHP support as outlined above.

The service should be delivered by 2 Managed Clinical Networks (Dublin and Cork- Map 1) supported by the National Neurology Steering Group. Each paediatric centre should have one local paediatrician and one community nurse with responsibility for epilepsy, as outlined in figure 7.3.

There should be:

1. A single tertiary-quaternary Paediatric hospital in Dublin.
   This centre would have 8-9 Consultant Paediatric Neurologists ( including an academic post ), all with general training (particularly epilepsy) but with sub-specialisation such as:
   - Epilepsy (including pre-surgical evaluation)
   - Neuromuscular
   - Movement Disorders
   - Cerebral Vascular disease
   - Neurometabolic disease
   - Neuroimmunology
   - Neonatal Neurology
   - Academic: any of the above areas of sub-specialisation

This national Paediatric Neurology service (total pop. under 19 years 835,990) would provide a service to Leinster, Connaught, and Ulster (ie Donegal, Cavan, Monaghan) and a quaternary service for Munster. The service would be provided through managed clinical networks, with distance learning programmes, Paediatric Epilepsy Training (PET) courses etc. in addition to outreach clinics (eg. Galway, Sligo, Donegal).

2. A second integrated service at Cork, with a minimum of 3 WTE Consultants of whom 2 would have expertise in epilepsy and neuro-muscular disorders. This service would link in with the units in Munster (Tralee, Limerick, Clonmel, Waterford) through the managed clinical networks, outreach clinics etc.

3. The possibility of establishing a third fully integrated Paediatric Neurology service (as outlined in section 1.6) to the West, (Connaught + Donegal pop. Under 19 years 181,326) has been considered.
This would require a minimum of 3 Consultant Paediatric Neurologists (to cover on call etc.) which would give a ratio of 1 Consultant per 60,000 children under 19 years approximately. The population served would be small and it could be argued that the volume of patients would lead to difficulty maintaining skills and expertise and a degree of isolation. In addition, families from Donegal may find Dublin more accessible than Galway. It is proposed that, at least in the short term, service be provided from Dublin through outreach clinics, managed clinical networks etc. as discussed in Section 1.7 working in parallel with the telelink services being developed in EEG and Neuroimaging. For example a network in Galway could serve Galway, Castlebar and Portiuncula, and so on.

An Outreach clinic would allow ease of access for the family, be informative and educational for the local Consultant Paediatrician and multidisciplinary team and allow integrated care in the community.

4. Clinical Paediatric Neurophysiology
   - Comments on Neurophysiology in The Comhairle na nOspideal Report (2003) are no longer relevant, in the light of the planned development of a single tertiary Paediatric Hospital in Dublin.

   - There is an urgent need for Consultant Clinical Neurophysiology input at both children’s hospitals in Dublin. These 2 WTE posts should be cross appointed with each having a major commitment at one of the childrens hospitals, ultimately working together at the new single Paediatric tertiary hospital.

   - A clinical neurophysiologist with experience in Paediatric EEG should be appointed to the service in Cork.

5. Specific areas for Improvement

   - The staffing (AHP etc.) in the current tertiary service should be increased to appropriate levels as outlined above.

   - Neuro-disability – particularly availability of assessment and therapy in the Community.

   - Neurorehabilitation - more beds needed with just 6 Paediatric beds available in the National Rehabilitation Unit.

   - Neonatal Neurology - availability of continuous EEG Monitoring and standardised screening and intervention by Occupational Therapy, Physiotherapy, Speech & Language for at risk infants (premature, asphyxiated babies etc.).

   - Transition to Adult Services – must be flexible and patient-centred.

   - Neurosurgery being addressed by the HSE.
6. New Developments

Following expansion in current Consultant Paediatric Neurology and Clinical Neurophysiology Manpower the following should be addressed:

- **Managed clinical networks** (using web based protocols, telelink diagnostics, video conferences/consultations) should be applied to Paediatric Neurology. The local resources as outlined above should be provided.

- **Outreach** clinics (as part of the managed clinical network) should be established in the short term serving the West and Northwest and the need for a fully integrated local Paediatric Neurology service be reviewed at least every 2 years.

- **A post-graduate training** programme in Paediatric Neurology should be developed in conjunction with the Programme in the UK possibly linked to Belfast.

- Paediatric Epilepsy Training (PET) courses (1-3) should be established nationwide i.e. incorporating Belfast.

- Distance learning programmes should be established.

- **An academic chair** in Paediatric Neurology should be established to encourage research. This position could be part time clinical (participating in on-call) and part-time academic to allow research.

- Review of achievements after five years following next Census.
Map 1: Proposal for delivery of Paediatric Neurology service through Managed Clinical Networks.

Yellow: Referrals to neurology tertiary centre.
Pink: Possible outreach clinics from neurology tertiary centre with acute referrals to same centre.
Blue: Referral to “quaternary” neurology e.g. epilepsy surgery, complex neurometabolic etc.
REFERENCES

1. The British Paediatric Neurology Association (BPNA)
   A Guide for Purchasers of Tertiary Services for Children with Neurological Problems
   January 1998

   “The District General Hospital has a resource for the provision of Neurological Services”
   Chapter 3 Paediatric Neurological Services; PP 12 - 15

3. Royal College of Physicians and Child Health (RCPCH)
   Guideline Appraisal and Summary
   (a) National Institute for Clinical Excellence (NICE)
   Epilepsy
   September 2004
   (b) Scottish Intercollegiate Guidelines Network (SIGN)
   Epilepsy
   March 2005

4. Dunkley C., Cross J. H.
   NICE Guidelines and the Epilepsies; how should practice change?.
   Arch. Dis. Child 2006; 91: 525-528

   Report of the Association of British Clinical Neurophysiologists

6. Hosking P.G.
   Specialist Nurse Role in the treatment of refractory epilepsy
   Seizure 2004; 13: 303-307

7. Royal College of Nursing
   Competencies: A competency framework and guidance for developing paediatric epilepsy and nurse
   specialist services 2005

8. Get Connected
   Developing an Adolescent Friendly health service
   National Conjoint Child Health Committee January 2000

9. Bridging the Gaps: Health Care for Adolescents
   RCPCH June 2003

10. The British Paediatric Neurology Association (BPNA)
    Clinical Network Document “A National Approach to Epilepsy
    Management in Children and Adolescents”
    2003, Editor – Dr. Richard Newton

11. Royal College of Paediatrics and Child Health
    Modelling the Future
    A consultation paper on the future of children’s health services
    September 2007

12. The British Paediatric Neurology Association (BPNA)
    A guide for the Purchaser of Services for Children with Neurological `problems.
    February 1995
13. The British Paediatric Neurology Association (BPNA)
   Paediatric Neurology Manpower Report 2005

14. Personal Communication BPNA Secretariat
   Manpower 2007

15. Comhairle Na nOspideal
   April 2003.

16. Nordic Medical Associations
   Physicians in the Nordic Countries 2006

17. Personal Communication
   Director Paediatric Neurology Service
   Royal Childrens Hospital Melbourne 2007

18. Rowen G. M. Meaney B.F.
   Paediatric Neurology Service in Canada: Demand Versus Supply
   J. Child Neurol. 2003; 18:180-184

19. Child Neurology Society (USA)
   Child Neurology Work Force Study: Executive Summary
   September 2003

20. Keane D.L. Humphreys P.
    Inventory of Paediatric Neurology "Manpower" in Canada

21. A Charter for Paediatricians Royal College of Paediatrics in Child Health June 2004

22. Central Statistics Office Ireland 2006

23. Royal College of Paediatrics and Child Health (RCPCH).
    Neurology CSAC (Chairman – Dr Richard Newton)
    An Independent Review of the Potential for the Establishment of a Post-Graduate Speciality Training
    Scheme in Paediatric Neurology between Our Lady’s Hospital for Sick Children, Crumlin and the
    Children’s University Hospital, Temple Street Dublin .

