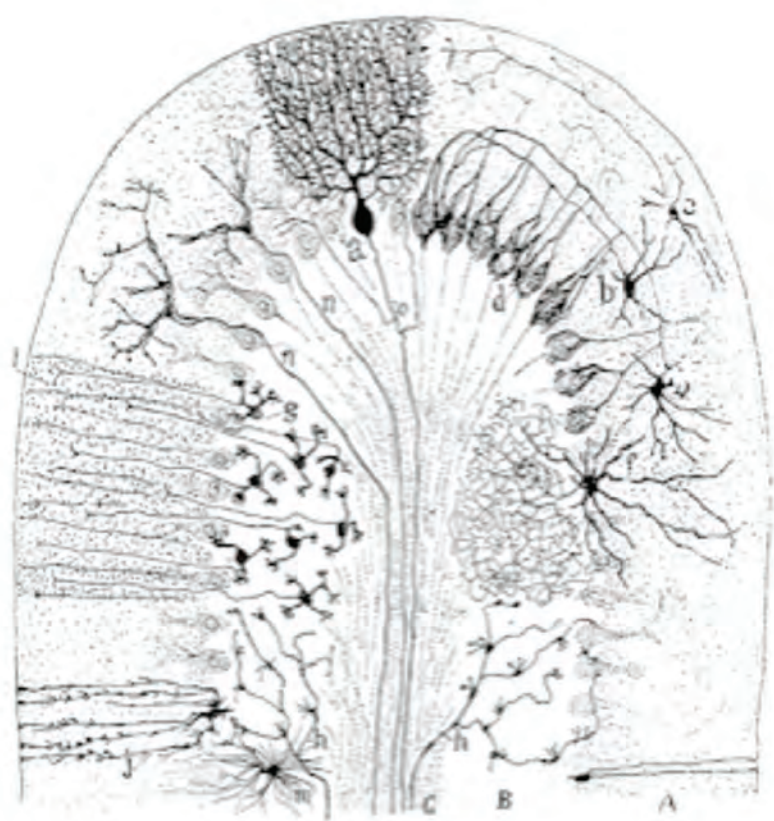


# National Clinical Programme for Neurology



## MODEL OF CARE



# Contents

<b>Contents</b> .....	<b>3</b>
<b>Contributors and Stakeholders</b> .....	<b>5</b>
<b>Abbreviations</b> .....	<b>7</b>
<b>Foreward</b> .....	<b>9</b>
<b>Executive Summary</b> .....	<b>14</b>
Scope .....	14
Context .....	15
Recommendations .....	20
<b>PART A - Introduction and Background</b> .....	<b>27</b>
1.1 Introduction .....	27
1.2 Prevalence .....	28
1.3 Social and Economic Factors .....	29
1.4 Burden of disease measures & mortality .....	30
<b>PART B Outline of the Neurology Programme</b> .....	<b>32</b>
2.0 Outline of Neurology Programme .....	32
2.1 Rationale for National Clinical Programme for Neurology .....	32
3.0 Aims & Objectives of the Neurology Programme .....	34
4.0 Scope of Neurology Programme .....	38
4.1 Care Pathways within the Neurology Programme .....	38
5.0 Mission, vision, core values and principles .....	40
6.0 A Neurology Service based on Best Practice .....	41
7.0 Evolution and function of the service .....	44
7.1.1 Hospital Utilisation .....	44
7.1.2 Neurology patients attending Emergency Departments .....	44
7.1.3 Inpatient Neurology Consultation Service .....	45
7.1.4 Inpatient admissions under Consultant Neurologist – emergency & elective .....	45
7.1.5 Hospitals without on-site Neurology Services .....	45
7.1.6 Out-Patient Services .....	46
7.1.7 Multidisciplinary Teams for outpatient services .....	47
7.1.8 Community based services for people with neurological conditions .....	47
7.1.9 Other disability and healthcare support in the community .....	48
7.2 Current status of service provision .....	49
7.3 Long term drivers & future of speciality .....	50
<b>PART C Neurology Programme Model of Care</b> .....	<b>54</b>
8.0 Neurology Programme Model of Care .....	54
8.1 Proposed model of care based on a managed clinical network structure .....	54
8.2 Core elements of the Model .....	55
8.3 How the Managed Clinical Network will operate in Practice .....	56
8.4 Roles / Functions in a Group Neurology Network .....	57
8.4.1 Roles/Functions at a tertiary level .....	58
8.4.2 Roles/Functions at a national level – National neurology steering group .....	58
8.5 Integration with General Practitioners .....	59
8.6 Integration with Neurorehabilitation and Palliative Care Services .....	61
8.6.1 Integration with palliative care .....	62
8.6.2 Integration with Rehabilitation services .....	64
8.7 Integration with Mental Health Services .....	66
8.8 Healthcare and Disability Supports in the Community for People with Neurological Conditions .....	66
8.8.1 Long term care .....	67
8.8.2 Disability supports .....	67
8.8.3 Medical Cards .....	67
<b>9.0 Patient Journey</b> .....	<b>68</b>
9.1 Neurological Patient Journey .....	68
9.2 Patient Experience Survey .....	71
9.3 Role of Not for Profit Organisations in Neurological Care .....	71
<b>10. Chronic Disease Management in Neurology</b> .....	<b>74</b>

10.1 The need for a population health approach.....	74
10.2 Self-Management .....	75
<b>11.0 Medications in Neurology .....</b>	<b>78</b>
11.1 Equitable Access to Medications.....	78
11.2 Medication Safety .....	78
11.3 Polypharmacy.....	79
11.4 Educated and Empowered Patients.....	80
11.5 Informed Choice/Joint Decision Making.....	82
11.6 Medication Supply and Funding.....	82
11.6.1 Primary care .....	83
11.6.2 Secondary care .....	83
<b>12.0 Requirements.....</b>	<b>85</b>
12.1 Current Status .....	85
12.2 Requirements.....	86
12.2.1 Access; .....	86
12.2.2 Staffing; .....	87
12.2.3 Specialist Expertise;.....	87
12.2.4 Health and Social Care Professionals and the Neurology Service; .....	87
12.2.5 Nursing .....	88
12.2.6 Neurosurgery.....	88
12.2.7 Neurocritical care .....	90
12.2.8 Neuroradiology & Interventional neuroradiology .....	91
12.2.9 Neuro ophthalmology .....	92
12.2.10 Neuropathology .....	92
12.2.11 Clinical Neurophysiology; .....	93
12.2.12 Administrative Support .....	93
12.2.13 Paediatric-Specific Priorities; .....	93
12.2.14 Space, Facilities and Equipment; .....	93
12.2.15 Evidence Based Practice and Research and Development; .....	94
12.3 Workforce Planning .....	94
12.3.1 Neurology consultants.....	94
12.3.2 Nursing .....	94
12.3.3 Health & Social care professionals.....	94
<b>13.0 Governance .....</b>	<b>97</b>
<b>14.0 Education/Training .....</b>	<b>102</b>
14.1 Medical Education.....	102
14.2 Health and Social Care Professionals .....	103
14.3 Nursing Education.....	104
14.4 Research .....	104
<b>15 Programme Metrics .....</b>	<b>106</b>
<b>16 Communications .....</b>	<b>113</b>
<b>17 Implementation .....</b>	<b>114</b>
<b>PART D Cross Programme Learning, Shared Initiatives and Special Populations .....</b>	<b>116</b>
1.0 Cross Programme Collaboration.....	116
2.0 Specialist populations .....	121
<b>PART E – Managed Clinical Networks .....</b>	<b>128</b>
<b>Part F; Appendices .....</b>	<b>134</b>
<b>Appendix 1 .....</b>	<b>134</b>
The roles of the Neurology Multidisciplinary team members.....	134
<b>Appendix 2 – Headache Pathway .....</b>	<b>158</b>
<b>Appendix 3 – Multiple Sclerosis Pathway.....</b>	<b>169</b>
<b>Appendix 4; Parkinson’s Disease Pathway .....</b>	<b>188</b>
<b>Appendix 5; Patient Pathway Motor Neurone Disease.....</b>	<b>208</b>
<b>Appendix 6; Transition Checklist .....</b>	<b>220</b>
<b>Appendix 7 – Neurology subspecialties .....</b>	<b>222</b>
<b>Appendix 8 –Neurology centre survey.....</b>	<b>232</b>
<b>Version Control.....</b>	<b>278</b>
<b>References.....</b>	<b>279</b>

# Contributors and Stakeholders

National Neurology Programme Working Group	
Professor Tim Lynch	Clinical Lead for National Clinical Programme of Neurology
Jacqui Scott Brian Magennis	Clinical Nurse Specialist General Neurology/MS Clinical Nurse Specialist Parkinson's Disease
Edina O'Driscoll (from 03/14) Noreen Curtin (until 03/14)	Programme Manager, Clinical Strategy & Programmes Division, HSE
Magdalen Rogers, NAI	Development Manager, Neurological Alliance of Ireland
Helen Cornelissen Elaine Harrington Dr Deirdre Murray Neil Austin Dr Robert Coen	Occupational Therapy Manager Senior Physiotherapist Clinical Specialist Physiotherapist Senior Clinical Neuropsychologist Senior Clinical Neuropsychologist
Dr Chris McGuigan Prof Niall Tubridy Dr Brian Sweeney Prof Orla Hardiman Dr Timothy Counihan	Consultant Neurologists

## Contributors

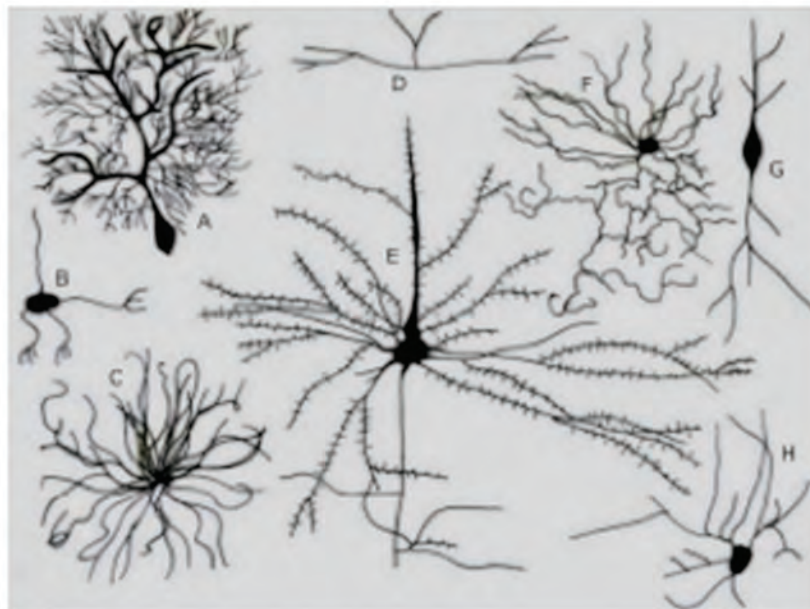
Neurological Alliance of Ireland  
 MS Ireland  
 Move 4 Parkinsons  
 Alzheimers Association  
 National Hospice Foundation  
 Migraine Association of Ireland  
 Association of Occupational Therapists of Ireland  
 Irish Association of Social Workers  
 Irish Association of Speech & Language Therapists  
 Irish Society of Chartered Physiotherapists  
 Irish Nutrition and Dietetics Institute  
 The Society of Chiropractors and Podiatrists of Ireland  
 The Irish Association of Orthoptists  
 Dr Jennifer Hoblyn, Bloomfield Health Services  
 Psychological Society of Ireland  
 National Clinical Programme for Critical Care  
 National Clinical Programme for Rehabilitation Medicine  
 National Clinical Programme for Epilepsy  
 National Clinical Programme for Palliative Care  
 National Clinical Programme for Trauma and Orthopaedics  
 MS Nurses  
 Edel Callanan  
 Irish Motor Neurone Disease Association  
 Kathy Maher, Irish Pharmacy Union  
 Dr Eddie O'Sullivan



## Clinical Advisory Group for the National Clinical Programme for Neurology

Aisling Ryan  
 Amre Shahwan  
 Blathnaid McCoy  
 Brian Murray  
 Brian McNamara  
 Bryan Lynch  
 Chris McGuigan  
 Colin Doherty  
 David Webb  
 Dan Healy;  
 Kevin Murphy;  
 Dominick McCabe  
 Donal Costigan  
 Helena Moore  
 John Lynch  
 Killian O'Rourke  
 Michael Hutchinson  
 Mary King  
 Michael Hennessy  
 Niall Tubridy  
 Norman Delanty  
 Niamh Mc Sweeney  
 Olivia O'Mahoney  
 Orla Hardiman  
 Martin Ruttledge  
 Paul Crowley  
 Gerard O'Connor  
 David Bradley

Sean O'Riordan  
 Timothy Counihan  
 Yvonne Langan  
 Elijah Chaila  
 Sean O'Sullivan  
 Simon Cronin  
 Richard Walsh  
 Sinead Murphy  
 Peter Boers  
 Danny Costello  
 Brian Sweeney  
 Peter Kelly  
 Janice Redmond  
 Joan Moroney  
 Lisa Costello  
 Ronan Kilbride  
 Brian Murray  
 Ronan Walsh  
 Fiona Molloy  
 Margaret O'Brien  
 Valerie Reid  
 Sean Connolly  
 John McHugh  
 Orna O'Toole  
 Shane Smyth  
 Peter Widdes Walsh  
 Tom Monaghan  
 Habibur Rahman



## Abbreviations

ALOS	-----	Average Length of Stay
AMAU	-----	Acute Medical Assessment Unit
AMU	-----	Acute Medical Unit
ANP	-----	Advanced Nurse Practitioner
CEO	-----	Chief Executive Officer
CHO	-----	Community Healthcare Organisation
CNM	-----	Clinical Nurse Manager
CNS	-----	Clinical Nurse Specialist
CPD	-----	Continuing Professional Development
CRT	-----	Community based rehabilitation team
CSO	-----	Central Statistics Office
CT	-----	Computed Tomography
DBS	-----	Deep brain stimulation
DNA	-----	Did not attend
DMT	-----	Disease Modifying Treatment
DOH	-----	Department of Health
ED	-----	Emergency Department
EPR	-----	Electronic patient record
EU	-----	European Union
FER	-----	Full Economic Rate
GP	-----	General Practitioner
HIPE	-----	Hospital Inpatient Patient Enquiry system
HIQA	-----	Health Information and Quality Authority
HSCP	-----	Health & Social Care Professional
HDU	-----	High Dependency Unit
HSE	-----	Health Service Executive
ICD	-----	International Classification of Diseases
ICGP	-----	Irish College of General Practitioners
ICU	-----	Intensive Care Unit
IDT	-----	Interdisciplinary team
IPU	-----	Irish Pharmacy Union
ISA	-----	Integrated Service Area
IT	-----	Information Technology
KPI	-----	Key Performance Indicator
LOS	-----	Length of Stay
LTI	-----	Long term illness

MCN	-----	Managed Clinical Network
MDT	-----	Multi Disciplinary Team
MND	-----	Motor Neurone Disease
MOC	-----	Model of Care
MMUH	-----	Mater Misericordiae University Hospital
MRI	-----	Magnetic Resonance Imaging
MS	-----	Multiple Sclerosis
NAI	-----	Neurological Alliance of Ireland
NICE	-----	National Institute for Health &
NSF	-----	National Service Framework (UK)
OPD	-----	Outpatients Department
PCCC	-----	Primary Community & Continuing Care
PCRS	-----	Primary Care Reimbursement Scheme
PD	-----	Parkinson's Disease
PHN	-----	Public Health Nurse
PWMS	-----	Patient with Multiple Sclerosis
RCPI	-----	Royal College of Physicians Ireland
RDPI	-----	Regional Directors of Performance Improvement
ROI	-----	Republic of Ireland
SIGN	-----	Scottish Intercollegiate Guidelines Network
TAS	-----	Treatment Abroad Scheme
WHO	-----	World Health Organisation
WTE	-----	Whole Time Equivalent
YLD	-----	Years of healthy life lost as a result of disability



## Foreward

*“Start by doing what is necessary  
then do what is possible  
and suddenly you are doing the impossible!”  
Francis of Assisi 1182-1226*

Neurology is the branch of medicine involved in the care of patients who present with a wide variety of neurological disorders; some of which occur frequently such as Alzheimer’s disease and other dementias, Parkinson’s disease, stroke, epilepsy, head trauma, multiple sclerosis, motor neurone disease, headache (and migraine) and other rarer disorders including Guillain-Barré syndrome, progressive supranuclear palsy, spinocerebellar ataxias and muscular dystrophies.

Neurologists see patients with both acute and chronic presentations. Epilepsy, stroke, head trauma, Guillain-Barré syndrome, acute delirium, meningitis and encephalitis amongst others are examples of neurological conditions which present acutely. Neurodegenerative disease such as Alzheimer’s disease, Parkinson’s disease, peripheral neuropathy, neuromuscular disorders and muscular dystrophy, epilepsy, migraine and headaches are classified as more chronic neurological illnesses.

### THE CHALLENGE AHEAD

*“Tis better to have tried and failed then never to have tried at all”*

Over 700,000 people in Ireland have a neurological condition and neurological conditions account for one in five acute medical admissions and one in eight patient attendances to a general practitioner.

Neurological disorders and cerebrovascular disease, when combined represents 7.1% of the total global burden of disease; measured in disability adjusted life years (DALY), for all causes and all ages. Cerebrovascular disease is the largest neurological contributor to this burden and accounts for 4.1% of total global DALY; followed by headache at 0.97%, migraine at 0.9%, tension-type headache at 0.07%. Meanwhile other neurological disorders account for 0.72%, with epilepsy at 0.7%, Alzheimer’s disease and other dementias at 0.46%, Parkinson’s disease at 0.08%, multiple sclerosis accounting for 0.4%, meningitis for 1.2% and encephalitis for 0.29%. Significantly, traumatic brain injury represents 1.2% of the total DALY. Stroke is the second leading cause of death globally and the third leading cause of premature death and disability measured in DALY. In addition there is a huge cost burden on society.

Mind and brain disorders were estimated to cost the European Union approximately €800b in 2012. Furthermore the global burden of neurological diseases is likely to increase with the ageing population as neurodegenerative diseases such as Alzheimer’s disease, Parkinson’s disease and other forms of dementia are expected to increase in prevalence. The model of care of The National Clinical Programme for Neurology is a blueprint for the future set up of acute and chronic neurological services for Ireland. It is intended that such services will be delivered in an efficient, equitable and cost effective manner by supported, skilled, professionals working in a multidisciplinary manner using a person-centred approach to care.

As neurology is essential to the effective management of patients in acute and chronic medical disorders it clearly has close connections to many other national programmes including epilepsy, stroke, acute medicine, old age medicine, critical care, radiology, rehabilitation medicine, palliative care, paediatrics and also to mental health services.

## WHAT HAS HAPPENED TO DATE?

*“There’s no point dwelling on what might or could have been, you just go forward”. Jack Nicholson*

Prior to the establishment of the Neurology Programme, a Neurology Needs Document was produced over a two-year period under the leadership of Dr. Marie Laffoy. This substantial body of work produced a report of three parts and detailed the strengths and weaknesses in neurological care in Ireland. The document served as an important background document to the Model of Care for the National Clinical Programme for Neurology (see [www.nai.ie](http://www.nai.ie)).

The Neurology Programme has evolved through a number of different iterations. Initially the programme focused on neurology outpatient services (supply, demand and capacity) under the leadership of Dr. Brian Sweeney working closely with Ms Sharon Morrow, OPD Programme Manager and Dr. Emer Feely from Public Health Medicine. The Neurology Outpatient Service (supply, demand and capacity) document was published in July 2010 outlining the strengths and weaknesses of the neurology services in Ireland. This was completed as part of the outpatient programme run by Dr. Barry White, then Director of Quality & Clinical Care Directorate within the HSE.

Subsequently, I took on the role of National Lead in 2011 using the above document and its recommendations leading to the appointment of nine of ten recommended consultant neurologists over the last five years.

The programme also broadened its objectives to address inpatient services, which include both acute and chronic neurological care. In particular the Programme recognises the extensive work undertaken by consultant neurologists to provide inpatient consultations for other medical and surgical services. The inpatient consult service is a crucial aspect to neurological care for all acute hospitals as it frequently leads to a change in diagnosis and management resulting in better outcomes for our patients.

It is of concern that many acute Irish hospitals do not have a neurologist on staff nor do they have access to a neurologist for inpatient consults or neurology outpatient service. It is likely this gap results in significant deficits in the management of patients with acute medical and surgical problems.

In the past, neurology concentrated predominantly on the diagnosis of complex neurological problems which had limited pharmacological or therapeutic options to address these devastating and disabling disorders. This has utterly changed in the last twenty years, with an increasing array of therapies that significantly improve patient’s lives. These include thrombolysis and intra-arterial thrombectomy in stroke care; multiple new medications and neurosurgery for epilepsy; deep brain stimulation surgery for Parkinson’s disease and other movement disorders; new monoclonal antibody therapy for multiple sclerosis that decreases risk of relapse by over two-thirds; new medication and therapeutic approaches such as Botulinum toxin for migraine and the advent of various immunotherapies for the many inflammatory disorders of neurology. With the increasing arsenal of effective therapies the demand for care increases.

However there is a National problem with equitable access to neurological care and pharmacological therapy. Availability of intravenous monoclonal antibody in multiple sclerosis varies across the country and can depend on whether the patient has private health insurance or not. A patient with private healthcare insurance can access monoclonal antibody therapy in private centres with relative ease, whilst a patient without insurance may or may not get access to the therapy depending upon

their postal address. Some hospitals limit the number of MS patients they treat with these high tech therapies because of limited resources. Hence if the patient with multiple sclerosis lives in the catchment area of a hospital that has reached its annual limit, the patient will not be able to receive the high tech therapy. Clearly this is an unsatisfactory situation and requires a national solution by providing central funding for these effective, but expensive, high tech therapies similar to that which has been done for chemotherapy for cancer patients.

The National Clinical Programme for Neurology has communicated and interacted with a huge number of other groups involved in care of patients with neurological illnesses and has conducted site visits to most of the eleven neurology units around the country. These visits were very insightful as they often highlighted the individual strengths of particular units but also the overall lack of available resources (staffing, infrastructure, inpatient beds, brain and spinal imaging etc). The programme has attempted to take what is best practice in certain units and use the best for the service development model nationally. For example the neurology outpatient services supply demand and capacity document clearly identified a number of units that were able to see more new patients than return patients because of:-

1. Dedicated outpatient space without having to compete with other services for clinic space.
2. Having an adequate number of consultant neurologists with different subspecialty expertise to increase access for patients to neurology clinics.
3. Access to clinical nurse specialists so that many return patients can be seen in nurse-led clinics; thus freeing up more slots in the consultant-led OPD clinics for new patients.
4. Adequate access to diagnostic services such as neuroimaging so that patients can get timely access to CT and MRI scans for diagnosis and management, e.g. acute relapse of multiple sclerosis.
5. Adequate access to specialist services from Health and Social Care Professionals (HSCP) including therapies and diagnostics.
6. Adequate number of NCHDs to staff the clinics & manage the inpatient service

The Neurology Programme has been enormously impressed by the hard work and dedication shown by the consultants, non-consultant hospital doctors (NCHDs), nurses, services allied to medicine and front line administration staff involved in the care of patients with neurological conditions. In Ireland, the neurology consultants do a vast amount of work to care for huge numbers of outpatients, inpatients including out-of-hours acute neurology and thrombolysis for stroke, inpatient consult service. At the same time many are involved in administration, medical management, fundraising, patient advocacy, education and high quality research in clinical neuroscience. For example Beaumont Hospital and Cork University Hospital provide an excellent 24 hour national on-call service for acute neurology patients with a consultant neurologist available 7 days per week. This acute neurology service is good for patient care and decreases length of stay. Proper support for these busy consultants is needed to avoid physician burnout which is prevalent in the speciality of neurology internationally.

Furthermore the Neurology Programme has identified significant innovation among the various neurology sites. Examples include the development of Neurolink at St Vincent's University Hospital, which provides a structured electronic referral and consultation service to local general practitioners and also to other hospital-based specialities for inpatient consultations including the ED department.

The success of NeuroLink is clearly apparent as it provides rapid consultant opinions on patients with acute and chronic neurological disorders and provides an outreach approach to patients in the community and beyond. Another example includes the availability of dedicated outpatient space to assess neurological patients who attend Cork University Hospital, the Dublin Neurological Institute at the Mater Misericordiae University Hospital, Galway University Hospital and at St Vincent's University Hospital. These three units have the flexibility to increase and expand outpatient clinics to meet the demand using their dedicated outpatient space.

A further example of innovation is the development and opening of the Dublin Neurological Institute [www.neurologicalinstitute.ie](http://www.neurologicalinstitute.ie) (DNI) at the Mater Misericordiae University Hospital in 2008. The DNI provides dedicated space for outpatient and day ward care for neurological patients. It is a non-profit charity and but an independent company. Thus it has the flexibility to employ staff to develop new services and meet the ever increasing demands. The DNI gets funding from fund raising, philanthropy, legacies, grant agencies and other sources. As a result it has been able to double the number of outpatients seen annually, and also increase day ward activity thus decreasing the demand on inpatient services. The DNI model has been copied to open a North West Neurological Institute (NWNi) in the grounds of Sligo General Hospital using unrestricted Pharma funding. In view of the ongoing problems with funding nationally I believe that the DNI and NWNi model of health care could be considered as a mechanism to increase and expand hospital neurological services nationally and also attract the best consultant neurologists back to Ireland by providing them with an efficient means to develop their best clinical academic service.

### **EDUCATION & RESEARCH**

***“Education is an admirable thing, but it is well to remember from time to time that nothing that is worth knowing can be taught”. Oscar Wilde***

The Neurology Programme highlighted the significant need for education and research in clinical neuroscience. There is a need attract increased numbers of NCHDs to the speciality of neurology to meet the increased demand for neurology care and expected expansion of consultant neurologists over the next decade. Some of these NCHDs should be encouraged to pursue academic neurology by supporting academic departments of neurology in collaboration with the Irish Universities and the Royal College of Physicians in Ireland. Moreover, the Neurology Programme identified the need for increased education and research opportunities for doctors, nurses and health and social care professionals as well as for patients their families and carers. For example, a series of videos have been developed for The Irish College of General Practitioners to provide advice on how to assess and examine a neurological patient, as well as more specific information on how to assess patients for Parkinson's disease, epilepsy and multiple sclerosis.

Increasing the knowledge of neurological disorders nationally is important, as this branch of medicine, given its complexity and expansive remit often intimidates medical students (“neurophobia”) thus leading to significant lack of awareness of many of the disorders and their management. As a result, patients frequently have delayed diagnosis, delayed or incorrect treatment and subsequent increased disability. Of note 110,109 (2.6%) of the Irish population were significantly disabled by their neurological condition in 2007 and this is expected to increase to an estimated 131,820 by the year 2021.

**WHATS LACKING**

*“The human mind is like an umbrella - it functions best when open”. Walter Gropius*

There are significant gaps in neurological services in the country. For example there is no neurologist in any of the Midland hospitals (Mullingar, Naas, Portlaoise, Tullamore) and there is only one neurologist in all of the northwest of Ireland (Donegal, Leitrim, Mayo, Roscommon, Sligo). The Midwest has only recently appointed a second consultant neurologist and is inadequately resourced from both space and staff perspective thus leading to prolonged waiting times for outpatient visits and there are no inpatient neurology beds. Meanwhile some hospitals have no inpatient neurology services with a limited outpatient service (Connolly Hospital, St Luke’s Kilkenny, Monaghan, Our Ladies Drogheda, Letterkenny). Other areas such as Cork, Galway and Dublin have relatively well developed neurological services but these still have long waiting lists for outpatient appointments mainly because of an increasing demand for diagnosis and treatment of the vast number of neurological disorders and the limited number of consultant neurologist in Ireland compared to international figures.

**THANKS TO**

This Model of Care document for neurology could not have been developed without the significant work completed by Dr. Marie Laffoy and her team in the Neurology Needs documents; Dr. Brian Sweeney working closely with Dr. Barry White; Dr. Emer Feely and Sharon Morrow for the Neurology OPD services document; Noreen Curtin who took on the role of Neurology Programme Manager in 2014 and handed on the baton to Edina O’Driscoll and more recently by the Neurology Working Group including Helen Cornelissen, Orla Hardiman, Elaine Harrington, Edina O’Driscoll, Mags Rogers, Jacqui Scott, Brian Magennis, Chris McGuigan, Timothy Counihan, Brian Sweeney and Niall Tubridy. Also noted are the contributions of consultant colleagues through the programmes clinical advisory group and their help and hospitality at various site visits.

In particular I would like to highlight the huge work done by Sharon Morrow, Noreen Curtin and Edina O’Driscoll, Neurology Programme Managers who worked away, often in the background, pulling together crucial data for this document, while at the same time communicating with an array of individuals. Without their trojan work the improvement in neurology in Ireland that we have seen in the last five years (the appointment of eleven consultant neurologists nationally) and the development of this document would not have happened.

The focus of the Neurology Programme is to improve access for patients to both outpatient and inpatient care which will lead to earlier diagnosis, earlier treatment, improved outcome and consequent improved quality of life. This will ultimately decrease cost to the State by decreasing disability.

I hope and believe that this Model of Care document can be used to rapidly improve neurological services nationally by providing dedicated space for outpatient and day ward and inpatient care; increase the number of consultants, NCHDs, nurse specialists, therapists and social care professionals; fund and resource highly effective medications and therapies so that disability and death can be decreased and support the development of academic clinical neuroscience in the country by the appointment of full professors of clinical neuroscience.

***Professor Tim Lynch***

***Clinical Lead***

***National Clinical Programme for Neurology***



## Executive Summary

Neurology is the branch of medicine dealing with disorders of the nervous system, including the brain, brain stem, spinal cord, root, plexus, peripheral nerves and muscle.

“There is ample evidence that pinpoints neurological disorders as one of the greatest threats to public health” (World Health Organisation (WHO), 2006). In Ireland, we need to prepare our services so that they can be responsive to the growing and changing needs of our ageing population. We also need to be prepared to deliver world class services in line with advancing new therapies driven by the neurosciences.

Nearly three quarters of a million people in Ireland have a neurological condition. It is projected that 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. It is estimated 44,000 people are newly diagnosed with a neurological condition in Ireland every year and over 110,000 are significantly disabled.

The total cost of disorders of the brain and mind was estimated at €798 billion in Europe in 2010. This estimate is likely to be conservative as some disorders could not be included due to limitations in the available data.

Reference to UK data would indicate that 10% of visits to Accident and Emergency Departments are for a neurological problem as are 20% of visits to the General Practitioner.

The management of people with neurological conditions crosses all divisions from acute hospitals, mental health, social care, primary care and health and wellbeing and requires an integrated approach.

The overarching aim of the neurology programme is that the patients should have equitable access to a high quality responsive service which provides accurate diagnosis and appropriate management for all neurological conditions. We aim for excellence in neurology care and the best outcome for our patients.

Specialist care should be provided by a Consultant Neurologist working with a team of specialist nurses, Health and Social Care Professionals including dietitians, medical social workers, neuropsychologists, occupational therapists, orthoptists, speech and language therapists, podiatrists, pharmacists and physiotherapists. Interfaces with other related services including neuropsychiatry, neurosurgery, neuroophthalmology, neuroradiology and neuropathology are also essential as well as others such as psychiatry, palliative care and rehabilitation medicine physicians.

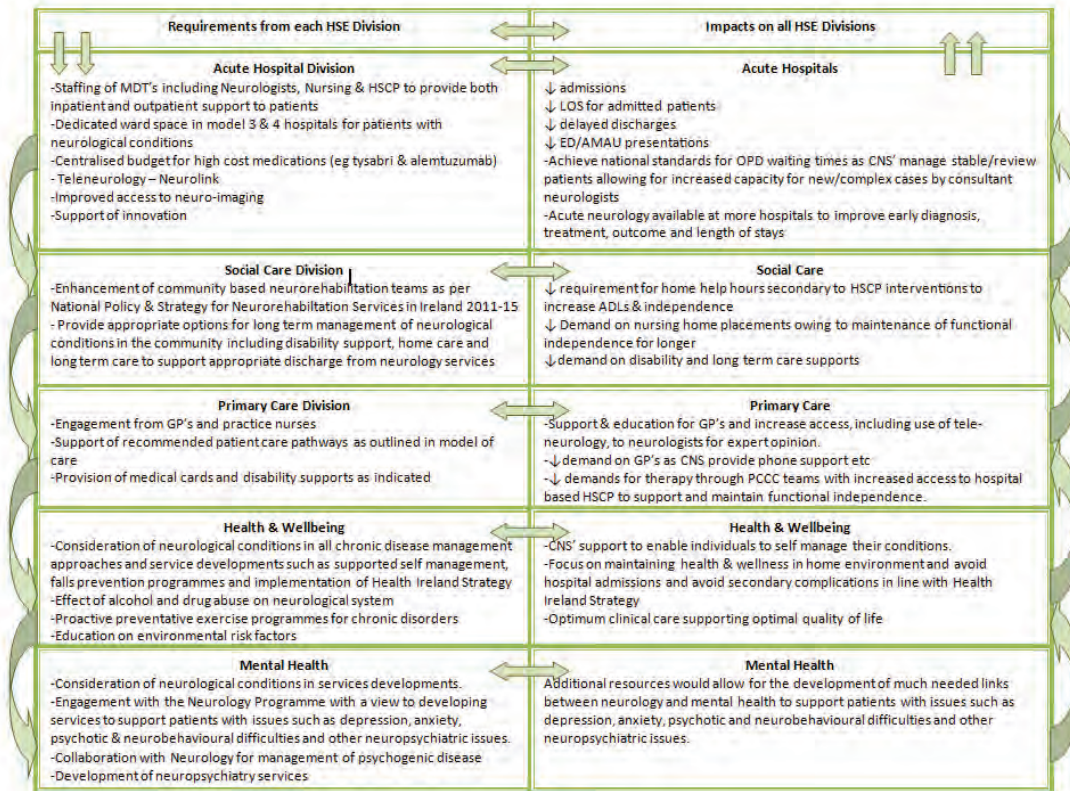
The Neurology Programme supports innovation. An example of this includes the development of a teleneurology service, NeuroLink, at St Vincent's University Hospital and the establishment of the Dublin Neurological Institute [www.neurologicalinstitute.ie](http://www.neurologicalinstitute.ie) (DNI) at the Mater Misericordiae University Hospital (MMUH) which has decreased the waiting times for outpatient significantly. The DNI works closely with the MMUH and HSE in providing a state-of-the-art service. The DNI model is one of excellence, efficiency and brings much-needed resources into Irish healthcare.

### i) Scope

The Model of Care (MOC) for neurology services has been developed by the National Clinical Programme for Neurology. The aim of this model of care is to provide a framework for neurology services which follows international best practice and should be delivered within an integrated service approach. It covers the full spectrum of care provided in hospitals (in-patient & out-patient). It also makes specific recommendations as to what type of care would



be considered best practice with respect to managing patients with long term neurological conditions in the community. While initial resource requirements are primarily hospital based, the Neurology Programme anticipates benefits will be seen across all HSE divisions (Table 1). The development, agreement and implementation of care pathways and standards of practice with all partners which cover the patient pathway from prevention and supported self-management through to acute hospital care will ensure that the level of care is appropriate to each patients needs.



**Table 1: Cross divisional requirements and impacts of implementation**

The MOC proposes that while the initial presentation of patients can vary (i.e. scheduled care/unscheduled care) access to the necessary services for diagnosis and management of neurological conditions should be equitable, efficient and consistent throughout the country regardless of where the patient resides.

ii) **Context**

The current model of care promotes best practice in the delivery of neurology services by adopting key international standards and promoting support for evidence-based and research-led practice throughout the service. The programme recognises that a key requirement of best practice lies in ensuring appropriate provision of staffing ratios, skill mix and training as well as access to space, treatments and diagnostic services.

The programme recognises the importance of involving people with neurological conditions and their families in the design and delivery of neurology services. The current model of care was developed in close partnership with the Neurological Alliance of Ireland, the national umbrella for neurological patient organisations. People with neurological conditions were consulted in relation to the development of pathways for Multiple Sclerosis, Headache and Parkinson's

Disease and reports from this consultation are included in the document. A specific section of the model of care is dedicated to improving the patient journey for people with neurological conditions. The programme recognises the important role of not-for-profit organisations in the infrastructure of neurological care in this country and the model highlights the range of services and supports they provide.

This document should also be read in conjunction with other relevant models of care developed through the National Clinical Programmes and Strategy Division, in particular the Models of Care of the Epilepsy<sup>1</sup>, Rehabilitation Medicine<sup>2</sup>, Older Persons,<sup>3</sup> Stroke<sup>4</sup> and Critical Care<sup>5</sup>. The publications of the National Clinical Programme for Palliative Care such as their needs assessment and competency framework should also be referenced (Department of Health (2001),<sup>6</sup> HSE (2014) <sup>7</sup> Together these models of care cover the continuum of care for patients with neurological conditions from acute management, diagnosis, hospital-based services (including therapy), specialist rehabilitation and continuing care in the community led by specialist neurorehabilitation teams supported by primary and continuing care (PCCC), palliative and the not-for-profit sector.

The Neurology Programme promotes the development of Advanced Nurse Practitioners (ANP) and the advanced practice within health & social care professions and potential development of Therapy-Led and more Nurse-Led clinics to enhance out-patient services. A key message within the forthcoming Epilepsy Model of Care promotes the above development of Advanced Nurse Practitioners (ANP) role in out-patient services.

The Epilepsy Programme also outlines how PCCC services and hospital-based services can work more closely to support the patient, by developing a suite of standard operating procedures (SOPs), which clearly outline the roles and responsibilities of all those involved in care of the patient with epilepsy. The Neurology Programme plans to emulate and expand on this work. The development of SOPs for the management of a range on neurological conditions, within various care settings, in collaboration with key stakeholders are future goals of the Neurology Programme.

The Epilepsy Programme also outlines a plan to build a managed clinical network with regional clinical leads referring into tertiary centres for specialist monitoring and treatment of patients.

Similarly, recommendations within this model of care are in line with recommendations within the model of care for Stroke, particularly in relation to management of acute patients within specialist neurology in-patient wards and the advancement of the use of telemedicine within neurology.

- 
- 1 National Clinical Programme for Epilepsy, Model of Care 2015 (forthcoming). Clinical Strategy & Programmes Division, HSE
  - 2 National Clinical Programme for Rehabilitation Medicine 2015 (forthcoming). Clinical Strategy & Programmes Division, HSE
  - 3 National Clinical Programme for Older People, Model of Care
  - 4 National Clinical Programme for Stroke, Model of Care July 2012. Clinical Strategy & Programmes Division, HSE, July 2012
  - 5 National Clinical Programme for Critical Care. Right Care, Right Now. Model of care for Adult Critical Care Oct 2014
  - 6 Department of Health and Children (2001) Report of the National Advisory Committee on Palliative Care. Dublin Stationary Office. <http://www.dohc.ie/publications/pdf/nacpc.pdf?direct=1>
  - 7 Palliative Care Competence Framework Steering Group. (2014). Palliative Care Competence Framework. Dublin: Health Service Executive. Accessible on [www.hse.ie/palliativecareprogramme](http://www.hse.ie/palliativecareprogramme)

Telemedicine is seen as a way to increase equity of access to healthcare. Traditionally, part of the difficulty in achieving equitable access to health care has been that the provider and recipient must be in the same place at the same time. Advances in information and communication technologies, however, have created unprecedented opportunities for overcoming this by increasing the number of ways that health care can be delivered (Craig and Patterson 2005)<sup>8</sup>.

The National Clinical Programme for Stroke has, through HIPE, developed a stroke register which should be considered for wider application across neurological conditions. The 'Network Model' is also referenced within the model of care for Stroke (HSE 2012). They state;

***"The proposed Irish model aims to balance the elements of stroke care that can be delivered safely and effectively at general hospitals with those that require expertise or technology that is available at a partnering regional hospital"***

Their model also proposes a governance structure for stroke that operates across the continuum of care for patients.

The Model of care for Rehabilitation Medicine further develops the need for specialist rehabilitation services for people with neurological conditions within acute hospital, post-acute hospital and community settings. When aligned, the model of care for neurology and the model of care for rehabilitation medicine should outline a more comprehensive view of the continuum of care for people with neurological conditions many of whom result in chronic conditions with disability that can improve or stabilize with rehabilitation.

The managed clinical network proposed within this model of care should be developed in tandem with the managed clinical rehabilitation network as described by the National Clinical Programme for Rehabilitation Medicine. The managed clinical rehabilitation network describes a network based on the hub & spoke model with a national tertiary centre for complex specialist rehabilitation, population based specialist rehabilitation services (in-patient) and community based specialist neuro-rehabilitation teams.

As neurology patients are frequently elderly Neurology services and services for older people will closely overlap with their respective populations served. Both services should work closely to provide appropriate care for the significant population of older people with neurological conditions. The Neurology service will look to the model of care for older people and the protocols they have developed for the management of patients in ED/AMAU and criteria/processes for identifying patients who may require admission to the specialist neurology ward. In general the Neurology Programme recommends the development of dedicated neurology wards for the care of patients with acute, sub-acute and chronic disorders. Similarly, protocols facilitating communication with community and primary care in preparation for discharge will be considered for application across wider neurology services.

Considering the progressive nature of many neurological conditions patients may require palliative care management. It is therefore advisable that all members of the neurology multidisciplinary team develop competencies in the management of palliative care needs. This recommendation reinforces the position of the National Clinical Programme for Palliative Care & the Department of Health (DoH 2001)<sup>9</sup> that palliative care is the responsibility of the

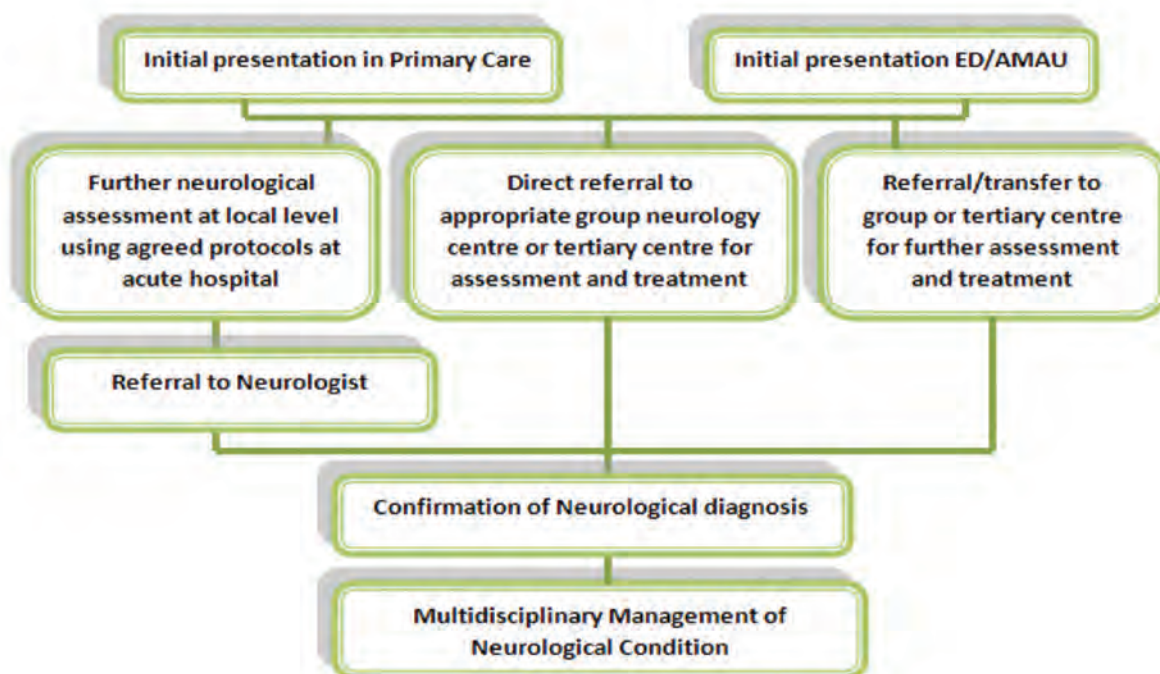
8 Craig, J, Patterson V. Introduction to the practise of telemedicine. Journal of telemedicine and telecare 2005; 11:3-9

9 Department of Health and Children (2001) Report of the National Advisory Committee on Palliative Care. Dublin Stationary Office. <http://www.dohc.ie/publications/pdf/nacpc.pdf?direct=1>



entire healthcare team. The Neurology Programme supports and recommends reference to the Competency Framework which has been developed by the National Clinical Programme for Palliative Care (HSE 2014)<sup>10</sup>.

Neurologists are required in the acute care of patients in intensive and critical care (ICU/HDU) units to assist with making an early diagnosis and management of conditions. In this regard, the Neurology Programme supports the recommendations of the National Clinical Programme for Critical Care patients with critical care needs following sudden onset of neurological illnesses and traumatic neurological injuries. These recommendations state that patients with neurocritical needs should 'access and benefit from neurocritical care neurospecialist services in a supra-regional neuroservices centre. The services provided in such a centre include neurosurgery, neuro-interventional radiology, clinical neurophysiology, neuropathology etc5.



**Figure 1: referral pathway for patients with neurological conditions**

The Programme acknowledges that the patient journey can be complex and it is the role of the programme to make recommendations on best practise at the key points along this journey as well as standardising this pathway/journey for patients whilst attempting to eliminate constraints or blockages (Figure 1). The programme takes cognisance of the fact that for the majority of neurology patients their patient journey is experienced in their own home or in the community. Patients primarily reside in their own homes and are admitted to acute hospital facilities for acute care interventions. As a consequence statutory and non-statutory organisations such as outpatient and follow up services need to liaise seamlessly with hospital

10 Palliative Care Competence Framework Steering Group. (2014). Palliative Care Competence Framework. Dublin: Health Service Executive

services to ensure close communication. The role of the voluntary not for profit organisations is a very important one for patients who gain support, assistance advice and therapeutic intervention through this avenue.

The Model of Care builds on the work outlined by Marie Laffoy and many colleagues in the 2007 review 'Neurosciences in Ireland; Strategic Review of Neurology and Clinical Neurophysiology services'<sup>11</sup>. This substantial review introduced the development of a managed clinical network (MCN) for neurology. This Neurology Model of Care Document proposes the development of a MCN for neurology within the newly forming networks, it is proposed that the MCNs will comprise national tertiary services specialising in the management of complex conditions, regional neurology services and local neurology services working together towards best patient outcomes.

The vision of achieving a world class neurology service for acute, subacute and chronic diseases is achievable in Ireland (Laffoy 2007<sup>11</sup>). The realisation of this vision requires that there are significant increases in staffing and resources and 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 across all divisions that is well resourced and where all parts of the service work together to achieve best patient outcomes.



**Figure 2: cross divisional supports**

It was the belief of the Laffoy review<sup>11</sup> and is also the belief of the National Neurology programme that the realisation of the managed clinical network for neurology, as outlined in this model of care is integral to achieving this vision.

11 Neurosciences in Ireland. Strategic Review of Neurology and Clinical Neurophysiology services, Dec 2007. [http://www.nai.ie/go/resources/guidance\\_policy\\_standards/guidance\\_poicy\\_standards\\_ireland/strategic-review-of-neurology-and-neurophysiology-services-in-ireland](http://www.nai.ie/go/resources/guidance_policy_standards/guidance_poicy_standards_ireland/strategic-review-of-neurology-and-neurophysiology-services-in-ireland)

### iii) Recommendations



#### 1. Optimising service delivery and Multidisciplinary care

Integrated services supporting the delivery of best practice in the field of neurology includes;

- Equitable access to diagnostics, treatments & management
- Patient-centered high quality service
- Effective services based on best available evidence
- Timely service
- Efficient – reducing waste & duplication
- Patient safety
- Excellence in outcomes
- Well trained staff

#### Sustaining services by addressing service gaps

- The model of care outlines the requirements needed to overcome significant gaps within the service. The delivery of a service based on international best evidence is dependent on these gaps being addressed.

#### Cohesive and comprehensive Multidisciplinary Team (MDT) care;

- The development of the role and staffing of the multidisciplinary team in the management of patients at inpatient, outpatient and community levels is outlined.
- The MOC for Neurology outlined in this document details how audiologists, dietitians, medical social workers, nurses, occupational therapists, orthoptists, orthotists, podiatrists, physicians, physiotherapists, neuropsychologists, speech and language therapists, other Health and Social Care Professionals (HSCPs), voluntary organisations and service providers will work with patients and collaborate with specialist colleagues in providing optimal care for patients in the Irish healthcare system.

#### Person centred approach to service delivery

- The Neurology Programme recognises the requirement for people with neurological conditions to be at the center in managing their care, and endorses the key principles outlined by the International Alliance of Patient Organisations against which services can be measured;
- Respect
- Choice & Empowerment
- Patient involvement in health policy

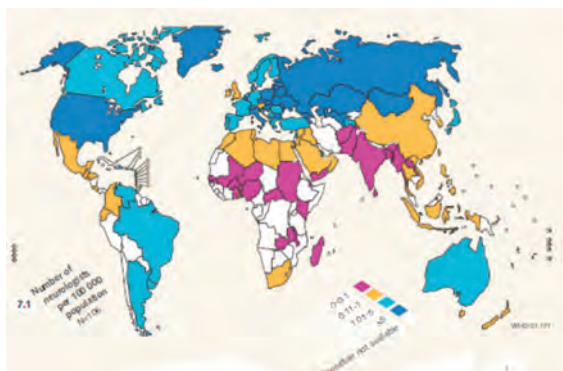


- Access and support
- Information

### Team working across the continuum of care

- Better integration across service delivery sites will foster a more cohesive approach in to management of patients. This applies across disciplines and specialities from acute management to palliative care needs.

## 2. Staffing and resourcing within neurology services



**Figure 3; ratios of neurologists per 100,000 populations globally**

Consultant neurologists should work in teams, and the number of consultant posts should be in line with international best practice. In Ireland the current ratio of neurologist to population is 1:132,352, ranging in some areas of the country to as high as 1:200,000. The median number across Europe is 4.84 per 100,000. The ratio recommended by RCP (2011) is 1:70,000<sup>12</sup>. Additional consultants would improve equitable access to early diagnosis and treatment and would ensure the safe expansion of neurology services and permit a

stronger interface between neurology, acute medicine and medicine for the elderly in the management of complex neurological disorders including cerebrovascular disease and stroke. Each neurologist should be supported by a full multidisciplinary team with competencies in neurology including clinical specialists in the Health and Social Care Professions and Nursing. Specific details are described in the requirements chapter where needs of a successful national neurology service are explored.

A significant amount of work has been done in reviewing outpatient waiting list and capacity. This work, undertaken in 2010 (Sweeney 2010)<sup>13</sup> led to the welcomed appointment of 9 of the 10 recommended additional Consultant Neurologist posts. While this went some way towards addressing the imbalance between demand and capacity, the ever increasing demands on services because of more effective treatments require significant further expansion in work force. Moreover, whilst welcomed this additional staffing was not accompanied by the perquisite addition of non-consultant hospital doctors, therapists and nurses which needs to be addressed.

The Neurology Programme recommends a national audit of staff working in neurological services across all disciplines and all divisions & service delivery sites. A truly meaningful gap analysis of current service provision against international best practice cannot be undertaken until there is accurate information on current staffing levels. While the programme undertook a very helpful qualitative review of staffing across services, this review was limited in that it focused primarily on hospital based services.

12 Royal College of Physicians. Local adult neurology services for the next decade. Report of a working party. London: RCP, 2011

13 Sweeney B et al. Neurology OPD services – supply, demand and capacity Nov 2010

### 3. Service configuration and managed clinical networks

Specific focus is given to in-patient services, with recommendations that patients, with neurological diagnoses are cohorted on specific neurology wards to improve outcomes, decrease length-of-stay and stimulate education and research in clinical neuroscience. Irrespective of the 'level' of the service, for all in-patient neurology services the following is recommended

- No service/hospital should have a Neurologist working in isolation.
- Building a service around one individual is unsustainable. It leaves both the individual and the service exposed to risk. The considerable demands on a neurology services are detailed in this model of care. Given the extent of these demands the Neurology Programme would recommend that each hospital, with a neurology service, should have a minimum of 3 Neurologists covering that service.
- Neurology in-patient beds should be cohorted to ensure that neurology patients are treated by specialists in neurology in a contiguous area. The benefits both for outcomes and cost (reduced length of stay) are detailed within this document. Supporting protocols will be adapted from the Model of Care of the Clinical Programme for Stroke.
- The Neurology Programme recommends the development of neurology services within all Model 3 and Model 4 hospitals as complex neurology patients do better under the care of a neurology service.
- Further development of the recommendations contained within the Laffoy Review (Laffoy 2007)<sup>11</sup> and the models of care for both Epilepsy and Stroke whereby networks with clear links to local, regional and national services are described, and an overarching governance structure within the new hospital groups outlined.
- The Neurology Programme recommends the provision of dedicated OPD space and facilities for neurology clinics (e.g., DNI and SVUH neurology OPD). Nationally, there appears to be more scope for neurology units with protected space to accommodate new patients and expand their services.
- The neurology programme also draws on work initiated by the National Clinical Programmes for Epilepsy and for Rheumatology in relation to out-patient services. These programmes outline the significant role which health & social care professionals and nurses play in the assessment and management of patients in an outpatient setting. Similar roles are in existence across neurology services with a number of Clinical Nurse Specialists in MS, PD, Deep Brain Stimulation (at the DNI), however significant resources are required to ensure services develop across the country to ensure that variation in patient experience is limited.
- The Neurology Programme advocates the collaborative and coordinated care delivered by a team working in an interdisciplinary way. Key factors distinguishing the interdisciplinary team (IDT) from the multidisciplinary model is that team members work closely together in goal setting, treatment, decision making (Albrecht et al 2001)<sup>14</sup>.

---

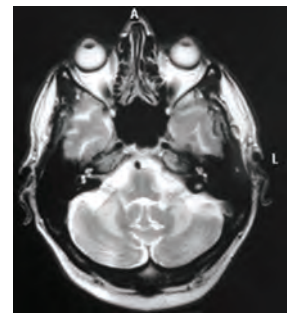
14 Albrecht G, Higginbotham N, Freeman S (2001) Transdisciplinary thinking in health and social science research: definitions, rationale and procedure. *Health Social Science: A transdisciplinary and complexity perspective*, 4, 78-89

#### 4. Links to other health specialties

- Gaps are also identified outside of direct service provision such as links with community based services and long term care. Standard operating procedures describing the roles and responsibilities for the management of patients with neurological conditions will be developed, based on similar SOPs developed within the National Clinical Programme for Epilepsy and implemented nationally.
- Clear lines of communication will need to be developed to support collaboration between hospital based staff and colleagues in the community to ensure continuity of care for patients.
- Support for GP's in the management of chronic neurological conditions is required, both in terms of specific educational programmes and direct defined links with hospital based neurology services. Implementation of the care pathways in Headache, Multiple Sclerosis, Parkinson's Disease and Motor Neurone Disease should also provide guidance on the appropriate management of patients presenting with these conditions in primary care settings.
- Developing links with services in the North of Ireland are also recommended, specifically in relation to the development of an 'All-Island' approach to Deep Brain Stimulation. The programme has highlighted this as a need and is available to support the development of such an initiative.
- Collaboration with colleagues in other specialty areas is also recommended, including genetics, neuropsychiatry, and rehabilitation specialists to name a few.

#### 5. Medicines management and access to diagnostic and support services

- Equitable access to diagnostics and treatments is one of the overarching aims of the neurology programme. To this end the programme has specific recommendations with respect to referrals, neuroradiology services and a centralised management system for funding of high cost medications (e.g., monoclonal antibody therapy in Multiple Sclerosis). This would avoid local variations in accessibility and support standardisation of care. Access to scans is no longer only required for diagnostic purposes but are also crucial in the management of conditions such as Multiple Sclerosis, stroke, epilepsy, acute delirium, encephalitis and brain tumours.
- Education and information on medicines are key tools in empowering patients to better manage their own conditions thus improving self-esteem, autonomy and independence. It has also been shown to have a direct relationship with compliance with medications and improved patient outcomes.
- The programme also acknowledges the need for collaboration with acute hospital services in the management of neurological patients in an in-patient setting, particularly in relation to medication needs, timing of medicines administration and risks for polypharmacy. Neurologists provide an essential inpatient consult service to other specialties for the diagnosis and management of complex cases



15 Costello D, Renganthan R, O'Hare A, Murray B, Lynch T. Audit of an inpatient neurology consultation service in a tertiary referral centre. Value of the consulting neurologist. Irish Medical journal 2005;98:134-137. Ali E, Chaila E, Hutchinson M, Tubidy N. The "hidden" work of a hospital neurologist: 1000 consults later. Journal of Neurology 2010;17:e28-e32

(Costello et al, 2010<sup>15</sup>). Due to the limitations of current data collection systems, this service is often under reported and unacknowledged across services.

## 6. Education and training

- Education and training are recognised as key focus areas for the programme, both for staff and service users alike. One of the strengths of neurology services in Ireland, as identified in the Laffoy Review (Laffoy 2007)<sup>11</sup>, is the dedication of the workforce.
- Education and training opportunities will not only support our workforce, but will allow for service development, particularly the development of advance practice in both nursing and HSCP. Advanced Nurse and advanced / extended scope HSCP practitioners would have the scope to undertake extended duties with respect to out-patient, day and outreach services.
- Specialist services will have a recognised role in education, training, research and development in the field of neurology. They will also act as a resource for advice and support to local teams in the management of patients with neurological conditions and be supported by the development of clinical specialist posts which allow for protected time for research, education and supervision.
- The programme also proposes the development, with all key stakeholders, of a competency framework for clinicians working within neurology services. Within this framework, reference to existing frameworks, both within neurology and other specialities (i.e. palliative care competency framework) will be considered.

## 7. Research and Programme Metrics

***“I don’t mind lies, but I hate inaccuracies”. Samuel Butler***

High quality research performed by the multidisciplinary team can be considered a significant quality indicator for any health services. The neurology programme recognises the critical need for the design and delivery of specialist neurology services to be informed by ongoing research to monitor best practice.

The Neurology Programme encourages participation in research of various forms including neuroscience, phenomenological and qualitative research, health service delivery research using both formative and summative research methodologies, population based research and translational research.

The core objectives of the Irish Brain Council are also supported and are outlined as follows;

- △ Promote enhanced funding of all aspects of brain research
- △ Promote networking of research –working to our strengths and to the benefit of people with brain disorders
- △ Developing career tracks including;
- △ PhD and Post-doctoral training schemes for young graduate in Ireland
- △ Career opportunities for qualified scientists
- △ Clinician scientist training schemes and clinical academic jobs in University Hospitals
- △ Increase links with Irish Universities to appoint Professors of Clinical Neuroscience

Protected research time is too frequently eroded by the increasing demands of an ever-expanding clinical service. By creating research-specific posts, we would protect meaningful, undisturbed research time, thus enhancing the output of various research groups.

The Neurology Programme also recommends the development of a national neurology register. Specific service development plans are dependent on accurate data on the prevalence and incidence of neurological conditions nationally. Service improvements, particularly relating to ongoing management of patients within the community are also dependent on such a register which includes information on the functional status of patients and outcomes of interventions. Such a database is also recommended within the model of care for the National Clinical Programme for Rehabilitation Medicine.

The importance of establishing a centrally held Registry cannot be underestimated; it could provide critical information that would enable a better overall allocation of resources and more effective overall management of the disease. A study in 2011 concluded that 'Patient Registries should be central to the planning, delivery and review of healthcare in Ireland' (MRCG & IPPOSI 2011)<sup>16</sup> A register would also enable monitoring of trends at the national level, over the course of time and the ability to respond accordingly.

The programme also acknowledges the need to capture information on levels of disability impacting on the lives of those with neurological conditions and patient satisfaction with services.

Data on workforce numbers across all services would also be key to service development.

Specific key performance indicators cannot be developed for neurology services until a clear picture of baseline status is known. This is a particular challenge in neurology considering;

- ▲ the number of conditions presenting which require intervention
- ▲ the number of sources of referrals
- ▲ the number of sites across which services are delivered
- ▲ the movement of patients across these sites
- ▲ the number of divisions within which services are delivered
- ▲ the long term nature of neurological disease
- ▲ the existing gaps in information on neurology activity with data not captured accurately on;
  - activity on patient numbers
  - support provided by neurology to other specialities
  - presentation in EDs/AMAUs
  - diagnostic activity
  - waiting lists
  - nurse & therapy led interventions.

## 8. Cross programme collaboration

The Neurology Programme recognises the opportunity to learn from colleagues within the Clinical Programme & Strategy Division. Considering the breadth of neurological

16 The Medical Research Charities Group (MRCG) & Irish Platform for Patients' Organisations Science and Industry (IPPOSI) 'Towards a National Strategy for Patient Registries in Ireland: Considerations for Government' Oct 2011



conditions and the variety of service settings in which those with neurological conditions can present, the programme will look for opportunities to collaborate with colleagues in enhancing services for those with neurological conditions. Specific examples proposed include:

- Transitional needs of adolescents moving from paediatric to adults services in collaboration with the National Clinical Programme for Paediatrics & Neonatology
- Development of standard operating procedures for the management of neurological conditions in a number of settings expanding on work already undertaken by the National Clinical Programme for Epilepsy
- Potential for development of protocols and guidelines for the diagnosis and management of rare neurological conditions including the development of condition specific clinics to promote potential centers of expertise/reference networks in collaboration with the National Clinical Programme for Rare Diseases
- Development of neurology in-patient services in partnership with the National Clinical Programme for Acute Medicine
- Consideration of expansion of existing TRASNA system in collaboration with the National Clinical Programme for Stroke to provide remote acute teleneurology services to hospitals to assist with diagnosis and condition management.
- Potential for joint clinics for the management of patients with neurological conditions with neurorehabilitation needs in collaboration with National Clinical Programme for Rehabilitation Medicine
- Enhancing of links with medicine for the elderly to ensure that patients of specialist geriatric teams have access to specialist neurology opinion, and older persons with neurological conditions have access to specialist geriatric services as appropriate in collaboration with the National Clinical Programme for Older People.
- Promotion of the competency framework developed by the National Clinical Programme for Palliative Care amongst clinicians working with patients with chronic neurological conditions.

The above proposals are detailed further in Part D of this model of care.

The Model of Care is divided into sections for ease of reading.

PART A	Introduction and Background
PART B	Outline of the Neurology Programme
PART C	Neurology Programme Model of Care
PART D	Cross Programme Collaboration
PART E	Managed Clinical Networks
PART F	Appendices including Care Pathways



# PART A

## Introduction and Background

### 1.1 Introduction

The development of the proposed model of care outlined in this document is based on key policy developments and reforms within the Irish health services with detailed consideration of the following publications and or activities;

- The Strategic Review of Neurology and Clinical Neurophysiology Service 2007 (Laffoy 2007<sup>11</sup>). This review was commissioned by the National Hospitals Office in 2007. The aim of the review was to identify the current provision and future requirements for neurology and neurophysiology services in Ireland. The report described the epidemiology of neurology services in Ireland, examined current levels of service provision, reviewed evidence in relation to service delivery and put forward a network based model of service provision.
- The report is a key reference document for the current model of care as it represents the most comprehensive examination of neurology needs in Ireland to date, incorporating and expanding on the recommendations for the development of neurology services outlined in the Comhairle na nOspideal, Review of Neurology and Neurophysiology Services, 2003
- The Laffoy review (Laffoy 2007) not only looked at current service provision, but also made specific recommendations on innovation, technology and research requirements.
  - The National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland 2011-2015 published in 2011<sup>16</sup> outlines the significant issues in relation to services in Ireland including resource issues, fragmented service delivery and overall lack of access to specialist neurological rehabilitation for the majority of those needing it. Implementation is currently being led by Health Service Executive (HSE) disability services with representation from the National Clinical Programmes of Rehabilitation Medicine and Neurology in addition to representatives from the Department of Health, Primary Care, Social Care, Neurological Alliance of Ireland and Health & Social Care professionals on the steering group charged with developing an Implementation Framework. Implementation of this strategy will address a critical area of support for neurology services in terms of improving access to neurorehabilitation for the entire cohort of people who need it.
- This Model of Care document incorporates the National Standards for Safer Better Healthcare<sup>17</sup>, from the Health Information and Quality Authority (HIQA), June 2012. By incorporating national and international best available evidence, these standards promote healthcare that is up to date, effective and consistent. These standards, approved by the Minister for Health (2012) provide a sound basis for planning, funding and providing healthcare services to work towards achieving and maintaining high quality, safe and reliable care. It is hoped that service users will use the National Standards to understand what high quality and safe healthcare should be and what they should expect from a well-run service.

---

17 National standards for better safer healthcare, Health Information and Quality Authority, June 2012.

- National Healthcare Charter<sup>18</sup>, National Advocacy Unit, Quality and Patient Safety Directorate, HSE 2012. This Charter was developed with input from many parties including patient advocacy groups and individual advocates. It is designed to involve service users in influencing the quality of healthcare in Ireland. The Charter and principles within it will be used to support the implementation of the National Standards for Safer Better Healthcare. This Charter and recognition of the key role of service users has directed the extensive consultations of the Neurology Programme with stakeholders including service users, families, carers and groups representing services users.
- The Establishment of Hospital Groups as a transition to Independent Hospital trusts. A report for the Minister for Health, Dr. James Reilly, TD, 2013. In November 2012 the 'Future Health: A Strategic Framework for Reform of the Health Service 2012-2015' was launched. This provides the overarching policy framework for the establishment of hospital groups. Hospitals have been divided into one of six groups, with each group containing between six and eleven hospitals, and includes at least one major teaching hospital and an academic partner. The Managed Clinical Network proposed in the model of care will operate within this framework but will also need to develop strong links with each of the nine Community Healthcare Organisations.
- The Reform of Primary Care, 2012-2015. The objectives of this report include building the capacity of primary care teams. A network of primary care centres would be integral in chronic disease management programmes. The Neurology Programme recognises that hospital based services are critically dependent on appropriate services in the community including primary care teams.
- HSE Chronic Illness Framework, July 2008. The key goals of this framework is to provide individuals, groups and carers with early diagnosis, education, optimum clinical and social care in the most appropriate setting, stable control of their condition, self-management support, avoidance of complications and improved outcomes.
- Healthy Ireland – A framework for improved health and wellbeing 2013-2015 (March 2013), Department of Health, is our national framework for action to improve the health and wellbeing of the people of Ireland. Its main focus is on prevention and keeping people healthier for longer.

## 1.2 Prevalence

It is estimated that 700,000 persons in Ireland are affected by neurological disease with approximately 44,000 people being diagnosed with a neurological condition in Ireland every year with the prevalence likely to increase in the coming years as the population ages (Laffoy 2007<sup>11</sup>). It is estimated that 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.

The challenges associated with the lack of large scale population based studies on the prevalence of specific neurological conditions in Ireland and the problems associated with relying on extrapolations from other countries with different population profiles are highlighted in the Laffoy Review (Laffoy 2007)<sup>11</sup> and apply to this document also. Applying general prevalence rates from one population to another does not take account of the age and gender structure,

---

18 National Healthcare Charter, National Advocacy Unit, Quality and Patient Safety Directorate, HSE 2012

geography or ethnicity of the Irish population. Our population is young and prevalence figures from other countries may over estimate diseases that are prevalent in older age groups. As our population ages, the same prevalence rates may underestimate these diseases. (Laffoy 2007:11). There is a vital requirement to support and develop large scale prevalence studies in Ireland for the main neurological conditions. There are significant challenges for neurology services in planning for the delivery of care without accurate prevalence data on current and future need, including regional variations.

Neurology has the highest number of conditions listed in the International Classification of Diseases (ICD).

Migraine is the most prevalent neurological condition affecting over 500,000 people and is the neurological condition which presents most frequently to primary care services. Epilepsy is the second most prevalent condition affecting over 30,000. More than 6,000 people have Parkinson's disease, up to 9,000 have been diagnosed with Multiple Sclerosis with approximately 10,000 suffering a head injury each year.

### 1.3 Social and Economic Factors

Based on data from the Review of Neurology and Clinical Neurophysiology Services, 2007 (Laffoy 2007) Ireland's population is likely to increase to 5.5 million by 2031. It is projected that there will be an upward shift in the population pyramid, with a major expansion in the numbers aged 50 years of age and over. As many neurological conditions have a higher prevalence in older persons, Ireland's projected ageing population will result in greater prevalence of neurological conditions.

According to the Laffoy review (Laffoy 2007)<sup>11</sup> it is estimated that;

- 2.6% of the Irish population (110,109) were significantly disabled by their neurological condition in 2007. This will increase 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 over 50,000 new diagnoses annually by 2021.
- Approximately 62,000 persons were caring for a person with a neurological condition in 2006. This will rise to 75,000 in 2021.

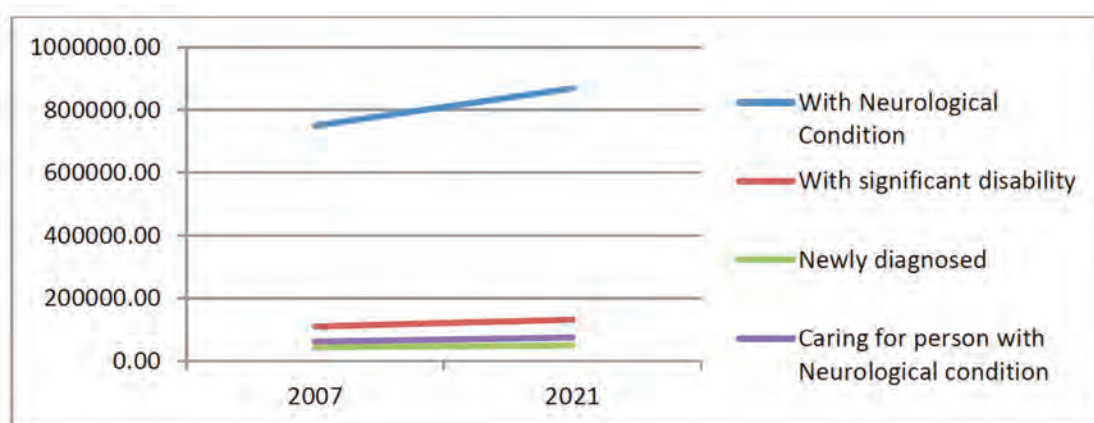
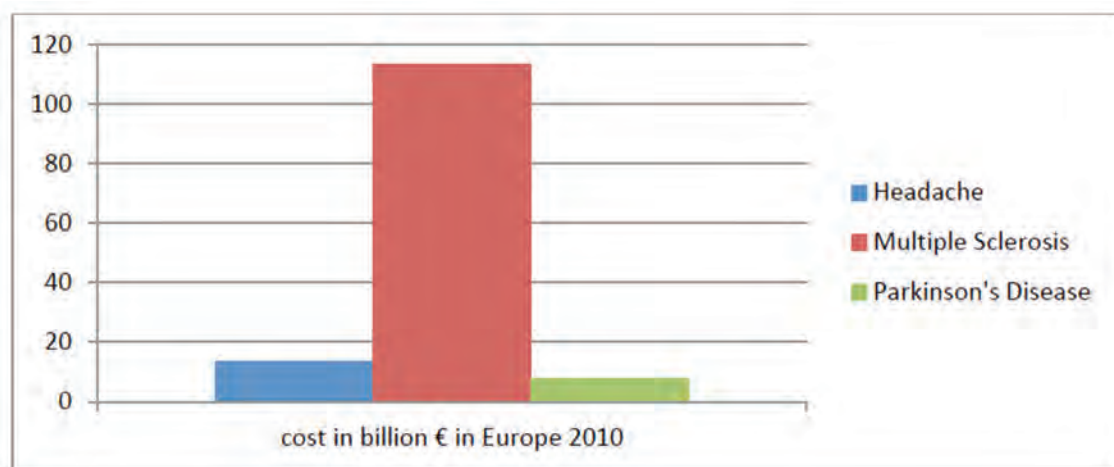


Figure 4; Number of people impacted by Neurological Conditions in Ireland (between 2007 – 2021; projected)

The Cost of Disorders of the Brain and Mind in Europe study (Gustavsson et al 2010)<sup>19</sup> aimed to estimate the total cost per person related to each disease in terms of direct and indirect costs, and an estimate of the total cost per disorder and country. This study covered 30 countries (EU27 + Iceland, Norway and Switzerland) with a total population of 54 million people. They looked at best available estimates of the prevalence and cost per person for 19 groups of disorders of the brain (covering over 100 specific disorders).

The total cost of disorders of the brain was estimated at €798 billion in Europe in 2010 (Gustavsson 2010). This estimate is likely to be conservative as some disorders could not be included due to limitations in the available data. Direct costs constituted the majority of costs (37% direct healthcare costs and 23% direct non-medical costs) whereas the remaining 40% were indirect costs associated with patient's production losses. Unemployment and retirement due to illness are prevalent among those with neurological conditions, estimated at up to 58% in those with MS (Julian et al 2008)<sup>20</sup>.

With respect to some specific conditions, the cost (in billion €PPP 2010) were as follows;



**Fig 5 – Cost (per billion €) spent across Europe in 2010.**

It has been estimated from this study that the European per capita cost of disorders of the brain was on average €1,550 per annum.

In Ireland, it is conservatively estimated that there are over 40,000 in-patient admissions of patients with neurological conditions annually (Laffoy 2007). Currently, it is not possible to capture data on whether these admissions were avoidable, but with the full economic rate (FER) of bed days costed at approx €840 per night, and average Length Of Stay (LOS) estimated at 18 days, these admissions amount to a likely could cost of over €604,800,000 per annum. This does not include cost of out-patient appointments/services, burden on family members or indeed indirect costs such as loss of productivity.

## 1.4 Burden of disease measures & mortality

One billion people are reportedly affected worldwide, and the incidence of neurological conditions is increasing as the population ages. Deaths from neurological disorders (table 2) are an important cause of mortality and constitute 12 per cent of total deaths globally.

19 Gustavsson, A et al, Cost of disorders of the Brain in Europe 2010; Eur Neuropsychopharmacol. 2010 Oct; (10): 718-79

20 Julian, Laura J., et al. "Employment in multiple sclerosis." Journal of neurology 255.9 (2008): 1354-1360.

Neurological conditions are also very significant in terms of YLDs (years of healthy life lost as a result of disability) contributing to over 14 percent of YLD's globally by 2030 (WHO - Neurological Disorders, public health challenges, 2006) – see table 1

CAUSE OF CATEGORY/SEQUELAE	2030	
	YLDs (100,000 population)	Percentage of total YLDs
EPILEPSY	55.6	0.71
ALZHEIMERS & OTHER DEMENTIAS	203.9	2.60
PARKINSON'S DISEASE	17.1	0.22
MULTIPLE SCLEROSIS	18.4	0.23
MIGRAINE	96	1.22
CEREBROVASCULAR DISEASE	177.8	2.27
NEURO-INFECTIONS	45.6	0.58
NUTRITIONAL DEFICIENCIES & NEUROPATHIES	133.9	1.71
NEUROLOGICAL INJURIES	360.8	4.60
<b>TOTAL</b>	<b>1109.1</b>	<b>14.14</b>

Table 2: YLDs per 100 000 population associated with neurological disorders and other diseases and injuries with neurological sequelae and as percentage of total YLDs projected for 2030<sup>21</sup>.

With respect to mortality, the World Health Organisation (WHO) describes deaths attributed to neurological disorders world wide as per table 2 below;

	Deaths			Deaths		
	Deaths	% total	Per 100,000	Deaths	% total	Per 100,000
	2015			2030		
POPULATION	7103,297,899			7917,115,397		
Total DALYs	63,458,962			73,247,767		
EPILEPSY	130,569	0.21	1.84	139,276	0.19	1.76
ALZHEIMER & OTHER DEMENTIA	513,230	0.81	7.23	671,372	0.92	8.48
PARKINSON'S DISEASE	127,294	0.20	1.79	166,418	0.23	2.09
MULTIPLE SCLEROSIS	16,669	0.03	0.23	17,012	0.02	0.21
MIGRAINE	0	0	0.00	0	0	0.00
CEREBROVASCULAR DISEASE	6,466,232	10.19	91.03	7,787,646	10.63	98.36
POLIOMYELITIS	654	0	0.01	577	0	0.01
TETANUS	145,640	0.23	2.05	95,587	0.13	1.21
MENINGITIS	106,372	0.17	1.50	69,946	0.10	0.88
JAPANESE ENCEPHALITIS	7,282	0.01	0.10	4,318	0.01	0.05
<b>TOTAL</b>	<b>7,513,942</b>	<b>11.84</b>	<b>105.78</b>	<b>8,951,162</b>	<b>12.22</b>	<b>113.06</b>

Table 3: (Adapted from) Deaths attributable to neurological disorders, by cause, projections for 2015 and 2030

21 World Health Organisation 2006 - Neurological Disorders, public health challenges



# PART B

## Outline of the Neurology Programme

### 2.0 Rationale for National Clinical Programme for Neurology

***The rationale for the establishment of the programme in keeping with the overall aims of the Clinical Programmes and Strategy Division was to look at issues across the service delivery continuum for patients with neurological conditions with reference to quality, access and value.***

“There is ample evidence that pinpoints neurological disorders as one of the greatest threats to public health” (World Health Organisation (WHO), 2006). In Ireland, we need to prepare our services so that they can be responsive to the current growing and changing needs of our ageing population and also the increasing new therapies driven by neuroscience.

Although neurological conditions are common, life-changing and disabling, they have not received the same high profile or resourcing in Ireland as other less prevalent or less disabling conditions.

It is a recognised fact that neurology services in Ireland are typically under-resourced and will require funding and further development to meet the current and ever increasing demand on services. This has been highlighted through a series of reviews by the Irish health service, as well as through the efforts of individual clinicians and the testimonies of patients and patient representative organisations through the national advocacy group, the Neurological Alliance of Ireland (NAI).