24. The British Paediatric Neurology Association (BPNA) 2002
    Recommendations for Higher Specialist Training Programmes in Paediatric Neurology. Induction for
    Deanery Advisors.

25. Sharples P.M. et al
    Avoidable Factors contributing to death of children with head injury.
    BMJ 1990; 300: 87-91

26. Rennie J., Boylan G.
    Treatment of Neonatal Seizures
    Arch. Dis. Child Fetal Neonatal Ed.
    2007; 92: F148 – F150

27. Wootton R.
28. Blanchet K.D
   Innovative Programs in Telemedicine
   Telemed. J. and e-health
   2006; 12: 7-14

29. Editorial
   Child Neurologists Wait for Better Evidence
   The Lancet 2007; 6:663
8. Development of Neurology Services

A New Model of Care for Neurology Services in Ireland – The Managed Clinical Network

Key Points

- A Clinical Network Model that enables a population based provision of neurology services is required. This represents a fundamental change from the fragmented, ad hoc, institution focused way in which neurology resources have been allocated to date. The Network Model facilitates integration of services so that they become more responsive to the needs of patients and their families.

- Reflecting the low base of existing neurology resources, implementation of the new model requires a number of developments to happen at the same time. Key hospital based services must be placed on a sustainable footing while new service connections and pathways are put in place with Primary Health Care, Community Health services and the voluntary sector.

- The Network Model creates new roles and responsibilities at local, regional and national level. The structures and mechanisms to deliver these require the active participation and involvement of all stakeholders.

8.1 Introduction and Background

The provision of first class care for people with neurological conditions requires specialist, multidisciplinary, integrated and quality assured care that meet patient needs in a timely manner and on a population basis. Based on the epidemiology of neurological conditions, the feedback from the consultation exercise, information on waiting lists and waiting times and the experience of neurology patients and their families, it is clear that current neurology services in Ireland are not meeting the level of need in the country.

In light of these considerations, and having undertaken a review of experience and good practice both within Ireland and elsewhere, the Steering Group has accepted the Subgroup’s recommendation that a managed Clinical Network Model offers the best scope for the future configuration of neurology services in Ireland. Such a model offers the greatest opportunity to ensure that neurology services are provided in an integrated manner across traditional boundaries to provide efficient, equitable and high quality services. It will involve taking existing scarce resources, and enhancing, redeploying and “re-connecting” them so as to best meet population needs.

The managed Clinical Network concept is based on collaboration between service providers in different locations, centres or parts of the health system to achieve identified improvements in care for patients with certain conditions / disease types. It recognises that the full spectrum of service provision can only be delivered by agreeing how the different parts of the system are going to contribute and work together. Health care professionals working either in
primary, secondary and / or tertiary care agree what type of service they can each best provide for a certain category of patients, based on available evidence, resources and capacity. Each part of the network supports other parts of the network so that patients receive better care and achieve better outcomes.

The Scottish Executive Health Department gives the following definition:
“Managed Clinical Networks are defined as linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a co-ordinated manner, unconstrained by existing professional and health board boundaries, to ensure the equitable provision of high quality, clinically effective services throughout…the country”. (Scottish Executive Health Department. Introduction of Managed Clinical Networks within the NHS in Scotland. NHS MEL (1999) 10).

The Clinical Network Model delivers all the features of a high quality neurology service which:

- Is modern, flexible, responsive and person centred, providing care as close as possible to the patient.
- Ensures timely, appropriate access to multidisciplinary care. (In this model, care can be provided by GPs and health professionals working in Primary Care Teams and / or Primary and Social Care Networks, Voluntary Agencies and / or Hospital based Neurology Teams).
- Is equitable, integrating national, regional and local neurology services and promoting appropriate regional self-sufficiency.
- Ensures clinical excellence and good governance. It promotes the use of new technology to improve patient care. Evidence based practice, quality, prompt access and equity are to the fore and are measured.
- Investment in training, research and development are a core part of the service.
- Ongoing support for patients and their carers living with long term disease or disability is provided.

The core elements of the Model include:

- **Population based networking of available resources, with regional decision making and governance, within a National framework.** The deployment of existing neurology resources will be largely a matter for agreement and management at regional level, based on national HSE plans and frameworks. This will ensure that all stakeholders (e.g. PCCC, GPs, Voluntary agencies, Hospital Neurology Teams, Hospital Network Managers etc) can participate in decision making about how neurology services are developed and managed for the people in their area. Referral guidelines and the development of care pathways across traditional service / institutional boundaries will flow from this.

- **Role clarity at every level**: Each element of the network understands its role in service provision and the level of support it is expected to provide to (and receive from) other elements. There is active management of the connections in the network.
• **Grouping and reconfiguring of resources**: The resources of the network are grouped and configured across traditional boundaries, so that the best possible service is provided to patients by the Network. This should enable most services to be provided as close to the patient’s community as possible, while the less frequently needed, highly specialised services are focused at national level. This places the Neurology Clinical Network model firmly in the context of the HSE’s Transformation Programme.

• **Focus on local care**: In this model, priority is given to enhancing integration with other services especially Primary Care, PCCC and smaller hospitals. MOST care is provided as close to the patient’s community as possible, with PCCC and local hospital services empowered to play key roles.

Although the workings of the model are described below in relation to medical neurology, it could logically be applied as the model for all neuroscience services. It also supports the development of specific disease based models within the Neurosciences.

### 8.2 Proposed workings of a Clinical Neurology Network in Ireland:

For Adult neurology it is proposed that four Clinical Neurology Networks be established (co-terminus with the four HSE administrative areas). The proposed paediatric structure is given in chapter 7. Each Network would be led by a neurologist – The Area Clinical Neurology Director of the Network. In addition a National Neurology Steering Group will be established to provide leadership across the service, develop standards, guidelines, performance criteria and promote quality care, innovation and research.

Services for the neurology patient are envisaged at 3 levels (see also Diagram 8.1):

1. **Local level** – this includes Primary Care and the nearest Acute General Hospital

2. **Regional Neurology Service** – the regional centres with a neurology service collaborate to function as a Regional Neurology Service, operating as a Clinical Network in each of the four HSE’s administrative areas (Table 8.1). These regional centres support Acute General Hospitals and Primary Care professionals in the management of neurological patients, in a planned and co-ordinated way. They are supported by the National Neuroscience Centres.

3. **National Neuroscience Centres** – the two neuroscience centres, as outlined in the Comhairle Report (2003), are Beaumont Hospital and Cork University Hospital. While the National Neuroscience Centres are part of the appropriate geographic Clinical Network and provide tertiary services, they also have a national leadership role as part of the National Neurology Steering Group (see Table 8.1).
Table 8.1 Existing Hospital Neurology Service Locations, by HSE Administrative Area

<table>
<thead>
<tr>
<th>HSE Administrative Area</th>
<th>Existing / Proposed* Neurology Services</th>
</tr>
</thead>
</table>
| Dublin – North East     | Beaumont Hospital (National Neuroscience Centre)  
Mater Hospital          |                                        |
|                         | North East                               |
|                         | The Children’s Hospital, Temple Street   |
| Dublin – Mid Leinster   | St. James’ Hospital                      |
|                         | AMNCH Tallaght                           |
|                         | St. Vincent’s Hospital                   |
|                         | Our Lady’s Hospital, Crumlin             |
| South                   | CUH (National Neuroscience Centre)       |
|                         | Mercy University Hospital (shared Out of Hours rota with CUH) |
|                         | Waterford Regional Hospital*             |
| West                    | UCHG                                    |
|                         | Mid Western Regional Hospital*           |
|                         | Sligo General Hospital*                  |

* indicates new service that is being established as per initial funding allocation in 2006 and 2007

Figure 8.1: Diagrammatic representation of how persons with neurological conditions in the community could access care within a National Clinical Network:
1a: Person with suspected neurological condition presenting to primary care professionals

Where the person with a neurological condition presents to a Primary Health Care Professional (GP, PHN and Allied Health Professionals etc.) an initial clinical assessment takes place, with the following possible outcomes:

- Further neurological assessment is conducted at primary care level, either by Primary Care Team members or staff from the Primary and Social Care Network, using protocols agreed with the Regional Neurology Network / National Neurology Steering Group. This may involve direct access to specific diagnostic tests / imaging, either at the nearest Acute General Hospital, at a Regional Hospital or via telemedicine

  OR

- Direct referral to the appropriate Regional Neurology Network centre or National Neuroscience Centre for further assessment and treatment

  OR

- Immediate transfer to nearest appropriate ED if resuscitation / stabilisation required.