The most comprehensive examination to date of neurology service provision was the 2007 report on neurology and neurophysiology services submitted to the National Hospitals Office (Laffoy 2007<sup>11</sup>). This review undertook an in-depth consultation with all the key stakeholders, engaging in a series of site visits to each of the neurology centers nationwide and engaging with a range of representative groups, including patient organisations. In addition, the report attempted to project the increased prevalence of neurological condition as the Irish population ages and take into account the increasing demands on neurology services into the future. The review also addressed future training and research needs of the speciality.

The Strategic Review of Neurology and Clinical Neurophysiology Services, 2007<sup>11</sup> (also referred to as the Laffoy Review) concluded that;

***‘current provision of neurology services in Ireland is not sustainable, nor is it able to meet demands. It lacks integration and cohesive/comprehensive multidisciplinary care. The structure and system need to be overhauled, so that care is delivered as close to the patients community as possible with Primary Community and Continuing Care (PCCC) and local hospital services empowered to play key roles, while enhancing specialist and tertiary services to provide support for patients with rare and complicated conditions which could not be managed at a local level.’***

The Neurology Programme model of care aims to provide a clear framework for many of the key recommendations in the Laffoy Review (2007) by outlining mechanisms to address the following:

1. **Integration**<sup>11</sup>: pathways will be developed for the main neurological conditions in order to improve integrated care, including a clear outline in the model of care of the importance of links with other services such as neurorehabilitation and palliative care.
2. Recommendations regarding the **restructuring of neurology services** nationally: outlining a network based approach to neurology services providing an important update to the Laffoy Review<sup>11</sup> in terms of configuring the framework to take account of the new hospital groupings and the value of specialist centers for rare neurological disease and complex cases.
3. **Sustainability**<sup>11</sup>: the recognition that addressing critical resource needs will be key to meeting current and future demand. The programme is in the process of gathering up-to-date information on current resourcing to inform priorities in this area going forward.
4. **Cohesive and Comprehensive MDT care**<sup>11</sup>: recommendations to enhance the effectiveness of multidisciplinary care including models of nurse-led and therapy-led practice as well as making recommendations on staffing and training needs in this area.

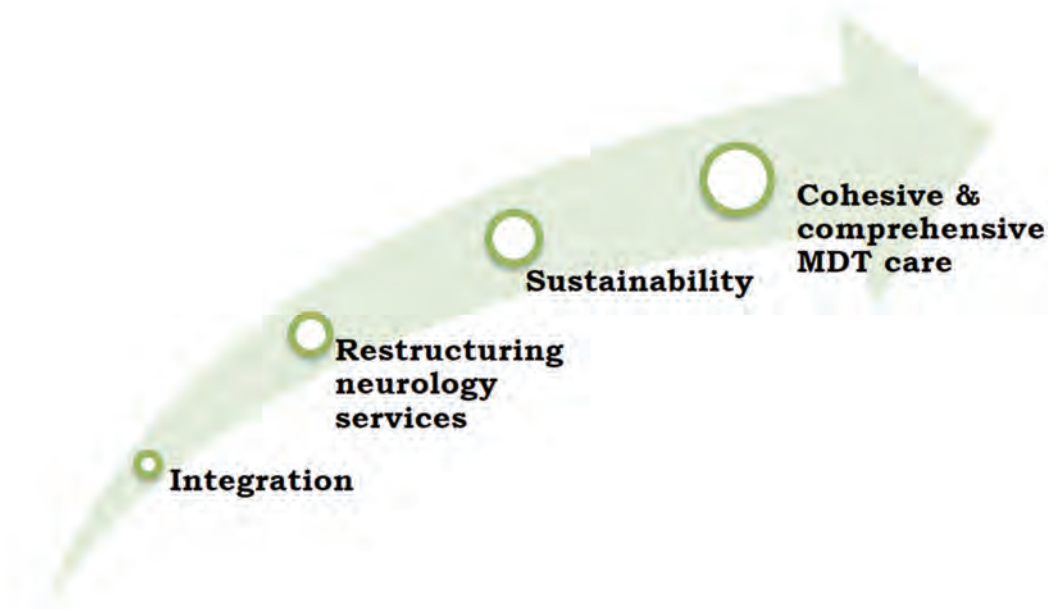


Figure 6 - key recommendations from Laffoy Review

### 3.0 Aims & Objectives of the Neurology Programme

The Neurology programme, as a national clinical programme, has three main aims;

- To improve access to all service
- To improve the quality of neurological in Ireland
- To add value for patients and the health system

The programme has broken these down into smaller more measurable objectives and targets. These targets will eventually be developed into key performance indicators for the neurology programme and neurology services. To advance to this stage the critical need to appropriately resource neurology services needs to be addressed, in addition to the development of a national database for patients with neurological conditions. This is further developed in the programme metrics section where suggestions are made relating to how appropriate information could be gathered across services.



Figure 7 - overarching aims of the National Clinical Programme

### Aim 1; Improve access to appropriate neurology services

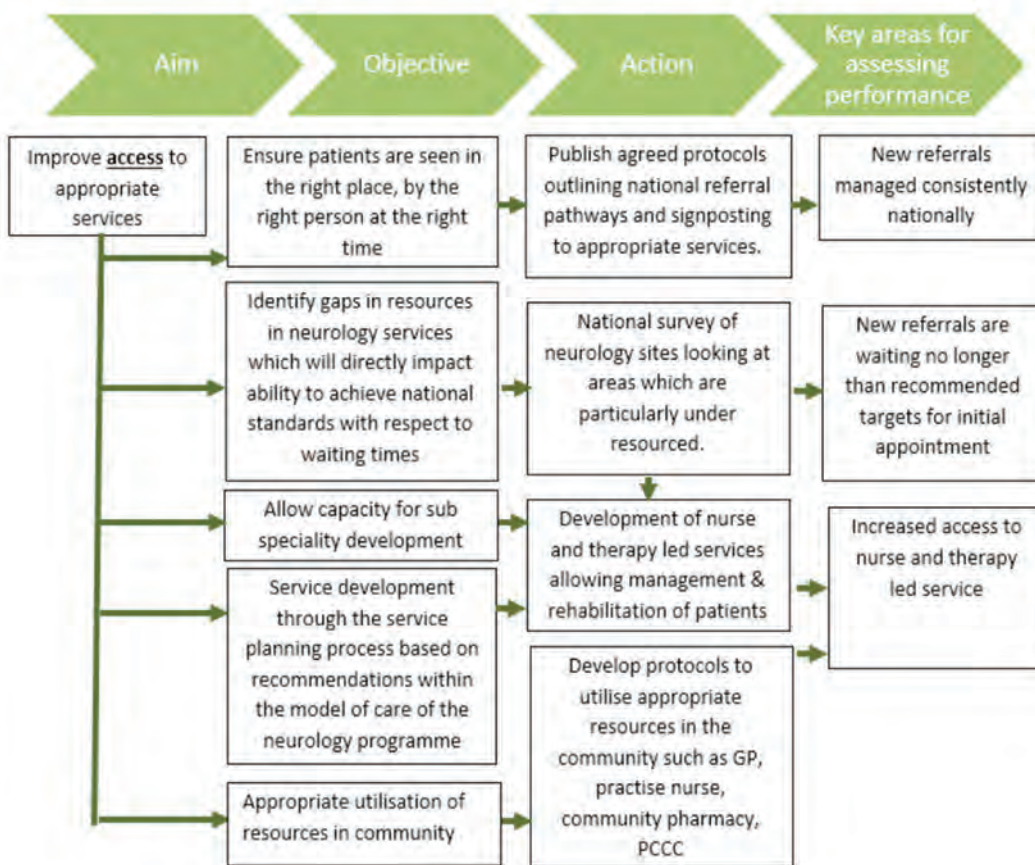


Table 4; Neurology Programme aims with respect to access

**Aim 2; Improve safety and quality in the delivery of patient centred neurological care**

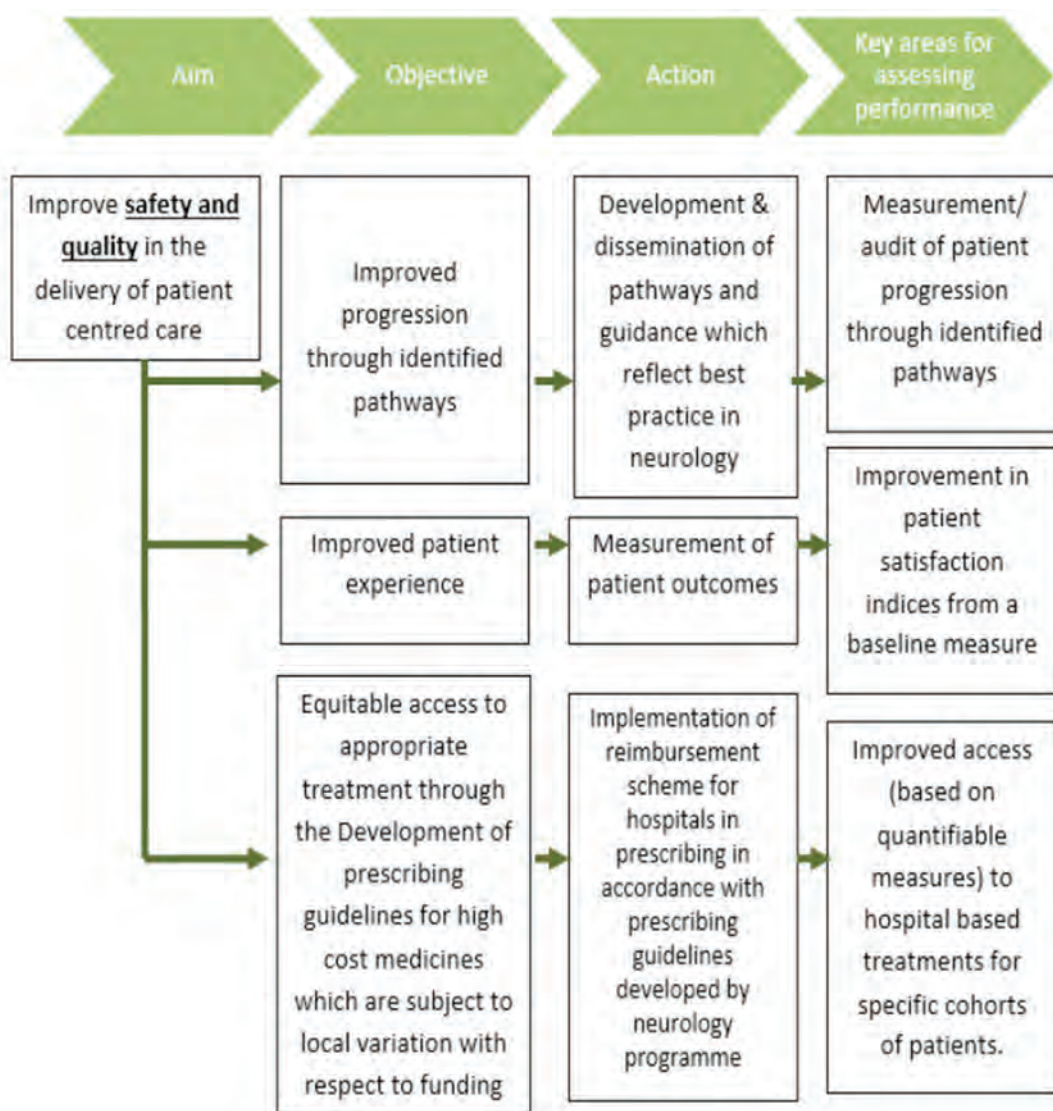


Table 5; Neurology Programme aims with respect to safety and quality



**Aim 3; Improve value for both patient and health services across neurology services**

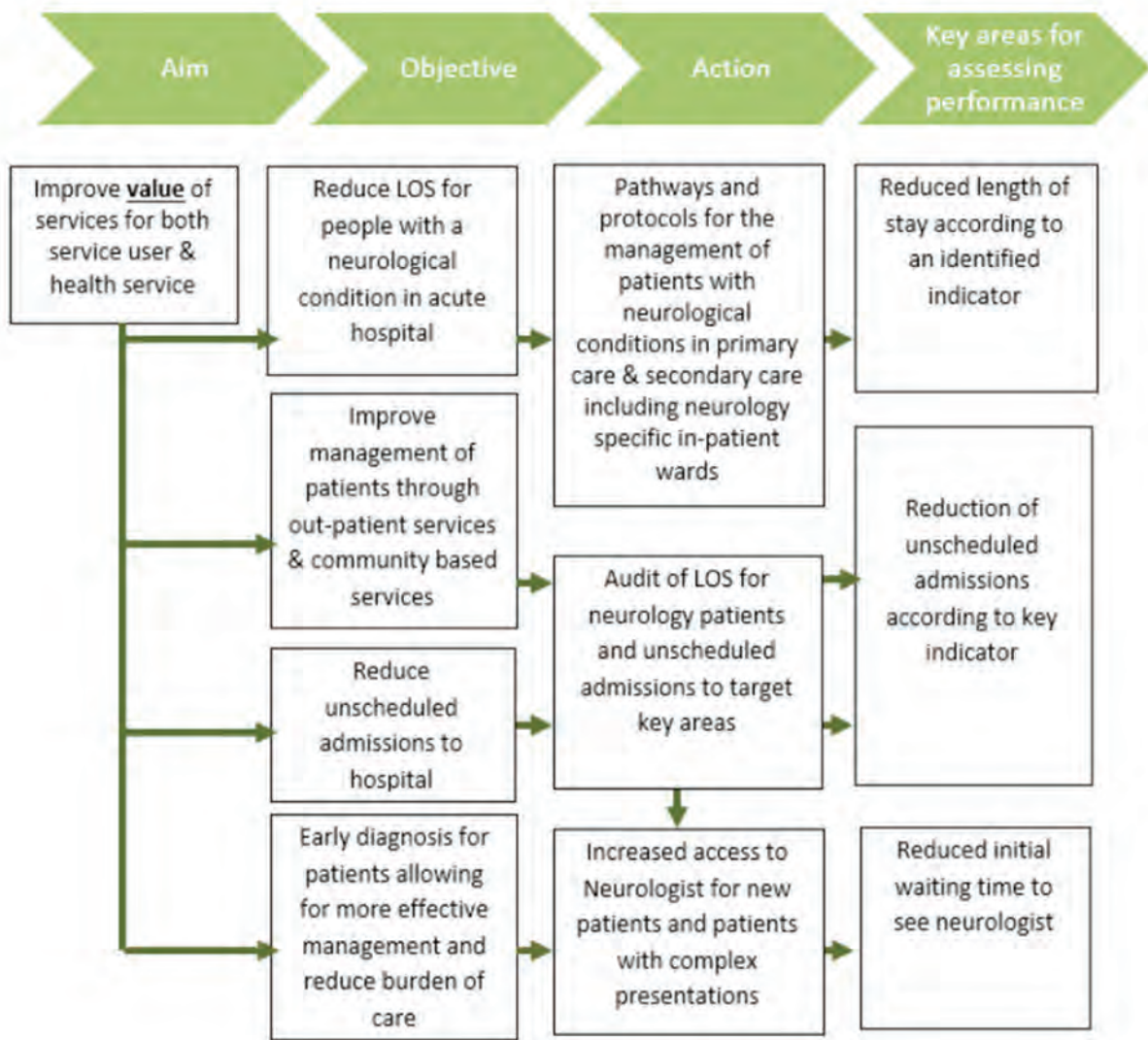


Table 6; Neurology Programme aims with respect to cost effectiveness and value

## 4.0 Scope of Neurology Programme

The neurology model of care has been developed to address the need for strategic development of neurology services. The scope of the programme is to provide a framework for neurology services which follows international best practice and should be delivered within an integrated service approach. It covers the full spectrum of care provided in hospitals (in-patient & out-patient) and recognizes that critical role that primary and continuing care services play in the management of patients with neurological conditions and the need for these services to be developed nationally.

Neurology services are significantly impacted by the capacity of other areas within the health services to manage the needs of people with neurological conditions. This continues to have a significant influence both on the appropriate management of neurological conditions and on the effective use of a specialist hospital based neurology service. The importance of access to neurorehabilitation services, an effective model for the management of neurological conditions in primary care and appropriate facilities for step down and long term care were emphasised in the Laffoy review 2007<sup>11</sup> as critical to the delivery of neurology services in Ireland.

It is anticipated that this model of care will provide a planning guide towards achieving equity of access, appropriateness of care and consistency of service quality for neurology patients in hospitals as in/out patients across the country.

The scope of the programme does not include paediatric neurology services. However the programme recognises the key need for adult neurology services to develop effective linkages with these services. The work of the programme in this area is outlined in detail in Part D of this model of care.

### 4.1 Care Pathways within the Neurology Programme

Included in this model of care are recommendations with respect to generic standards for neurology services which would be applicable to all services and conditions. In addition to this, the neurology programme has developed specific care pathways for 3 conditions that represent a high proportion of all neurological chronic conditions in both primary and secondary care. These conditions are;

1. **Multiple Sclerosis** – Currently there are up to 9,000<sup>22</sup> (1.84% prevalence) persons with multiple sclerosis in Ireland (Lonergan et al 2011) (Appendix 2)
2. **Parkinson's Disease** – over 6,000 people in Ireland have Parkinson's disease (1% prevalence rate). (Appendix 3)
3. **Headache** - the term headache disorder encompasses a number of conditions which vary in severity, incidence and duration. As a consequence, establishing their overall prevalence is difficult. Globally, it is estimated that the prevalence among adults is 47%. Headache is thought to effect up to 90% of the population throughout their lifetime (WHO 2000<sup>23</sup>). (Appendix 4)

22 Lonergan R, Kinsella K, Fitzpatrick P, et al. Multiple Sclerosis prevalence in Ireland: relationship to Vitamin D status and HLA phenotype. *J Neurol Neurosurg Neuropsychiatry* 2011;82:317-322

23 World Health Organisation March 2000. Headache disorders and public health

4. While not as prevalent as the above mentioned conditions, a specific pathway for the management of patients with **Motor Neurone Disease** (MND) will also be included within this model of care. Like most neurodegenerative disorders, the needs of these patients are so complex, 'they require comprehensive anticipatory care (NHS 2013<sup>24</sup>)' with early access to specialist multidisciplinary expertise. This care should be provided by a neurologist/neurology service with appropriate level of experience of this condition. (Appendix 5)

The patient care pathways within this MOC for the above four conditions are a multidisciplinary outline of anticipated care, placed in an appropriate timeframe, to help a patient with these specific conditions or set of symptoms move seamlessly through a clinical experience to positive outcomes.

Variations from the pathway may occur as clinical freedom is exercised to meet the often complex and varying needs of the individual patient.

These patient care pathways will help to reduce unnecessary variations in patient care and outcomes. They support the development of care partnerships and empower patients and their carers.

Under the National Dementia Strategy (DoH 2014)<sup>25</sup>, pathways for dementia care will be developed which will incorporate a range of services and supports, both in the hospital and community. It will be necessary for neurology services to be involved in the development of these pathways and include links to appropriate services for people presenting with dementia in neurology services, particularly those under 65 years.

---

24 NHS Commissioning Board, 2013/2014/2014 NHS Standard Contract for Neurosciences: Specialised Neurology (Adult).

25 Department of Health 2014. The Irish National Dementia Strategy

## 5.0 Mission, vision, core values and principles

*The Mission of the National Neurology Programme is to develop a framework to support the development of a multidisciplinary, high quality and responsive service for all people with neurological conditions in Ireland which is delivered in a timely and efficient manner.*

To meet the needs of both current and indeed future patients with neurological conditions, the vision of the Neurology Programme is to develop a service which is safe, responsive and able to offer the following to all patients;

- Early and appropriate assessments, diagnosis and equitable management
- Integrated Care Pathways across the continuum of care
- Development of properly resourced services to support the patient journey

The realisation of this vision requires a number of changes to the way the service is planned and delivered. This includes changes to current structures and systems to enable the development of a flexible, accessible, multidisciplinary service that is well resourced and ensures that all aspects of the service work together to achieve best patient outcomes.

The Neurology programme is committed to core values and principles associated with ensuring that patients:

- (a) Receive the treatment and care they require at all stages of their condition
- (b) Have access to information about their condition and that diagnosis and information about their condition is communicated in a supportive way
- (c) Have the right to choices about their care and treatment and be involved in decisions about their care

The programme is committed to ensuring that all those who work in neurology services are supported to deliver on their potential and have opportunities to engage in research and training in an environment that is safe and that recognises high quality care, innovation and best practice.

## 6.0 A Neurology Service based on Best Practice

A neurology service, based on best practices, acknowledges that for optimal care, patients need the support of a wide range of professionals who may be based in a variety of organisations including health, social care, primary care and other sectors including voluntary and not-for-profit organisations. While it is not feasible to have all services provided in the one location, or by the one service provider, barriers between services, either real or perceived, should not exist as they can impede the delivery of person centered care (NHS 2005)<sup>26</sup>

Consideration was given to published literature on best practice within neurology services and elements from a number of publications have been identified as and applicable to Irish Neurology services in Ireland. In particular, the quality dimensions of the UK National Health Service (NHS) Clinical Standards for Neurological Health Services were considered applicable across all health services (NHS 2009)<sup>27</sup>.

These dimensions are<sup>27</sup>.

- Patient centred; providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions
- Timely; reducing waits and sometimes harmful delays for both those who receive and those who give care.
- Effective; providing services based on scientific knowledge to all who could benefit
- Equitable; providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location and socioeconomic status<sup>27</sup>.
- Efficient; avoiding waste including waste of supplies, ideas, energy, unnecessary duplication and management of rare diseases in non-specialist centres
- Safety; avoiding injuries to patients from the care that is intended to help them

The National Programme for Neurology attempts to incorporate these standards of care, considered best practice in the field for health services, into the model of care for the programme. The aim of the neurology programme is to;

26 NHS, March 2005. Action on Neurology; Improving Neurology Services – a practical guide,

27 NHS – October 2009. Neurological health services; clinical standards





**Fig 8; overarching aims of the National Clinical Programme for Neurology**

This can be achieved by ensuring that each individual, regardless of where they live (Laffoy 2007<sup>11</sup>);

- Has easy access to ensure an early diagnosis
- Is assessed by the right person at the right time i.e. assessed by clinicians in all the relevant disciplines who specialise in neurological conditions.
- Has timely access to investigations that promote care within timescales dictated by their clinical needs
- Is encouraged to participate in decision making on a partnership basis when desired
- Has easy access to all the relevant required professions, information and services that enhance the short and long term management of their condition
- Has access to appropriate integrated multidisciplinary care
- Has access to the required assistive technology / equipment / appliances as required.

While the provision of care and support to patients with complex neurological conditions has some associated element of risk of harm, the Neurology Programme, through the development of this model of care attempts to minimize unnecessary or potential harm by limiting variance in the treatment and management of patients. The implementation of the recommendations within the model in line with international best practice will assist with maximizing safety outcomes for all service users.

The Neurology Programme also acknowledges that quality and safety improvement in healthcare is 'underpinned by a shared understanding by all the workforce of the inherent risk which can be reduced by the manner in which services are designed and delivered' (National Standards for Safer Better Healthcare, HIQA, June 2012<sup>17</sup>). While the programme has played a role in designing how services should be delivered, the actual delivery of safe services is in the hands of a dedicated workforce working in local, regional and national services.

The Neurology programme also draws on the quality standards contained within the 'National Service Framework for Long-term Conditions'<sup>28</sup> (UK DoH, March 2005) with respect to best practice in the area of neurology. At the heart of the National Service Framework (NSF) are 11 quality requirements.

1. A person centred service
2. Early recognition and diagnosis
3. Emergency and acute management
4. Early and specialist rehabilitation
5. Community rehabilitation and support
6. Vocational rehabilitation
7. Providing equipment and accommodation
8. Providing personal care and support
9. Palliative care
10. Supporting family and carers
11. Caring for people with neurological conditions

The Neurology Programme also strives to achieve best practice with respect to;



Figure 9 - best practice areas for development

28 UK DoH, March 2005. National Service Framework for Long-term Conditions'

## 7.0 Evolution and function of the service

The following section looks at current delivery of neurology services in Ireland across the continuum of care including inpatient and outpatient services referencing the Laffoy Review (2007)<sup>11</sup> as being the most comprehensive review of services in Ireland to date. The Laffoy Review suggests that Neurology services in Ireland developed in an ad hoc fashion over the years which led to significant discrepancies with regard to availability of services, both at inpatient and outpatient levels, across the nation.

This section also addresses long term drivers which will impact on the future development of Neurology as a speciality.

There are currently 11 neurology centres nationally, with outreach & consultation to a number of other Model 3 and 4 hospitals. For the purposes of this MOC, a neurology centre is defined as having a consultant neurologist with a corresponding MDT team comprising the required range of HSCPs and Nurses on staff. Currently there is significant variance across centres with respect to size of centre, with some sites having a single neurologist and others having up to 5 neurologists on staff. The Neurology Programme recommends that neurology services across all hospital groups are developed to ensure equitable access to both in-patient and outpatient services.

### 7.1.1 Hospital Utilisation

Information relating to hospital activity continues to be limited (Laffoy 2007)<sup>11</sup>. The Hospital Inpatient Enquiry (HIPE) system is the system used for recording inpatient and day case hospital activity. Unfortunately, for Neurology, the system is unable to generate accurate data as there is no one-disease group code in the HIPE database for neurological conditions. Neurology has the highest number of conditions listed in the International Classification of Diseases (ICD10). The biggest neurological sub-group on HIPE is seizure & headache, accounting for almost 30% of all neurological HIPE episodes.. Data from the Laffoy review 2007<sup>11</sup> identifies the following;

- The main reason for admission to hospital in Ireland annually for patients with a neurological condition was due to convulsions/epilepsy (approx 7,000 per year)
- There are approximately 1,500 admissions due to Multiple Sclerosis annually
- Only 17% of neurological admissions are day cases
- Neurological conditions have a long average length of stay (ALOS) – the ALOS for acute stroke is 18 days. For neurodegenerative conditions the ALOS is 23 days.

### 7.1.2 Neurology patients attending Emergency Departments

There is limited Irish data on presentation of patients with neurological presentations to Emergency Departments (ED). UK data would indicate that 10% of visits to Emergency Departments are for a neurological condition.

Another issue pertains to the fact that patients being admitted through EDs and Acute Medical Admissions Units (AMAU), particularly those with sudden onset and/or traumatic neurological conditions, are not always referred to a neurologist, but managed under the care of consultants including general surgeons, rheumatologists, emergency & orthopaedic physicians, cardiologists, respiratory physicians to name but a few.

The Neurology Programme will work on addressing this issue through the development of integrated care pathways/protocols for triaging patients in emergency settings. It is acknowledged that any such developments will need to be undertaken in collaboration with colleagues in both National Clinical Programmes for Acute Medicine and Emergency Medicine. Similar care pathways have been developed by the National Clinical Programme for Epilepsy, Older Persons and Rehabilitation Medicine.

### 7.1.3 Inpatient Neurology Consultation Service

Inpatient referrals to the neurology service are an important and significant part of the work of a consultant neurologist and other clinical staff. This work is crucial to acute medicine and surgical services. Standard hospital statistics fail to record the importance of intra-speciality referrals which take up a significant portion of the clinician's working day. Speciality specific referral in neurology has been shown to expedite diagnosis and treatment and leads to a significantly reduced length of stay in hospital (Ali et al, 2010)<sup>29</sup>. It is reported that inpatient referrals, on average, constitute approximately 35 hours per week and comprise a significant workload. In hospitals served by a single handed consultant neurologist, consultation services in addition to in-patient and out-patient case load is frequently unmanageable and as a consequence unsafe.

The demands on neurologists are likely to increase with advances in critical care management of patients. Improved survival rates can lead to new complications secondary to both illness and treatment. Neurological complications double both the length of stay in hospital and the likelihood of death; the mortality rate for patients with neurological complications is 55% compared to 29% for those without (Saif et al 2003)<sup>30</sup>. It is therefore unsurprising that neurologists are being increasingly called upon to review patients, particularly in intensive care units.

### 7.1.4 Inpatient admissions under Consultant Neurologist – emergency & elective

In addition to managing patients admitted through the ED/AMAU who require neurology consultation, consultant neurologists also manage patients under their care who are admitted either emergently or for elective procedures/assessments. Depending on a number of factors, some neurologists may have dedicated beds and/or neurology ward for which they are responsible. This is in addition to out-patient services.

Inpatient neurology services require dedicated in-patient beds supported by neurologists, nurses and HSCP with specific competencies in neurology.

### 7.1.5 Hospitals without on-site Neurology Services

There are numerous hospitals around the country with no access to neurology – either on-site or via outreach. In these hospitals demand is placed on non-neurologist consultants to assess and treat patients who present or who are admitted with neurological conditions. Many neurological problems present in an ill-defined manner, which can lead to inappropriate use of expensive investigative tools and resources. Non-neurology consultants often find it difficult to manage patients with complex neurological conditions, thus increasing the risk of delayed diagnosis and poor clinical outcome.

29 Ali E, Chaila E, Hutchinson M, Tubridy N. The 'hidden' work of a hospital neurologist: 1000 consults later. *European Journal of neurology* 2010; 17: e28-e32

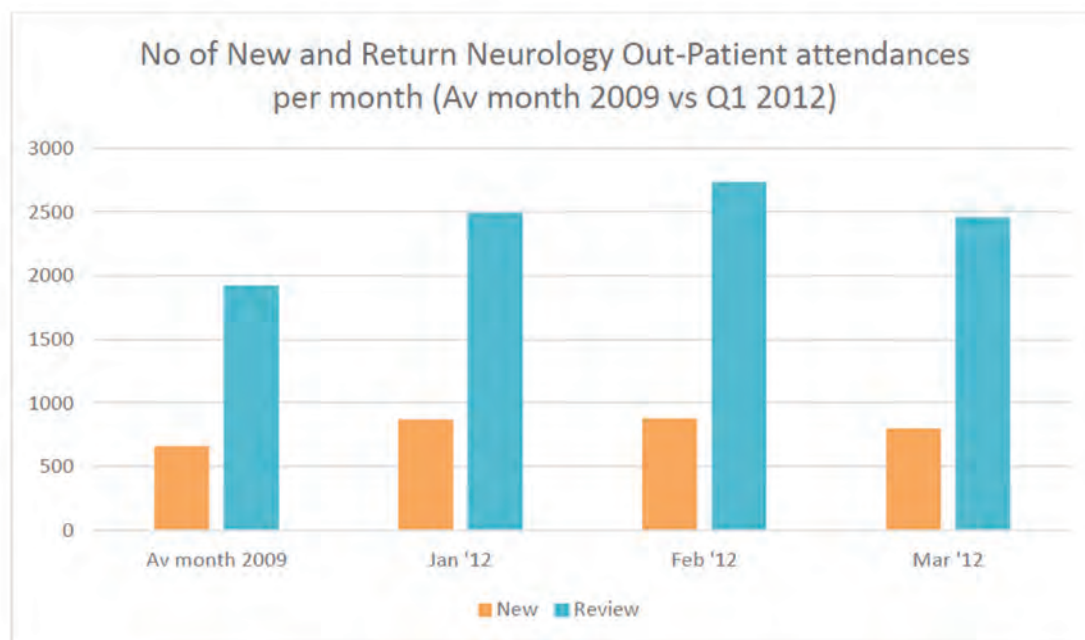
30 Saif S M Razvi, Bone I. Neurological consultation in a medical intensive care unit. *J Neurol Neurosurg Psychiatry* 2003; 74 (suppl III):iii 16-iii23

Neurological consultation or admission directly into the care of a neurologist is likely to lead to a more tailored diagnostic workup, reducing cost and improving outcomes for the patient.

### 7.1.6 Out-Patient Services

The Laffoy Review 2007<sup>11</sup> identified a number of significant weaknesses in relation to outpatient services; these included waiting times, insufficient resources at specialist and community levels, limited access to diagnostics and specialist multidisciplinary care and poor integration between hospital and community services.

Out-patient Department (OPD) services have seen significant improvements with the introduction of additional consultant posts. Table 6 below shows summary information with respect to increase in patient numbers in both 'new' and 'review' categories.



**Table 7; Number of new and return neurology outpatient attendances per month**

While out-patient capacity has increased, so too has the number of patients requiring neurology services with the net result that waiting times remain outside of national targets in many areas of the country.

The Protocol for the Management of Outpatient Services, (HSE, SDU & NTPF December 2012)<sup>31</sup> has identified minimum standards for waiting time targets. The maximum waiting time guarantees for first appointment with a consultant are;

- 12 months by 30th November 2013
- 26 weeks by 30th November 2014
- 13 weeks by 30th November 2015

Data from April 2014 shows that at that time there were 12,015 people awaiting neurology out-patient consultant services. Of these, 38% were waiting longer than 6 months.

31 NTPF 2013. SDU Technical Guidance, Scheduled Care 2013. Out-patient Waiting Times.



The Association of British Neurologists (ABN) recommends that a job plan should not normally contain more than three outpatient sessions, including subspecialty clinics, in a week, each of which will normally be no more than four hours (ABN 2014<sup>32</sup>). If a new to review ratio of 1:2 is considered, this would indicate that nationally, the service should provide approx 480 new patient slots per month and 1056 review patient slots. The table above however demonstrates that the monthly patient numbers in Ireland are far in excess of the ABN recommendations.

It should also be noted that the above demand for out-patient services on consultants are in addition to demands for the consultation and management of inpatients admitted under their care.

These figures would indicate that neurology services, unless resourced appropriately, will always continue to struggle with the capacity vs. demand ratio and that the national targets are unlikely to be achievable without significant additional resources.

Additional administrative support is also required across all out-patient neurology services. Currently, a significant proportion of clinicians' time is taken doing routine administrative tasks which is not considered the most effective use of their specialist expertise. Outpatient services with appropriate level of administrative support are generally more efficiently run and lead to an improved patient experience.

### 7.1.7 Multidisciplinary Teams for outpatient services

Access to a multidisciplinary team in an out-patient setting varies significantly across the country. While some neurology services have dedicated HSCP hours to support their outpatient activity, this is not the norm, and access to the various HSCP's is very limited in the majority of centers.

Multidisciplinary intervention in outpatient services has been proven to positively impact both patient outcomes and experience. The Neurology Programme strongly recommends that all neurology services have access to a dedicated MDT, with competencies & experience in neurological conditions, to support and enhance their outpatient activity.

The Neurology Programme also recommends that the role of the MDT in assessment and management of patients in the outpatient setting is further developed.

Currently in-patient beds are often required to coordinate multidisciplinary care for patients with complex neurological conditions as it remains difficult to both source and secure this level of specialist MDT support in a community setting in the absence of dedicated supports for patients with neurological disorders.

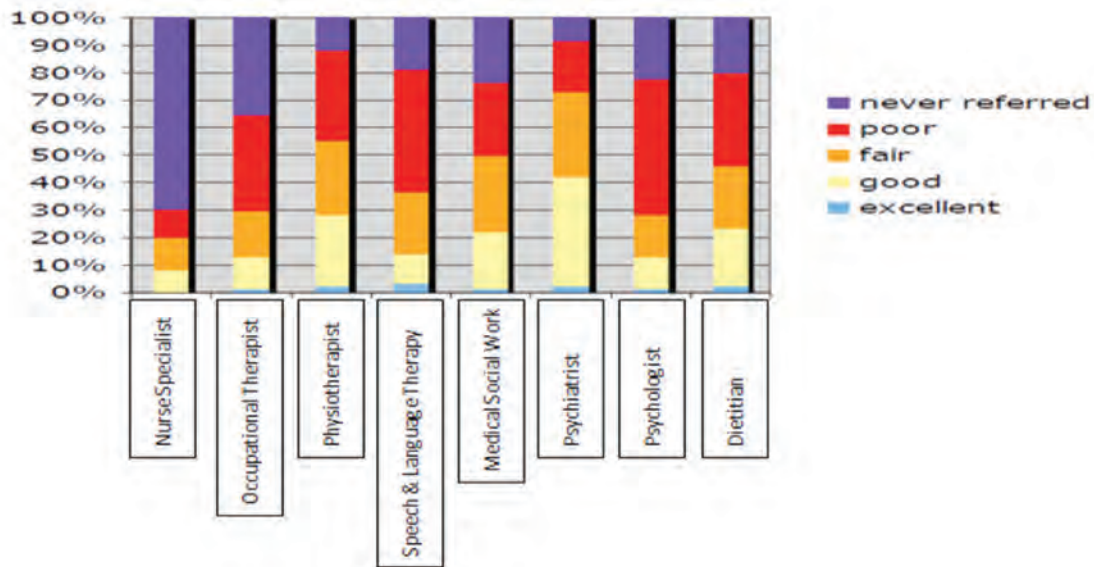
### 7.1.8 Community based services for people with neurological conditions

Services delivered to neurology patients in the community setting, are in general treated as part of the general caseload of community based therapy staff or in many cases, specialist staff working with voluntary agencies. It is recognised that currently the number of community based health and social care professionals (HSCPs) who work with neurology patients is inadequate to meet the needs of the patients requiring their services.

---

32 Llewelyn Gm Kinton L. ABN: Job Planning for NHS consultant neurologists and clinical academic neurologists 29/5/14. ABN Services and Standards Committee.

The table below from Laffoy 2007 highlights the lack of community based nurse and health and social care professionals (previously referred to as allied health professionals) as per the perception of General practitioners (GP).



**Table 8; Laffoy Review 2007<sup>11</sup> Access to Allied Health Professionals as perceived by General Practitioners**

Patients requiring support in the community are prioritised with regard to urgency of need. Many neurology patients with chronic disease such as PD & MS are not initially considered urgent cases, however without consistent support and appropriate management, their function often deteriorates and they become urgent and require hospital admission. The current ‘weighting’ / prioritisation system in community services does not support the needs of many patients with neurological conditions. HSCP interventions through PCCC teams are often short term with minimal opportunity for follow-up.

It is also recognised that therapists in the community may not have specific specialist expertise or experience in managing the complex needs of patients with neurological conditions. Appropriate measures need to be implemented to support HSCP’s and ensure that all HSCPs are adequately resourced and supported in terms of upskilling, opportunities for continuing professional development (CPD) and for professional clinical supervision.

The Neurology Programme strongly supports the implementation of community based neurorehabilitation teams as described in both the National Strategy & Policy for Neurorehabilitation Services in Ireland<sup>16</sup> and the Model of Care for the National Clinical Programme for Rehabilitation Medicine<sup>2</sup>.

The absence of such services across the country impacts directly on the function of the hospital based neurology services.

### 7.1.9 Other disability and healthcare supports in the community

A more comprehensive examination of the gaps in community based services for people with neurological conditions is provided later in this document in relation to links between the neurology service and other health services.

## 7.2 Current Status of Service Provision

Up until the recommendations of the Higgins (DoH 2013)<sup>33</sup> report relating to hospital groups were implemented Neurology services were grouped within regions (HSE 4 administrative areas) with each region having a nominated regional lead neurologist. With the introduction of the Hospital Groups, neurology services will need to reconfigure and address the alignment of local, regional and tertiary centres within each group. It is anticipated that each hospital group will have a minimum of one fully comprehensive neurology centre with a wide range of outreach services & support available to other hospitals within the group. Each group has an academic partner and in addition links with other academic centres may need to be forged with respect to research on rare/genetic/related conditions and education of clinical neurosciences.

Clinical research centres should be accessible within each group to support maintenance of the highest standards in basic and applied research and access to clinical trial services.

Group / Academic Partner	Group Members	Group	Group Members
Dublin North East	<a href="#">Beaumont Hospital</a> Our Lady of Lourdes, Drogheda Connolly Hospital Cavan General Hospital Rotunda Hospital Louth County Hospital Monaghan Hospital	South/South West	<a href="#">Cork University Hospital</a> <a href="#">Waterford Regional Hospital</a> Kerry General Hospital <a href="#">Mercy University Hospital</a> South Tipperary General Hospital South Infirmary Victoria University Hospital Bantry General Hospital Mallow General Hospital Orthopaedic Hospital Kilcreene
RCSI		UCC	
Dublin Midland	St James Hospital <a href="#">Tallaght Hospital</a> Midlands Regional Hospital, Tullamore Naas General Hospital Midlands Regional, Portlaoise Coombe Women & Infants University Hospital	West/North West	<a href="#">University Hospital Galway</a> Merlin Park Hospital <a href="#">Sligo Regional Hospital</a> Letterkenny General Hospital Mayo General Hospital Portiuncula Hospital Roscommon County Hospital
TCD		NUI Galway	

33 Department of Health 2013. The Establishment of Hospital Groups as a transition to Independent Hospital Trusts. A report to the Minister for Health, Dr James Reilly, TD. Published Feb 2013

Group / Academic Partner	Group Members	Group	Group Members
East	Mater Misericordiae University Hospital St Vincent's University Hospital Midlands Regional Hospital, Mullingar St Lukes Hospital, Kilkenny Wexford General Hospital	Mid-West	Mid-Western Regional Hospital Limerick Ennis General Hospital Nenagh General Hospital St John's Hospital Limerick Mid Western Regional Maternity Hospital
UCD	Holles Street Hospital Our Lady's Hospital, Navan St Columcilles Hospital St Michael's Hospital Dun Laoghaire Cappagh National Orthopaedic Royal Eye & Ear Mid-West	UL	Mid-western Regional Orthopaedic Hospital

**Table 9; Hospital Groups with neurology centres highlighted**

The table above outlines the 6 hospital groups. The centres highlighted in green are those with on-site Neurology Services. This demonstrates that access to neurology service is not equitable across the hospital groups. There is also a 7th group incorporating Children's Hospitals.

The existing neurology centres are co-terminus with the regional epilepsy centres as detailed in the model of care for the National Clinical Programme for Epilepsy.

While the neurology centres are hospital based, the neurology managed clinical network will need to be developed in collaboration with both hospital groups and community healthcare organisations as it is wholly recognised that neurology services will remain significantly impacted by the capacity of other areas within the health services to manage the needs of people with neurological conditions. The importance of the development of community based neurorehabilitation services, the implementation of an effective model for the management of neurological conditions in primary care and appropriate facilities for step down and long term care options are key determinants for the success of any managed clinical network for neurology.

### 7.3 Long Term Drivers & Future of Speciality

#### a) **New modalities of treatment**

Increasing complexity of conditions like MS, where new therapies are available but need close monitoring will impact on consultants work load. Appointment of lead clinicians with specific expertise in advanced management and therapeutics of specific conditions will be required. In some instances, fully centralised care for complex diseases / management strategies and therapeutic clinical trials will be required.

New technologies such as the introduction of Deep Brain Stimulation (DBS) will also require centralised care. DBS is effective in the treatment of patients with medically refractive Parkinson's disease, dystonia and essential tremor. Following the outcome of a Health Technology Assessment carried out by the Health Information and Quality Authority (HIQA) in 2012<sup>34</sup>, this service is currently funded under the treatment abroad scheme.

'A national DBS service should comprise a multidisciplinary team of appropriately trained professionals with access to the requisite resources to ensure they achieve the required minimum caseload and to ensure that patients receive optimal care according to their individual needs (HIQA 2012)'.

It is likely that a DBS service will be required on the island of Ireland in the near future to improve patient care and outcomes.

## b) Future Disease Burden

As referred to previously, the aging population will see a significant increase in the numbers of patients presenting with complex neurological conditions. With Ireland's growing population, the number of neurologist per head of population will further reduce over the coming years. This will lead to longer waiting times and delayed review by consultants with consequent non achievement of agreed national waiting times.

Age Group	Male	Female	All
Under 45	1,509,142	1,500,838	3,009,980
45-64	520,243	522,636	1,042,879
65-74	149,774	155,054	304,828
75-84	75,054	97,095	172,149
85 and over	18,486	39,930	58,416

Source: *Census of Population 2011, de facto basis*

### Table 10; Central Statistics Office population projections

The total population is expected to rise to between a low of 4.57 million and a high of 4.91 million by 2021. The number of older males (i.e. aged 65 or over) will rise to between 322.651 and 339.505 by 2021 which is equivalent to an increase of between 70.2 and 79.1 % on existing numbers. The number of older females is anticipated to rise to between 375.835 and 389.101 by 2021 which is equivalent to a smaller percentage increase for males of between 52.3 and 57.6 %.<sup>35</sup>

34 Health technology assessment of a national deep brain stimulation service in Ireland. Health Information and Quality Authority. November 2012.

35 Connell, P; Pringle, D/ Population Aging in Ireland – projections 2002-2021, Report No 81, National Council on Ageing and Older People.



	UK neuro numbers report	2006 Irish census; 4,234,925	CSO population projections for Ireland		
			2016; 4,811,000	2021; 5,070,000	% of pop
Persons living with neurological conditions	17%	725,987	824,743	869,143	17.1
1. Help with daily activities	0.6%	25,410	28,866	30,420	0.6
2. Disabled by neurological conditions	2%	84,899	96,220	101,400	2
3. Neurological condition but able to manage lives on a daily basis	14.5%	615,879	699,657	737,323	15
Each year number newly diagnosed with neurological condition	1%	43,559	48,110	50,700	1
Number caring for person with neurological condition	1.5%	61,709	71,790	74,601	1.5

**Table 11; Future Disease Burden as percentage of population**

**c) Increased need for access to neuroimaging in diagnosis and monitoring**

Current access to MRI and other imaging including interventional radiology is considered as an obstacle to swift and appropriate neurological assessment and subsequent management. Many hospitals have lengthy waiting time for 'routine' outpatient MRI. The demand is set to increase with the projected increasing population as outlined above. The obstacle is not only access to imaging, but also the MDT approach to interpretation of imaging.

With the diagnosis of MS, the National Institute for Health and Clinical Excellence (NICE) Guidelines in the UK reference recommend a timeline of 6 weeks from receipt of referral to neurology consultation and then a further 6 weeks to a diagnosis of MS. An audit of clinical practise undertaken in 2011 (Kelly et al 2011)<sup>36</sup> demonstrated that adherence to this guideline in the UK was not achieved in 9% of patients included in the audit specifically as a result of limited access to MRI.

Increasing access to MRI will reduce waiting times, however increasing access can only be achieved by investment in additional radiology, and where possible, neuro-radiology posts.

**d) Potential for the development of specialist centres for the management of specific neurological conditions**

The National Clinical Programme for Neurology recognises that the need for tertiary specialist services may arise where volume may not exist within local services to maintain specialism/competency.

36 SB Kelly, E Chaila, K Kinsella, M Duggan, C McGuigan, N Tubridy and M Hutchinson. Multiple Sclerosis, from referral to confirmed diagnosis: an audit of clinical practice. Multiple Sclerosis Journal, 17(8) 1017-1021 (2011)

**e) New services developing in response to need**

Examples of this would be the development of specialist narcolepsy services and potential for improved Deep Brain Stimulation services in Ireland. Any service development will need to be carefully planned considering challenges within the system with respect to sources and indeed space.

The development of the Dublin Neurological Institute is an example of a new service which was developed in response to need. In this instance, the need was space and resources. This Institute model, which is a non-profit charity, but an independent company compliments the health service as it attracts funding from fundraising, philanthropy, and grant sources and other mechanisms which supports the hospital's neurology services. In view of the of the ongoing problems with funding nationally, the Dublin Neurological Institute model of healthcare could be considered as a possible mechanism to increase and expand hospital based neurological services nationally.

**f) Telemedicine**

As detailed in the recommendations section of the executive summary, telemedicine is seen as a way to increase equity of access to healthcare. Traditionally, part of the difficulty in achieving equitable access to health care has been that the provider and recipient must be in the same place at the same time. Advances in information and communication technologies, however, have created unprecedented opportunities for overcoming this by increasing the number of ways that health care can be delivered (Craig & Patterson 2005)<sup>37</sup>.

**g) Research networks and collaborations which will require research posts and dedicated clinician time to ensure that Irish neurology can contribute to the development of innovative approaches to the management of neurological disease.**

---

37 Craig, J, Patterson V. Introduction to the practise of telemedicine. Journal of telemedicine and telecare 2005; 11:3-9

# PART C

## Neurology Programme Model of Care

This model of care focuses on the development of services configured in a managed clinical network (Laffoy 2007<sup>11</sup>). A hospital-based network represents only one stage of the journey for patients with chronic neurological conditions. Patients with a neurological diagnosis spend the majority of their time living in their homes in the community with the support of their general practitioner, public health nurse, local therapists, and other service providers such as home helps, voluntary agencies and support groups.

A cohesive managed clinical network draws together the expertise of all the neurology service clinicians and care providers who support each individual through all stages of the patient journey (Laffoy 2007<sup>11</sup>).

In addition this model of care, describes how services should be configured, makes recommendations with respect to service provision and places key hospital services on a more sustainable footing.

### 8.1 Proposed model of care based on a managed clinical network structure

***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 development of quality service provision for people with neurological conditions requires the provision of specialist, multidisciplinary, integrated and quality assured care that meet patient needs in a timely manner and on a population basis (Laffoy 2007)<sup>11</sup>.

A managed Clinical Network Model offers the best scope for the future configuration of services for neurology patients in Ireland. Such a model offers the greatest opportunity to ensure that Neurology services are developed in a way which is integrated across traditional boundaries to provide efficient, equitable and high quality services across the country.

The Managed Clinical Network concept is based on collaboration between service providers in different regions, centers 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 work together in a symbiotic fashion. 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 for patients (Laffoy 2007)<sup>11</sup>.

A high quality neurology services would need to reflect the broad range of needs of its services users and as such should support timely, appropriate access to multidisciplinary care. Some of this care can be provided by GPs, HSCP's/nurses working in primary care, social care and/or with other service providers.

The Neurology Programme recognises that change on this scale is a very large undertaking and such change needs to be managed appropriately in collaboration with all stakeholders. Delivering better care to whole populations across organisational and professional boundaries requires sustained work over long periods, and at all levels of the system of care<sup>38</sup>.

## 8.2 The core elements of the Model include the following (Laffoy Review 2007)<sup>11</sup>:

- **Population based networking of available resources, with regional decision making and governance, within a National framework / guidance (Laffoy 2007)<sup>11</sup>.** The deployment of existing neurology resources will largely a matter for agreement and management at hospital group and CHO level, based on national HSE policies and frameworks. This will ensure that all stakeholders (e.g. PCCC, GPs, Voluntary Agencies, Hospital Neurology Teams, and Hospital Network Managers etc) can participate in decision-making about how neurology services are developed and managed for the people in their area.
- **Clearly outlined roles at every level (Laffoy 2007)<sup>11</sup>:** 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. A flexible approach will be required for the active management of the connections in the network to promote effective interdisciplinary communication.
- **Grouping and reconfiguring of resources (Laffoy 2007)<sup>11</sup>:** The resources of the network are grouped and configured across traditional boundaries, so that the best possible service is provided to patients within the network. This should enable most services to be provided as close to the patient's home / community as possible, while the less frequently needed, highly specialised services are focused at regional / national level.
- **Focus on local care (Laffoy 2007)<sup>11</sup>:** In this model, priority is given to enhancing integration with other services especially Primary Care, Community rehabilitation teams (CRT) through the reconfigured 'Community Healthcare Organisations' (see figure 5 below) and smaller hospitals. The majority of care should ideally be provided as close to the patient's community as possible, with PCCC, CRT and local hospital services empowered to play key roles through training and support.

38 Greene A et al. Do Managed clinical networks improve quality of diabetes care? Evidence from a retrospective mixed methods evaluation. Qual Saf Health Care. 2009 Dec. 18 (6):456-61. Doi: 10.1136/qshc.2007.023119

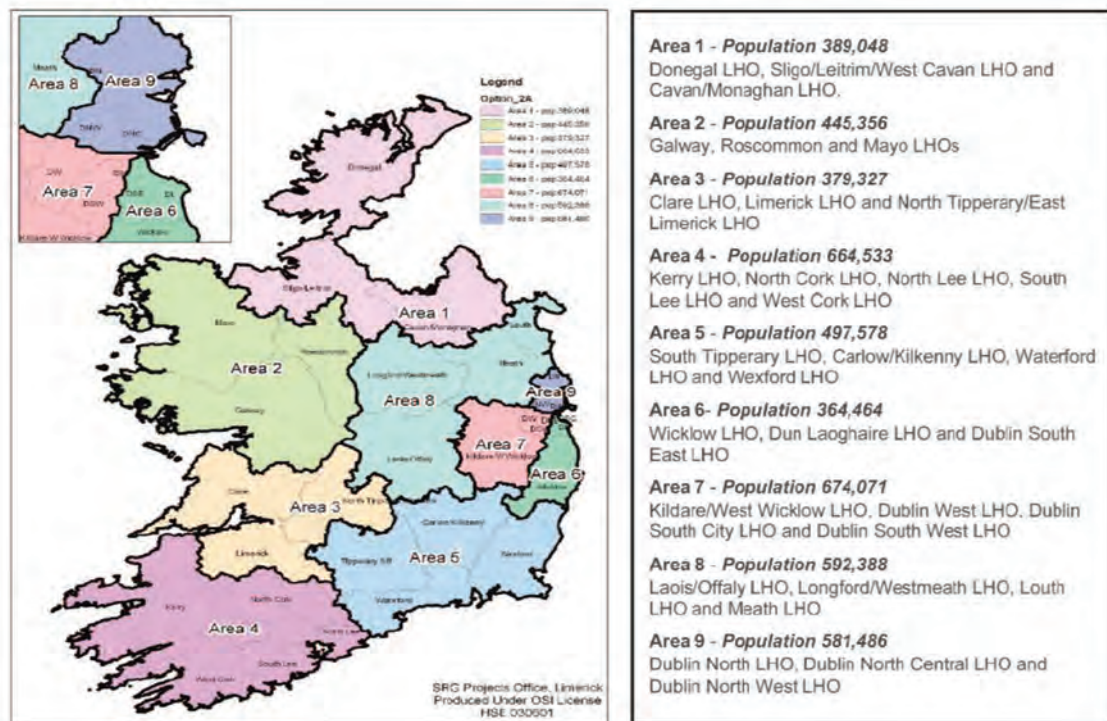


Figure 10: Community Healthcare Areas

### 8.3 How the Managed Clinical Network will operate in Practice

It is proposed that six Clinical Neurology Networks be established in line with the new hospital groups. Each Network will be supported by Community services which are configured into 9 Community Healthcare Organisations (CHO's). Each Network is supported clinically by a neurologist i.e. group neurology leads. In addition, a National Neurology Steering Group will be established to provide clinical guidance across the service, assist with developing clinical standards, guidelines and promote quality care and innovation and research.

Services for the neurology patient are envisaged at 3 levels (Laffoy Review 2007<sup>11</sup>):

- 1. Local level** – this includes the patient's GP, Primary Care HSCPs and nurses, Community Rehabilitation Teams (from CHO) and the nearest Acute General Hospital
- 2. Regional/Group Neurology Service** – the hospitals with a neurology service (existing or proposed) collaborate to function as a Group Neurology Service, operating as a Clinical Network in each of the six Hospital Groups. These group centers will support hospitals within the group, CRT and Primary Care professionals in the management of neurological patients, in a planned and coordinated way.
- 3. National Tertiary Centers** – in addition to the two neuroscience centers, Beaumont Hospital and Cork University Hospital; as outlined in the Comhairle na hOispeadéal Report (2005)<sup>39</sup>, tertiary centers can be further developed across the service. Since the publication of this report a number of tertiary centres have developed across the country. Tertiary centers will generally have teams with sub specialism in some of the low volume / high complexity conditions within neurology. Tertiary centers will also have a significant role with regard to supporting colleagues in training, education and research.

39 Comhairle na hOispeidéal, 2005. *Committee to review neurosurgical services*,





**Fig 11; visualisation of levels of neurology services**

#### 8.4 Roles / Functions in a Group Neurology Network (Laffoy 2007)

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

- Establish the clinical leadership of the group network.
- Establish and maintain an effective interface with hospital network structures (i.e. hospital group) and with national neurology services, to facilitate ongoing planning and development of group neurology services, within the overall national framework.
- Agree the group priorities / objectives for service development, consistent with the 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.
- Develop and agree management and referral protocols for neurology patients with Acute Hospital Division, CHO & PCCC services within the group/CHO, taking account of 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 which will be through the new Community Healthcare Organisation (CHO) structure.
- Ensure that the regional neurology service participates in ongoing development and implementation of the overall national framework for neurology services.
- Work in partnership with other regional/group networks in relation to clinical (e.g. referral / assessment / management pathways), research, training or other relevant matters.
- Establishing effective links between neurology and other specialisms as required for the management of neurological conditions. Palliative care and rehabilitation services are outlined in detail later in this section but referral pathways must also be established to meet the needs of patients in relation to areas such as pain management, dementia care and mental health.

### 8.4.1 Roles/ Functions at a tertiary level (Laffoy 2007)<sup>11</sup>

Tertiary services within neurology are services dedicated to specific sub-specialty care. Patients will often be referred from group/local services to a tertiary service if the group/local service does not have the specific resources required to provide treatment/management in line with best practice. 'Resources' can refer to equipment/access to beds and/or personnel.

Tertiary services generally manage patient cohorts with low volume but high intensity needs.

Tertiary services have an active role in education, training, support and research into the particular condition/population they support.

### 8.4.2 Roles / Functions at National Level – National Neurology Steering Group (Laffoy 2007)<sup>11</sup>

The establishment and successful functioning of the National Neurology Steering Group involves a number of activities and roles:

Establish and maintain an effective interface with the Acute Hospitals Division, National Hospitals Office, PCCC and CHO's, the Group 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 group 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 groups 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.

Ensure effective collaboration with other relevant national structures e.g. Expert Advisory Groups etc.

Irrespective of the 'level' of the service, for all in-patient neurology services the following is recommended

- No service/hospital should have a Neurologist working in isolation .
- Building a service around one individual is unsustainable. It leaves both the individual and the service exposed to risk. The considerable demands on a neurology services are detailed in Section 7., given the extent of these demands the Neurology Programme would recommend that each hospital, with a neurology service, should have a minimum of 3 Neurologists covering that service.
- Neurology in-patient beds should be cohorted to ensure that neurology patients are treated by specialists in neurology in a contiguous area.

There is international evidence, to support the cohorting of patients with neurological conditions in one dedicated ward area where they have access to specifically trained medical, nursing and therapy staff. One such study by Skelly et al 2014<sup>40</sup> showed that patients with Parkinson's disease treated on a ward specifically dedicated to patients with Parkinson's disease, in a general hospital, had improved care in terms of reduced medication errors, significantly reduced length of stay and better perceived experience of care by the patient. In that study ALOS was reduced by almost one third (from 13 days to 9 days)

Similarly, stroke units have demonstrated the potential for reduced mortality, improved functional independence, reduced likelihood of rehospitalisation and decreased length of stay (Sun et al 2014)<sup>41</sup>.

A local review of HIPE data from the Mater Misericordiae University Hospital for equivalent 6 month periods, the first in early 2013 when there was a named ward treating cohorted neurology patients and the second from admissions listed as neurology when patients were not in one contiguous area, but placed throughout the hospital, shows that efficiencies can be achieved both in terms of service delivery i.e. bed days used and in terms of patient outcomes i.e. reduced length of stay.

	Neurology services on one ward	General Neurology admissions
No of Discharges	233	171
Bed days used	5171	4116
ALOS	19 days	21 days

**Table 12; summary finding of impact of cohorting neurology patients in one specialist ward**

Currently in Ireland there are only 4 hospitals which have dedicated neurology wards. The Neurology Programme proposes the reconfiguration of all current neurology beds within model 3 and model 4 hospitals to form neurology specific wards. This proposal is in keeping with the recommendations of the joint report on 'adult neurology services for the next decade' by the Royal College of Physicians and the Association of British Neurologists (RCP 2011)<sup>42</sup> whereby acute neurology ward areas led by consultant neurologist and specialist staff are advocated.

## 8.5 Integration with General Practitioners

It is essential to ensure a strong relationship between hospital-based neurology services and general practitioners to facilitate a well co-ordinated approach to care for patients. The 2007 Laffoy Review<sup>11</sup> reported on a survey carried out with GP's to explore ways in which this integration could be developed. Potential suggested areas for development included;

40 Skelly, R, Brown, L, Fakis, A et al. 'Does a specialist unit improve patients outcomes for hospitalized patients with Parkinson's Disease?' Parkinsonism and related Disorders 2014. <http://dx.doi.org/10.1016/j.parkreldis.2014.09.015>

41 Sun, Y, Paulus, D et al. A systematic review and meta-analysis of acute stroke unit care: what's beyond the statistical significance? BMC Medical Research Methodology 2013, 13:132

42 Royal College of Physicians. Local adult neurology services for the next decade .Report of a working party. London: RCP, 2011.

- Guidelines; GP's advocate the development of guidelines for referrals and on the management of common neurology conditions as well as awareness of patient pathways.
- Access; greater access to diagnostic imaging is required for GP's. This would reduce the burden on consultant services and improve community care. (The 2011 HIQA report<sup>43</sup> recommended that the possibility of a direct access service for GP's to radiology services should be investigated).
- Improved links; GP's request better service integration including better links with rehabilitation services.
- Chronic disease management; Chronic disease management in primary care needs to be developed. The Neurology Programme welcomes the development of integrated programmes within the Clinical Strategy & Programmes Division of the HSE and sees this as a way of supporting a system of chronic disease management across all relevant divisions.
- 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; There is an opportunity for hospital based neurologists to improve IT capability and electronic communication with GP's e.g. the development of a national neuro-telelink type service and other ICT based services (e.g. electronic referrals) should be viewed as a priority. The development of neurolink provides direct access to GPs for a neurological opinion and avoids delays and unnecessary appointments for those who do not need to see a neurologist.

While these potential areas for development were initially identified in Laffoy Review 2007<sup>11</sup>, they are consistent with current recommendations identified by the neurology programme and contained within this model of care for example;

- Training modules/ education on both general neurology and management of specific conditions within neurology for GP's. A number of such modules have been developed in collaboration with the Irish College of General Practitioners (ICGP) including 'how to carry out a neurological examination', 'the management of Parkinson's disease' and the 'management of MS) with additional proposed modules to follow.
- Pathways for the management of specific neurological conditions which include guidelines for general practice
- Development of condition specific clinics such as PD, MS & Headache in addition to recommendations re: nurse and therapy-led clinics
- Improved referral management and audit of same
- Exploration of possible national applications of telemedicine. The development of teleneurology has been identified as a priority of the neurology programme, however to be effectively implemented, it will require additional resources.

---

43 HIQA, March 2011. Report and recommendations on patient referrals from general practice to outpatient and radiology services, including the national standard for patient referral information.

The National Clinical Programme for Epilepsy provides a key example for the Neurology Programme to follow in terms of the management of neurological conditions at primary care level. They have developed a significant suite of standard operating procedures which detail roles and responsibilities for all involved in managing the care of patients with epilepsy across all settings with a specific group of Standard Operating Procedures (SOPs) focused on management of the patient by the GP. These SOPs give guidance, based on evidence-based practice, on how patients should be managed, providing both reassurance to the GP's and ensuring consistent patient care across the country. A similar suite of SOPs will, it is proposed, be developed by the Neurology Programme.

### 8.6 Integration with Neurorehabilitation and Palliative Care Services

There are some important areas of overlap between respective roles of neurologists, rehabilitation physicians and palliative physicians (RCP 2008)<sup>44</sup>. Given the current pressure on resources within the health service, an understanding of the interface between neurology, rehabilitation and palliative care is essential to ensure that service provision is comprehensive and coordinated for people with long term neurological condition.

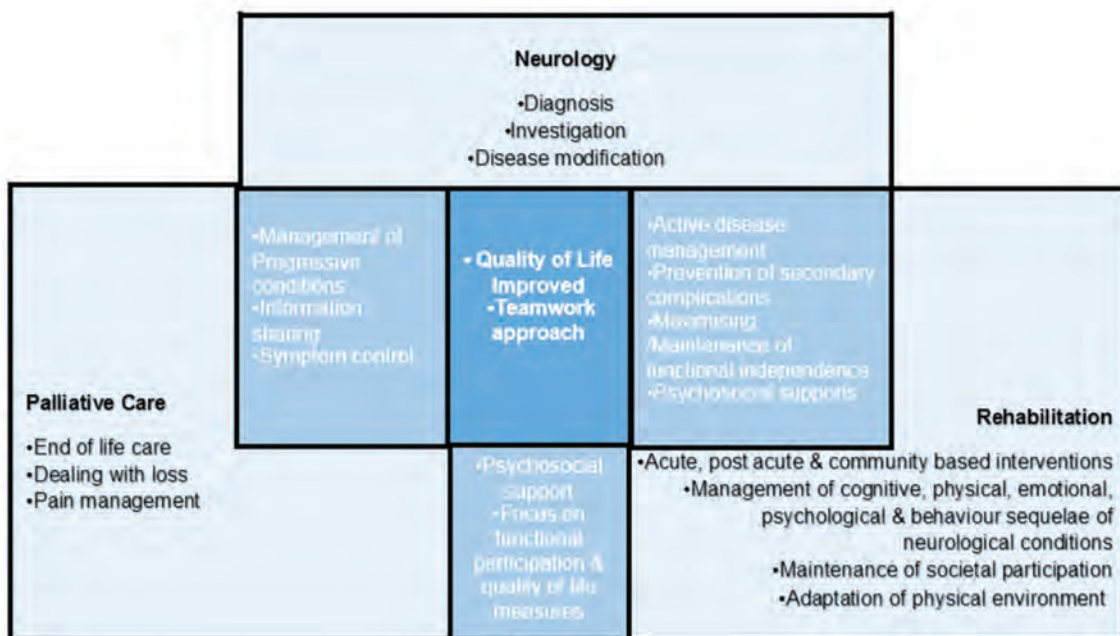


Fig 12; Interfaces between Neurology, Rehabilitation and Palliative Care

44 Concise guide to good practise – long term neurological conditions: management at the interface between neurology, rehabilitation and palliative care. RCP. National Guidelines, March 2008.



## 8.6.1 Integration with Palliative care

The place for palliative care in non-cancer patients is increasingly recognised (Concise guide to good practice; number 10, long-term neurological conditions: management at the interface between neurology, rehabilitation and palliative care. National Guidelines, March 2008), especially in rapidly fatal neurological conditions such as Motor Neurone Disease and in end stage MS, Parkinson's Disease, PSP, CJD and others.

Early referral to specialist palliative care services and an integration of palliative care support & approach into the patient pathway for all patients with progressive neurological conditions is recommended. A report launched in 2014 by the Neurological Alliance of Ireland and the Irish Hospice Foundation "palliative care needs of people with advancing neurological conditions in Ireland"<sup>45</sup> outlines a series of recommendations for including specialist palliative care in the multidisciplinary management of neurological conditions and encouraging the use of a palliative care approach by all those working with those with progressive neurological conditions.

Individuals with progressive neurological conditions can benefit from early and ongoing palliative care support throughout the course of their disease. Palliative care support should be provided by all members of the MDT involved in the treatment/management of patients with long-term neurological conditions.

Palliative care is increasingly concerned with quality of life issues for patients, and not confined to the final stages of their illness. While the provision of specialist palliative care in dedicated palliative care/hospice facilities is one element of palliative care, the Neurology Programme supports the increasing realisation that palliative care is not limited to the specialist service, but should be considered an over-arching approach/philosophy of care for people with neurological conditions which are life limiting.

Palliative care can be seen as a continuum of care in itself with three distinct levels of support/intervention (Irish Hospice Foundation & Health Service Executive 2008<sup>46</sup>) – see figure 8.

### Level 1: Palliative care approach

- Many individuals with progressive and advanced disease will have their care needs met comprehensively and satisfactorily without referral to specialist palliative care units or personnel. This level refers to the practice of palliative care principles by all health care professionals.

### Level 2: General Palliative Care

- This is an intermediate level of care which is provided by health care professionals with some training and experience.

### Level 3: Specialist Palliative Care

- Specialist palliative care services are those services with palliative care as their core speciality.

45 Weafer JA 2014. The Palliative Care needs of People with Advancing neurological Disease in Ireland. A Report prepared for the Neurological Alliance of Ireland and the Irish Hospice Foundation.

46 Health Service Executive & Irish Hospice Foundation 2008. Palliative care for all. Integrating palliative care into disease management frameworks. Dublin.

Palliative care provision is the responsibility of the whole healthcare team and uses a team approach to planning and providing care tailored to meet the individual needs of the person and their family / carers. Within a healthcare team there are three levels of palliative care provision with increasing specialisation from level 1 to level 3:



**Fig 13; adapted from the National Clinical Programme for Palliative Care**

It is recommended that all members of the MDT working with patients with progressive neurological conditions should have competencies in the provision of level 1 and level 2 palliative care provision.

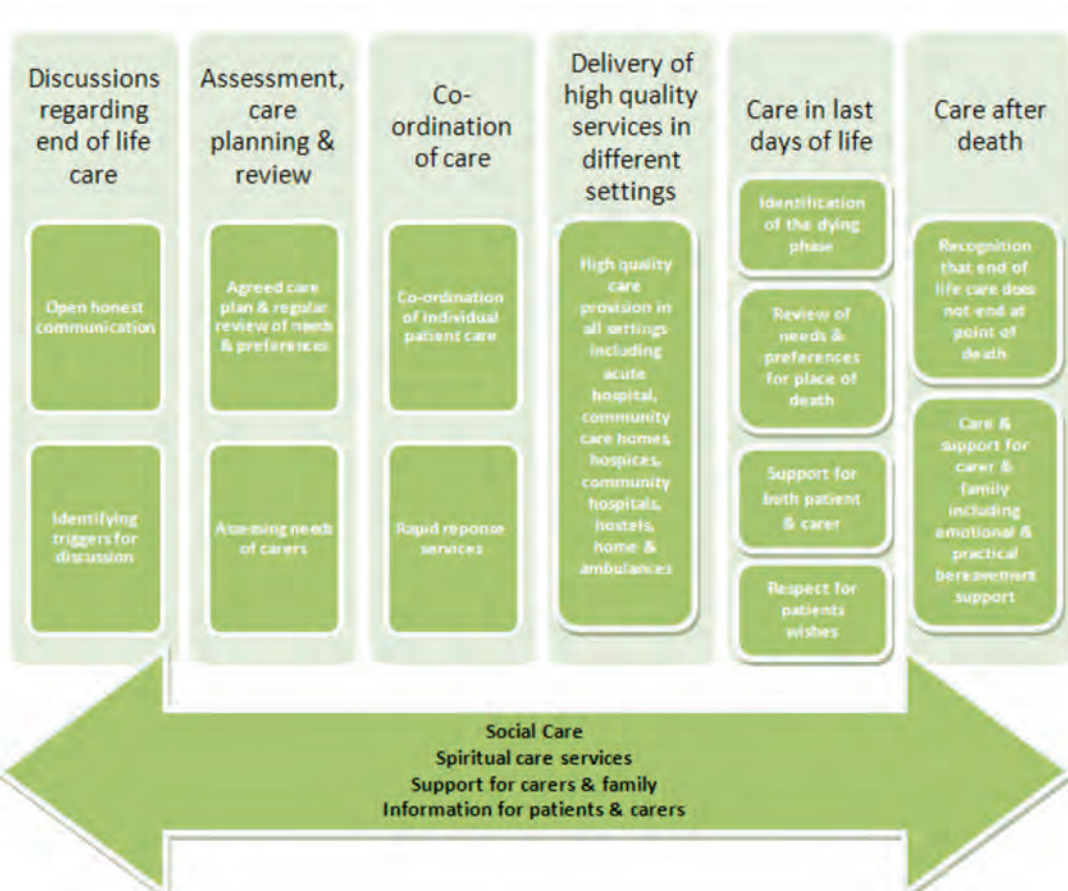


Fig 14; Adapted from 'End of life care in neurological conditions: a framework for implementation'. The National Council for Palliative Care, the Neurological Alliance & NHS National End of Life Care Programme. 2010<sup>47</sup>

The value of providing different levels of palliative care for individuals with neurological conditions is increasingly recognised. The Clinical Programme for Palliative Care has also published a competency framework for all disciplines of staff working across all levels of palliative care provision<sup>7</sup>. This is a valuable educational tool and would be recommended for consideration for all staff working in neurology services.

### 8.6.2 Integration with Rehabilitation Services

The Strategic Review of Neurology and Neurophysiology (Laffoy 2007)<sup>11</sup> recognised that "rehabilitation facilities are a key aspect of neurology services and the management of discharges from acute neurology units". The report noted the impact of the dearth of acute, post-acute and community based rehabilitation facilities as a critical factor impacting on effective service delivery in neurology.

The Comhairle na nOspidéal report on Neurology and Neurophysiology services (2003)<sup>48</sup> also recognised the issue of "access to and the scarcity of facilities for neurologically disabled patients requiring both short term and long term rehabilitation".

47' End of life care in neurological conditions: a framework for implementation'. The National Council for Palliative Care, the Neurological Alliance & NHS National End of Life Care Programme. 2010

48 Report of the Committee to review Neurology and Neurophysiology Services, April 2003. Comhairle na nOspidéal

There is strong evidence from Cochrane and other systematic reviews that multidisciplinary rehabilitation can improve the experience of living with a long-term neurological condition, both at the level of functional activity and societal participation. There is also disease-specific evidence that multidisciplinary care improves outcomes in rapidly progressive disease (Rooney et al, 2014)<sup>49</sup>. It is acknowledged that any person with disability due to a long term neurological condition should have timely and ongoing access to specialist rehabilitation medicine services which can assist with ongoing medical management, coordinated multidisciplinary team interventions, holistic support and disability management.

Evidence of the efficacy of neurological rehabilitation is accumulating and has been shown to;

- a) Reduce length of stay in hospital
- b) Improve functional outcomes
- c) Improve productivity in patients i.e. return to work rates
- d) Reduce carer distress

The National Service Framework (NSF) for long term conditions (BSRM, London 2009)<sup>50</sup> emphasises the need for local rehabilitation services as close to the individual's home as possible and recognises that people's need for rehabilitation changes over time so that a range of different services need to be provided.

It also recognises the need for specialist services for people with more complex needs and therefore recommends that rehabilitation services are planned and delivered through co-ordinated networks in which specialist neuro-rehabilitation services work both in the hospital and the community to support local rehabilitation teams.

The NSF recognises the need for complex specialist services to support people with profound and complex disability. (BSRM, 2009)

These recommendations are in keeping with the recommendations of the National Strategy and Policy for Neurorehabilitation<sup>16</sup> and the model of care of the National Rehabilitation Medicine Clinical Programme<sup>2</sup> which the National Neurology Programme references.

The model of care for the rehabilitation medicine programme aims to improve access to specialist neurorehabilitation in both hospital and community which is a recognised critical requirement for an effective neurology service.

All patients with neurological conditions benefit from rehabilitative input, however the intensity and goals of rehabilitation programmes may differ depending on the nature of the condition, the stage of the disease and the participation of the patient. Both the model of care for the Rehabilitation Medicine Programme and the Strategy and Policy for Neurorehabilitation services outline 3 distinct levels of specialism within neurorehabilitation

49 Rooney J, Byrne S, Heverin M, Tobin K, Dick A, Donaghy C, Hardiman O. A multidisciplinary clinic approach improves survival in ALS: a comparative study of ALS in Ireland and Northern Ireland. *J Neurol Neurosurg Psychiatry*. 2014 Dec 30. pii: jnnp-2014-309601.

50 BSRM Standards for Rehabilitation Services Mapped onto the National Service Framework for Long term conditions. British Society of Rehabilitation Medicine. 2009



**Fig 15; levels of specialism within Neuro-rehabilitation**

As neurorehabilitation can for some diagnoses be a life-long process and patients' needs can vary significantly across their lifetime, it is anticipated that in practice, patients should transition easily between services offering varying levels of specialism and that re-entry along any point of the continuum is ensured.

Shared care of patients between Consultants in Rehabilitation Medicine and Neurology could also be facilitated by telemedicine. One such system is the TRASNA telemedicine system. The TRASNA system, led by the National Clinical Programme for Stroke (HSE 2012)<sup>4</sup>, aims to link patients, doctors, nurses, HSCP's and hospitals together on a shared secure network. The goal is to improve patient access to senior clinical expertise, which would not otherwise be available, or which would require the patient to travel long distances. The potential for extending the remit of such a system should be explored as it could allow for simultaneous review of patients by both neurologist and rehabilitation physician and MDT.

### 8.7 Integration with Mental Health Services

While this is an area which has received little attention in an Irish context to date, there are strong anecdotal reports describing the challenges faced by people with neurological conditions in accessing supports for mental health issues such as depression and anxiety and accessing specialist services for neurobehavioural problems. The Neurology Programme recommends that neuropsychiatry and neuropsychology supports should be developed nationally at both hospital and community level and should be accessible to people with neurological conditions and their families/carers.

### 8.8 Healthcare and Disability Supports in the Community for People with Neurological Conditions

As outlined throughout this document, the delivery of effective neurology services is critically dependent on the capacity and responsiveness of other areas of the health service to meet the needs of people with neurological conditions. The previous sections outlined the need for neurorehabilitation and palliative care supports for people with neurological conditions.



### 8.8.1 Long term Care

There is no effective strategy in place to co-ordinate effective long term care for people living with neurological conditions in the community. Many of these individuals could be accommodated within their homes if appropriate home care supports were available. Others will need appropriate respite and residential facilities including step down and transitional services for those recovering from stroke/acquired brain injury. This has a significant impact on the delivery of neurology services, leading to delayed discharges and lengthy hospital stays.

### 8.8.2 Disability Supports

Provision of equipment, PA services and other disability supports are important particularly in the context of the progressive nature of many neurological conditions where delays in accessing support can result in loss of functioning and independence and increase requirements for unscheduled hospital care and residential care. The provision of disability supports is also constrained by the “silo” funding that also operates within the health service where access to these supports is based on age.

### 8.8.3 Medical Cards

As well as providing medications and GP services, the medical card is a gatekeeper to accessing therapy services and other supports in the community for people with disabling neurological conditions.

## 9 Patient Journey

The Neurology programme is committed to improving the patient journey of people with neurological conditions. In order to facilitate this, the programme has engaged in a dialogue with patient organisations, through their national umbrella the Neurological Alliance of Ireland. Patient focus groups have also been involved in consultation on the specific pathways for MS, Parkinson's disease and Headache.