1b: Person with suspected neurological condition presents to Acute General Hospital ED

Where the person with a neurological condition presents to the Emergency Department of an Acute General Hospital, initial clinical assessment takes place, with the following possible outcomes:

- Immediate resuscitation / stabilisation if required

  OR

- Further neurological assessment is conducted, using protocols agreed with the Regional Neurology Network and national Neurology Steering Group. This may involve direct access to specific diagnostic tests / imaging, either on-site, at a Regional Hospital or via telemedicine

  OR

- Referral / transfer to the appropriate Regional Neurology Network Centre or National Neuroscience Centre for further assessment and treatment.

Once a neurological condition is diagnosed, the person may either:

- Continue to be managed appropriately at local level, either in primary care or in the Acute General Hospital, according to protocols agreed with the Regional Neurology Network or National Neurology Steering Group

  OR

- Commence initial treatment at the appropriate Regional Neurology Network centre or National Neuroscience Centre and have follow up treatment at primary care level or in the Acute General Hospital

  OR
• Commence treatment at a Regional Neurology Network centre or the National Neuroscience Centre, with follow up treatment also provided by this Service

OR

• Commence treatment at the appropriate Regional Neurology Network centre or National Neuroscience Centre, with follow up treatment shared between this Service and either Primary Care or the Acute General Hospital.

People with an established diagnosis of neurological disease often live with their condition for many years. Most of their health needs will be met within their community, in partnership with their GP, Primary Care Team and specialist input from staff of the Primary and Social Care Network. Hospital based neurology teams will work with Primary Care Teams and voluntary providers to ensure that the right care is delivered as close to where patients live as possible. This may involve outreach clinics or joint assessments with primary care professionals, agreement of shared care protocols and care pathways, the use of telemedicine and provision of advice by phone or email, reviews at the neurology centre when necessary, support with advocacy, life skills and employment and so on. Primary Care Teams will also ensure that Key Workers are available to co-ordinate care for those with complex needs. (See Section 8.4 for further details on the new model of Primary Care).

2. Person referred to Regional Neurology Network Centre from either Primary Care or Acute General Hospital

It is envisaged that:

• Each Regional Neurology Network will provide a comprehensive range of general neurology services, staffed by a full multidisciplinary team

• Each Regional Neurology Network may develop subspecialties, as part of an agreed programme of development in the region and nationally. Based on the epidemiological analysis which has been conducted (Chapter 2), the most appropriate further development of subspecialties in each region will need to be determined. This must reflect local / national priorities and ensure optimal utilisation and maintenance of existing clinical skills and expertise (including Continuing Professional Development (CPD) requirements). The following subspecialties and / or dedicated services may need to be developed within each Regional Neurology Network:
  o Epilepsy
  o Headache
  o Movement Disorder
  o Cognitive decline

The National Strategy for Stroke services will make recommendations about Stroke Service developments.
Each Regional Neurology Network will:

- Have an appropriate Neurophysiology service (i.e. to support both the general and subspecialty work undertaken in the region) (See Section 8.2.1 below).
- Develop particular links (up to and including the provision of outreach clinics and in-patient consults) with named Acute General Hospitals in the region.
- Develop particular links and protocols with related specialties e.g. Geriatric medicine, Psychiatry, Pain etc
- Develop and agree clinical protocols / guidelines with Acute General Hospitals and Primary Care professionals (including Primary Care Teams) in the region. Pathways may also be agreed with other Regional Networks as necessary (for example, to reduce waiting times or to access a particular subspecialty).
- Each discipline within the Regional Neurology Network team will put protocols / persons in place to ensure education and training for primary care staff (covering both general and patient specific topics).
- All members of the Regional Network will participate in agreed monitoring and audit activities to ensure that service delivery and outcomes are continually improving.
- Each Regional Neurology Network will, in partnership with Acute General Hospitals and Primary Care services in the region, put in place joint specialist appointments in key disciplines such as nursing, physiotherapy, occupational therapy and speech and language therapy. The new model of Primary Care suggests that such specialist appointments would be to the Primary and Social Care (P&SC) Network. The exact mechanism for such appointments is yet to be agreed but one suggestion is that post holders would provide expert clinical assessment and advice on management as follows:

<table>
<thead>
<tr>
<th>P&amp;SC Network commitments:</th>
<th>Hospital Commitments:</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Clinical assessment / development of management programme for complex patients (referral by protocol only)</td>
<td>- Clinical assessment / development of management programme for complex inpatients (referral by protocol only). Ongoing treatment will be conducted by the relevant staff at ward level</td>
</tr>
<tr>
<td>- Conducts treatment programmes in clearly defined circumstances – ongoing treatment will be conducted by the relevant staff at PCT level</td>
<td>- Training / education for Hospital based colleagues</td>
</tr>
<tr>
<td>- Training / education for Primary Care colleagues / patients / carers</td>
<td></td>
</tr>
</tbody>
</table>

It is envisaged that such Joint appointments would be put in place between:

a. P&SC Network and local Acute General Hospital. (The Regional Neurology Network will be providing an agreed level of outreach Neurology service at General Hospitals which do not have an on-site Neurology department)

AND

b. P&SC Network and Regional Hospital, which does have an on-site Neurology Department.
This would ensure that:
- the expertise of the Clinical Specialist is deployed for the benefit of the most complex cases, whether they are in-patient or living in the community
- Specialist staff move seamlessly between hospital and community settings, depending on where there is greatest clinical need, thus enhancing what either PCCC or NHO service provision alone offers.
- Consistent clinical standards are applied across all settings.
- There are opportunities for further training and development of staff
- Recruitment and retention are optimised
- Patient needs, rather than institutional priorities, are at the centre of service delivery

Depending on the population of an area and the health infrastructure therein, an Acute General Hospital or Regional Centre may have a number of joint Clinical Specialist AHP appointments with different P&SC Networks.

The creation of these joint appointments is suggested as the best way forward initially. Once the “pool” of staff with advanced levels of expertise increases, Regional Networks may deploy additional Neuro specialist staff to work mainly in the P&SC Network or mainly in the Hospital setting.

Joint Clinical Specialist AHP appointments between P&SC Network and Hospital:

3. Person referred to National Neuroscience Centre from Primary Care, an Acute General Hospital or Regional Neurology Network

- Based on agreed protocols, the National Neuroscience Centres will receive referrals that cannot be appropriately managed at by other hospitals in the Network.
- Each of the National Neuroscience Centres will provide a full range of general and subspecialty neurology services, taking account of those subspecialty areas which are provided in the Regional Neurology Networks.
The National Neuroscience Centres will be part of the geographic Regional Network. They will have referral pathways for tertiary services (e.g. HSE West may have links with Beaumont in respect of patients in the north west of the region, while patients in the south of the region may be linked to Cork University Hospital). In addition the National Neuroscience Centres will, with others, be part of the National Neurology Steering Group and enable the further development of neurology services in an agreed integrated manner.