This chapter will examine

- (a) The issues that impact on the patient journey and the work of the programme in addressing these
- (b) The role of not for profit organisations in neurological care

### 9.1 Neurological Patient Journey

Neurological conditions are sometimes very complex and difficult to diagnose, leading to unsatisfactory patient experiences and difficulties in care and management at any / each stage of the patient journey:

- The long-term nature of many neurological conditions, resulting in changing needs over time as the individual ages and/or the condition progresses;
- The rapidly progressing nature of some neurological conditions, with treatment, care and requirement for equipment / assistive devices being required at short notice in response to sudden / increasing disability
- Transition across different health care settings. The initial onset or the diagnosis of a neurological condition is typically managed within an acute hospital setting with the individual discharged to a community setting, potentially in a different geographical location;
- Complex sequelae of neurological conditions presenting with problems in the following areas; physical, motor, sensory, cognitive, behavioural, communication, psychosocial and or emotional effects of the condition. Managing these consequences requires the input of a large number of different health professionals. It is estimated that a person with a neurological condition may seek specialist care / advice from as many as 30 different health professionals and agencies involved in their care;
- The limited number of specialist personnel involved in the management of neurological conditions. These may be located in specialist centers or hospital services with the challenge of making this expertise and information available to staff working in a range of non-specialist healthcare settings.

In Ireland, these issues, compounded by years of under-investment and under-development of neurology services mean that the patient journey for people with neurological conditions is often characterised by long delays, inappropriate care in inappropriate settings, lack of an integrated approach to their needs and inability to access the services and treatments they require.

The Neurological Alliance of Ireland (NAI) has identified some of the following issues from a patient journey mapping exercise with individual patient organisations and testimonies from

patients which informed its' 2010 report "The Future for Neurological Conditions in Ireland: A Challenge for Healthcare; an Opportunity for Change"<sup>51</sup>

- Early and appropriate intervention is critical: A detrimental effect was reported by delayed diagnosis and access to the increasing array of appropriate treatments for people with neurological conditions in Ireland in terms of increased disability and the need for more intensive long-term support at later stages of the condition.
- Integrated care pathways can significantly improve patient journeys. People experience inappropriate care due to a lack of understanding of their needs. Guidelines and protocols for the management of specific neurological conditions are required to allow staff in a range of general healthcare settings to identify and respond to the needs of people with neurological conditions. There is a critical need to co-ordinate the delivery of services through a single point such as key worker or case manager.
- Appropriate patient journeys require appropriate services: People with neurological conditions require access to a range of specialist services and expertise at each stage of their condition. There is a significant dearth of these services across the country, and in the capacity of existing services to meet the level of need.

The following steps could be taken to improve the patient journey and patient experience of individuals with neurological conditions

1. Managing key transition points in the patient journey, e.g. transition from paediatric to adult services and to older persons services or from hospital to community to ensure effective co-ordination of care.
2. Providing information on relevant support organisations at an early stage to patients and families and following a protocol for the communication of a neurological diagnosis (see next section)
3. Key interfaces with services such as mental health and palliative care to provide specialist supports around specific needs of people with neurological conditions
4. Providing targeted information for healthcare professionals on the range of services and supports provided by patient organisations. The NAI provide a specially designed web resource for this purpose [www.neuronetwork.ie](http://www.neuronetwork.ie)
5. Addressing the deficits in neurology services in terms of staffing, facilities and access to treatments which delay patient access at key points and reduce the capacity for ongoing management of their needs
6. Addressing the critical dearth of specialist services in terms of neurorehabilitation and long term care which leave patients over-dependent on already overstretched neurology centers for their therapy needs and without appropriate services in the community
7. Training, guidelines and pathways, particularly for staff in general healthcare settings, including primary care, to improve the management of neurological conditions in the community
8. Improved discharge planning and follow up care to prevent the inappropriate, delayed and distressing patient journeys which continue to be experienced by many Irish people with neurological conditions. This requires putting new services in place, in the context of historical underdevelopment of neurorehabilitation and long term care services in the community for people with neurological conditions.

---

51 Neurological Alliance of Ireland 2010. The Future for Neurological Conditions in Ireland: a challenge for healthcare; an opportunity for change.

9. Involving people with neurological conditions in their own care through self-management and supported self-care.
10. Supporting people with neurological conditions who may have issues in relation to their capacity to make decisions about issues that affect their care and treatment and wider aspects of their lives. The forthcoming legislation on assisted decision making (capacity) will provide a statutory framework which will address the area of assessing capacity and introduce new structures for supported and substitute decision making. The legislation will have important implications for people with neurological conditions and their families but also for all those working with people with neurological conditions where capacity may be an issue. Acquired Brain Injury Ireland has prepared a very informative briefing paper on assisted decision making (capacity) legislation and its implications. [http://www.abiireland.ie/docs/Policy\\_Briefing\\_Paper\\_Assisted\\_Decision\\_Making\\_Bill\\_2013.pdf](http://www.abiireland.ie/docs/Policy_Briefing_Paper_Assisted_Decision_Making_Bill_2013.pdf)
11. People with neurological conditions should be supported in future decisions about their care through the use of advanced care planning tools and supports.
12. Educating, empowering and including family carers as key partners in the delivery of care

The Neurology Programme is working with the Neurological Alliance of Ireland, the umbrella for not for profit organisations, to improve key features of the patient journey as follows:

### **Communication of Diagnosis**

The programme is working to develop/adopt a protocol for the communication of a neurological diagnosis and the provision of information.

This will aim to address the following:

- a) The need to have due regard for the need for privacy, time and support when communicating the diagnosis. Special consideration needed when giving a diagnosis where cognitive decline is an aspect of the condition.
- b) The need to consider the implications for the patient's relatives when diagnosing a genetic neurological condition
- c) Provision of an opportunity to discuss the diagnosis with a member of the neurology team at that time and/or at a time of the person and family member's choosing in the next few days or weeks after diagnosis
- d) Provision of information about the relevant support organisation(s). The NAI website [www.neuronetwork.ie](http://www.neuronetwork.ie) provides a complete guide to the services and supports provided by neurological organisations in the not for profit sector
- e) Training for all members of the neurology team in the communication of diagnosis, negative test results etc.

Cork University Hospital has developed a patient information leaflet with key information for people with neurological conditions and their families

[http://www.cuh.hse.ie/Our\\_Services/Clinical\\_Services/Neurosciences/Services\\_Provided/Neurology\\_Patient\\_Information\\_Leaflet\\_Mar\\_2011.pdf](http://www.cuh.hse.ie/Our_Services/Clinical_Services/Neurosciences/Services_Provided/Neurology_Patient_Information_Leaflet_Mar_2011.pdf)

Discharge planning, integrated care and early access to diagnosis and treatment.

The model of care will incorporate recommendations for improved discharge planning and is working to promote integrated care through the development of care pathways for specific neurological conditions.

The programme is working to identify key resource requirements from the survey of neurology centres carried out with the support of the Neurological Alliance.

## 9.2 Patient Experience Survey

A nationwide NAI survey “Living with a Neurological Condition in Ireland” 2014 reference questioned five hundred patients who had been diagnosed with a neurological condition, and their family members about their satisfaction with different aspects of their care (table 11). The results outlined below, clearly indicate that there are significant aspects which must be addressed to improve services that are delivered to this patient group. The Neurology Clinical Programme is currently working with the Neurological Alliance of Ireland to design and pilot the first patient experience survey of Irish people with neurological conditions in order to provide baseline information for the programme.

	Very Satisfied	Satisfied	Not Sure	Dissatisfied	Very Dissatisfied
Info available about condition	28%	23%	21%	16%	12%
Support in linking to services	17%	25%	25%	17%	16%
Support in planning for future needs	9%	21%	30%	21%	19%
Getting referred to services	15%	24%	26%	20%	14%
Being involved in decisions about care	21%	23%	34%	11%	11%
Support in managing effects of condition	18%	25%	25%	20%	13%
Psychological support around condition	11%	21%	32%	22%	15%
Understanding of condition by health pros	20%	25%	19%	19%	16%
Practical support to live independently	15%	23%	31%	16%	16%

Table 13; results from NAI survey “Living with a Neurological Condition in Ireland” 2014

## 9.3 Role of Not for Profit Organisations in Neurological Care.

The Neurology Programme considers it important to highlight the vital role of not for profit organisations as part of the overall infrastructure of neurological care in this country and therefore as a key support for neurology service delivery.



The Neurological Alliance of Ireland (NAI) is the umbrella organisation dedicated to representing the voice of 700,000 Irish people with neurological conditions and their families. It plays a unique and crucial role in research, policy development and advocacy in relation to neurological care services in Ireland. The NAI currently receive no funding from the health service. It is vital that funding for the NAI and other not for profits is placed on a sound footing going forward given the value of these organisations as crucial resources for the development of neurological care in this country.

Not for profit organisations, which serve as direct service providers also support people with neurological conditions and their families and act as a vital bridge between neurology services and the rest of the healthcare system. This has been evident particularly in the context of very underdeveloped services, particularly in the community, for the management of neurological conditions in Ireland. In many cases these organisations work directly with neurology services to accept referrals and to design and deliver appropriate responses to the needs of people with neurological conditions and their families. They also play a key role in supporting healthcare staff in non-specialist settings in identifying and meeting the needs of people with neurological conditions. The table below indicates the wide range of services and supports provided by the not for profit sector.

#### 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
- Provision of Caseworker 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 specialist nurses, occupational therapists, social workers, speech and language therapists, 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
- Access to and provision of assistive enabling technology
- Development of specialist services to respond to the needs of people with neurological conditions in areas such as palliative care and neuropsychiatric support
- Expanding on the specialist nurse-led helpline services.
- Improving accessibility through provision of transport services and social activities and groups.
- Self management and supported self care, including targeted programmes and ongoing support
- Support and information to enable the individual and family to plan for future care needs and make decisions about their future with the condition

### Support and Advocacy

- Education and support in relation to diagnosis and management of a neurological condition
- Specialised support and education for family members
- Support groups, seminars, conferences and other meetings which offer crucial opportunities for information provision and peer support
- 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.
- Provision of trained advocates working directly with people with neurological conditions to identify and access the services they require
- Support for the multidisciplinary team around effective discharge planning
- Ongoing access to peer support for people with the condition and their families.

### 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 clinical and social research on neurological conditions Patient organisations act as a vital link between researchers and people with neurological conditions and between researchers and policy makers
- Supporting clinical research through fundraising and acting as a vital link between researchers and people with neurological conditions
- Supporting and promoting the involvement of patients in research into neurological conditions
- 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 around the development of guidelines and practice in the management of neurological conditions.

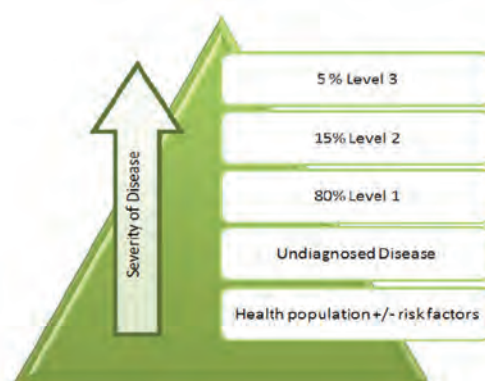
### Consultation to Inform Policy Development

- 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.
- Not for profit play a key role in identifying needs and existing gaps in services for the people they represent and working to highlight and advocate for these needs both at local and national level.

## 10. Chronic Disease Management in Neurology

### 10.1 The need for a population health approach

In addition to practical resource driven issues, the success of this model of care will be supported by a population health approach taken with respect to the prevention and management of chronic conditions. This approach highlights that the majority of the population currently do not have a neurological condition and may or may not have, or be exposed to, risk factors which predispose them to such conditions. In addition, there are those who have an undiagnosed neurologic condition who require early diagnosis, secondary prevention and appropriate management. Figure 11, which applies to all chronic conditions, shows the segmentation of complexity as it relates to the chronic conditions. It is important to appreciate that these three levels are not distinct cohorts of patients; people in each level can improve or deteriorate and move between levels.



**Fig 16; segmentation of complexity as it relates to chronic conditions**

**Level 1:** Individuals who have a neurological condition which is well controlled by the patients themselves with primary care support maximising of self-management participation (approximately 80% of patients).

**Level 2:** Individuals with more complex illness. They may have one or more chronic illnesses of varying severity, but are not at risk of hospitalisation if they are well managed in the community (approximately 15% of patients). These patients can be monitored by self-management participation and identified via achievement or non-achievement of specific treatment goals.

**Level 3:** Individuals with complex conditions, often with significant complications. They require specialist care, intensive intervention and are at high risk of hospitalisation (Approximately 5% of patients).

The focus on population health is gaining momentum within the health services as awareness develops that unless 'we make some significant changes, we are facing an unhealthy and costly future' (HSE 2014)<sup>52</sup>.

Within neurology, it can be said that disease prevention does not just stop at preventing the onset and impact of the condition, but looks at the wider aspect of reducing the impact of the disease on all aspects of the person's life. Disease prevention is thus classified as primary, secondary or tertiary (Gutenbrumer et al 2007)<sup>53</sup>. Examples of same are outlined in the table below.

52 Health Service Executive. April 2014. Preventing Chronic Disease: Defining the Problem. Report from the Prevention of Chronic Disease Programme.

Prevention	Characteristics	Setting in which preventative measures are undertaken	Examples
<b>Primary</b>	Avoid Disease or injury	Political & societal arenas Primary care	Reduction of risk for cerebrovascular disease & head trauma
<b>Secondary</b>	Avoid effect & complications of disease or injury	Acute Hospital & early rehabilitation	Prevention of falls, immobility & contractures
<b>Tertiary</b>	Avoid effect of disease/injury on the person's life i.e. limitation of activities	Post-acute & maintenance – rehabilitation services	Treatment of behavioural problems following ABI, access to full MDT

**Table 14; Adapted from White Book of PRM in Europe, J Rehabil Med 39**

Programmes aimed at preventable aspects of neurological disease, such as “Hello Brain” ([www.hellobrain.eu](http://www.hellobrain.eu)), have significant value in providing information and promoting healthy lifestyle choices.

## 10.2 Self-Management

Central to the population health approach is a commitment to develop the personal skills and self-management capabilities of the population. This is a core element of the chronic illness model building on traditional health education programmes to address the management of Neurological conditions.

Over the past two decades, the role of self-management in chronic diseases has gained momentum. Self-management programmes are now acknowledged as a key element of quality care. In addition to participation self-management programmes have been demonstrated to improved health care behaviours, health outcomes and to reduce healthcare utilization. A recent publication analyzing the impact of chronic disease management programmes with respect to healthcare savings has shown ‘significant reductions in ER visits (5%) at both 6-month and 12 month assessments as well as hospitalizations (3%) at 6 months’ among participants in a chronic disease self-management programme (Ory et al 2013)<sup>54</sup>.

Self-management education for people with neurological conditions should fit into the patient journey and pathway for the various conditions. Shared care and interface working between primary and secondary care is essential here. Group behavioural programmes are equally as effective and use resources more efficiently than individual education.

53 Gutenbrumer C, Ward CB & Chamberlain M A. White book on physical and rehabilitation medicine in Europe. Journal of rehabilitation medicine. January 2007. Supplement No 45.

54 Ory, MG et al. The impact of Chronic Disease Self-Management Programmes: Healthcare Savings through a Community Based Intervention. BMC Public Health. 2013; 13 (1141)

There is a need for committed investment in this area. While this will necessitate an initial outlay with respect to training of staff etc, research (Lorig et al 2001)<sup>55</sup> has demonstrated that effective delivery of self-management programmes can lead to a 1:4 cost-to-savings ratio.

Self-management is a person-centered approach which enables individuals and their carers to take an active role in caring for and managing their own condition. Self-management support may be viewed in two-ways;

- ▲ as a portfolio of tools and techniques which includes the provision of information, education and other supportive interventions to increase the person's knowledge, skills and confidence in managing their condition
- ▲ as a fundamental transformation of the traditional patient- health professional /caregiver relationship into a collaborative ongoing partnership, that includes care-planning, goal-setting and problem solving strategies<sup>56</sup>.

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

In terms of neurological conditions, the most recent systematic review<sup>57</sup> of research in this area concludes that self-management strategies are applicable to neurological disease. The review found evidence of a significant effect of a number of individual condition-specific self-management programmes for multiple sclerosis, Parkinson's disease and traumatic brain injury.

The Neurology Programme recognises the recommendations of the Population Risk Pyramid Model below demonstrating that a significant proportion of people (up to 80%) with chronic conditions will be able to self-manage their health condition(s), supported by their family and carers and a range of healthcare and other community-based services (DoH UK 2006)<sup>58</sup>

---

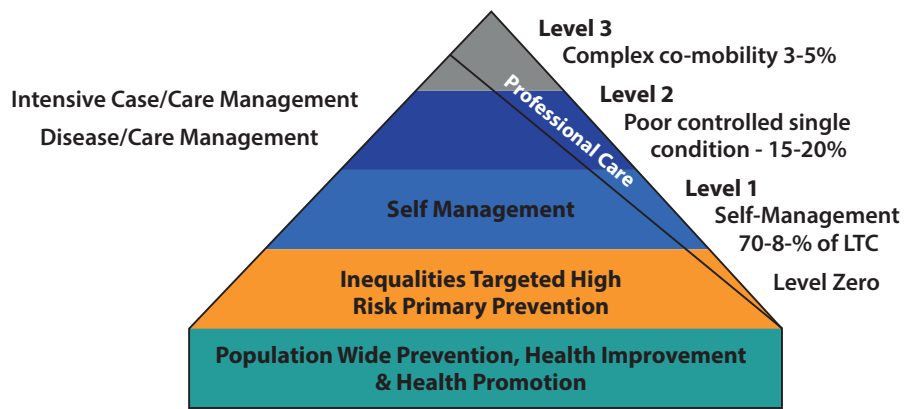
55 Lorig, K etc al. Effect of a self management programme on patients with chronic disease. *Effective Clinical Practice*, Nov/Dec 2001

56 [www.chcf.org/documents/chronicdisease](http://www.chcf.org/documents/chronicdisease)

57 <http://www.ncbi.nlm.nih.gov/pubmed/22234713>

58 Department of Health, UK, 2006. A guide to developing local strategies and good practice.





**Figure 17; Population Model<sup>59</sup>**

It should be remembered that the person's capacity to self manage can be affected by the effects of the condition and increasing disability, particularly in the case of progressive neurological conditions. There should be a focus on including people with neurological conditions in decisions about their care through advanced care planning and the use of assisted decision making. The forthcoming legislation on assistive decision making will have important implications for people with neurological conditions, particularly those in the palliative phase, where capacity may be an issue by providing for a range of supports to promote and assist the person's involvement in key decisions in relation to their care and treatment.

<sup>59</sup> Improving the Health and Wellbeing of People with Long Term Conditions in Scotland: A National Action Plan, Dec 2009

## 11. Medications in Neurology

### 11.1 Equitable Access to Medications



Neurology care has entered a therapeutic era with an increasing array of medications and other treatments that alter the course of disease, improve patient outcome and decrease disability. Patients will demand access to these new treatments and neurological services will have to meet this demand.

It is essential that patients have equitable access to medications deemed appropriate to their care. It is acknowledged that while many neurological medications are high cost, there is evidence supporting the cost effectiveness long term with respect to reduced burden of care, reduced number of hospital admissions, improving quality of life and reducing disability.

The Neurology Programme supports a national approach to the provision of medications for managing neurological conditions. This will avoid local variations in accessibility. The Neurology Programme has provided the HSE drugs committee prescribing guidelines for a number of high cost medications in multiple sclerosis. The aim of this collaboration is to develop a central reimbursement scheme so that hospitals providing these medications to their patients will not have to absorb this cost in their own budgets and patients can get access to effective treatment whether public or private and wherever they live.

### 11.2 Medication Safety

Medication safety does not look solely at the safety of individual medications, but rather the use of medications and how all health care professionals (pharmacists, physicians, nurses, administrators and decision makers) have a role to play in ensuring the system is both safe and effective (Mackinnon 2007)<sup>60</sup>. The concept of 'the right medication in the right dosage form to the right patients by the right route at the right time with the right documentation' is central to medication safety.

Neurology faces particular challenges in relation to this considering the various settings in which medicines are prescribed, administered and taken by patient, i.e. in hospital, out-patient setting, General Practitioner's office etc. The Institute of Medicine (IOM) is an independent, nonprofit organization that provides unbiased and authoritative advice to decision makers and the public, suggests that the majority of medication prescribing and use occurs in the ambulatory environment (Galt 2005).<sup>61</sup> It notes that most Healthcare Professionals will check for allergies when considering prescription of a particular drug, but was 'not routine for offices to proactively identify and screen for contraindications and precautions to medications'.

The current Irish healthcare system does not easily facilitate seamless transfer of information for patient services such as in neurology. Multiple providers and systems are in place however systems operate in isolation with no immediate linkage to facilitate transfer of patient information. One set of healthcare record notes held in one particular location may reference a change in medication or a medication compliance issue, but this information may not be readily available to all involved in this patients current or future care, for example patients may be admitted to a different hospital and frequently the records from prior admissions are

60 MacKinnon, N. Safe and Effective: the eight essential elements of an optimal medication-use system. Canadian Pharmacists association 2007.

61 Galt, K. Rule, M. Clark B E. Bramble, JD. Taylor, W. Moores, KG. Best Practices in Medication Safety: Areas for Improvement in the Primary Care Physician's Office 2005.

not available resulting in repetition of assessment and multiple expensive investigations. It is hoped that the planned unique patient identification system and eventual electronic patient record will help minimize medication safety related risks.

### 11.3 Polypharmacy

The issue of polypharmacy is particularly pertinent for many patients with neurological conditions, considering the complex and changing needs of the patient and the often chronic nature of their condition. The Neurologist needs to 'mix and match' medications while remaining diligent to minimize drug interactions. Medication schedules require regular review and patients, relatives and carers should receive comprehensive education in relation to changes in their prescription. This is particularly important when a medication is being stopped, as patients can at times be reluctant to stop taking a medication that they themselves feel has been of benefit.

The chronic, fluctuating needs of patients with long term neurological conditions puts patients at great risk of polypharmacy. Their changing needs would indicate that patients are being seen often by their GP, Neurologist, other medical specialists such as old age medicine and psychiatry, and on occasion, emergency department doctors. Each of these physicians may prescribe medications for the patient in line with specific treatment guidelines. However, little information exists on how to fit all of these guidelines together into one patient's clinical management.

Avoidance of polypharmacy requires regular review of the patient's complete medication list, with an assessment of each medicine for criteria such as indication, efficacy, and adverse effects. Pharmacists and clinical nurse specialists play a significant role in assisting patients to understand the dangers of polypharmacy and informing patients to highlight this issue with prescribers and providing an important link to GP's and community services.

Particular note should be made with regard to the reported over-prescription of some medications in the management of neurological conditions. This is seen most often in the prescribing of anti-psychotic medications in those presenting with dementia. Nearly 90% of people with dementia experience behavioural and psychological symptoms as a result of the condition. These distressing symptoms can often be prevented or managed without medication. However, people with dementia have frequently been prescribed antipsychotic drugs in the first instance.

The National Dementia Strategy in Ireland identifies that more research is needed in Ireland on use of anti-psychotics and also states (2014: 27<sup>62</sup>) that

"Pharmacological and non-pharmacological treatments and interventions should go hand-in-hand. People with dementia are more likely to experience psychopathology during the course of their illness and in some cases the use of psychotropic medications is appropriate in conjunction with environmental interventions. However, anti-psychotic drugs should only be used when all other non-pharmacological interventions have first been tried and exhausted (NICE Guidelines CG42, 2006). While the use of antipsychotic medications can be effective at controlling behavioural and psychological symptoms of dementia BPSD, they are not without risk and if prescribed should be reviewed at regular intervals and discontinued when clinically indicated"

## 11.4 Educated and Empowered Patients.

Many specialties within healthcare are organised to respond and treat acute illness and are facing challenges with respect to managing chronic disease. Chronic diseases are now the biggest cause of death and disability worldwide. This development is forcing a fundamental shift in health systems and health care, and as a consequence, in roles and responsibilities of patients.<sup>63</sup>

The International Alliance of Patient Organisations (IAPO) Declaration on Patient-Centred Healthcare (www.patientsorganizations.org 2014)<sup>64</sup> outlines five key principles against which models of care can be measured to determine patient-centeredness. These are outlined in Fig 13 below;



**Fig 18; IAPO key principles to determine patient centeredness**

The IOM (Institute of Medicine) defines patient-centered care as: “Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions<sup>65</sup>.”

The Neurology Programme acknowledges the importance of information sharing through clear communication between service providers and patients/service users. For patient’s to be active participants in their own health care management, they need to have access to the most relevant and up-to-date information. This information should be available to patients’ in an accessible way, i.e. with consideration given to their preferred learning style. Effective communication is considered a core competency of all staff working in acute care and in rehabilitation settings to enable delivery of a patient-centered care model.

63 Patient Empowerment – Living with Chronic Disease; the European Network on Patient Empowerment. Available at [http://www.enope.eu/media/14615/a\\_series\\_of\\_short\\_discussion\\_topics\\_on\\_differen.pdf](http://www.enope.eu/media/14615/a_series_of_short_discussion_topics_on_differen.pdf). Accessed 2.6.15

64 [www.patientsorganizations.org](http://www.patientsorganizations.org) accessed 2.6.15

65 Institute on Medicine 2001. “Crossing the Quality Chasm: A New Health System for the 21st Century” Available at; <https://www.iom.edu/~media/Files/Report%20Files/2001/Crossing-the-Quality-Chasm/Quality%20Chasm%202001%20%20report%20brief.pdf>

Providing accurate, objective information about a condition has been proven to have a positive effect in a patient's compliance with their prescribed medication.<sup>66</sup> Edward Leigh has described in his book a set of guidelines for prescribing physicians which can assist in helping patients understand their medication. These are;

- a) Confirm that the patient understands the reason for the medication. The patient should have a basic understanding of the nature of their disease and the rationale behind the medicine being prescribed.
- b) Basic information about the medication. This should include;
  - Brand/generic name
  - Function
  - How/why/when/length of time the medication is taken
  - Possible side effects
  - Foods/liquids/activities to be avoided
  - Medication storage
- c) Ask about use of herbal remedies, over the counter medications, vitamins and mineral supplements which could potentially interact with prescription medication.
- d) Financial issues; patients may not take medications because of financial hardship. This is particularly relevant considering the high cost of many of the Neurological medications and reductions in eligibility for medical cards.
- e) Dosage issues; in some cases dosages have to be adjusted after beginning the medication and it is important that the patient is fully aware of these changes and how to manage same.
- f) Verify patients' understanding of the information given. Again, in neurology where many conditions may affect cognitive function, correct processing of the information and retention of same cannot be assumed.
- g) Involve family/care givers with respect to education around medication as they may be in a position to support the patient either directly by giving them their medication or indirectly by providing prompts etc.

Educating patients about key issues regarding their medicines not only increases compliance, it reduces the risks of the patient receiving contra-indicated treatments in when they are admitted to hospital. The importance of understanding their medication should be emphasized to patients in addition to the need to question any changes to their medications which differs from their regular medication regimen. Discrepancies between prescribed medications and actual medications being taken are potentially dangerous. The discrepancies recorded

---

66 Leigh, E. Teaching Patients about their Medications: The keys to decreasing non-compliance. Available at [http://www.communicatingwithpatients.com/articles/teaching\\_about\\_meds.html](http://www.communicatingwithpatients.com/articles/teaching_about_meds.html). Accessed 2.6.15



most often involve patients taking medications for which there is no documentation in the healthcare record, patients not taking documented medications and differences in dosages. (Gleason et al 2004)<sup>67</sup>

As referred to in section 10, the neurology programme recognises the population health model figure 12, which proposes that approximately 20% of patients will require support in managing their condition including their medication. The degree of education and responsibility for self-management needs to be determined for each individual. In some cases, it may be more appropriate to provide information and education to a nominated family member/carer.

The role of the Irish Platform for Patients, Science and Industry (IPPOSI) is acknowledged in increasing awareness and informing patients and patient organisations on issues relating to medication and treatment and involvement in clinical trials and providing a platform for these groups to engage with relevant stakeholders and to contribute to the development of policy and practice in these areas.

### 11.5 Informed Choice/Joint Decision Making

The benefits of adequate education can not only reduce the symptoms of illness, but increase self-esteem, autonomy and independence.

Although shared decision making by patients and clinicians has been advocated, little is known about the degree of participation in decision making that patients actually prefer or about clinicians' appreciation of these preferences. A study by William M. Strull et al (1984)<sup>68</sup> proposed that clinicians underestimated patients' desire for information and discussion but overestimated patients' desire to make decisions.

A study by Edward Guadagnoli 1998<sup>69</sup> looking at patient participation in decision making about their treatment concluded that;

- a) patients want to be informed of treatment alternatives
- b) they, in general, want to be involved in treatment decisions when more than one treatment alternative exists, and
- c) the benefits of participation have not yet been clearly demonstrated in research studies.

The study also proposed that physicians should endeavor to engage patients in decision-making, albeit at varying degrees, when more than one effective treatment option exists. For this to happen, methods should be developed to evaluate a patient's level of "readiness" to participate in decision-making and that interventions that match the patient's level of readiness be applied to increase participation (Guadagnoli 1998)<sup>69</sup>.

### 11.6 Medication Supply and Funding

When prescribing new medications, availability of supply and cost implications, both in the primary and secondary care settings, must be considered.

67 Gleason, KM. Groszek, JM. Sullivan, C. Rooney, D. Barnard, C. .Noskin, GA. Reconciliation of discrepancies in medication histories and admission orders of newly hospitalized patients. *Am J Health-Syst Pharm.* 2004; 61:1689-95

68 Strull, WM. Lo, B. Charles, G. Do patients want to participate in medical decision making? *JAMA* 1984; 252 (21): 2990-2994

69 Guadagnoli, E. Ward, P. Patient participation in decision-making. *Social Science & Medicine.* Vol 47, Issue 3. 1998; 329-339

## Primary care

Some neurological conditions are included in the Long Term Illness Scheme (LTI), e.g. epilepsy and Parkinson's disease. Medicines directly related to the treatment of the condition are supplied free of charge. Therapies not directly related to the specific LTI condition (often it can be difficult to determine which medication is being used for the condition) are dispensed in accordance with the patient's relevant community drug reimbursement scheme.

For the prescribed drugs that are included in community drug reimbursement schemes;

- Patients with medical cards currently pay a standard dispensing fee per item.
- Patients that do not have medical cards pay a standard fee per month (currently €144) for all medicines dispensed.

Problems often arise for patients when drugs are not covered under these community reimbursement schemes;

- Novel therapies awaiting a decision on re-imburement status may be made available on a named-patient basis free of charge from the license holders. Any decision to commence patients on such therapies, must take into account the possibility that these therapies may not receive reimbursement status in Ireland. If reimbursement is not approved, the drug therapy may no longer be available or the patient may have to personally fund ongoing treatment.
- Unlicensed therapies often have supply and access problems, with continuity of supply not guaranteed. They also may not be funded under the community drug reimbursement schemes. Patients with medical cards can apply to have the cost covered under the hardship scheme, though approval for drug funding under this scheme is not guaranteed and is not standardised nationally. Patients without medical cards have to personally fund the total additional cost of unlicensed medicines, i.e. they are not included in the standard monthly prescription fee.

High tech therapies (e.g. disease modifying drugs in MS) are prescribed by hospital consultants only and dispensed by community pharmacies. Patients require a new high-tech prescription from their hospital consultant at least every 6 months.

## Secondary Care

Certain drug therapies are restricted to hospital use and are not available in the primary care setting. The following factors must be taken into account when considering starting patients on hospital only therapies.

- Novel therapies for chronic neurological conditions very often have significant cost implications and may significantly impact hospital budgets.
- Drug therapies are routinely restricted to hospital only use due to the route of administration (i.e. intravenous) or due to potential side effects such as anaphylaxis. In addition, some community based therapies require treatment initiation in the hospital setting. When commencing patients on a hospital only therapy, give consideration to the availability of a location for drug administration and also the availability of nursing and medical staff to supervise drug administration.
- Intravenous cytotoxic and/or mutagenic therapies (e.g. mitoxantrone, cyclophosphamide) require preparation in an aseptic environment that protects the operator from the drug being compounded and also ensures sterility of the product being prepared. When

commencing patients on cytotoxic preparations, give consideration to staffing resources in aseptic compounding units where these products are prepared.

- Some novel oral therapies with specific monitoring requirements are restricted to hospital only supply (e.g. novel hepatitis C therapies) for outpatients. Outpatient dispensing can have significant legal, financial and human resource implications for hospital pharmacy departments.
- Before commencing clinical trial agents or compassionate use therapies, give consideration to continuity of supply when the clinical trial is complete and/or the period of compassionate use ends.

For the reasons outlined above, it is recommended that before patients are commenced on novel therapies restricted to the hospital setting, the possibility of using the drug into the hospital is planned with the appropriate hospital management staff, e.g. finance, pharmacy, nursing, so that resources can be assigned. New treatments for neurological disorders are thankfully increasing and we need to be able to provide these particularly if they change the outcome, quality of life and disability of the patient. In addition to this some drug therapies that were previously hospital based only are now becoming available in the community.

## 12 Requirements

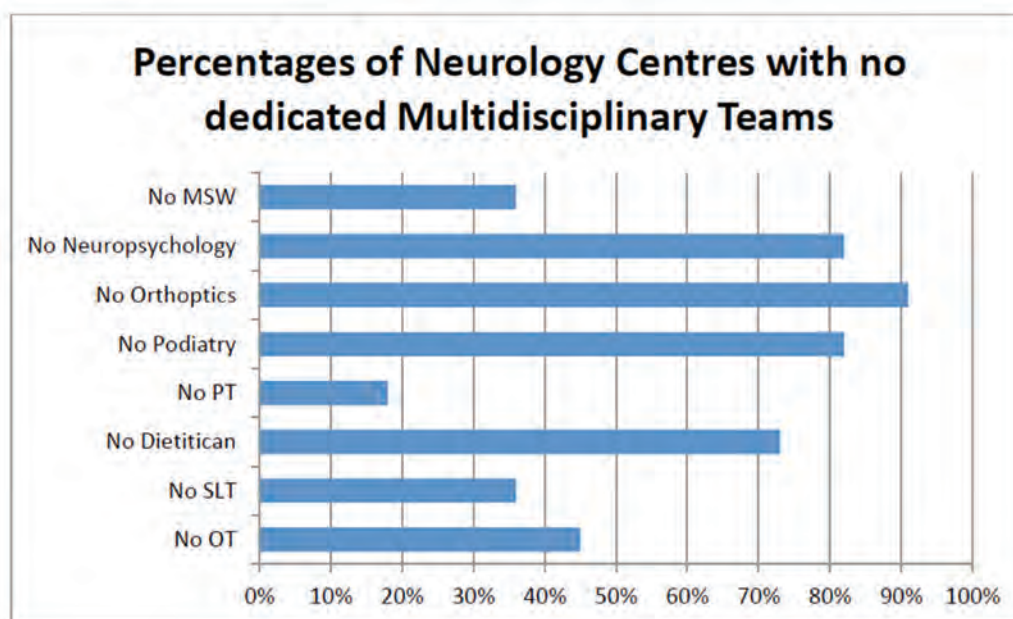
### 12.1 Current Status

The National Neurology Programme, in collaboration with the Neurological Alliance of Ireland have developed and circulated a national survey of neurology services. The survey was developed by a sub group of the Neurology Programme working group, with a representative from the NAI, programme manager and members of the neurology multidisciplinary team. The aim of the survey was to get a comprehensive overview of current resourcing and aspects of service provision across inpatient and outpatient services (appendix 8).

The survey was circulated to all 11 neurology centers nationally. There has been a 100% response rate. All answers are their subjective responses based on the reality of their experiences. Results have not been cross referenced with the HSE's HIPE data/waiting times from the Business Intelligence Unit etc.

The survey found that only 45% of neurology centers have access to dedicated neurology beds. Some of those with beds reported that their beds were not protected and were often used to meet demands placed on their hospital's by ED. 54% of neurology centers have no access to 'day-beds' to which they can admit patients for assessment or treatment.

Access to dedicated multidisciplinary team members varies significantly across the services as outlined in chart below.



**Fig 19; percentages of centers with no access to ancillary services**

With respect to outpatient services, all centers offer consultant-led outpatient clinics and 64% have nurse-led clinics. It should be noted however that the figure for nurse-led clinics includes epilepsy ANP-led services. Epilepsy centers saw a significant expansion of their nurse led services following additional resources in the HSE Service Plan 2011. Regional Epilepsy Centers are co-terminus with 6 neurology centers and as such, the figure of 64% is attributed predominately to epilepsy nurse-led clinics.

Only 36% of centers offer therapy-led clinics. This is not surprising as dedicated therapy hours for neurology services are significantly limited nationally.

Access to diagnostics is also a challenge for many centers. While all centers have access to CT & MRI, access to out-of-hours imaging is limited. This can make the management of acute neurology patients difficult. Only 3 of the centers (27%) have dedicated access to neuroradiology and only 27% have direct/dedicated access to interventional neuroradiology. Difficulty with accessing these diagnostics has led to increased waiting times. In 70% of neurology centers waiting time for routine MRI is in excess of 12 months.

Only 9% of centers report that they have good access to rehabilitation services, either hospital or community based. 100% of services indicated that access to nursing homes ranged from moderate to very limited, with no service reporting 'good' access to these services. As a result there are many patients with neurological disabilities in acute hospitals awaiting transfer to more appropriate rehabilitation and long term care units.

## 12.2 Requirements

There are currently 34 approved neurologist posts across the country\*. For the current population Ireland requires 64 neurologists (1:70,000) with corresponding multidisciplinary and nursing teams are needed as determined by international best practise standards. Initially, additional consultant posts should be directed towards those units with less than 3 Neurologists. Additional posts should then be considered in line with nationally determined service development priorities and the strategy of the relevant hospital group. It should be noted that with anticipated growth in population i.e. up to 4.91 million by 2021, the population based requirements for Neurologists will increase to 70 WTE.

To achieve the required standards in neurological services, the following need to be considered (as per Laffoy 2007)<sup>11</sup>;

### 12.2.1 Access;

Access to services should be equitable across the country and not vary depending on staffing levels in different hospitals/primary care. Access to services includes initial access to consultant neurologist, access to diagnostic and therapy services and access to treatments either as an inpatient, day patient or out-patient.

There is a shortage of inpatient beds which impacts directly on accessibility. The demand on the limited number of dedicated neurology beds is likely to worsen as the population ages as predicted. Without appropriately staffed community teams to which these patients can be discharged, access to these limited inpatient beds will also be impacted.

In line with recommendations of the Acute Medicine Programme, the Neurology Programme recognises that it would not be feasible or appropriate to have dedicated neurology in-patient beds in all hospitals within current resources. However the Neurology Programme and the Acute Medicine Programme will need to work closely together bearing in mind that 1 in 5 acute medical admissions have a neurological problem.

While model 1 (community or district) & model 2 (local) hospitals should have outpatient neurology services and Neurology Consultative Services, cohorted inpatient services should be considered for model 3 (general/regional hospitals) and model 4 (tertiary) hospitals.

\* information is correct as of Jan 2015



### 12.2.2 Staffing;

Neurology services require specialist multidisciplinary staff. Shortages of neurology personnel (hospital and community) result in delayed admissions, diagnosis, treatment and delayed discharges. The number of specialist personnel needs to be enhanced so that the service can be made more responsive to patient needs. Each Neurologist should be supported by a full multidisciplinary team at inpatient and outpatient level. The necessary requirements for a core multidisciplinary team are outlined in the executive summary of this document.

### 12.2.3 Specialist Expertise;

Additional neurologists, with specialist and generalist expertise are needed to support the timely diagnosis of patients with neurological conditions. Regional self-sufficiency will allow for more scope for tertiary/specialist care for complex cases. General neurology services and ongoing multi-disciplinary review and management should be available within each area supported by regional neurology unit. There is a need for more specialist therapists and greater opportunities for GPs to develop an interest and expertise in neurology.

### 12.2.4 Health and Social Care Professionals and the Neurology Service;

The needs of patients with neurological conditions can be varied and extensive, with many requiring a high intensity of therapeutic input, both in terms of range of HSCP interventions, and number of treating therapists. This level of dependency needs to be acknowledged and provided for with respect to HSCP intervention.

The central role of Health and Social Care Professionals (HSCP's) needs to be appropriately staffed/resourced and expanded, with respect to the care of patients with neurological conditions.

All neurologists require the support of a multidisciplinary team and specialist nursing. Expansion of the role of a range of Health and Social Care Professionals, including audiology, dietetics, occupational therapy, orthoptics, orthotics, physiotherapy, neuropsychology, medical social work, podiatry and speech and language therapy, should be endorsed, particularly in the management of patients with neurological conditions and their families.

Patients need access to the appropriate type and level of HSCP services throughout the course of their condition. Geographical location and fragmented funded should not be a barrier to accessing same. If services are delivered in different settings, it is imperative that good communication links exist between these settings in order to provide a seamless patient-centred service. A document such as a 'Neurology Passport of Care' is recommended for patients moving between different care settings. Patients in the early stages of disability or with minimum disability should be able to access HSCP services. Investment of resources to this patient group may avoid unnecessary 'crisis' interventions at a later stage. It may also support the patient with respect to continued ability to maximise independence and maintain employment.

The UK National Service Framework for Long-Term conditions<sup>28</sup> (which confined its brief to neurological conditions) detailed the importance of the Health and Social Care Professional in the management of neurological conditions. HSCPs help people with neurological conditions to maintain independence within the limits of their condition and help to reduce the burden of disease and improve quality of life. With support many patients remain in the workforce and contribute to the state. Challenges arise around the fact that there are no internationally

recognised staffing ratios for HSCPs treating people with neurological conditions. It is important that resource requirements are patient-needs based into the future.

A single and/or uniform database dedicated to the provision of any of the HSCP services to patients with neurological disorders is required. Without same, it will be difficult to estimate accurately the number of neurological patients in Ireland who currently receive and/or have received HSCP services (either within hospital or community settings) or those who require HSCP services

### 12.2.5 Nursing

An adequate number of specialised Neurology CNS/ANP e.g., Movement Disorders, Multiple Sclerosis, Epilepsy to ensure that services across the Networks are managed

### 12.2.6 Neurosurgery

Neurosurgery concerns the operative and non-operative management of patients with disorders of the central and peripheral nervous systems. While the speciality initially developed through the treatment of cranial trauma and intracranial mass lesions, advances in microsurgery techniques etc have substantially enhanced and widened the scope of effective neurosurgical treatments (NHS 2013)<sup>70</sup>.

There are currently 2 neurosurgical units in the Republic of Ireland; one in Beaumont Hospital, Dublin and one in Cork University Hospital. The catchment area served by the neurosurgery unit at Beaumont is all areas outside of Munster, with the unit in Cork providing services to approximately 1 million people living in Munster<sup>71</sup>. Both centres are recognized as national neuroscience units, reflecting the requirement for integrated neurosurgical and neuromedical care for patients with complex brain disease.

There should be agreed transfer protocols between neurosurgical and referral centres for cases of trauma, subarachnoid haemorrhage, space occupying lesions, hydrocephalus and other acute conditions (HSE 2013)<sup>72</sup>. There is a need for a well-developed transport system to deliver patients safely and in the shortest time possible to the most appropriate location for treatment. A system similar to the National Neonatal Transport Programme should be considered<sup>73</sup>. This is a 24/7 retrieval service within the national ambulance service providing transfer to tertiary care. An efficient retro-transfer service is also provided, facilitating transfer of patients back to regional/local hospitals.

Pathways for the repatriation of patients to appropriate Neurology/Neurorehabilitation setting should be agreed as part of the managed clinical network to enable the efficient and responsive working of the neurosurgical unit.

70 NHS Commissioning Board, 2013. NHS standard contract for Neurosurgery (Adult),

71 Report of the committee to review Neurosurgical services in Ireland, Dec 2005. Comhairle na nOispeal, Health Service Executive

72 Model of Care for Acute Surgery, 2013, Clinical Strategy & Programmes Division, HSE

73 National Clinical Programme of Paediatrics and Neonatology, Model of Care for Neonatal Services in Ireland, Draft 2015

The aims and objectives of a neurosurgical service are to;

- Reduce the morbidity and mortality of neurosurgical conditions
- Minimise pain and disability
- Optimise functional recovery
- Improve quality of life for neurosurgical patients

To achieve these aims, neurosurgical patients should receive the highest levels of patient centred, multidisciplinary care in the most appropriate environment (HSE 2013)<sup>72</sup>.

It is increasingly recognised that better clinical outcomes can be achieved in units with appropriate numbers of specialist staff with relevant skills and experience, high volumes of activity and access to the appropriate diagnostic and treatment facilities.

The Model of Care for Acute Surgery 2013<sup>72</sup> outlines guidelines with respect to service provision for both centres providing Neurosurgery, and those referring into these centres.

#### **Outside the Neurosurgical centre:**

- Immediate advice is available from a consultant neurosurgeon on a 24-hour basis to units receiving unscheduled and acute surgical patients
- All acute cases, especially those that might require operative intervention or where transfer to the neurosurgical unit is not appropriate, must be discussed with the consultant or senior neurosurgeon on call
- There are image link facilities between all referring hospitals with the ability for immediate consultant decision regarding management
- There are agreed transfer protocols between neurosurgical and referral centres for cases of trauma, intracranial haemorrhage, spinal cord compression, acute hydrocephalus and other acute conditions
- Existing guidelines (such as adult traumatic brain injury, suspected spinal trauma, suspected subarachnoid haemorrhage, suspected malignant brain tumours in adults, spinal tumours and suspected spinal infections) and future guidelines adhered to
- Health & Social care professionals with specialist skills are available to support neurosurgical patient care.
  - There are adequate HSCP available, appropriate to the volume and patient mix for the patients being cared for
  - Psychological advice and support is available as necessary<sup>72</sup>

#### **Within the Neurosurgical centre (HSE 2013)<sup>72</sup>;**

- A consultant neurosurgeon must be available on site within 60 minutes in a neurosurgical centre
- Patients are reviewed by an appropriate consultant within 12 hours of admissions, or before if their condition dictates
- Adequate theatre facilities with competent nursing support, imaging/interventional imaging and radiology support, anaesthesia and critical care facilities are available on a 24 hour basis
- Neuroanaesthesia, critical care medicine and neuroradiologists are available at all times and are consultant led
- Daily ward rounds are carried out by senior trainees (at a minimum BST3 or HST1) with consultant cover
- Unscheduled neurosurgery admissions are audited using routinely collected data

### 12.2.7 Neurocritical care

The six proposed Group Neurology Network (Managed Clinical Network) structures align with the six Hospital Groups' structures to provide a tiered delivery 'levels' structure or pathway whereby critically ill patients with neurology conditions access an appropriate level of neuro-critical care, as needed. Thus, critically ill neurology patients' needs are met either-

1. at a sub-regional or Local level (nearest Acute General Hospital or Model 3 Hospital) or
2. at a regional level (Regional/Group Neurology Service, Model 4 Hospital) or
3. at a supra-regional or national level (National Tertiary Centre, Level3s Neuro-Critical Care), as appropriate.

With resource, this aligned tiered Neuro-Critical Care delivery structure is designed to meet the needs of critically ill neurology patients.

Critical Care Neurology includes conditions e.g. acute severe traumatic brain injury with or without Neurosurgery operative procedures (craniotomy, craniectomy etc), Guillain-Barré syndromes, intracranial haemorrhage with or without Neuro-Interventional Radiology or Neurosurgery intervention, acute brain ischaemia +/- neuro-specialty interventions, acute seizure disorders inc. status epilepticus, acute CNS infection, acute hypoxic-ischaemic encephalopathy (HIE), acute spine and acute spinal cord injury etc.

The provision of Neuro-Critical Care is identified in and defined by the National Standards for Adult Critical Care Services 2011. Level3(s) Care (Neuro-Critical Care) defines the Level of Critical Care required for a critically ill neurology patient in a supra-regional or national level Neuro-Critical Care Service. The National Standards are published by the Joint Faculty of Intensive Care Medicine of Ireland (JFICMI<sup>74</sup>).

Critically ill neurology patients who require neuro-critical care, access a Neuro-Critical Care Service (Neuro-ICU) (or Neuro-spinal injury unit) with neuro-specialty services e.g. Neurosurgery, Interventional Neuro-Radiology, Clinical Neuro Electrophysiology with EEG, Neuropathology etc. as part of the Critical Care Pathway. Inter-ICU transports of critically ill patients will be operated by the National Adult Critical Care Retrieval Service as part of the National Transport Medicine Programme, on commencement.

#### Recommendation

In line with current evidence (see evidence base below), the National Clinical Programme for Critical Care recommends all critically ill patients with acute severe brain injury are immediately referred for Level 3(s) Neuro-Critical Care, as appropriate, with Neurosurgery and Neuro-specialty interventions, as appropriate, to a supra-regional or national Neuro-specialty centre. Currently, in Ireland, Beaumont Hospital and Cork University Hospital both provide Level 3(s) Neuro-Critical Care in their ICUs. Adequate Level 3(s) Neuro-Critical Care capacity and transport resource is required to meet the needs of neuro-critical care patients.

#### Evidence base

Evidence presented by the UK Trauma Audit and Research Network (TARN) shows that treatment of patients with severe traumatic brain injury at neurosurgery centres is associated with a two-fold increased survival rate, when compared with patients who were not referred to neurosurgery centres.

74 Joint faculty of Intensive care medicine of Ireland, 2011. National Standards for adult critical care services. Dublin: JFICMI.

	Neurosurgery	Non-neurosurgery
Injury severity score (ISS)	25	26
Mortality	35%	61%

**Table 15; Extract from Patel, TARN, Lancet 2005 (366: p1541)**

The UK National Confidential Enquiry into Patient Outcome and Death (NCEPOD) 2007 Report, Trauma: Who cares? recommends “all patients with severe head injury should be transferred to a neurosurgical/critical care centre irrespective of the requirement for surgical intervention” (p19) (Findlay, NCEPOD 2007<sup>75</sup>).

Similarly, the NHS National Institute for Health and Clinical Excellence (NICE) Head injury-Clinical Guideline (CG176, revised 2014, p31) recommends that “transfer would benefit all patients with serious head injuries (GCS8 or less) irrespective of the need for neurosurgery” (NICE, 2014<sup>76</sup>).

The Phillips Report: National Report on Traumatic Brain Injury in the Republic of Ireland 2008<sup>77</sup> published by the Traumatic Brain Injury Research Group provides the following recommendations for severe traumatic brain injury and neurocritical care: ‘Neurosurgical management: Provision of sufficient neurocritical care facilities in Ireland, so that all patients with a severe TBI (GCS 3-8) can be treated in a neurosurgical unit in line with international best practice, irrespective of their need for operative intervention.’ (Phillips, 2008 p. 7).

Furthermore, in 2013, the UK NHS National Institute for Health Research (NIHR) Health Technology Assessment programme published a study entitled Risk Adjustment in Neurocritical care (RAIN), concludes the “results...support current recommendations that all patients with severe TBI would benefit from transfer to a neurosciences centre, regardless of the need for surgery” (Harrison, 2013<sup>78</sup>).

### 12.2.8 Neuroradiology & Interventional neuroradiology

The radiologist, in particular the neuroradiologist plays a key role in the neurology service. They provide expert consultation to the referring neurologist and aid in choosing the proper examination, interpreting the resulting medical images, correlating medical image findings with other examinations and tests. All neurology centers should ideally have access to the services of neuroradiology<sup>79</sup>. Weekly MDT conferences with neuroradiologists are recommended. Neurology centers should also have dedicated access to neuroimaging to reduce delays in diagnosing neurological conditions.

75 Findlay, G et al, 2007. Trauma: who cares? A report of the National Confidential Enquiry into patient outcome and Death (NCEPOD)

76 National Institute for Health and Clinical Excellence (NICE), 2007. Head Injury: Triage, assessment, investigation and early management of head injury in infants, children and adults. London: NICE

77 Phillips, J, 2008. Phillips report: national report on traumatic brain injury in the Republic of Ireland 2008. Dublin: Traumatic Brain Injury Research Group.

78 Harrison, DA et al, 2013. Risk Adjustment in Neurocritical Care (RAIN) – prospective validation of risk prediction models for adult patients with acute traumatic brain injury to use to evaluate the optimum location and comparative costs of neurocritical care: a cohort study. London: NIHR

79 <http://www.radiologyinfo.org/en/careers/index.cfm?pg=understanding> (accessed 30.1.15)



Interventional Neuroradiology is an area where dramatic advances have been made possible by advances in medical technology, such as neuroimaging (particularly digital subtraction cerebral angiography and angiographic road-mapping), and development of revolutionary medical devices. Many medical conditions which were intractable fifteen years ago can now be cured using current endovascular techniques. Indeed, even within the field of interventional neuroradiology, new technology and devices introduced within the past five years have allowed interventional neuroradiologists to increase the number of life-threatening cerebrovascular diseases which can be treated effectively<sup>80</sup>. Considering this, the demands for interventional neuroradiology are set to increase significantly as the efficacy of such treatments is demonstrated. One such example is endovascular treatment in patients with acute ischaemic stroke (in addition to standard care). This treatment has demonstrated improved functional outcomes and reduced mortality (Goyal et al 2015)<sup>81</sup>. Interventional neuroradiology will need to expand to provide this life saving and life changing therapy.

### 12.2.9 Neuro ophthalmology

Neuro-ophthalmology straddles the fields of neurology and ophthalmology, often dealing with complex systemic diseases that have manifestations in the visual system including vision, visuospatial, eye movements and pupillary reflexes. Some of the common problems evaluated by neuro-ophthalmologists include: optic nerve problems (such as optic neuritis and ischemic optic neuropathy), visual field loss, unexplained visual loss, transient visual loss, visual disturbances, double vision, abnormal eye movements, thyroid eye disease, myasthenia gravis, unequal pupil size, and eyelid abnormalities.

Problems with visual processing may contribute to and or exacerbate symptoms such as headaches, visual field loss and difficulties with balance and posture. Vision problems are among the most common dysfunctions to occur following a neurological event. In most cases, they are secondary to the neurological event but they can become a primary interference to performance<sup>82</sup>.

Access to neuro-ophthalmology for the diagnosis and management of these conditions is considered essential as visual loss is associated with functional dependence and progression of disability (West et al 1997)<sup>83</sup>.

### 12.2.10 Neuropathology

The neuropathologist examines biopsy tissue from the brain, muscle, nerve and spinal cord to aid in diagnosis of disease.

The tissue is examined grossly and microscopically for signs of Alzheimer Disease and other dementias, neoplasms, vascular disease, inflammatory processes, tumours or developmental abnormalities. The neuropathologic diagnosis has a crucial role in patient care<sup>84</sup>. Neuropathology

80 Amon Y Liu, MD 'Update on Interventional Neuroradiology'. Perm J. 2006 Spring; 10(1): 42–46. Published online Spring 2006. PMID: PMC3076983

81 Goyal M et al. Randomised assessment of rapid endovascular treatment of ischaemic stroke. New England Journal of Medicine Feb 11, 2015.

82 <http://www.experts.com/content/articles/Simmons-Grab-Visual-Dysfunction-Neurological-Event.pdf>

83 West S K et al. Functional and visual impairment in a population based study of older adults. The SEE Project. Investigative Ophthalmology & visual science, January 1997, Vol 38, No 1

84 <http://pathology.duke.edu/anatomic-pathology/subspecialties/neuropathology>. Accessed 2.6.15

should be accessible to all neurologists. While not available in all sites, protocols should be in place to allow for rapid access to these services as required.

Over recent years there have been numerous important discoveries in complex diseases including brain tumors, traumatic brain injury, Alzheimer's disease, frontotemporal dementia, Parkinson's disease and amyotrophic lateral sclerosis driven by the advances in understanding of the genetic, molecular and cellular bases of diseases.

The neuropathologist is also crucial to the correct interpretation of autopsy data and coordinating the Brain Bank which is a vital service for the diagnosis of disease and resource for research into neurological disease.

### 12.2.11 Clinical Neurophysiology;

Each academic teaching hospital that has a neurology department requires a clinical neurophysiology service. Access to clinical neurophysiology should be considered an extension of a neurologic consultation. As referred to previously, accurate and timely diagnostic services are best practice in terms patient-centered care, but also central to improving cost effectiveness.

### 12.2.12 Administrative Support

Dedicated administrative support is an essential requirement of all neurology services. They are considered part of the neurology team. Considering the complex and oftentimes cognitive difficulties facing patients with neurological conditions administrators should have additional training with respect to managing patients both face to face in clinics and also over the phone. Many patients are distressed about their neurological disease and require frequent reassurance and support over the phone. Dedicated administrative services provide a consistent support to both the team (neurologist, nurse & HSCP) and patients and are core to the smooth and efficient running of services.

### 12.2.13 Paediatric-Specific Priorities;

Multi-disciplinary paediatric services need to be provided on a regional basis. Comhairle na nOspideal recommendations in paediatric neurology should be implemented i.e. two per million population. This requires the appointment of four additional paediatric neurologists nationally.

### 12.2.14 Space, Facilities and Equipment;

Sufficient resources, in terms of space, facilities and equipment / assistive devices / seating systems and enabling technology are required in all settings, acute, rehabilitation, primary and community and continuing care. The importance of same should not be underestimated. Investment in additional staff is of little benefit if they do not have the space to assess and treat patients. This is the case in both in-patient and out-patient services. Of particular need is access to MRI as referenced in MS patient pathway.

One potential way to address this issue can be seen at the Mater Hospital where the Dublin Neurological Institute, a not-for-profit charity, has been developed. The Institute has had a direct impact on both outpatient and day patient services of the Mater Hospital, providing space, facilities and specialist expertise. This model could be considered for national application as an innovative approach to addressing a long standing challenge to services.

This applies to treatment for individual patients and for group interventions. This should also include facilities for clinical work and Information and Communication Technology (ICT) to support data collection / audit.

### 12.2.15 Evidence Based Practice and Research and Development;

Clinical research for physicians, surgeons, therapists and nurses is essential to ensure the appropriate development of services for patients with neurological conditions and urgently needs to be resourced at the clinical/care delivery level. Research and education are crucial to improving patient care.

## 12.3 Workforce Planning

It should be noted that **this section does not include data in relation to Stroke** as that is addressed in the model of care for the National Clinical Programme for Stroke<sup>4</sup>.

### 12.3.1 Neurology Consultants

There are currently 34 Approved Consultant Neurologist posts in the country. This is for a population of 4.5 million which equates to a ratio of 1:132,352. In 2004/2005 the European median number was 4.84:100,000 with huge variations throughout the region.

To meet recommended ratios, Ireland needs a minimum of one consultant neurologist per 70,000 population, or a minimum of 64.3 neurologists. Currently there is a shortfall of 30 consultants. To equal the US ratio, for Ireland the ratio would be 3.92:100,000 or 89.6 neurologists.

### 12.3.2 Nursing

It is recommended that in an in-patient setting, patients with neurological conditions should be admitted onto a Neurology Ward. Each neurology ward should have a CNM with relevant experience in the area of neurology and staff nurses again with appropriate experience.

With in-patient neurology services anticipated in each model 3 and model 4 hospital, the requirement for nurses in neurology is likely to be significant.

In addition to this, The UK National Institute for Health and Clinical Excellence recommends that for a population of 500 000 people, at least three nurses working with patients with multiple sclerosis (MS), three nurses working with patients with Parkinson's disease (PD), and nine nurses should be available for epilepsy (Christodoulou 2012)<sup>85</sup>. Each Consultant out patient service should be supported by the appropriate number of Clinical Nurse Specialists, be they general neurology clinics or condition specific clinics i.e. MS, PD or Headache.

These posts should be further developed into Advanced Nurse Practitioner posts to achieve the best possible patient outcomes.

### 12.3.3 Health & Social Care Professionals

The Neurology Programme recognises the need for full multidisciplinary intervention for patients, both at an acute hospital level, and for rehabilitation of cognitive, physical and emotional sequelae of Neurological conditions.

---

85 Christodoulou, M. Neurological nurse specialists: a vital resource under threat. *The Lancet Neurology*, Vol 11, No3, p210-211, March 2012

There is a growing body of evidence to support the efficacy of multidisciplinary team (MDT) intervention even in the very acute management of patients. One such study (Mudge et al 2006)<sup>86</sup> draws attention to the trends in reduced 'index length of stay (7.3 days vs. 7.8 days)' for patients treated by a full MDT in acute care. The same study reports reduced mortality (6.4 to 3.9%), less functional decline of the patients in hospital and patients' ratings of health status improved. Additional staffing costs were offset by potential bed-day savings.

Determining appropriate staffing levels for health and social care professionals within neurology is a significant challenge. Different methods include ratios i.e. where staff are provided within a set ratio per measure such as number of patients or population is one method or staffing according to acuity as another method.

The challenge within neurology services is that patients present in many ways i.e. through Emergency Departments, through primary care services etc. Their level of acuity depends not only on their diagnosis but on their stage of illness and level of supports at home.

One paper completed a review of workforce ratios in nine allied health professions (Cartmill et al 2012)<sup>87</sup>. They reviewed 12 papers where figures were given for the ratio of different HSCP to bed or patient numbers. They found that there is a scarcity of research into staffing ratios for HSCP's with significant variation between different settings and varying patient groups. The only setting with recognised ratios for HSCP's is Rehabilitation.

**If we consider the definition of rehabilitation to be;**

'a process of assessment, treatment and management by which the individual is supported to achieve their maximum potential for physical, cognitive, social and psychological function, participation in society and quality of living'.

The argument can be made that all interventions of HSCP's within Neurology are rehabilitative in nature. If this were the case, the following ratios of staffing (table 12 &13) should apply to inpatient services and community based rehabilitation services.

<b>Ratio of HSCP for In-patient Specialist Rehabilitation Service for every 20 beds</b>	
<b>Physiotherapy</b>	4 WTE
<b>Occupational Therapy</b>	4 WTE
<b>Speech &amp; Language Therapy</b>	1.5-2.5 WTE (depending on whether patients with tracheostomy are accepted)
<b>Clinical Psychologist</b>	1.5-2 WTE
<b>Social Worker</b>	1-1.5 WTE
<b>Dietitian</b>	0.5-0.75 WTE. (These ratios are for medically stable patients for more acute care, dietitian staffing should be more reflective of the AFRM 2011 standards 1.0 WTE per 10 patients)

**Table 16; Ratio of HSCP for inpatient rehabilitation services<sup>44</sup>**

86 Mudge, A. Laracy, S. Richterm K & Denaro, C (2006) Controlled trial of multidisciplinary care teams for acutely ill medical inpatients: enhanced multidisciplinary care. *Internal Medicine Journal*, 36:558-563.

87 Cartmill, L. Comans, T. Clark, M. Ash, S. Sheppard, L. Using staffing ratios for workforce planning: evidence on nine allied health professions. *Human resources for Health* 2012, 10:2

<b>Minimum HSCP provision for community specialist rehabilitation services to support people with Long Term Neurological Conditions (population 1 million)</b>	
Physiotherapists	6
Occupational Therapists	10
Speech & Language Therapists	4
Clinical Psychologists	4
Social Workers	8
Dietitian	2

**Table 17; Ratio of HSCP for community based rehabilitation services for patients with long term neurological conditions**



### 13 Governance

The National Programmes are part the Clinical Strategy and Programmes Division which was established to improve and standardise patient care by bringing together clinical disciplines and enable them to share innovative solutions to deliver greater benefits to every user of HSE services.

The Clinical Strategy and Programmes Division of the HSE has established common clinical governance structures on a national and regional basis for all programmes.

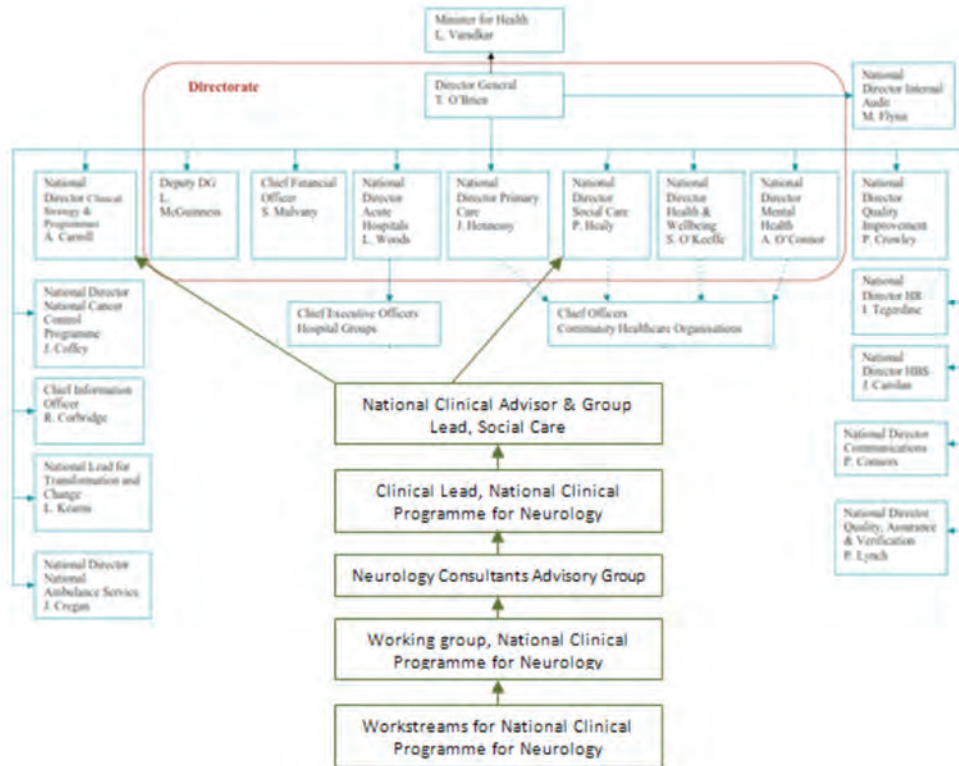


Fig 20; HSE Governance Chart

Clinical governance means corporate accountability for clinical performance, built on the model of the CEO/GM/Area Manager or equivalent working in partnership with the Clinical Director, Director of Nursing/Midwifery and service/professional leads. Clinical governance is about people receiving the right care, at the right time, from the right person in a safe, honest, open and caring environment (QPSD, HSE 2014)<sup>88</sup>.

Clinical Governance is organised and delivered in accordance with the report of the Commission on Patient Safety and Quality Assurance (2008), Code of Governance of the Health Service Executive (2011), Standard 5 of the Health Information and Quality Authority National Standards for Safer Better Healthcare (2011) and Standard 8 of the Mental Health Commission Quality Framework (2007). Formalised governance arrangements ensure that everyone working in the service is aware of their responsibilities and accountability in this respect and work towards achieving this.

88 National Clinical Programmes Model of Care Development Checklist Governance for Quality and Safety. Quality and Patient Safety Division, Oct 2014

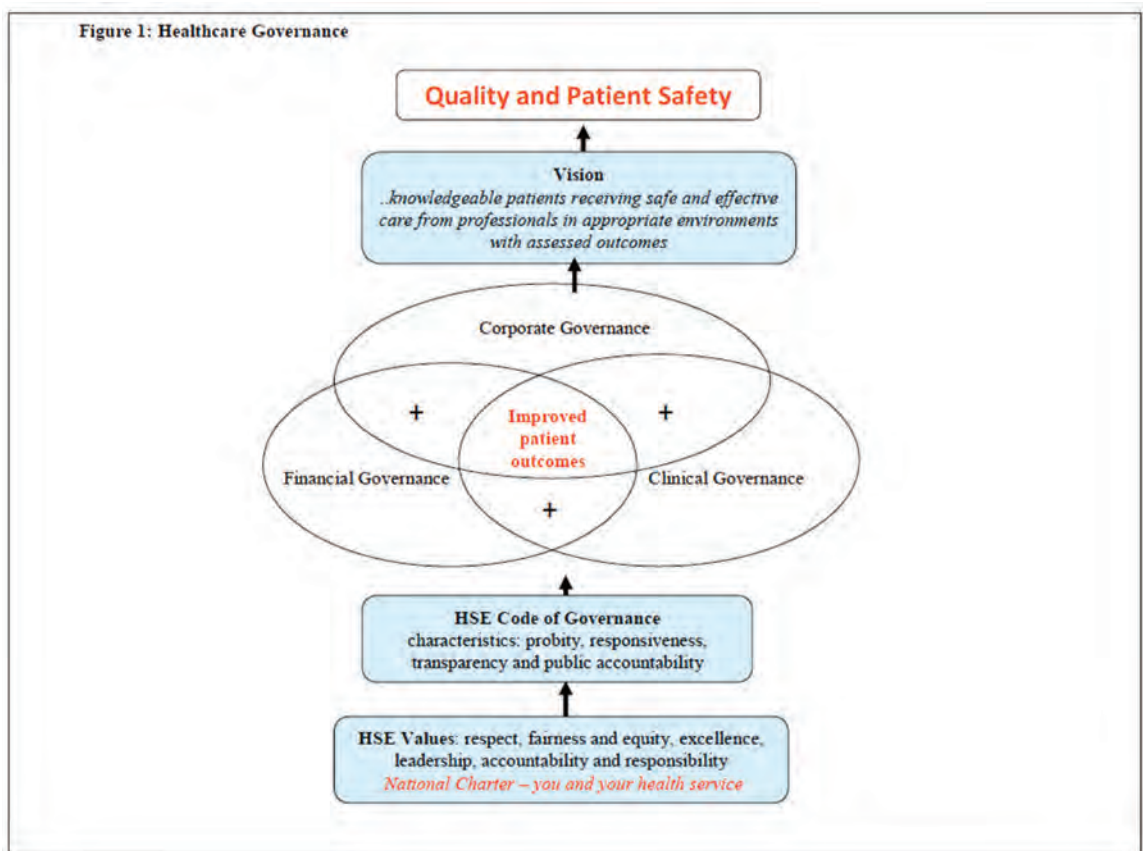


Fig 21; from HSE Working Group for Clinical Governance Development informed by the HSE Code of Governance (2011), the Standards of the Health Information and Quality Authority (2011) and the Mental Health Commission (2007).

Effective governance arrangements recognize the interdependencies between corporate, financial and clinical governance across the service and integrates them to deliver high quality, safe and effective healthcare. Effective governance and accountability can be achieved by embedding leadership and operational management at a corporate and clinical level. This is underpinned by 6 key steps:

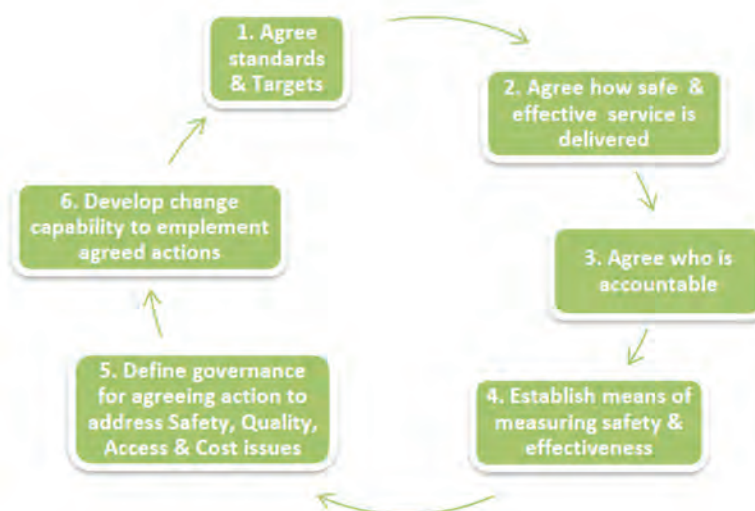


Fig 22; key steps underpinning effective governance

### 13.1 Governance of the National Neurology Clinical Programme

The Neurology Programme follows the structure as outlined below:

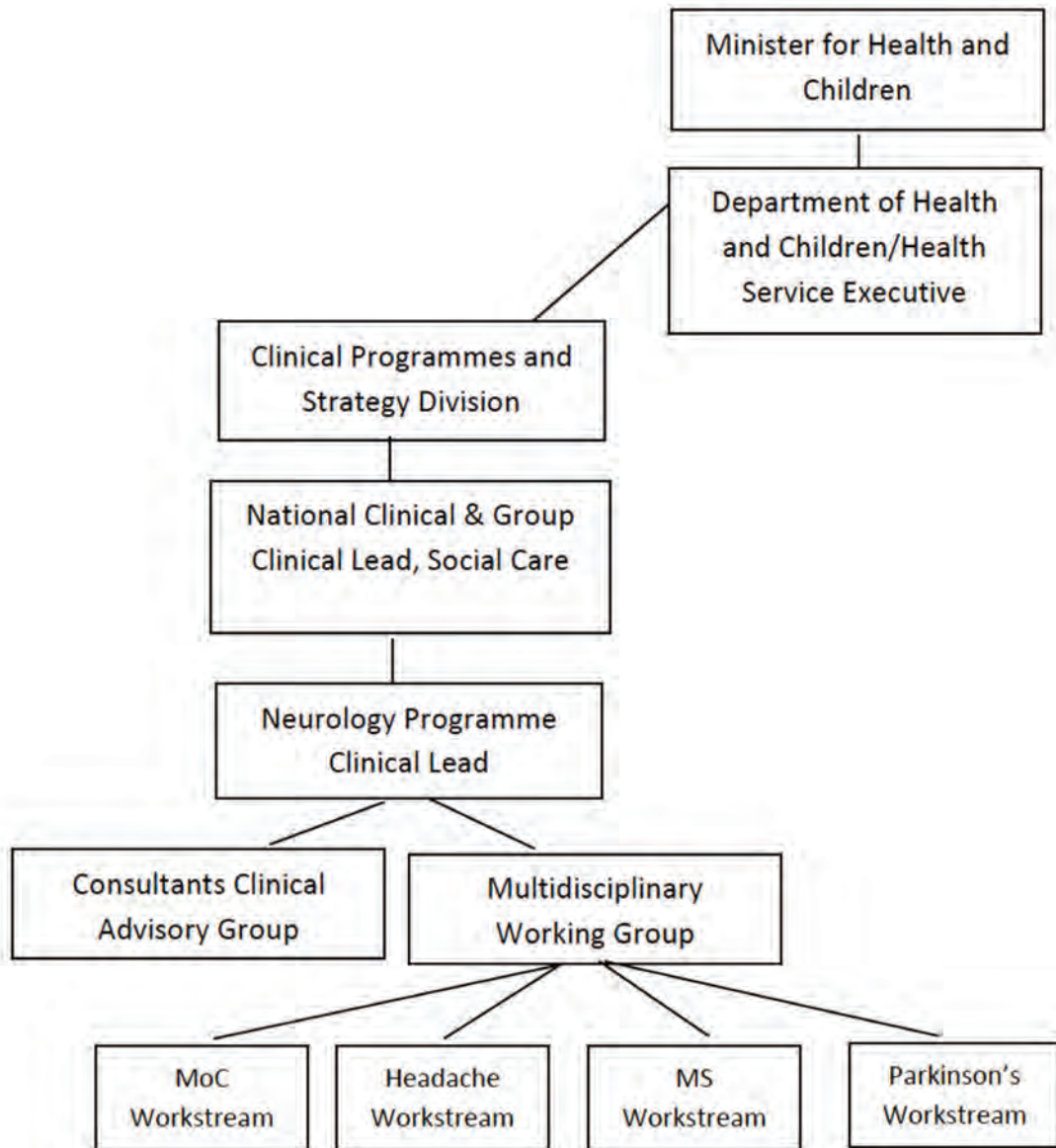


Fig 23; Governance of the National Clinical Programme for Neurology

- **Programme Clinical Lead** supported by clinical and operational teams at a central and programme level. The national clinical lead is accountable for the work streams, current and future, of the Neurology Programme
- **Clinical Advisory Group:** the clinical advisory group provides a forum for strategic vision and clinical input into the planning process of the work of the programme. It will also have a role to play in supporting and facilitating the implementation of recommendations from the neurology programme as being the nationally agreed strategic model. The clinical advisory group is a physician group, representing the Royal College of Physicians, Ireland. The neurology programme is also supported by the HSE's Director of Nursing/Midwifery Reference Group and the National Therapy Managers Advisory Group (under the auspices of the Therapy Professions Committee).

- **Working Group:** Multidisciplinary groups, representing professional bodies with expertise, and patient representatives. This group includes representatives from consultant, nursing, and health and social care professions. The Therapy Leads on the Working Group established sub advisory groups in the following Therapy Professions; Nutrition and Dietetics, Occupational Therapy, Orthoptics, Physiotherapy, Podiatry and Speech and Language Therapy. These Professional Advisory Groups contributed to surveys / audits / requests for submissions / feedback and served as expert advisors in their clinical field for the Therapy Leads. Similarly, the Nurse Leads on the Working Group established sub advisory groups in the different neurological subspecialties for input from expert nursing contributors in the different fields.
- **Group Lead Physicians:** For the Neurology Programme, six consultants in neurology provide representation for each of the hospital groups, working closely with the National Clinical Lead.

In the future, at such a time as the managed clinical networks are fully operational, it would be anticipated that the clinical oversight of the neurology service could be supported by a national neurology steering group. The membership of this group will include national clinical lead, national programme manager, group consultant leads, HSCP, nursing and network managers in addition to representatives of all major stakeholder including hospital group CEO, Finance and Disability services. This group will have responsibility for determining areas for development across neurology services including but not limited to;

- Developing guidelines and protocols for neurology services
- Implementation of guidelines, models of practice & service protocols
- Educational goals – CPD requirements
- Fostering research and development
- Identifying service development priorities
- National standards for neurology services
- Development of competencies for staff working in the area
- Audits

A central tenet of clinical governance is the elimination of unnecessary variation in practice. Having a single governing body which set priorities and targets for the delivery of neurology will assist in achieving this standard.