8.2.1. Disease Specific and Specialist Services:
The Network Model supports the development of subspecialty interests within the regions and nationally, as long as they are consistent with the agreed national priorities for neurology.

The recent proposal for the development of specialist epilepsy services illustrates how the model could work in such instances:
- National epilepsy service based at one institution. Twenty-four hour telephone service offered.
- A number of regional epilepsy centres, at least 2 of which would include specialist paediatric epilepsy services
- Linked to enhanced neurophysiology services
- Centres linked via telemedicine
- Certain centres would then take a lead on services such as specialised investigation, epilepsy surgery, neuropsychiatry, inpatient care, Specialist Assessment Units, complex epilepsies etc.

This approach to the provision of epilepsy services shows how one centre can lead nationally but in close collaboration with named regional centres. It also offers the opportunity for a region to provide disease-specific or specialist services for other regions, in a planned and structured manner.

8.3. Clinical Neurophysiology
Clinical Neurophysiology (CN) is a relatively new but expanding investigative and diagnostic specialty. It is firmly based in the results of neurophysiological and electrophysiological research. A comprehensive CN service is led and directed by a consultant in clinical neurophysiology and is an integral component of a modern clinical neuroscience service. It is an extension of the neurologic examination, and is not just a set of laboratory tests.

There are four principal groups of investigations in neurophysiology:
1. Electroencephalography (EEG)
2. Nerve Conduction Studies (NCS) & Electromyography (EMG)
3. Evoked Potential (EP) studies
4. Intraoperative monitoring (IOM)
Increasingly, treatment options are also becoming available in CN (e.g. Transmagnetic Stimulation, administration of botulinum toxin). Many CN studies (particularly EEG, EP & IOM, and some NCS) are recorded by technicians, whereas most NCS, all needle EMG, and several motor IOM studies are carried out by CN consultants. All investigations are interpreted and reported by CN consultants.

While between 30 and 50% of neurophysiology referrals come from neurology teams, the remainder comes from other specialties. The establishment and development of neurophysiology services should reflect this. The main specialties that refer patients for neurophysiological investigations include:

- Neurology – adult and paediatric
- Neurosurgery
- Paediatrics
- Orthopaedic Surgery
- Rheumatology
- Endocrinology (especially diabetology)
- Psychiatry
- Plastic Surgery
- General Medicine
- Intensive Care Medicine
- Spinal Injuries & Rehabilitation
- Ophthalmology
- ENT

8.3.1. The Increasing Need for Neurophysiology Services

Tertiary referrals to the Clinical Neurophysiology service are increasing for the following reasons:

- The potential diagnostic value of the CN service is becoming more widely known
- The number of consultants in the referring specialties throughout Ireland is increasing,
- Specialised CN services such as inpatient video-EEG and intra-operative monitoring are now accepted international standards of care.

Based on 1990 statistics from the pan-London group, submitted to the Association of British Clinical Neurophysiologists (ABCN) Neuroscience Review team in 1993, there is an annual workload of 5,500 tests per million population per year. A caseload of 2,000 investigations per whole-time consultant per year was proposed by the ABCN. Where the service consists wholly of routine EMGs, the ABCN-recommended caseload is 750 per consultant per year. The ABCN acknowledge that these numbers cannot be achieved in departments where many non-routine, complex, time-consuming and labour-intensive tests are performed. The British Society of Neurophysiologists recommends 3 consultant CNs per million population, while the Royal College of Physicians
recommends 0.75 CNs per 250,000. **It is therefore estimated that for the current Irish population a minimum of 12 consultant Clinical Neurologists are required.**

### 8.3.2. Developing Clinical Neurophysiology Services in the Network Model

To support the Clinical Network Model, it is recommended that each Neurology network should have a Clinical Neurophysiology department with the required infrastructure, staffing and equipment (See Appendix 8.1 for details). Each Major Academic Teaching Hospital that has a department of Neurology on site should also have a Clinical Neurophysiology department. The exact configuration of sessional commitments between base / outreach sites within each Regional Neurology Network would need to reflect service demands and be consistent with the findings of the National Strategic Review and agreed national priorities for the neurosciences. The potential for neurophysiology-related telemedicine is already being piloted in a link between Sligo General Hospital and Beaumont Hospital. Such innovations may enable greater levels of outreach and support to be provided within the Regional Neurology Network.

### 8.4. Interface with Primary, Community and Continuing Care Services:

A key feature of the Managed Clinical Network Model is the recognition of the Primary Health services as an integral part of neurology care and of the need to provide support and skills transfer to these services. PCCC, Disability services and the voluntary sector all play increasingly important roles in managing long-term conditions. Though neurology is becoming increasingly interventional and therapeutic in nature, offering a wider range of management options than ever before, in future specialist neurology services must be better able to support primary care and community based services in the ongoing management of neurology patients in their community. In the Network model, priority is given to enhancing integration with other services especially Primary Care, PCCC and smaller hospitals. Most care will be provided as close to the patient’s community as possible, with primary care and local hospital services empowered to play key roles.

The Primary Care model which is currently being developed by the HSE involves the provision of additional health professionals, reconfiguration of existing posts and the provision of services, which are currently restricted to hospital, within local communities.

Each Primary Care Team (PCT) will be part of a Primary and Social Care Network, which will link 3 - 5 teams, with responsibility for the community based health care needs of populations from 30,000 to 50,000 people. Primary Care Teams will be able to draw the necessary expertise from their Primary and Social Care Networks, in order to meet the needs of their enrolled populations. The vast majority of services will be provided by core Primary Care Team members. However, when the Team forms the opinion that a patient or client has a complex set of needs requiring input from more specialised staff, these are provided to the PCT (on behalf of the client) by the Primary and Social Care Network. This provides new opportunities to reconfigure many services for neurology patients which have traditionally been hospital based, so that they are increasingly provided at local level. **It is**
recommended that multi-disciplinary personnel with expertise in neurological disorders be available at the Primary and Social Care Network level and that that have very close working links with hospital services.

In the new Primary Care Model, a PCT Key Worker, on behalf of the individual, works to ensure a smooth continuum of care. Intra and inter professional referrals are the responsibility of the PCT Key Worker, not the patient. The emphasis is on the role of a service or professional in the provision of care and their accountability in the care plan, not on complicated referral pathways or boundaries between services.

Although this move towards Primary Care Teams and Primary and Social Care Networks is the agreed strategic direction for the HSE, it will take significant time, effort and investment to achieve. The Neurology Clinical Network model envisages that the development and sharing of resources for Neurology / Neuroscience patients between Hospitals, Primary Care Teams and Primary and Social Care Networks is planned and agreed at local level, in keeping with Regional / National Frameworks and Guidance. It ensures that strong partnership with the voluntary sector continues to be a feature of future developments.

The managed Clinical Network Model for Neurology / Neuroscience services embodies the spirit of the HSE Transformation Programme, fitting well with PCCC plans and supporting the overall goal to provide high quality services closer to home.

8.5 Implementing the managed Clinical Network Model

Moving to a Managed Clinical Network model for Neurology in Ireland will be a fundamental change from the fragmented, ad hoc, institution focused way in which neurology resources have been allocated to date. The Network approach means that neurology resources will be deployed across traditional boundaries on a population basis. Reflecting the low base of existing neuroscience resources, implementation of the new model requires a number of developments to happen at the same time. Key hospital based services must be placed on a sustainable footing while new service connections and pathways are put in place.