As neurology services can be delivered in a number of settings, providers/treating teams will primarily be bound by governance arrangements within their own service division/hospital group. This will apply to risk management and patient safety. It is essential that governance structures within the neurology networks align and are compatible with existing governance structures both hospital groups and Community Health Areas.

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

For the delivery of neurological care, these systems will ensure adherence to good standards, including ethical standards and systems for making and dealing with complaints.

Clinical decision-making support tools in the form of patient pathways have been developed by the neurology programme to ensure that the care given is standardised with minimum variation and is wholly evidence based.

Clinical governance also challenges poor performance through regular appraisal and assessment. While the national steering body can determine the competencies/standards against which staff performance can be measured, this aspect of governance will ultimately be managed locally through existing structures i.e. clinical director, medical board or relevant head of discipline, however the Neurology Programme would recommend team-based performance management (TBPM) as a mechanism for managing performance across the service.

The use of TBPM;

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



## 14 Education/Training

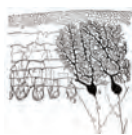
*CFO asks CEO, "What happens if we invest in developing our people and then they leave us?"*

*CEO: "What happens if we don't, and they stay?" - Peter Baeklund*

Education and training at undergraduate and postgraduate level is vital to maintain excellence in neurology and will be key to the successful implementation of the proposed model of care. It will be addressed at national level and also at hospital group level in collaboration with academic partners. The national tertiary specialist units will serve a recognised role in education, training, research and development in the field of Neurology. It should also act as a resource for advice and support to local as well as regional and community based teams in the management of patients with Neurological conditions.

The importance and requirements re: healthcare audit should be embedded in training to develop and sustain a culture of best practice. It is the duty of all healthcare professionals to ensure they deliver care to the highest standard to their patients/clients so by definition all staff should be auditing their work (HSE 2007)<sup>89</sup>.

### 14.1 Medical Education



The number of Specialist Registrars (SpRs) varies annually as neurology SpRs usually complete a period of research during their training. There is a need to increase the number of SpR training posts in neurology to match the proposed increase in consultant numbers. To ensure a suitable pool of applicants coming to higher specialist training (HST), it is necessary to ensure adequate training levels at basic specialist training level (BST) and ultimately to medical school entry (RCPI 2014)<sup>90</sup>. It is vital that the best NCHD's are retained in Ireland by making the BST training and recruitment to the SpR programme as accessible as possible.

#### Higher Specialist Training in Neurology

The current curriculum for HST in Neurology is a 5 year programme, and entry is dependent on completion of a 2 year BST programme. The curriculum is developed by the Royal College of Physicians in collaboration with the National Speciality Director (NSD). The current curriculum recognises the following as being essential competencies consistent with practise in the speciality of Neurology;

- Patient care that is appropriate, effective and compassionate dealing with health problems and health promotion.
- Medical knowledge in the basic biomedical, behavioural and clinical sciences, medical ethics and medical jurisprudence and application of such knowledge in patient care.
- Interpersonal and communication skills that ensure effective information exchange with individual patients and their families and teamwork with other health professionals, the scientific community and the public.
- Appraisal and utilisation of new scientific knowledge to update and continuously improve clinical practice.
- The ability to function as a supervisor, trainer and teacher in relation to colleagues, medical students and other health professionals.

89 HSE Quality and Risk Management Standard 2007

90 Royal College of Physicians of Ireland. Medical Workforce Planning Feb 2014

- Capability to be a scholar, contributing to development and research in the field of Neurology.
- Professionalism.
- Knowledge of public health and health policy issues: awareness and responsiveness in the larger context of the health care system, including e.g. the organisation of health care, partnership with health care providers and managers, the practice of cost-effective health care, health economics and resource allocations.
- Ability to understand health care and identify and carry out system-based improvement of care (RCPI 2012)<sup>91</sup>.

The development of sub speciality areas should be planned on a national basis taking a national perspective into consideration. This is to ensure sufficient populations exist to maintain the highly specialised skills of staff. It may be preferable, particularly for less prevalent conditions, to increase capacity in existing sub speciality units and the development of systems which promote rapid assessment, diagnosis and treatment rather than pursue the development of sub speciality units within all services where there may not be adequate volumes of patients to ensure best outcomes.

The absence of Professorial positions in Neurology/Neuroscience in Irish Universities is noted and needs to be addressed so that teaching and research into basic and clinical neuroscience is supported and developed. This will lead to better neurologists and better patient care.

## 14.2 Health and Social Care Professionals

Training and education on all conditions which may present to a neurology service is very challenging given the number of conditions and the lack of current staffing volumes. Some neurological conditions share common features or impairments such as motor, cognitive, perceptual, swallowing and/or communication deficits. It is essential for HSCPs to be knowledgeable in the wide variety of neurological conditions and for them to be knowledgeable in managing neurological conditions, managing chronic conditions and supporting patients throughout the course of their illness and the functional implications of same.

Education and assisting the education of others will be part of the role of most disciplines and this will happen both formally through supervision, in-service training etc, but also informally as team members work together.

A competency framework for HSCP's will be developed in collaboration with the Neurology Programme. This will outline specific competencies that will be considered essential requirements for staff working in the area of Neurology at all grades.

The Dutch organisation ParkinsonNet has developed Guidelines for several professions including, Occupational Therapy<sup>92</sup>, Physiotherap<sup>93</sup> and Speech-Language Therapy. <sup>94</sup>For the Physiotherapy Guideline (1st European Physiotherapy Guideline for Parkinson's Disease) 5 Irish physiotherapists secured funding to participate in training in the Netherlands Upon

91 Royal College of Physicians of Ireland. Higher Specialist Training in Neurology, July 2012

92 Guidelines for Occupational Therapy in Parkinson's Disease Rehabilitation, Ingrid Sturkenboom, Marjolein Thijssen, Jolanda Gons-van Elsacker, Irma Jansen, Anke Maasdam, Marloes Schulten, Dicky Vijver-Visser, Esther Steultjens, Bas Bloem, Marten Munneke, <http://www.parkinsonnet.nl/>

93 <http://parkinsonnet.info/news/the-european-physiotherapy-guideline-for-parkinson's-disease>

94 [http://parkinsonnet.info/media/14829977/dutch\\_slp\\_guidelines-final.pdf](http://parkinsonnet.info/media/14829977/dutch_slp_guidelines-final.pdf)

completion of their training, these 5 therapists coordinated and facilitated training nationally – across varying service delivery divisions with the end result that currently there are 150 physiotherapists trained to the standard determined by international best practice. This example demonstrates how training can be rolled out in a systematic way and could be replicated across the other professions.

### 14.3 Nursing Education

An experienced, dedicated nursing workforce with competencies in caring for patients with neurological needs is required to ensure the highest quality of care for patients. Senior nurses need to be equipped with management and leadership skills to support a culture of ongoing education, training, practice and professional development.

Each neurology service should explore developing the role of the Advanced Nurse Practitioner (ANP) as a key role that can provide autonomous nursing care and lead on development of nursing in neurology- in response to service needs.

Each Neurology Service should include a designated Clinical Nurse Specialist with specialist knowledge and experience in neurology and/or particular conditions with each ward/ area with neurology patients being managed by a designated CNM with specialist knowledge in neurology.

The role of staff nurse remains integral to the treatment/management of patients with neurological conditions and should continue to be developed. The programme recommends that the availability of associated education and development in the area neurology nursing is explored. This will support the development of nurses along a clinical (CNS and ANP) and managerial (CNM) career pathway within neurology services. In this regard, the Neurology Programme will look to the achievements of the National Clinical Programme for Epilepsy. Within this clinical programme, the role of the nurse was emphasized and a Curriculum developed for a Master's Programme in Advanced Practice in Epilepsy.

Investment in the continued professional development and competency attainment for nursing staff working within neurology settings should be a priority. Such an investment together with an increased ratio of staff with appropriate experience working with patients has been demonstrated to yield positive outcomes with respect to;

- Cost avoidance for adverse outcomes
- Cost avoidance for hospital days
- Economic benefits of patients increased functional independence.

### 14.4 Research



High quality research performed by the multi-disciplinary team can be considered a significant quality indicator for any health service. Such research should be directed towards improving safety and care for the beneficiaries of the service locally, regionally and nationally.

It should also contribute to the international efforts to improve understanding of the basic mechanisms of the disorder and its treatment. As has been

demonstrated in other conditions all patients attending regional centres or outreach clinics should be offered the opportunity to be enrolled in research projects with the following aims;

1. Promotion of health research to build evidence based practice in the field of neurology
2. Development of research links between health care providers and academic researchers
3. Evaluation of new and existing health technologies
4. Development of research that reflects clinical realities
5. Development of research that reduces the physical, psychological, and financial burden of care and enables people to fulfill their potential for health.

The proposed model of care recognises the critical need for the design and delivery of specialist neurology services to be involved in and informed by ongoing research to inform best practice. There will be an important role for the programme at national level to disseminate the findings and recommendations of this research to staff working at all levels in the provision of neurology services and work collaboratively with our local health care providers in order to support research development and promote the development of relevant and forward thinking neurology practices.

The National Clinical Programme for Neurology encourages participation in research of various forms including phenomenological and qualitative research, health service delivery research using both formative and summative research methodologies, population based research, translational research and basic mechanisms of epilepsy. Joint programmes for clinical trials with industry are also encouraged to develop and test new treatments. As has been demonstrated in other areas, Ireland has the unique potential for the delivery of national population based data with cooperation across institutional and geographic boundaries which are embedded in the governance structure of the care delivery service and which can be replicated for research purposes.

The National Clinical Programme for Neurology supports the core objectives of the Irish Brain Council which are;

- Promote enhanced funding of all aspects of brain research
- Promote networking of research –working to our strengths and to the benefit of people with brain disorders
- Develop career tracks. These could include;
  - PhD & Post-doctoral training schemes for young graduate in Ireland
  - Career opportunities for qualified scientists
  - Clinician scientist training schemes & clinical academic jobs in University Hospitals

The introduction of additional full and part time research positions for clinical neurologists is a key component in supporting brain research in Ireland. Protected research time is too frequently eroded by the increasing demands of an ever-expanding clinical service. By creating research-specific posts, we would protect meaningful, undisturbed research time, thus enhancing the output of various research groups. Furthermore, we could build a more structured mentoring program for neurology trainees in research and consider introducing a mandatory under-graduate program in research project development. Consequently this employment initiative would not only serve to protect present-day research, but it would also play a critical role in advancing the future of brain research in Ireland

## 15 Programme Metrics



### 15.1 Gaps in information on neurology activity currently available

There are challenges with interpreting the info on neurology activity captured by current info systems

- **The data does not capture all neurological activity:** There were 3,663 in-patient discharges from the speciality of neurology in 2014. Of these, 1,990 (54%) were from two centres (University Hospital Cork and Beaumont Hospital). It should be noted that many more patients will be admitted to hospital requiring neurological care. However, in such circumstances the patient may be admitted by a general physician or another speciality with neurologists providing appropriate support care as required. Similarly, there are many conditions which have a significant neurological basis to them (e.g. pain management, spinal injuries, etc) which are not categorised specifically as “neurological”.
- **Neurology provides support to other specialities which is not captured:** Evidence from the UK shows that 7% of all admissions to hospitals have a neurological component to them. It further shows that of all admission episodes mentioning a neurological condition, only 43% had a primary diagnosis of a neurological condition. This suggests that much neurological related work focuses on collaborative and multi-disciplinary working with other specialities.
- **The New: Return ratio should be interpreted with care.** The New:Return OPD ratio nationally was 2:6. Care should be exercised in interpreting the variation in ratios due to differences in the complexity of patients across centres, the infra-structural and organisational differences within hospitals and the available of primary care services for neurology patients.
- **Current Information Systems do not capture information which is of critical importance to neurology services**

### Presentation of Neurological Cases in Emergency Departments

Currently no national information on ED presentations is available on a speciality basis. We cannot determine the current demand and presentation level within ED. There are estimates however that one in five presentations to emergency department is for a neurological condition.

### Diagnostic Activity

There is currently no diagnostic activity information available so we cannot at this point profile the diagnostic activity associated with neurological conditions. However, given the high diagnostic requirements within neurology, it is expected that diagnostic related activity (particularly MRI and CT) would be high for these categories of patients. Data from the UK Compendium of Neurological Statistics 2012-2013 indicates that for this period:

- one third of all CT scans in the public health service were for inpatients with a diagnosis mention of a neurological condition
- 28% of MRIs for the same period were for outpatients with a diagnostic mention of a neurological condition
- nearly half of all CT and MRI were for inpatients and outpatients with a diagnostic mention of a neurological condition.



## ● Total number of return Out-patient visits per episode of care

Currently at national level, only single attendance data for out-patients is available. We cannot determine the total patient based activity for neurology patients nationally. The UK compendium of neurological statistics 2012-2013 showed that while 45% of outpatient attendees with a neurological condition had one appointment per year, 11.3% of patients with a neurological condition attending outpatient services had ten or more appointments per year, indicating the chronic nature of many of these conditions requiring multiple presentations.

## 15.2 Waiting Lists



Currently waiting list management is undertaken locally. As such, this data is not readily or easily accessible. Setting targets in relation to service improvement is challenging in the absence of such data.

Currently, there is no formalized mechanism to capture data on community services, access to therapy or any services delivered through primary care services, although some aspects can be imputed from disease specific register data such as that for MND. Inclusion of a 'needs analysis' within this database would also be useful in terms of service development, i.e. identification of services the patient would benefit from versus service the patient actually received. Knowing where the strengths and gaps are with community services provides important information for hospital based services i.e. if Consultants felt that patients with long term conditions were sufficiently supported locally, they could more confidently discharge patients with an open appointment for review as needed, as opposed to routine review appointments.

There is no means of capturing the patients' level of disability or severity of impact as diagnosis alone does not give us this information. We also do not routinely collect any information on outcomes or patient satisfaction.

## 15.3 Information requirements in relation to achieving the aims and objectives of the neurology programme

Performance monitoring is a continuous process that involves collecting data to determine if a service is meeting desired standards or targets. It is dependent on good quality information on health and social care which can only be achieved by having a systematic process to ensure that data is collected consistently.

Unlike other major condition areas, data on incidence, service provision and patient outcomes relating to neurological conditions are not routinely collated, published or analysed. This makes it very difficult to establish a baseline from which progress can be measured and to understand what type of activities result in the best outcomes (NAI 2013).<sup>95</sup>

95 The Neurological Alliance: Navigating Neurology services: helping strategic clinical networks to be a success story. Sept 2013.

This is a particular challenge for the Neurology Programme considering;

- The number of conditions presenting which require intervention (currently approx. 100 ICD codes)
- The number of sources of referrals
- The number of sites across which services are delivered
- The movement of patients amongst these sites
- The number of divisions within which services are delivered
- The long term nature of neurological services

The identification of key performance indicators (KPI's) within the delivery of neurological services is not the challenge in itself. There are many targets which could demonstrate better patient outcomes and service delivery, however it is the collection of data to support these KPI's which is the challenge.

The result of this is that in relation to neurology services, the focus is on only one specific aspect of their journey through the system and does not look at the service as a whole across the continuum of care or give real direction in relation to service or quality improvement.

In terms of the continuum of care, it is necessary to know what is being done where, by whom and what the outcome is. At present, such data is not available. While the Neurology Programme can look to international studies/systems in relation to benchmarking and identifying standards/guidelines, the task of determining the gap between Neurology Services provided in Ireland and internationally recognised best practice is significant, particularly in relation to access to service/outcomes.

This will be an essential requirement of the health service as we move towards a system of costing bundles of treatment in preparation for activity based funding. Data will need to be collected nationally and should flow centrally to allow for benchmarking and comparison of performance across sites/geographic areas.

The tables below represent the key objectives and targets of the neurology programme. The table also lists the information requirements to support these performance measures.

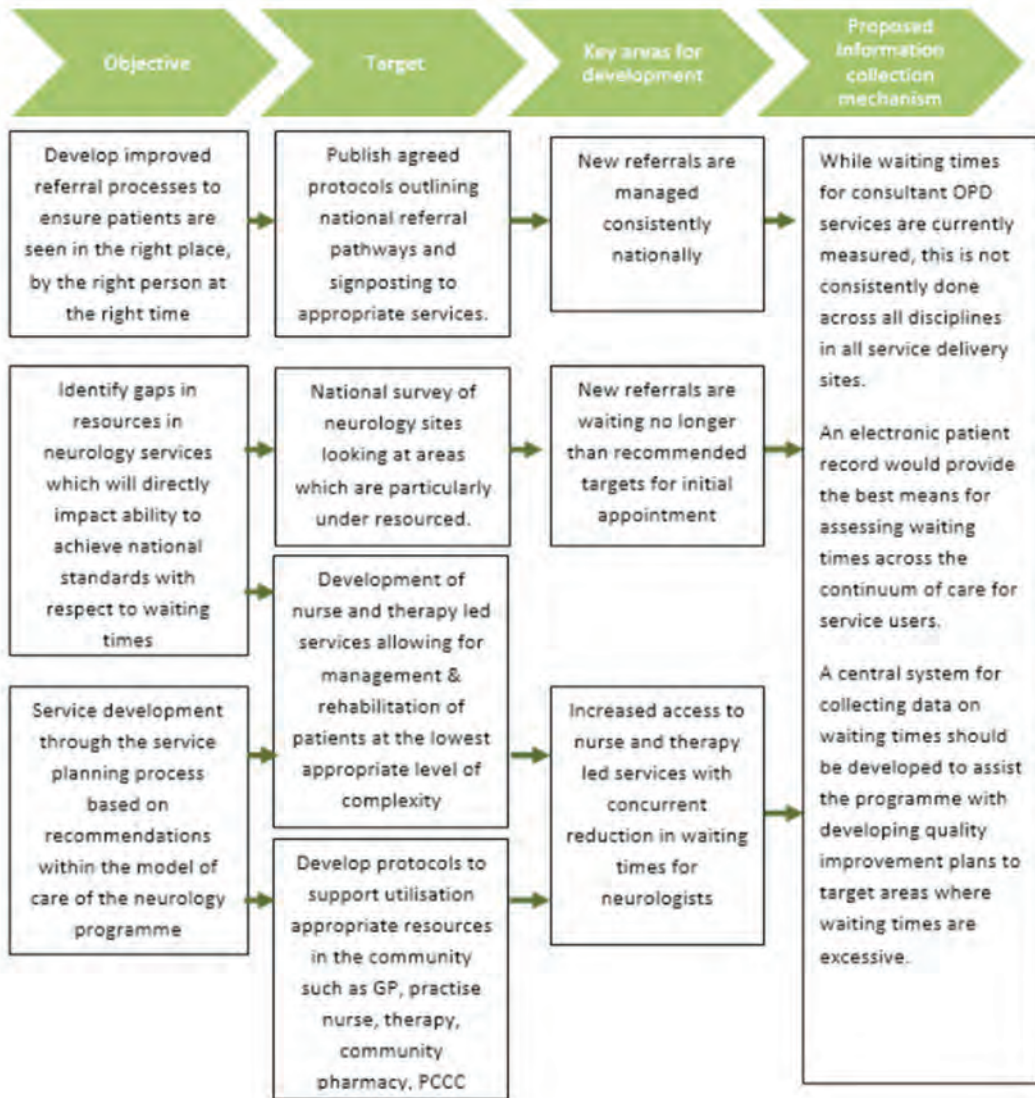


Figure 24; information requirement to support proposed performance measures

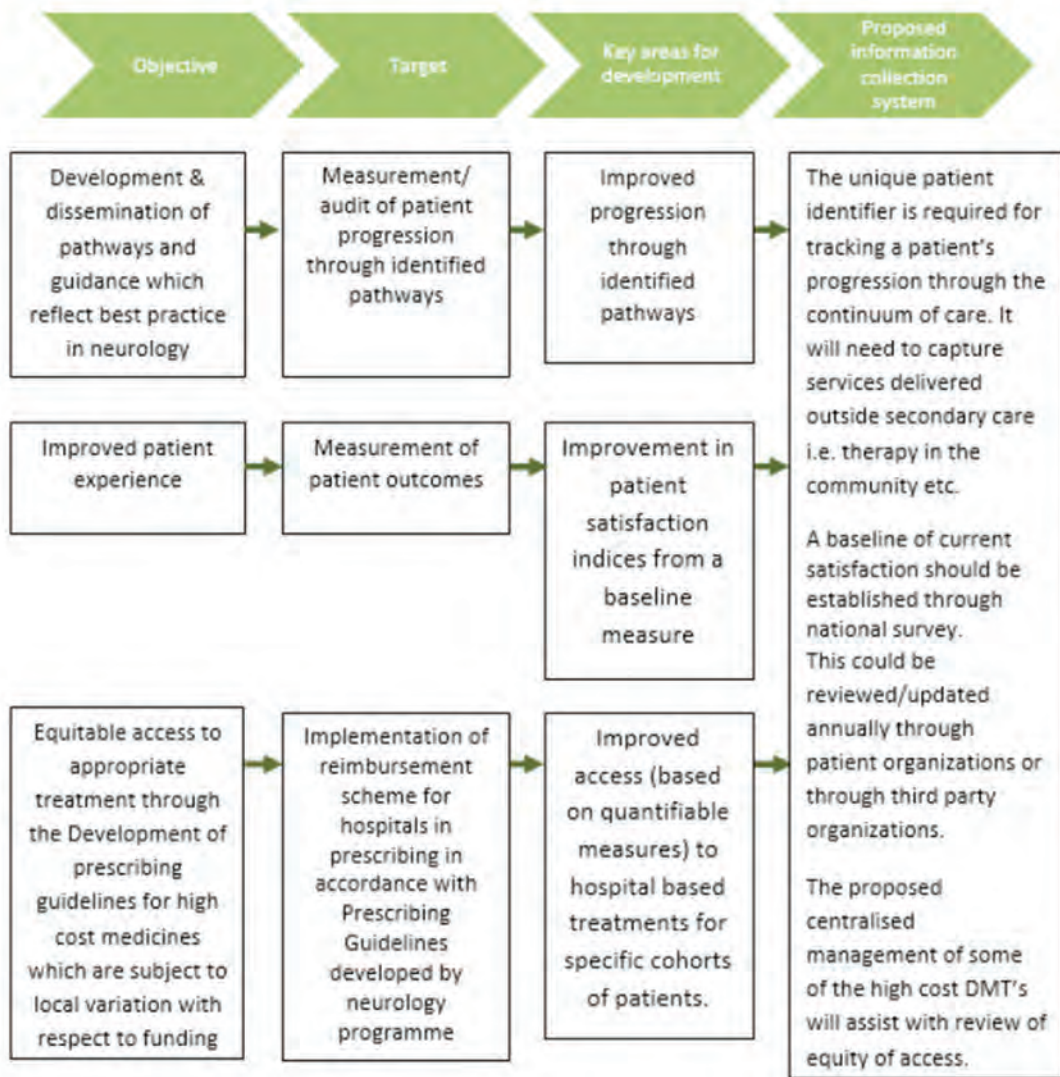


Figure 25; information requirement to support proposed performance measures



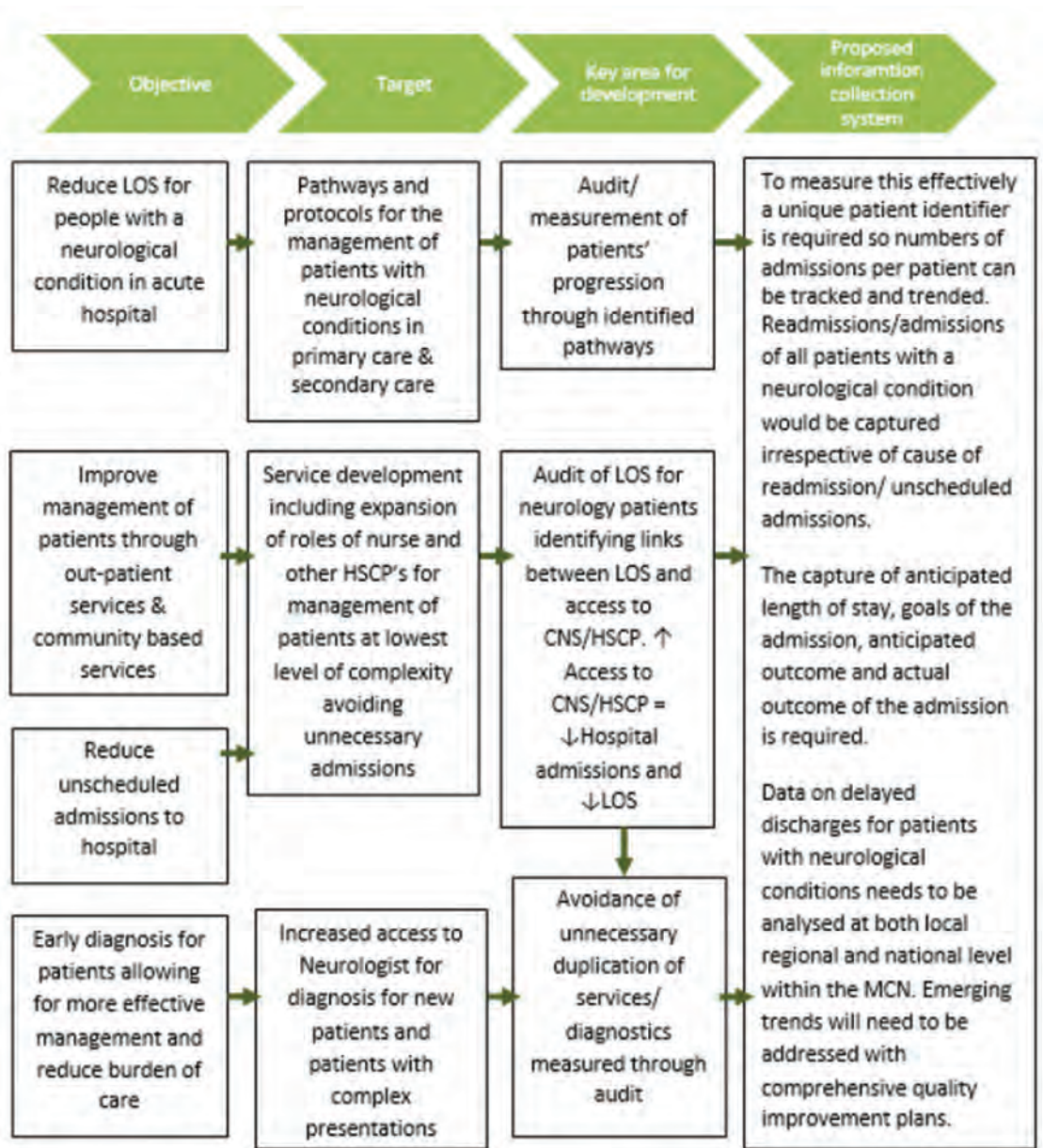


Fig 26

### 15.3.1 Development of overall Neurology registrar based on electronic patient record or other data gathering system

Neurology services will require a comprehensive data gathering and management system similar to the National Clinical Programme for Epilepsy Electronic Patient Record for management of patients with epilepsy. This web based record has revolutionized care of patients with epilepsy, as it is live patient information accessible to all key stakeholders involved in the management of the patient. This system would be considered the 'Gold Standard', and while it would be significant challenge to expand such a system to include all neurological conditions, such as concept should be explored.

More targeted Registers for rare disease can also provide useful information regarding disease incidence, prevalence, management and outcomes. The success of the Irish MND Register (the longest continuously running register of its kind in the world) demonstrates that collation of data from patients with rare diseases can improve outcome, promote research, and provide extensive and valuable data both for service planning and health economic analyses.



The Neurology Programme recommends the development of an overall national neurology registrar. Specific service development plans are dependent on accurate data on the prevalence and incidence of neurological conditions nationally. Service improvements, particularly relating to ongoing management of patients within the community are also dependent on such a registrar which includes information on the functional status of patients and outcomes of interventions. Such a database is also recommended within the model of care for the National Clinical Programme for Rehabilitation Medicine. The importance of establishing a centrally held Registry cannot be underestimated; it could provide critical information that would enable a better overall allocation of resources and more effective overall management of the disease. A study in 2011 concluded that 'Patient Registries should be central to the planning, delivery and review of healthcare in Ireland'. (MRCG & IPPOSI 2011)<sup>96</sup> A registry would also enable monitoring of trends at the national level, over the course of time and the ability to respond accordingly.

### 15.3.2 Data on Workforce;

The lack of workforce data is a gap across neurology services. While information is available on hospital based staffing, exact whole time equivalency designated to neurology services cannot be accurately determined. A comprehensive analysis of all staff i.e. medical, nursing and health & social care professionals across all service delivery divisions would be of significant benefit. It would allow analysis of the supply and distribution of health workers across the services and the identification of underserved areas within the country.

---

96 The Medical Research Charities Group (MRCG) & Irish Platform for Patients' Organisations Science and Industry (IPPOSI) 'Towards a National Strategy for Patient Registries in Ireland: Considerations for Government' Oct 2011

## 16 Communications

The importance and benefits of user involvement within healthcare is widely accepted and there is a wealth of available evidence which indicates that the unique perspective of users can prove to be a valuable resource when it comes to determining what constitutes good quality care. The World Health Organisation's international conference in primary care in 1970 explicitly stated that "people have a right and a duty to participate individually and collectively in the planning and implementation of their healthcare".

The Neurology Programme from its inception has sought to be as inclusive as possible in terms of geography, service user organisations and individual service users. The programme has been committed to close engagement with patient organisations in the development of the model of care and in the individual pathways. The Neurological Alliance of Ireland, the umbrella group for neurological patient organisations, is represented on the working group of the National Clinical Programme for Neurology. The NAI have worked closely with the programme, including on a joint survey of neurology centers to examine current resourcing and needs within neurology services. The programme has engaged directly with the relevant patient organisations in the development of specific pathways for headache, Parkinson's disease, Motor Neurone Disease and multiple sclerosis.

The programme recognises the importance and benefit of service user involvement within healthcare. The section on the patient journey in the model of care was developed in consultation with the NAI and the programme is planning to develop an instrument to gather baseline information on patient experiences of neurology services, which can be used to identify and target specific issues and assess progress over time.

The Neurology Programme has consulted with professional representative bodies and individuals in order to reflect the roles of all of the specialists involved in neurology services and provide them with an opportunity to inform the development of the model of care. This ongoing process of engagement will continue with an online consultation on the model of care and opportunity for feedback across the wide range of stakeholders.

## 17 Implementation

An Implementation Framework will be developed for the Neurology Programme to include the following areas

Programme plans going forward	Actions
<p>1. <b>Review of priority areas for resourcing based on the findings from the national survey of neurology centres</b></p>	<ol style="list-style-type: none"> <li>1. Recommended targeted interventions on a site specific and national basis based on the priority issues identified from the national survey of neurology centres</li> <li>2. Review of current outreach from neurology centres and capacity issues in relation to this</li> <li>3. Review of hospitals currently without a neurology service and recommendations for additional resources required.</li> <li>4. Detail minimum requirements for each neurology centre going forward:               <ul style="list-style-type: none"> <li>– Neurologists</li> <li>– NCHD's</li> <li>– HSCP's</li> <li>– Nursing</li> <li>– Administration</li> <li>– Dedicated neurology beds</li> </ul> </li> <li>5. Development of relevant business cases and submissions to the estimates process for service development as outlined above.</li> </ol>
<p>2. <b>Review of access to diagnostics</b></p>	<p>Recommendations to address access issues and waiting times for diagnostic services on a national basis</p>
<p>3. <b>Equitable access to high cost MS medications</b></p>	<p>Continued collaboration with HSE drugs committee to develop reimbursement scheme for these medications to minimise variation with respect to access</p>

<p><b>4. Establishment of National Steering Group for Neurology as an ongoing resource to guide implementation of the recommendations of the model of care</b></p>	<p>Development of a detailed framework for the establishment of managed clinical networks in neurology</p> <p>Identification and promotion of best practice within neurology through the development of care pathways, guidelines and standard operating procedures.</p> <p>Development of an education and research strategy for neurology based on the recommendations of the model of care including the development of a competency framework for clinicians working in neurology</p> <p>Advice and guidelines on the introduction of new treatments</p>
<p><b>5. Cross Programme Collaborative Projects</b></p>	<p>Working with the National Clinical Programme for Rehabilitation Medicine with respect to the development of regional neurorehabilitation facilities and community based neurorehabilitation teams.</p> <p>Engage with National Clinical Programme for Stroke to consider application of TRASNA system to other neurological conditions.</p> <p>Liaison with National Clinical Programme for Epilepsy when considering Standard operating procedures for managing various conditions in different care settings.</p>
<p><b>6. Specific projects in relation to the future development of services</b></p>	<p>Engagement with relevant stakeholders in pursuit of an all-Island Deep Brain Stimulation Service</p>

# PART D

## Cross Programme Learning, Shared Initiatives and Special Populations

### 1.0 Cross Programme Collaboration

#### 1.1 National Clinical Programme for Paediatrics & Neonatology

Whilst the National Clinical Programme for Neurology concentrates on adult services paediatric services are also taken into account. As such, transition issues are considered and the need for the transition process to be properly addressed is recognised.

##### 1.1.1 Transition to adult services

Transition to adult services is the planned move of a patient's care from a paediatric to an adult health care provider. Transition is a step necessary to achieve the best outcomes possible for patients and their families in areas of health, independence and adulthood. Transition can be defined as 'a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-orientated healthcare systems'<sup>97</sup>(Blum et al, 1993, cited by DH/Child Health and Maternity Services, 2006)

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

Transferring care to adult physicians should be 'a guided educational and therapeutic process, rather than an administrative event' (Viner 1999)<sup>98</sup>. It should also recognise that transition in health care is only one element of the wider transition from dependent child to independent adult and that in moving from 'child centred to adult health services, young people undergo a change that is systemic and cultural, as well as clinical'. Encouraging young people to develop as much independence as possible, both from their families and health care staff will help bridge the gap to adult service.

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

- Self-Advocacy
- Independent health care behaviour
- Sexual health
- Psychosocial support
- Education & vocational planning
- Health & lifestyle

97 Blum et al, 1993, cited by DH/Child Health and Maternity Services, 2006)

98 Viner, R. Transition from paediatric to adult care. Bridging the gaps or passing the buck? Arch Dis Child 1999; 81:271-275



By the final phase, the young person should have a considerable degree of autonomy over their care. They should be aware of their own health care needs and how best to access support or seek advice and further information/education if needed.

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

- Effective communications between hospitals for transfer of medical records and imaging results.
- Flexibility with respect to timing of transition. Not all young people will be ready to make the transfer to adult services at the same time. Issues such as cognitive and physical development, emotional maturity and the status of their health/prognosis should be taken into account when planning transition.
- Appropriate educational interventions are necessary to assist the adolescent understand the disease, treatment rationale, taking appropriate action and learning how to seek help from health professionals and navigate the health system.
- Concerns about equivalency of service are highlighted as potential challenges for successful transition.
- The Neurology Programme advocates the use of a transition checklist (see appendix 6) to guide transition from paediatric to adult services. The neurology programme recommends that each site serving paediatric patients with neurological conditions should refer to the checklist, even when paediatric and adult services are in the same hospital as evidence would suggest that geographic collocation does not always translate into smooth transition between services.

An ever increasing number of children with neurological conditions are being seen in adult services. The conditions most often seen can include;

- Cerebral palsy
- Spina Bifida
- Spinal cord injury
- Acquired brain injury
- Epilepsy
- Narcolepsy
- Musculordystrophy
- Movement disorders

While in-patient neurology services may be required in some instances, many of these conditions would be considered stable, and the children will transition from paediatric to adult neurology services as out-patients with continuing OPD MDT input and support from other specialist services such as rehabilitation, therapies, nursing, social services and educational support.

## 1.2 National Clinical Programme for Epilepsy

As Epilepsy is a neurological condition, diagnosed and managed by Neurologists, there is significant collaboration between the Epilepsy Programme and Neurology Programme. With 34 neurologists in the country, there is overlap in membership of the Epilepsy Consultants Advisory Group and Neurology Programme Consultants Advisory Group. The advantages of this are numerous with the same cohort of Consultants approving pathways, standard operating procedures etc across general neurology and epilepsy.

### 1.3 National Clinical Programme for Rare Diseases

The National Clinical Programme for Rare Diseases was established in December 2013. Rare neurological conditions are considered within scope for this programme therefore a representative from the Neurology Programme sits on the Consultants Advisory Group for the Rare Disease Programme. While many of the neurological conditions considered 'rare' appear in childhood, increased life expectancy over recent years has meant that these previously considered 'paediatric' conditions are now appearing in adult neurology services.

Rare diseases can also develop in adulthood. While some of these are genetic in origin (e.g. Huntington's disease and some adult onset muscular dystrophies) others present in the second half of life (e.g. Motor neuron disease, frontotemporal dementia, progressive supranuclear palsy) are progressive and require specialist tertiary and quaternary services with sufficient critical mass to support excellence.

More collaboration between neurology and neuro-genetics is recommended and adult genetic services including diagnostic laboratory facilities need to be developed to support this. While there are a number of medical geneticists, presently, their services are accessed through paediatric hospitals. While they would have adult patients, these patients attend their services based within paediatric hospitals. Service user feedback would indicate that the treatment of adult patients in paediatric units is not felt to be appropriate.

Issues in relation to low staffing numbers for clinical genetic consultants and genetic counsellors are impacting on diagnosis and access to genetic counselling for people with neurological conditions and their families.

Additional collaboration should be considered in the future including exploration of the possibility of developing protocols and guidelines for the diagnosis and management of rare neurological conditions including the development of condition specific clinics to promote potential centres of expertise / reference networks for specific rare conditions

### 1.4 National Clinical Programme for Acute Medicine

Linkages with acute medicine programme (AMP) are essential particularly with respect to admissions of patients with neurological conditions, both scheduled and unscheduled. 1 in 5 acute medical admissions have a neurological cause. Dissemination of patient pathways will need to be done in collaboration with the AMP, particularly for patients presenting in the AMAU's.

Development of Neurology in-patient services, particularly the recommendation for cohorting of patients with neurological conditions to improve patient outcomes and decreased length of stay can only be achieved in partnership with our colleagues in the AMP.

### 1.5 National Clinical Programme for Stroke

Overlaps/synergies between the neurology and the stroke programmes are numerous including recommendations relating to the management of patients in the community as appropriate and the focus on health promotion and self-management.

The Neurology programme would also like to explore with the stroke programme the potential for expansion of the existing TRASNA (telemedicine rapid access for stroke and neurological assessment) and develop clinical and educational links between hospital networks and indeed with the tertiary services i.e. access to neurology opinion for patients with complex presentations, or patients who may not be able to travel to tertiary or regional units.