The Clinical Network Model creates new roles and responsibilities at local, regional and national level. The structures and mechanisms to deliver these require the active participation and involvement of all stakeholders. The roles and functions within each region and at national level are envisaged as follows:

8.5.1 Roles / Functions in a Regional Neurology Network

The purpose of establishing a Regional Neurology Network is to ensure that the energy and resources of service providers within each region are focused to achieve clear objectives to improve services. These objectives are agreed and understood by all key stakeholders. The establishment and successful operation of a Regional Clinical Neurology Network involves a number of strategic activities /roles:

- Establish the clinical leadership of the regional network.
• Establish and maintain an effective interface with hospital network structures in the region and with national neurology services, to facilitate ongoing planning and development* of regional neurology services, within the overall national framework.

• Agree the regional priorities / objectives* for service development, consistent with the findings of the National Needs Assessment and agreed national priorities for neurology.

• In conjunction with other Networks, agree and implement a schedule of monitoring and audit activities to support service improvement and research and to meet local / national requirements (e.g. HSE Performance Monitoring, HIQA).

• Develop and agree management and referral protocols for neurology patients with Acute General Hospitals and PCCC services within the region, taking account of the findings of the National Needs Assessment and agreed national priorities for neurology. A critical element of this will be establishing and developing working arrangements with Primary and Social Care Networks and Primary Care Teams.

• Provide continuing strategic leadership and representation of the regional neurology service. This is critical to the success of ongoing dialogue and engagement with key regional stakeholders such as other specialties (e.g. Geriatric Medicine, Psychiatry, General Medicine etc), GP representatives, PCCC services and voluntary sector.

• Ensure that the regional neurology service participates in ongoing development and implementation of the overall national framework for neuroscience services.

• Work in partnership with other regional networks in relation to clinical (e.g. referral / assessment / management pathways), research, training or other relevant matters.

*These activities / functions are strategic in nature, reflecting the overall development needs of neurology within a given region. Once new / reconfigured services are agreed, implementation will proceed through the relevant operational line management structures e.g. a new post for a Primary Care Team will be implemented through PCCC / LHO structures; new imaging equipment for an acute hospital will be put in place by the relevant hospital manager / radiology department etc.

8.5.2 Roles / Functions at National Level – National Neurology Steering Group
The establishment and successful functioning of the National Neurology Steering Group involves a number of activities and roles:

• Establish a national governance structure

• Establish and maintain an effective interface with the NHO, PCCC and Population Health Directorates, the Regional Clinical Networks and relevant Expert Advisory Groups to facilitate ongoing planning and development of neurology services at national level.

• Ensure there is effective dialogue at all levels so that regional priorities / objectives for service development and the ongoing development of national services are consistent with agreed national priorities for neurology.
• Co-ordinate and agree management and referral protocols for neurology patients between different care settings
• Lead the development of relevant Disease-specific approaches to care and ensure relevant networking arrangements are put in place throughout the regions to support the delivery of agreed approaches.
• Ensure that Neurology services are appropriately engaged with national planning and delivery of relevant education, training and research. This includes the agreement of, and provision of guidance on, appropriate monitoring and audit activities to be undertaken within the Regional Networks.
• Ensure effective collaboration with other relevant national structures e.g. Expert Advisory Groups etc.

A clear set of mechanisms need to be put in place to ensure that the roles and functions outlined above are delivered and to ensure that the new model has a robust governance framework. Getting these mechanisms right, and managing them actively, is critical if Neurology services are to be transformed.

8.5.3 Proposed Clinical Neurology Network Configuration
Four Managed Clinical Networks supported by a National Steering Group. This approach:
• Ensures that all parts of the service are integrated through national and regional leadership.
• Ensures consistency on service development / delivery, management and quality at all levels within each region and nationally
• Ensures each HSE Area moves towards self sufficiency and equity of service provision
• Reflects existing HSE decision making mechanisms, ensuring that decision making about neurology services is streamlined with all other relevant decision making
• Optimises opportunity for local input in design of neurology services
• Co-terminus with PCCC structures, facilitating links with Primary and Social Care Networks
8.5.4 How the Neurology Network Model Might Work in Practice – Case Studies

Headache
Mary O’Connor (aged 25) has been having headaches since she was 19 years of age. The headaches occur infrequently but are severe and she has to leave work, sometimes for a full day. Mary has been self-medicating with paracetamol and NSAIDs but they are not effective. She attends her GP who has received headache management training provided by a Neurologist and Clinical Nurse Specialist from the Regional Neurology Network. Using the protocols outlined during the training sessions, the GP diagnoses migraine. Mary is prescribed medication and is put in touch with the Migraine Association for further advice and support. This approach is effective. Two years later, Mary’s headaches become more frequent and harder to manage. Her GP contacts the local GP-run headache clinic for advice on management. The GPs who run this clinic work closely with the Regional Neurology Network Team. Having completed and emailed an electronic pro-forma case summary to the Clinic, Mary’s GP receives a telephone call from the Clinical Nurse Specialist two days later. She
Mary’s case with the GP running the Clinic and they recommend a change in medication for Mary. Mary responds well to the new drug regime, and continues to attend Migraine Association events for ongoing support.

**Epilepsy**

John O’Dowd is a 28 year old man who is brought by ambulance to ED following a first grand-mal seizure which occurred on a Saturday afternoon while watching a rugby match with his friends. Following initial assessment in ED, John is treated according to the protocol which has been set out by the Regional Neurology Network. The Medical SHO on-call contacts the specialist epilepsy unit which is on-call for the national epilepsy service that weekend for advice on further management. Once John’s condition is stable he is discharged from ED with a follow-up appointment at the regional specialist epilepsy centre for full assessment. John attends the regional centre on two occasions for his assessment and associated investigations. Each attendance involves a 100 mile round trip. Once the assessment has been completed, John commences on a treatment regime, and receives ongoing support by telephone from the Clinical Nurse Specialist at the regional centre. It takes several months for John to adjust to his diagnosis and treatment regime. During this time he sees a medical social worker at his local hospital to address issues of how his diagnosis is affecting both himself and his family. The social worker carries out a psychosocial assessment and develops appropriate intervention(s) e.g. psychological, emotional and practical, liaising as required with other agencies. He also attends for further follow up at the same hospital to which he initially presented, where a neurology outpatient clinic is provided on an outreach basis by the regional specialist centre. This is far more convenient for John. John’s GP has received a copy of the findings of the assessment of the regional Epilepsy Team and collaborates with the local neurology outpatient service to ensure the optimal management of John’s condition. After four attendances at the local neurology outpatient clinic, John continues to manage his condition with the guidance of his GP, based on the protocols set out by the Epilepsy Team as part of the Regional Neurology Network. John and his GP can contact the Clinical Nurse Specialist as necessary with ongoing queries and attends for an annual review at the regional specialist epilepsy centre.

**Multiple Sclerosis**

Brian Higgins is a 38 year old man who attends his GP complaining of vertigo following a recent URTI. His GP prescribes an antihistamine and his symptoms settle quickly. One month later, Brian presents with an unsteady gait. Following assessment, his GP feels that he needs a full neurological work-up and refers Brian to the neurology outpatient clinic at the nearest acute general hospital for investigation. This clinic is provided on an outreach basis by the Regional Neurology Network.

The team at the local neurology outpatient clinic suspect that Brian may have Multiple Sclerosis. He is referred to a larger hospital for an outpatient MRI appointment and is seen again at the neurology OPD three weeks later. Based on the findings of all of the investigations and the MRI, the neurologist makes a diagnosis of Multiple Sclerosis and breaks the news to Brian and his wife. Brian receives counselling and support from the clinical psychologist or medical social worker as appropriate and the clinical nurse specialist all of whom are members of
the Regional Neurology Network team. They offer to put Brian in contact with the MS Society but he declines. The medical social worker also addresses practical issues which include financial implications of his diagnosis and an application for a medical card.

Brian is referred back to his GP and remains well until 2 years later, when he has a relapse which requires admission to a regional acute hospital, under the care of the Regional Neurology Team for 3 days. While he is in hospital Brian is visited by an inreach worker from the MS Society, who remains in contact with him following his discharge from hospital. He is also assessed by the neurology team physiotherapist. Brian is discharged back to the care of his GP and the Primary Care Team who will arrange further outpatient physiotherapy.

Over the next 5 years, Brian has 2 further relapses requiring hospital admission, and he has ongoing mobility problems. The medical social worker coordinates the provision of a package of care, which necessitates a means test and liaison with the various necessary services. The medical social worker provides ongoing support and regular review, including contact details in the event of difficulties arising. He receives a package of care at home which varies according to his condition, but which has included visits from the local PHN, a home assessment by an OT, who provides equipment and appliances, and physiotherapy at the local hospital. He is coping well, uses a walking aid and is under the care of the local Primary Care Team. The MS Society worker keeps in touch with Brian and provides ongoing advice and support.

Ten years later, Brian has increasing mobility difficulties. He is assessed by the occupational therapy service for appropriate aids and seating. Because of his complex needs at this stage, the local OT and the specialist neurological OT from the Primary and Social Care Network do a joint visit and agreed the most appropriate prescription. Respite services are arranged by the local PHN and MS Society, ensuring that Brian and his wife can have a break at least once or twice a year. The Primary Care Team maintain links with the Regional Neurology Team and can arrange intensive rehabilitation for Brian when necessary to maintain his independence and function. Initially, Brian had to be admitted to the Regional Hospital when he needed rehabilitation, but more recently, he has been able to avail of this service in a HSE Community health facility by AHPs that are appointed to the Neurology Network.

**Alzheimer’s Disease**

Margaret Kelly is a 72 year old lady who attends her GP with her daughter, who has become concerned about her mother’s behaviour (mood swings) and forgetfulness. Her GP suspects that Margaret has Alzheimer’s disease, and refers her to the Dementia service operated by the Regional Neurology Network at a large Acute Hospital 35 miles away. The Dementia team, comprising Neurologist, Psycho-Geriatrician, Clinical Nurse Specialist, Medical Social Worker and Clinical Psychologist, conduct a full clinical and psychosocial assessment. The diagnosis of Alzheimer’s disease is confirmed following an MRI. The Dementia Team develop a management plan for Margaret, and provide her family with some initial information. They are given contact details of the Alzheimer Society. The finding of the assessment and the management plan is sent to the GP.
When Margaret and her daughter attend the GP for follow up, they discuss the local support options available. The Alzheimer Society have already provided Margaret’s daughter with details of a day care and drop in centre in the nearest town, 7 miles away. Although they do not wish to avail of this service now, the GP advises them to keep in mind for the future. They agree that the local PHN will call to assess Margaret in her home and to give general advice and support. The GP outlines to Margaret and her daughter how the Primary Care Team can help them on an ongoing basis. The GP can access the medical social worker for psychological, emotional and practical support as per the needs of the Margaret and her daughter. Margaret continues to live with her daughter and is managed at home for some time. The Public Health Nurse calls regularly and after 18 months, Margaret begins to attend the day centre run by the Alzheimer Society. This gives Margaret’s family a break and enables Margaret to join in more social activities such as dancing, singing and reminiscence therapy. As Margaret’s condition progresses, Margaret is admitted three times a year for respite care to a Dementia Unit attached to the local Community Hospital. She and her family are supported at home by a Home Help and the continuing input of the Primary Care Team.

8.5.5 Discussion
Successful implementation of the Clinical Network Model depends on the achievement of the roles and activities outlined in 8.2 above. While the various roles and tasks could be split up and assigned among the range of existing staff, this would not bring sufficient focus or energy to ensure progress. Clinical leadership is central to successful implementation. This leadership must be recognised and supported by management structures in the HSE. It is recommended that:

- For each Regional Neurology Network, a Neurology / Neuroscience Committee is put in place. The Terms of Reference for this Committee would reflect the roles / tasks outlined in 8.5.1. This Committee, comprising representatives of all relevant stakeholders across the HSE and voluntary providers, would be chaired by a Regional Director of Neurology / Neuroscience. Such appointments would be part time and for a fixed term. They could be rotational in nature.

- At national level, a National Neurology / Neuroscience Steering Committee is put in place. The Terms of Reference for the National Neurology / Neuroscience Steering Committee would reflect the roles / tasks outlined in 8.5.2 above. This Committee would liaise closely with relevant Expert Advisory Groups.

- Clarity of leadership and direction at regional level and national level would then be achieved. The roles and functions Area Clinical Directors of Neurology will for the basis for their job descriptions.
8.6 Rehabilitation

Requirements for Neuro-Rehabilitation; Integration with Specialist Neurology and General Health Services

Introduction
Rehabilitation is the process of active change by which a person who has become disabled acquires the knowledge and skills for optimal physical, psychological and social function. It is a process that aims to restore personal autonomy to those aspects of daily life considered most relevant by people with neurological conditions, service users and their family carers.

People with neurological conditions require access to different types of rehabilitative treatment at various stages in their condition. There should be no gaps or delays in the provision of these services, particularly for people with progressive conditions, complex needs or high levels of dependency.

Rehabilitation services need to be planned in the context of a long-term approach to the management of a neurological condition. The aim of rehabilitation is to maintain existing roles within the family, at home, community and work through a multidisciplinary approach focused on an individualised care plan for the person and their family. For progressive and long-term neurological conditions, the services required will change over time.

A national rehabilitation strategy is required to meet the needs of patients who are disabled by their condition.

As part of this Strategic Review meetings were held with the Peter Bradley Foundation and Bri. In those meetings the harsh reality of the long-term consequences of head injury (acquired brain injury) became apparent. There are at least 30,000 people living in Ireland with the long term consequences of head injury whose lives have been suddenly and devastatingly changed. Prevention of head injury and, in particular road traffic crashes, is a crucial strategy that needs priority from many sectors e.g. construction industry, road safety groups, health service and transport authorities. There are effective preventive measures for transport related head injuries i.e. motor-cycle and cycle helmets.

Personnel Needs in the Area of Neuro-rehabilitation
Neurological conditions have a wide range of effects on the physical, intellectual and social wellbeing of the individual that require long term support and treatment appropriate to their needs. The following personnel are required for the multidisciplinary rehabilitation of neurological conditions:

- Case Manager
- Clinical Neuropsychologist
• Occupational Therapist (neuro specialist)
• Physiotherapist (neuro specialist)
• Social Worker
• Speech and Language Therapist (neuro specialist)
• Rehabilitation Consultant
• Rehabilitation Assistants
• Neuro-psychiatrist

It was recognised during this Review that there are insufficient specialised allied health professionals available in the community for people living with neurological conditions. This is particularly evident with respect to neuropsychological and neuro-psychiatric services. These deficits impact on the rehabilitation of people with neurological conditions in need of assessment and treatment programmes for the management of their condition. Lack of these specialised services leads to a range of complex behavioural and psychological consequences that cannot be managed appropriately in the community or in general residential settings.

Voluntary organisations are involved in the rehabilitation of people with neurological conditions through a wide range of services including home supports, residential care, community programmes, access to assessment and treatment programmes and long term educational and vocational supports. They need to be integrated with local primary care teams and other statutory services in the community.

Service Needs at Each Stage of Rehabilitation

Acute rehabilitation
Rehabilitation facilities are a key aspect of neurology services and the management of discharges from acute neurology units. However, there is a lack of acute rehabilitation facilities at the main neuroscience centres leading to delayed discharge and inappropriate placements

Post-Acute (transitional) rehabilitation
Many neurological conditions lead to progressive deterioration in function over time while others such as stroke or acquired brain injury can cause significant long term disability. The lack of regional specialised centres for the provision of rehabilitation on an inpatient and outpatient basis means that there are long waiting lists for the current national centre and not all those who require the service can access it.

Community rehabilitation
Due to the complex nature of neurological disorders, there is a need for specialised multidisciplinary neurological teams in the community. Experience in the UK and elsewhere has proved that certain common, complex and
challenging neurological conditions, including acquired brain injury, multiple sclerosis and dementia require condition-specific teams.

**Specialist Residential and Home Support Services**
People with progressive or disabling neurological conditions may require a range of supports to enable them to continue to live in the community. These include modifications to their home, access to aids and appliances and ongoing therapies to maintain their level of function. Delays and gaps in service provision can lead to deterioration of function and hospital admission.

Many people with cognitive or behavioural challenges will require lifelong residential options with varying levels of support in order to accommodate their changing needs. Some individuals will require residential care because of significant injury or deterioration in their condition. This needs to be provided in an appropriate setting with staff who have had specialised training to care for people with neurological conditions.

Due to the variable and unpredictable course of many neurological conditions, a comprehensive neuro-rehabilitation service needs to be able to respond to a wide variety of different problems and significant changes in the person’s level of function. For this reason, a person with a neurological condition has to be managed in a variety of different settings with specialised staff experienced to meet their needs.

**Palliative Care**
In cases where a person has a progressive neurological condition it will be necessary to provide end-stage care treatment and support both in relation to their rehabilitation and maintenance of function. Access to services and supports related to both palliative care and the specific neurological condition will be essential.

**Case Management in the Provision of Rehabilitation Services**
The person with a neurological condition is typically referred to their local primary care team from the acute hospital or post-acute setting (certain conditions such as acquired brain injury and stroke will require step-down care before they are referred back into the community). At this stage, the individual should under the care of case manager who has specialised knowledge of their needs and the services available to them. The case manager works closely with the local primary care team and can be from a statutory or voluntary agency. Integration of voluntary and statutory services is essential to prevent fragmentation and duplication of services and to optimise use of current resources.

The case manager is required to manage all referrals both within the primary care team and to the range of other long term supports that may be required by the individual with a neurological condition. These may include access to home supports or residential care together with longer-term access to vocational rehabilitation and community support.
Recommendations in relation to rehabilitation

1. A national rehabilitation strategy is required. This should address neuro-rehabilitation requirements.
2. Services need to be developed to meet patient needs at all stages of rehabilitation from acute, post acute through to community and long-term care.
3. More specialist staff are required to provide rehabilitation services, most notably rehabilitation consultants, neuropsychologists and neuropsychiatrists.
4. Specialised multidisciplinary neurological teams need to be put in place to manage neurological conditions in the community.
5. Rehabilitation services need to be co-ordinated centrally by a specialised case manager whose role it is to link specialist and general services and the work of statutory and voluntary agencies to provide for the needs of the person with the condition.

8.7 Dementia

Dementia is a syndrome due to a disorder of the brain, usually chronic or progressive in nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Alzheimer’s disease is the most common form of dementia.

The disease has wide ranging effects on the person, their family and carers. Approximately 38,000 people in Ireland have dementia and the prevalence is increasing as the population ages. Early diagnosis is essential. Care delivery is difficult requiring the input of many disciplines including geriatricians, old age psychiatrists, adult psychiatrists, neurologists, psychologists and Primary Health Care teams. Navigating the health care system can be difficult for these patients. There are many challenges being faced by patients and their families including:

- Access to accurate diagnosis
- Access to multi-disciplinary care throughout the patient journey
- Care of patients who are under the age of 65 years
- Accessing appropriate services for all age groups in a timely manner both in hospital and in the community.

Though dementia was not the primary focus of this Strategic Review, it is clear that there are a number of unmet needs faced by patients and their families. Therefore it recommended that a specific national strategy for dementia be developed.
9. **Recommendations of the Neurology Review and Implementation**

1. **Developing a Patient Centered Service**
   1. People who are suspected of having a neurological condition should have prompt access to specialist neurological expertise for an accurate diagnosis and treatment as close to home as possible.

2. People with long-term complex neurological conditions should:
   i. Have a multi-disciplinary assessment of their needs.

   ii. Have an individual care plan that addresses their health and social needs. The person with the condition and their family should have an integral role in the development of this plan.

   iii. Receive multi-disciplinary care as close to home as possible.

   iv. Be assigned a named patient care coordinator and be involved in the decision as to who this person will be.

   v. Be supported in understanding and managing their condition.

   vi. Have the information they need to make informed decisions about their condition and care.

   vii. Receive timely, ongoing, high quality rehabilitation advice and support services suitable for their needs in different settings, as required.

   viii. Have access to appropriate vocational assessment and support to enable them to find, regain or remain in work and access other occupational and educational opportunities.

   ix. Receive timely, appropriate assistive technology/ equipment and adaptations to support independent living.

   x. Be put in touch with the relevant patient support organisations as a formal part of their treatment pathway.

3. A support plan for the carer should be an integral part of the care plan.

2. **Service Structure**

1. A National Neurology Steering Group should be established to provide clinical and managerial leadership, set standards and performance targets – *Target to establish the National Steering Group - June 2008.*
2. Neurology services should be delivered in a Managed Clinical Network Approach which includes all aspects of the service including voluntary services, as described above. *Target to establish the Network Approach - June 2008.*

   i. The four Clinical Networks will be accountable (reporting on a quarterly and yearly basis) on all aspects of their service including funding utilisation.

   ii. New neurologist appointments should be to the Network rather than to an institution. A multidisciplinary team of allied health professionals (the number and type of AHPs required will depend the type of neurology service being provided) and specialist nursing are needed for each neurologist. These will also be appointed to the Network to ensure real integration between hospital, community, disability and other services.

   iii. Facilities for the delivery of neurology services outside the acute hospital setting should be identified in each Network. This is especially important for patients who need on-going AHP services and rehabilitation.

   iv. All neurology units should have links to local academic and research facilities.

   v. The Networks should develop outreach services with hospitals in the region that do not have a neurology service – on a needs basis e.g. outpatient services.

   vi. A greater focus should be placed on enabling ambulatory day care and in providing care as close as possible to the patient / family through structured services with Primary Health Care and Community Services.

3. **Neurology Personnel**

1. The current required number of adult consultant neurology posts needs to be increased to a ratio of 1/100,000 population in accordance with Comhairle na nOspideal recommendations. This requires a minimum of 42 adult posts nationally. Priorities for additional adult neurologists are:
   - The West (which currently has the lowest number per 100,000 population).
   - Additional neurologist posts should be allocated to Limerick, Sligo and Waterford so that no neurologist operates single handed and to enable regional self-sufficiency.
   - The two National Centres should be resourced in accordance with Comhairle recommendations.
   - Thereafter existing neurology centres in the four networks should be staffed to appropriate recommended levels.

2. The neurology centres in the four Regional Networks should be staffed with multidisciplinary teams. The type and number of AHP and specialist nursing input should be determined on the basis of what is essential for the multi-disciplinary team to operate effectively.
3. While it is recommended that AHP/ Specialist Nurse appointments should to the Network, rather than to an institution, it will be necessary for a number of AHPs in each discipline to be located, perhaps on a rotational basis, to the community service so as to foster integration and enhance neurology skills in the community services.

4. Specialist nurses with expertise in neurological conditions e.g. movement disorders, multiple sclerosis, epilepsy should be available to work across all parts of the network.

5. All externally funded clinical AHP posts should be mainstreamed.

4. Paediatric Neurology

1. Paediatric neurology services should be provided by a Clinical Managed Network from Dublin and Cork with outreach services nationally, as described in Chapter 7.

2. A ratio of one paediatric neurologist per 100,000 childhood population is required i.e. 12 paediatric neurologists for the current population.

3. Allied Health Professionals should be appointed at the same time as paediatric neurologist appointments in accordance with the needs of the service.

4. The need for dieticians to be appointed to each of the paediatric neurology centres for the management of the ketogenic diet for children with epilepsy is a priority.

5. The need for the appointment of clinical neuro-psychologists in each of the paediatric neurology centres is a priority.

6. In relation to consultant (and team) staffing:
   i. Three consultant paediatric neurologists (including an academic post) should be appointed to the tertiary-quaternary hospital in Dublin within the next three years. Within five years there will be a need for two additional whole-time consultant paediatric neurologists to Dublin bringing the total complement to nine.

   ii. The post in Cork (CUH) should be restructured making it a whole-time post. In addition a second whole-time consultant paediatric neurologist without commitment to general paediatrics should be appointed to CUH as a priority. Within the next five years a third whole-time consultant paediatric neurologist to CUH.
7. Two clinical neurophysiologists with a special interest in paediatrics should be appointed - one at each of the Dublin Children's Hospitals and ultimately working together at the new tertiary Children's hospital. They should have links to an adult hospital and have specialist expertise e.g. spinal monitoring.

8. Consideration should be given to establishing a Specialist Training Programme in paediatric neurology.

5. **Clinical Neurophysiology**
   1. Each academic teaching hospital that has a neurology service should also have a clinical neurophysiology service which is led by a clinical director, who is on the Specialist Register, and who will set clinical governance and performance criteria and undertake audit. Smaller neurology units should be linked electronically with clinical neurophysiology units.

   2. Clinical Neurophysiology centres should conform to best-practice in terms of space and equipment.

   3. A higher specialist medical training programme for clinical neurophysiology should be developed. This should be linked to European centres for curriculum development and training planning.

   4. The training of clinical measurement technologists is central to the provision of a clinical neurophysiology service. The training programme should be linked to the clinical neurophysiology service to ensure that new technologists meet the requirements of the service. Clinical neurophysiologists should collaborate with the training centres and contribute to the teaching programme.

   5. Ireland’s current population requires 12 clinical neurophysiologists. Each major clinical neurophysiology department requires four senior technology personnel and two basic grade technologists.

6. Teaching, research and audit are essential components of the service.

6. **Service Integration**
   1. The development of a sustainable approach to chronic illness management rests on ensuring that there is real integration between all parts of the service and the voluntary sector including:
      
      i. Developing plans and protocols to link hospital, community services and other relevant services
      ii. Developing PCTs and social care networks to facilitate patients to have multidisciplinary treatment in the community with access to specialists as required. This will bring care closer to the patient and is a key step toward providing a more equitable, accessible service for patients while reducing the burden on hospital services.
iii. A joint approach to the management of patients with long term neurological conditions by AHPs in hospital and community settings. Therapists with expertise in neurology will be available at social care network level in each of the disciplines.

iv. Hospitals in the network will facilitate the transfer of specialist neurology skills to AHPs and nursing personnel in the community through joint training, joint continuing professional development, joint appointments etc.

v. Guidelines of care and support for GPs in managing patients with long term neurological conditions will be developed. This will be initiated by neurologists in the Network in association with GPs in the region.

vi. Enhanced training for GPs who will be encouraged to be more involved in the neurology service e.g. GP managed and run migraine clinics under leadership of consultant are successful in Ireland.

vii. Research with GPs will be encouraged and facilitated.

7. Voluntary sector

1. The services provided by voluntary organisations should be recognised as a core component of the Network.

2. Voluntary organisations should be integrated with all other neurology services in the network.

3. Funding requirements for voluntary organisations needs to be examined.

8. Technology

1. The significant role of technology in the management of long term neurological conditions cannot be underestimated. Major developments in this area are in the interest of patients, GPs and specialist neurology services. Substantial investment in dedicated facilities and in technological research are required on a national basis. The National Steering Group should provide advice in this regard. In addition a wide range of complex expertise is required in this emerging field including strong academic research to enable the safe delivery of new techniques and the assessment of specialist training requirements to deliver hi-tech neurological care. In this way the rapid dissemination and utilisation of technology on a Network basis will be facilitated.

2. ICT projects of proven efficiency and effectiveness should be developed, in particular the use of telemedicine for neurophysiology services and remote video assessment of patients.

3. The development of the National Electronic Patient Record should be prioritised. This will have benefits for many services.
4. The possibility of developing electronic referrals to neurology units on a national basis should be explored.

5. In the context of developing a national Movement Disorder Programme the establishment of a Deep Brain Stimulation Service in Ireland should be considered. This should meet the same standards as defined by National Specialised Services Commissioning Group (NSSCG) in the UK. (see Appendix 6.1)

6. In relation to the use of Natalizumab (Tysabri), this new treatment should be provided under strict neurologist control as outlined in Section 6 of the main report and in Appendix 6.2.

7. A national epilepsy network should be established.

8. The neurology community should link with HIQA in the context of Health Technology Assessment.

9. **Academic Developments and Research**
   1. Neurological research should be fostered and promoted so as to enhance patient outcomes and quality of life.

   2. Neurological epidemiological information systems need to be developed. These systems should also reflect service utilisation, support performance management and facilitate research / audit including the role of technology across all disciplines.

   3. Collaborative ventures in neurology between academic, clinical and industry sectors should be encouraged so as to develop programmes to improved care and outcomes for neurology patients.

   4. Consideration should be given to developing an Irish Neurology Bio-bank to support the planned neuroscience clinical database.

   5. There is a need to increase the number of academic clinicians in Irish Medical Schools in line with the recommendations of the Fottrell & Buttimer Reports. Consideration should be given to increasing the number of Neuroscience Chairs at the Universities.

   6. Research posts for AHPs and specialist nursing should be supported.

   7. Increases in academic funding of clinical and basic neuroscience research studies including new technologies should be in collaboration with Science Foundation Ireland, Health Research Board and Forfas.
10. Training

1. Training of medical, nursing, technology and allied health professional staff needs to be enhanced at undergraduate and post graduate levels. The numbers of specialist training posts should be determined at a national level so that future population demands can be met. This assessment of specialist training needs should be a role for the National Steering Group.

2. Training priorities should address the present and future skill mix in neurology – presently there is a lack of senior/clinical specialist therapy posts throughout the neurology sector and the role of the therapy assistant needs to be promoted.

3. GP Education and Training Schemes are responding to the growing prevalence of neurological conditions by providing training in neurology. Established GPs should be facilitated with ongoing training and greater integration with neurology services.

11. Rehabilitation

1. Each Neurology Network should have neuro-rehabilitation services to address acute, transitional and long-term rehabilitation needs of patients including residential facilities. This will reduce bed occupancy in acute hospitals and lead to better outcomes for those with neurological illnesses.

2. A National Rehabilitation Strategy is required which would address neuro-rehabilitation needs including the needs of people with acquired brain injury.

3. The specific service and rehabilitation requirements for those who have sustained a stroke are to be identified in the Stroke Strategy.

4. Rehabilitation facilities for chronic long term care of the under-65 age group in particular need to be developed.

5. The health needs of patients / families with Alzheimer’s disease requires specific strategic consideration. This should also take account of the requirements of younger Alzheimer’s patients.

Implementation

The above recommendations are multiple and challenging. They can not all be implemented in the short-term. The main priority is to establish the National and the Regional Clinical Network structures. This will serve as the basis for prioritising national and regional developments including staff numbers, training and research but most importantly it will get the Network in to action so that national and regional leadership develops, continuity of patient care becomes easier to achieve and patient needs are met.
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