The potential benefits for the TRASNA system in neurology, or indeed any telemedicine system would allow opportunity to be explored for;

- OPD clinics via TRASNA; having the ability to deliver clinics remotely would increase not only patient experience, efficiencies with respect to waiting time but would also go some way to addressing the ever increasing demand on space within larger regional/national hospitals out of which Neurology OPD services are generally run.
- Rapid opinion on acute cases
- It would also support the development of nurse-led clinics with access to Consultant opinion as appropriate.
- MDT meetings across hospitals would also be of great benefit

## 1.6 National Clinical Programme for Rehabilitation Medicine (RMP)

The National Clinical Programme for Neurology and the National Clinical Programme for Rehabilitation Medicine (RMP) share many key stakeholders, including service users. By agreement between the programmes, particular areas/conditions are detailed in either of the programmes Model of care and referenced in the other, but not duplicated in both. Examples of such include care pathways for sudden onset conditions such as acquired brain injury and spinal cord injury contained within the RMP model of care and referenced in the Neurology model of care and pathways for progressive and fluctuating conditions such as MS and Parkinson's Disease are detailed within the neurology model of care and referenced in the RMP model. As such the models of care of both programmes could in effect be considered a continuum as stakeholders and service users are common across both programmes.

## 1.7 National Clinical Programme for Older People

The National Clinical Programme for Older People has published Part 1 of a 3 part Model of Care. This initial publication has focused on the development of Specialist Geriatric Wards with dedicated Specialist Geriatric Teams to care for at risk frail older patients being admitted to acute hospital. The Model of Care also describes the requirement for access to on and off site rehabilitation and day hospital services for Older People if required. The Neurology Programme recognises that the prevalence of many neurological conditions increase significantly with age. Considering this, close linkages need to be further developed between the two programmes to ensure that patients of specialist geriatric teams have access to specialist neurology opinion, and older persons with neurological conditions have access to specialist geriatric services, where appropriate.

### **Transition to older peoples services for people with existing neurological conditions**

Links between neurology and older peoples services will require a focus not only on those patients developing neurological conditions with age, but also on the cohort of people who develop neurological conditions before the age of 65 years and transition to older peoples services once they reach the age of 65. There are significant issues in relation to this transition with very limited access to neurorehabilitation services for those over 65 years as well as access to other supports such as PA services. Pathways of care should reflect the need for a smooth transition to older peoples services among people with neurological conditions, ensuring that

service provision is based on need rather than on age. This will require significant changes in relation to the way in which services are currently delivered and funded within the health services.

### 1.8 National Clinical Programme for Palliative Care

The national clinical programme for palliative care advises that palliative care can be provided to people of any age and at any stage of their illness. Providing palliative care at an earlier stage in a person's illness can help to better manage symptoms and potentially reduce complications.

While there are palliative care specialists, provision of palliative care can be said to be the responsibility of the whole healthcare team. Within a healthcare team are three levels of palliative care provision with increasing specialisation from level 1 to level 3<sup>99</sup>;

- Level 1; Provided in any location or setting by all health care professionals as part of their role and using a palliative care approach.
- Level 2; provided in any location, using a palliative care approach by healthcare professionals who have additional knowledge of palliative care principles and use this as part of their role.
- Level 3; provided by health care professionals who work solely in palliative care, and have extensive knowledge and skills in this speciality.

To support healthcare workers the National Clinical Programme for Palliative Care developed a framework of core competencies. It is hoped that this framework will inform academic curricula and professional development programmes and so foster greater inter-professional and inter-organisational collaboration in palliative care provision.

It is felt to be appropriate that all members of the healthcare team working with patients with neurological conditions should be supported in achieving a Level 2 specialisation in palliative care provision.

## 2.0 Specialist populations

### 2.1 Intellectual disabilities

In Ireland, the Department of Health and Children use the phrase 'Intellectual Disability' and describe the condition as involving: "a greater than average difficulty in learning. A person is considered to have an intellectual disability when the following factors are present: general intellectual functioning is significantly below average; significant deficits exist in adaptive skills; and the condition is present from childhood (eighteen years or less) (Inclusion Ireland, 2009<sup>100</sup>)".

Intellectual disability is associated with an increase in other physical and mental health issues. Literature suggests that individuals with intellectual disabilities will attend 1.7 times more visits to a GP than the general population and have up to 4 times the number of prescriptions (Straetmans et al, 2007<sup>101</sup>).

Individuals with intellectual disabilities are recognised as a vulnerable group and socially excluded in society. In addition to genetic vulnerabilities to certain health conditions, they may be reluctant or unable to access health services, unaware of public health awareness campaigns or live in social settings which may not foster healthy lifestyles. In addition, their ability to undertake physical activities may be limited either due to lack of opportunity, or co-existing physical disabilities<sup>102</sup>.

With respect to co-morbid Neurological conditions, the most prevalent would be Epilepsy. The prevalence rate of epilepsy is around 10 times higher for an individual with mild intellectual disabilities than in the general population; the prevalence increases from this in line with the severity of the intellectual disability to around 30% of all individuals with intellectual disability (Bernal, 1995<sup>103</sup>).

The presence of intellectual disability has a number of effects on treatment options<sup>100</sup>;

- The individual may have limited communication skills resulting in subjective observation by clinical staff and family members becoming of higher importance. The relationship becomes indirect, not with the patient.
- The clinical picture can be complicated by overlapping multiple conditions meaning that a provisional diagnosis may sometimes only be confirmed by a successful trial and error response to treatment
- Treatment can have unexpected and ambiguous effects as multiple conditions result in different effects
- Improvements in condition may be due to normal developmental changes rather than a positive effect of treatment (e.g. epilepsy will often show a spontaneous improvement around age 4 in an individual with autism. This is a change in the condition rather than a change in response to treatment).

100 Inclusion Ireland National Association for people with intellectual disability, Annual report 2009

101 Straetmans MJAA, Van Schrojenstein Lantman-de Valk HMJ, Schellevis FG, et al. Health problems of people with intellectual disabilities: the impact for general practice. *Br J Gen Pract* 2007; 57:64-66

102 <http://www.welfare.ie/en/downloads/protocol4.pdf>

103 Bernal, J. (1995) 'Epilepsy' in Learning about intellectual disabilities and health accessed at [http://www.intellectualdisability.info/complex\\_disability/epilepsy.htm](http://www.intellectualdisability.info/complex_disability/epilepsy.htm) accessed August 2009



- There is limited supporting evidence as to the effectiveness of most treatments
- The issue of informed consent may be problematic.

Also of note within this population is the increased prevalence of early onset dementia, particularly in relation to individuals with Downs Syndrome. Prevalence is reported as follows;

Between 30 & 39 years	2%
Between 40 & 49 years	9.4%
Between 50 & 59 years	36.1%
Between 60 & 69 years	54.5%

**Table 18; Dementia in people with Down syndrome (Prasher 199<sup>5104</sup>)**

It can be difficult to determine the early changes that occur as a result of dementia as many indicators can be an exaggeration of already existing behaviours and deficits that exist because of the person's learning disability. Often the early signs can be missed and referral for assessment and diagnosis unnecessarily delayed (Kerr 2009)<sup>105</sup>.

## 2.2 Neurological Conditions & Pregnancy

A wide range of neurological problems occasionally complicate pregnancy, however pregnancy is not necessarily contraindicated for women with neurological conditions. These can be due to pre-existing neurological diseases such as epilepsy, MS, myasthenia gravis etc or new neurological disorders can occur such as facial nerve palsy, headache & eclampsia.

Ideally all women with a known neurological condition who is of child bearing age should engage in pre-conceptual counselling with their neurologist/neurology service and obstetrician. During this consultation, the woman should be advised about;

- Contraception
- Family planning
- Pregnancy including the possible risks associated with their condition on pregnancy and possible teratogenic effects of their medications.
- They should also all be prescribed folic acid as routine.

If the woman is already pregnant and did not consult her treating clinicians in advance, she should alert her obstetrician and neurologist as soon as possible for a review of medications for their teratogenic potential. Considering the wide range of therapeutic options for neurological conditions, it is rare that treatment of the condition is discontinued, but treatments with a lower risk should be considered.

At least 2 systems are used to classify the risk associated with specific medications: the US Food and Drug Administration (FDA) system and the automated Teratogen Information System (TERIS)<sup>106</sup>

104 Prasher V (1995) Age-specific prevalence: Thyroid dysfunction and depressive symptomology in adults with Down syndrome and dementia. *International Journal of Geriatric psychiatry* 10, 25-31

105 Kerr D. Down Syndrome and dementia. *Voice*, Winter 2009. Down Syndrome Victoria Members Journal

106 Armon, C. Neurologic Disease and Pregnancy. <http://emedicine.medscape.com/article/1149405-overview>

The FDA risk categories are as follows;

- Category A – Controlled human studies show no risk
- Category B – there is no evidence of risk in humans, but no controlled human studies are documented
- Category C - Risk to humans has not been excluded
- Category D – There is positive evidence of risk to humans from human or animal studies
- Category X – Contraindicated in pregnancy.

A similar classification is available with respect to potential effect of medications on breastfeeding infants.

Epilepsy has been shown to be the most common neurological condition presenting in pregnant women (To & Cheung 1997)<sup>107</sup>. Epilepsy itself is not a contraindication to pregnancy however seizure management should be optimised before pregnancy is considered.<sup>73</sup> The National Epilepsy Clinical Programme has developed a comprehensive standard operating procedure 'Women with Epilepsy' which addresses the management of women according to best practice, from family planning through to menopause<sup>108</sup>.

### 2.3 Dementia

Dementia is a global priority public health problem, such that health ministry's worldwide and medical education sectors alike need to prioritize resources for dementia research, education, and treatment. The rising incidence and prevalence of dementia in an aging population 'will create an increasing demand for the services of neurologists' (Menken 1998)<sup>109</sup>.

The report of a clinicians round table carried out by the Alzheimer Society of Ireland as part of the development of the National Dementia Strategy highlights the role of neurologists in the identification and management of dementia in those under 65 years. The report recommends the establishment of multidisciplinary teams involving geriatricians, old age psychiatrists and neurologists to respond to early onset cases and accept under 65 referrals, with links to memory clinics where necessary.

The publication of the National Dementia Strategy (NDS) means that more co-ordination and integration of services for people with dementia can be expected. It is important that neurologists are involved in the development of a care pathway for dementia and in other initiatives to improve the management of dementia in line with the recommendations of the NDS. It is important that neurology services are linked to care pathways for dementia to be developed as part of the implementation of the National Dementia Strategy. Other recommendations of the NDS include the assignment of a senior clinician within each hospital to lead on the implementation and monitoring of a dementia care pathway and appointment of a key worker within primary care for people with dementia. The neurology programme model of care will reflect the recommendations of the NDS in relation to the role of the neurology services in the management of the needs of people with dementia.

The National Dementia Strategy, published in December 2015, recognises the role of neurologists in the diagnosis and subtyping of dementia, particularly early onset dementia.

107 WK To, Cheung RTF. Neurological disorders in pregnancy. HKMJ Vol 3 No4 December 1997

108 <http://www.hse.ie/eng/about/Who/clinical/natclinprog/epilepsyprogramme/>

109 Menken, M 'Alzheimer's disease and the modified role of the neurologist in today's healthcare environment' + doi: 10.1212/WNL.51.1\_Suppl\_1.S61 Neurology July 1998 vol. 51 no. 1 Suppl 1 S61-S64

Early Onset Dementia (EOD) includes: early onset adult neurodegenerative; late onset forms of childhood neurodegenerative and reversible disorders. Late onset forms of childhood neurodegenerative may present in those under 35 years and include for example: mitochondrial disorders, lysosomal storage diseases and leukodystrophies (Kelley et al, 2009<sup>110</sup>).

### 2.3.1 Epidemiology of EOD

There are approximately 4000 younger persons with dementia in Ireland (Cahill, 2012<sup>111</sup>) and this is projected to reach approximately 5,000 individuals by 2046. In the UK there are reported to be 40,000 under 65 years with dementia. The prevalence in the UK is reported to be 54 per 100,000 aged 30-64 and 98 per 100,000 in the 45-64 year-old age group (Harvey et al, 2003<sup>112</sup>). Of note there is an exponential onset after aged 35 years (doubling every 5 years). The incidence rate is reported to be 8.3 new cases per year per 100,000 persons in the 50-64 year-old age group (Bickel et al, 2005<sup>113</sup>).

### 2.3.2 Background

Early Onset Dementia has specific diagnostic features compared to Late Onset Dementia (LOD). EOD has considerably expanded potential etiologies to consider with degenerative, vascular, inflammatory, infectious, toxic and metabolic causes. Genetic and metabolic causes are more commonly identified in individuals with earlier onset (Sampson et al, 2004<sup>114</sup>). Individuals with EOD can present atypically with behavioural, cognitive, psychiatric and neurological symptoms (Mendez, 2006<sup>115</sup>).

### 2.3.3 Burden

The burden for the individuals with these disorders, their family members and caregivers is significant and includes effect on

1. Emotions: such as loss of independence, changes in relationships, self-esteem and self-worth, depression (Beattie et al, 2002<sup>116</sup>) stigma, social isolation, guilt and helplessness (Roach et al 2008<sup>117</sup>) all being reported.
2. Physical
3. Financial: employment, health insurance, mortgages, difficulties getting pensions. US studies have reported that more than 60% of those with disabling cognitive impairment had income < 11,000 dollars per year and 29% aged 55-64 had no health insurance.

110 Kelley et al 2009. Rapidly Progressive Young-onset Dementia. *Cogn Behav Neurol* 2009 Mar; 22(1): 22-27

111 Cahill S, O'Shea E, Pierce M. Creating Excellence in Dementia Care. A research review for Ireland's national dementia strategy. DSIDC's Living with dementia research programme. School of Social work & Social Policy, TCD. Irish Centre for Social Gerontology. National University of Ireland, Galway. 2012

112 Harvey RJ, Skelton-Robinson M, Rossor M N. The prevalence and causes of dementia in people under the age of 65 years. *J Neurosurg Psychiatry* 2003; 74: 1206-1209

113 Bickel et al 2005 – get full reference

114 Samson EL, Warren JD, Rossor MN. Young onset dementia. *Postgrad Med J* 2004; 80:125-139

115 Mendez, Mario F. "The accurate diagnosis of early-onset dementia." *The International Journal of Psychiatry in Medicine* 36.4 (2006): 401-412.

116 Beattie AM, Daker-White G, Gilliard J, Means R. Younger people in dementia care: a review of service needs, service provision and models of good practice. *Ageing and Mental Health*, Vol 6, Issue 3, 2002

117 Roach P, Keady J, Bee P et al. Subjective experiences of younger people with dementia and their families: implications for UK research, policy and practice. *Reviews in Clinical Gerontology* May 2008; 8(2), pp 165-172

4. Family: Caregivers of individuals with EOD are most often the spouse (Svanberg et al, 2011<sup>118</sup>) and these individuals have higher rates of burden/stress/depression reported than in caregivers of those with LOD (Beattie et al, 2008<sup>119</sup>; Freyne et al, 1999<sup>120</sup>). Very importantly there is a lack of suitable community services that need to fit caregivers who work

### 2.3.4 Future Needs

1. Epidemiology and etiology studies
2. Research aimed at prevention and delay of onset
3. Education: caregivers, healthcare professionals, general public, employers and HR
4. Workplace accommodations analysis
5. Social Welfare benefits: disability services, medical cards
6. Age appropriate specialist services as opposed to the expansion of older person services with individualized EOD care pathways
7. Involvement of those affected in actual service planning....programs to meet their unique needs

### 2.3.5 Future Service Development

Based on work in the UK it has been reported that for every 500,000 individuals in the general population there needs to be a specialized EOD team with medical, neurologic and neuropsychiatric members (UK College and AS 2006<sup>121</sup>). These service teams will provide:

1. Case Management
2. EOD advisors
3. Community services and social care
4. Peer support
5. Will include stakeholder involvement in designs of services and programs
6. Research prospective studies to identify how changes over time will affect service needs
7. Help develop clinical trials to assess strategies for meeting needs

## 2.4 Acquired Brain Injury

Acquired Brain Injury (ABI) can be considered an umbrella term for patients presenting with damage to the brain received over the course of the person's lifetime. Conditions considered to be an ABI can include;

- Traumatic brain injury
- Stroke
- Brain haemorrhage
- Infection such as meningitis
- Anoxia/hypoxic ischaemia
- Encephalitis
- Toxic or metabolic insult

---

118 Svanberg E, Spector A, Stott J. the impact of young onset dementia on the family: a literature review. International psychogeriatrics. Vol 23, issue 03, April 2011, pp 356-371

119 Beattie et al 2008 – get full reference

120 Freyne, Aileen, et al. "Burden in carers of dementia patients: higher levels in carers of younger sufferers." International journal of geriatric psychiatry 14.9 (1999): 784-788.

121 UK college and AS 2006 – get full reference

The impact of the ABI on the person varies between individuals, meaning that symptoms can vary hugely, even between those with similar findings on imaging.

ABI is considered a specialist population within the neurology programme based on the range of impairments, initial presentation to services and management throughout the continuum of care.

The initial management of these patients should not vary significantly across hospitals/ settings.

Factors impacting on the patients initial management will be whether the patient requires neurosurgery i.e. transfer to one of the two neurosurgical sites. The decision as to whether surgery is required should be made based on the clinical scenario and imaging results reviewed by neurologist/neurosurgeon. Hospitals without access to necessary diagnostic imaging tools should arrange for appropriate transfer of the patient to a hospital equipped appropriately.

The neurologist plays a key role in the assessment and diagnosis of ABI in all settings. This is done through a detailed neurological assessment, including but not limited to assessment of higher cortical functioning, language, speech, spatial and temporal orientation as well as signs of aphasia, apraxia, visual field deficits and other signs of hemispheric dysfunction (Duarte 2007)<sup>122</sup>. Proper examination techniques and ability to interpret findings are of paramount importance.

Once the patient is stabilised and diagnosis of an ABI confirmed, the patient should begin on an appropriate care pathway. This pathway should include;

- Transfer to an appropriate environment
- Early referral for rehabilitation medicine assessment

Early engagement in rehabilitation is recommended for patients with an ABI and is most effective if the patient is transferred to a suitable environment. In the absence of an acute rehabilitation ward, a neurology ward should be considered. The pressure of an acute general ward may render it difficult for multi-professional rehabilitation teams to treat patients with complex needs and, in the absence of such treatment, attempts to alleviate symptoms such as anxiety and restlessness with medication may produce short term blunting of symptoms whilst delaying the recovery of cognitive functions needed for rehabilitation (Gutebrunner, 2007)<sup>123</sup>.

Patients presenting with mild ABI are missed within the current system. Patients presenting with a GCS <15, PTA of <18/18 and/or post-concussion symptoms should be monitored closely for a minimum of 4 hours. Any deterioration indicates a need for CT and abnormal results should be referred to neurosurgical centre for review.

Specific recommendations with respect to ongoing rehabilitative needs of this population (and others) are outlined in the National Policy and Strategy for the Provision of Neurorehabilitation Services in Ireland 2011-2015 and further detailed in the model of care for the National Clinical Programme for Rehabilitation Medicine.

122 Duarte RA, Fishman O. The Role of the Neurologist in assessment and management of individuals with acquired brain injury. *Acquired brain injury*. 2007 pp 39-63. ISBN 978-0-387-37574-8

123 Gutebrunner C, Ward AB, Chamberlain MA. White book on physical and rehabilitation medicine in Europe. *Journal of rehabilitation medicine*. Supplement No 45, Jan 2007.



## 2.5 Rare Diseases

Many neurological conditions come under the category of rare disease and would benefit from specialist services such as the establishment of multidisciplinary centres and the development of protocols and guidelines for the diagnosis and management of rare neurological conditions. Specialist centres have an important role to play in developing expertise, promoting best practice and fostering research and international collaborations. The Motor Neurone Disease clinic in Beaumont Hospital provides a very useful template for a specialist centre for rare neurological disease in Ireland.

# PART E – Managed Clinical Networks

## The key strengths of a Managed Clinical Network

***“the promotion of consistency and quality of service throughout the care pathway and the bringing of service user and provider views to the service planning process... developing services which are truly person-centred, delivered locally wherever possible but specialised where need be” (NHS HDL (2007) 21. Scottish Executive Health department***

Managed Clinical Networks are ideally suited to delivering service re-design, quality improvement, strategy and planning across pathways, working across boundaries of departments, teams, units and divisions. They achieve their results through consensus and collaboration, by enabling clinicians, patients and service managers to work together across boundaries to deliver safe, effective and person-centered care. The concept of Managed Clinical Networks (MCN's) in neurology was first introduced in the Laffoy Review 2007<sup>11</sup>. This model of care builds on the structure proposed in this review.

The development of MCN's in the context of improving quality and outcomes for the care of people with long term conditions such as neurological conditions is highly regarded. The principles outlined below are drawn from the Scottish Managed Clinical Network guidance document 'Strengthening the Role of Managed Clinical Networks (HDL (2007) 21. This is a model which has the potential for successful implementation in an Irish context.

### 1.1 Core Principles of Managed Clinical Networks

- Each MCN must have clarity about its management arrangements including the appointment of a Lead Clinician who is recognised as having overall responsibility for overseeing the functioning of the Network.
- Each MCN must have a defined structure that sets out the points at which the service is to be delivered and the connections between them.
- Each MCN must have an annual plan developed in collaboration with existing hospital and community management structures, setting out intended quality improvements.
- Each MCN must support the implementation of documented evidence base (such as National Clinical Effectiveness Committee (NCEC)/ Scottish Intercollegiate Guidance Network (SIGN)/ National Institute for Clinical Excellence (NICE) and/or other guidelines) into clinical practice.
- MCNs encouraged to undertake audit as well as relevant research and development.
- Each MCN must be multi-disciplinary and multi-professional in keeping with the network concept.
- Each MCN must include meaningful involvement of those for whom services are provided, and by the voluntary sector.
- MCNs educational and training potential should be used to the full, in particular through exchanges between those working in the community and primary care and those working in hospitals or specialist centers. All MCN's should ensure that all professionals involved in the network are participating in appropriate appraisal systems that assess competence to carry out roles while acknowledging that assessment of performance falls within the remit of local management structures.

- Each MCN must demonstrate continuing scrutiny of opportunities to achieve better value for money through the delivery of optimal, evidenced based care that adds value from the patient’s perspective, optimises productivity and reduces unwarranted variation.

## 1.2 Leadership

The leadership of an MCN is a distinctive role. MCN Lead Clinicians (who can be from professions other than medicine) require a number of skills, including clinical authority, ability to inspire a multidisciplinary team and to work in partnership across professional boundaries and with colleagues from other sectors.

The role description for the Lead Clinician should recognise time devoted to leading the network with allocation of protected time and specific core team to the role.

As part of this core team, each network should have a network manager. This role should focus on ensuring that the network functions effectively and achieves tangible progress in developing equitable, high quality, safe and effective person-centered services.

## 1.3 Accreditation

As with all healthcare services, delivery of neurology services through the network should be subject to a process of endorsement/quality assurance by the HSE, in particular the national quality standards, Safer Better Healthcare, and/or other quality standards deemed appropriate.

## 1.4 Structure of Managed Clinical Network

A national steering committee will support and guide the work of the network. Membership of the steering group should include representatives from all relevant stakeholders including national clinical lead, healthcare professionals including those from hospital, primary care and community settings, patients, hospital groups, community care teams, primary care, voluntary organisations etc.

Supporting the role of the steering committee are subgroups, some of which will be long term with public and patient involvement, quality assurance, education/training, while others will have a shorter life span and will focus on the delivery of specific, time bound pieces of work.

Each clinical network must be managed effectively. The leadership and management function of the MCN should be delivered via dedicated capacity of an appointed MCN clinical lead and MCN Manager as outlined above. The capacity of the management team will need to be flexible dependent on the stage of development of the clinical network.

The structure of a network derives from definition of points of entry to care, points of care delivery and the connections between same. A key task is to set out the mechanisms and principles governing the relations between points of care, as care pathways and guidelines. All professionals involved with care delivery are de facto members of the network.

## 1.5 Benefits of MCN's

Once established, MCN's will gather most up-to-date information and understanding not only of their local and regional services, but of developments in their clinical field. The involvement of the public and patients in network processes should also instil a clear view of the public's interests and priorities.

If a network is functioning properly, it will be working across the boundaries between the different sectors and professions in the health service.

### 1.5.1 Benefits for patients

- More efficient integrated care
- Consistent care regardless of location
- Improved access to appropriate services
- Understanding of how to re-access the services as the condition requires
- Care delivered in the appropriate setting and as near to home as is practicable.

### 1.5.2 Benefits for Staff

- Care that reflects the needs of persons with neurological conditions
- Coherent approach to the local implementation of the National Standards, Guidelines and Care Pathways
- MDT Service designed in line with national guidance
- Using the skills, knowledge and expertise of a range of staff in new ways
- Improved understanding of the roles required to deliver comprehensive service in the regions and locally

### 1.5.3 Benefits for managers/all services

- Improved access to services for patients
- Reduced unnecessary delays in hospital
- Partnership working to reduce delays in the system
- Improved understanding of the type of care needed, appropriate activities, service complexity and dependency.
- Cost effective services

## 1.6 Proposed Clinical Neurology Network Configuration

Six Managed Clinical Networks supported by a National Steering Group. This approach will:

- Ensure that all parts of the service are integrated through national and regional leadership.
- Ensure consistency of service development / delivery, management and quality at all levels within each region and nationally
- Ensures each region moves towards self-sufficiency and equity of service provision
- Reflects existing HSE decision making mechanisms, to ensure that decision making regarding neurology services is streamlined with all other relevant decision making
- Optimises opportunity for local input in design of neurology services

Neurological services can be provided in a number of settings as described above. The establishment of managed clinical networks (MCNs) for neurological services in each of the six hospital groups is proposed to facilitate the development of integrated quality services.

MCNs have developed in other countries and consist of linked groups of health professionals and organisations from primary, secondary and tertiary care working in a coordinated manner, unconstrained by existing professional and organisational boundaries to ensure equitable provision of high quality, clinically effective services. They have been well recognised as encouraging all those responsible for the delivery of care across all agencies, whether private, public or voluntary or providing health, social care or education services, to work together across agencies to ensure that they deliver more than the individual parts can working alone.

## 1.7 Neurology Networks in Practice (adapted from Laffoy 2007<sup>11</sup>)

### 1.7.1 Person with suspected neurological condition presenting to primary care professionals;

Where a person with a neurological condition presents to a Primary Care Professional in the first instance (GP, PHN and HSCP) (who may or may not be working in Primary Care Teams (PCCCs), 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 agreed protocols. This may involve direct access to specific diagnostic tests / imaging, either at the nearest Model 2 or 3 Hospital, at a Group Neurology Centre or via telemedicine
- Or
- Direct referral to the appropriate Group Neurology Network centre or Tertiary centre for further assessment and treatment
- Or
- Immediate transfer to the nearest appropriate ED/AMAU if resuscitation / stabilisation is required.

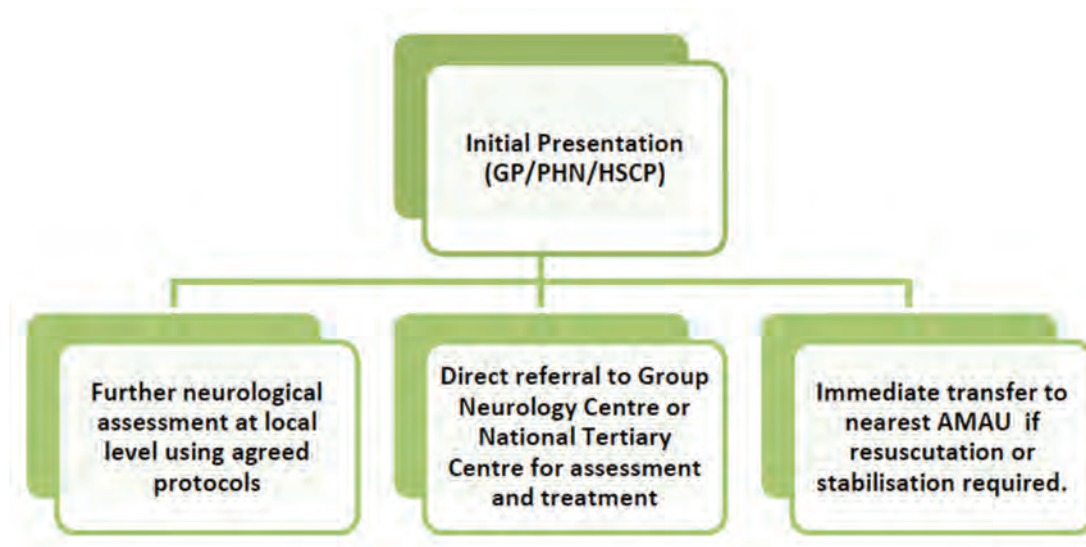


Fig 27; Pathway for initial presentation in primary care<sup>11</sup>

### 1.7.2 Person with suspected neurological condition presents to Emergency Department<sup>11</sup>

Where the person with a neurological condition presents to the Emergency Department, initial clinical assessment takes place, with the following possible outcomes;

- Immediate resuscitation / stabilisation if required
- Or
- Further neurological assessment is conducted, using agreed protocols. 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 Group Neurology Network Centre or Tertiary Centre for further assessment and treatment



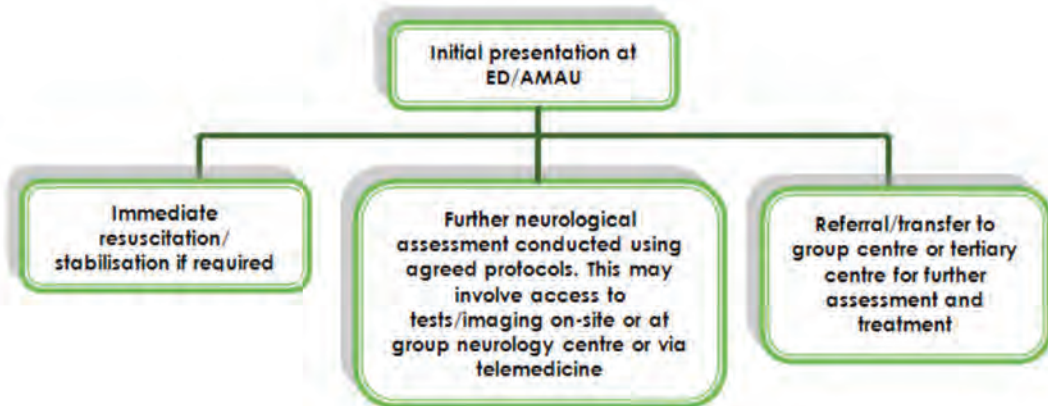


Fig 28; pathway following initial presentation in ED/AMAU<sup>11</sup>

### 1.7.3 When a neurological condition is diagnosed, the person may either<sup>11</sup>:

- Continue to be managed appropriately at local level, either in primary care or in the Acute General Hospital according to agreed protocols.  
Or
- Commence initial treatment at the appropriate Group Neurology Network Centre or Tertiary Centre and have follow up treatment at primary care level or in the local model 2 or 3 hospital.  
Or
- Commence treatment at a Group Neurology Network Centre or the Tertiary Centre, with follow up treatment also provided by this Service  
Or
- Commence treatment at the appropriate Group Neurology Network Centre or Tertiary Centre, with follow up treatment shared between this Service and either Primary Care or the local model 2 or 3 Hospital.

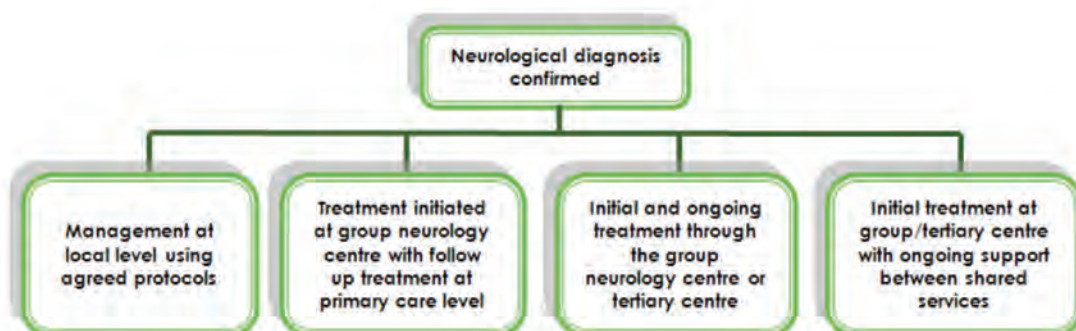


Fig 29; Pathway from confirmation of diagnosis<sup>11</sup>

### 1.7.4 Person referred to Group Neurology Network Centre from either Primary Care or Acute General Hospital (Laffoy 2007)<sup>11</sup>

- Each Group Neurology Network will provide a comprehensive range of general neurology services (both inpatient and out-patient), staffed by a full multidisciplinary team which will include a regional center of expertise.

- Each Group Neurology Network may develop subspecialties, as part of an agreed programme of development in the region and nationally.

#### 1.7.5 Each Group Neurology Network will (Laffoy 2007)<sup>11</sup>:

- Have an appropriate Neurophysiology, Neuroradiology, neuropathology, neuroophthalmology services (i.e. to support both the general and subspecialty work undertaken in the group).
- Develop links (up to and including the provision of outreach clinics and in-patient consults) with named level 2, 3 and 4 Hospitals in the group.
- Develop links and protocols with related specialties e.g. Medicine for the Elderly, Psychiatry, Orthopaedics, Pain Management and Palliative Care etc
- All members of the Group Network will participate in agreed monitoring and audit activities to ensure that service delivery and outcomes are continually improving.
- Each Group Neurology Network will, in partnership with Acute Hospitals and Primary Care services in the region, put in place joint specialist appointments in key disciplines such as clinical nutrition, nursing, neuropsychology, occupational therapy, orthoptics, physiotherapy, psychology, social work and speech and language therapy.
- Each neurology service should be supported by a full MDT.

#### 1.7.6 Person referred to Tertiary Centre from Primary Care, an Acute Hospital or Group Neurology Network (Laffoy 2007)<sup>11</sup>

- Based on agreed protocols, the Tertiary Centers will receive referrals that cannot be appropriately managed at by other hospitals in the Network.
- Tertiary centers have specific specialism within neurology, often in rare or complex conditions.
- Development of tertiary centers should be completed in collaboration with the national steering group which will assist with identifying national service priorities, to ensure equitable access to services for patients while avoiding duplication where appropriate.
- The Tertiary Centers will, with others centers, be part of the National Neurology Steering Group and enable the further development of neurology services in an agreed integrated manner.

# Part F; Appendices

## Appendix 1

### The roles of the Neurology Multidisciplinary team members

#### 1. The Neurologist

Neurologists are principal care providers or consultants to other physicians. When a patient has a neurological disorder that requires frequent care, a neurologist is often the principal care provider. In a consulting role, a neurologist will diagnose and treat a neurological disorder and then advise the primary care physician managing the patient’s overall health.

#### 2.0 Health and Social Care Professionals

The Department of Health identifies a list of 50 professions as Health and Social Care Professions. Health and Social Care Professionals (HSCPs) are highly educated and skilled professionals who make a significant contribution to the health, wellbeing and quality of life of the population. They achieve this by providing a broad range of services and interventions in diagnostic, therapeutic and social care domains across all areas of the health services. HSCPs are a key provider of core services to patients who present with neurological conditions.

In some countries HSCPs are referred to as Allied Health Professional (AHPs) and different combinations are included in these grouping depending on the country. In Ireland, CORU is the organisation responsible for regulating health and social care professionals. Its role is to protect the public by promoting high standards of professional conduct, education, training and competence across twelve health and social care professions.<sup>124</sup>

A subgroup of the HSCPs group is referred to as the ‘Therapy Professions’ and it comprises 6 professions, all of which are represented on the Neurology Clinical Programme by therapy leads. The following table outlines some of the HSCP in Ireland; including the therapy professions: Clinical Nutrition and Dietetics, Occupational Therapy, Orthoptics, Physiotherapy, Podiatry and Speech and Language Therapy which play a key role in delivering neurology services. In addition, many other professions included under the HSCP umbrella provide a valued and key role, whether as specialist in diagnostics or therapeutics, to the management of patients who present with neurological conditions.

DOHC Health & Social Care Professions		
Professions regulated † by CORU		
Therapy Professions		
1. Clinical Nutrition and Dietetics	7. Clinical Biochemists	13. Neurophysiologists
2. Occupational Therapy	8. Medical Scientists	14. Orthotist
3. Orthoptics	9. Medical Social Worker	15. Prosthetist
4. Physiotherapy	10. Psychology	
5. Podiatry	11. Radiography	
6. Speech and Language Therapy	12. Social Care Worker	35 additional professions on DoHC list.

**Table 1: HSCP Professions in Ireland**

† Currently regulated or scheduled to be regulated

Each discipline plays a specific role in the management of the patient throughout the course of their illness. The changing needs of the patient, over the course of their illness, will need to be met by a responsive system allowing and supporting access to relevant therapies as and when needed. As many services are provided through various settings/divisions within the healthcare service (e.g. acute in-patient, specialist multidisciplinary clinics, acute day care unit, in and out-patient rehabilitation and primary care), communication within multidisciplinary teams as well as between services is critical to successful patient management and discharge planning.

### 2.1 HSCP Role in the Continuum of Neurological Care

Therapy Professions work across the continuum of care in various settings. There is a demand for appropriate care to be provided as close to the patient’s home through Primary Care Teams and community rehabilitation teams. In addition specialisation within neurology requires HSCPs to develop specialist skills at hospital and community level.

Active acute rehabilitation, early supported discharge and community rehabilitation schemes enable a higher proportion of patient to return directly home, with reduced length of stay. The following table outlines the continuum of care and where services are provided in the current model of care.

Assessment → Treatment → Prevention → Rehabilitation → Re-ablement → Vocational Rehabilitation → Long Term Gain		
Service Delivery Settings	Roles Specific to Setting	Common Roles
Primary Care Teams	<ul style="list-style-type: none"> <li>Home setting specific assessment and management</li> <li>Monitoring</li> <li>Exercise classes/ group therapy</li> <li>Maintaining function</li> </ul>	<ul style="list-style-type: none"> <li>Working as part of a multidisciplinary team</li> <li>Assessment</li> <li>Goal setting</li> <li>Developing treatment plans</li> <li>Provision of medical devices and orthotics (hospital / community based funding)</li> <li>Communication with family and carers</li> <li>Patient / Family / Carer education</li> <li>Identification of requirement of need to change care setting and communication with relevant stakeholders</li> <li>Liaison with colleagues in other settings</li> <li>Feedback to GP / Consultant / MDT</li> <li>Supporting successful discharge through integrated care between services</li> <li>Supporting independent self-management</li> <li>Facilitating appropriate onward referral</li> </ul>
Acute – Inpatient Services	<ul style="list-style-type: none"> <li>Rapid assessment following admission</li> <li>Specialised rehabilitation during inpatient stay</li> <li>Access to specialised equipment</li> </ul>	
Acute – Outpatient Services	<ul style="list-style-type: none"> <li>Specialist assessment</li> <li>Access to specialist equipment for assessment and rehabilitation</li> <li>Multidisciplinary clinic attendance</li> <li>Support, education and outreach</li> <li>Advanced practice services (e.g. Splinting / Botulinum toxin injections)</li> </ul>	
Community based neurorehabilitation teams	<ul style="list-style-type: none"> <li>As for Primary Care Team with greater degree of specialisation</li> </ul>	
Specialist Rehabilitation Centers	<ul style="list-style-type: none"> <li>Intensive and specialised multidisciplinary rehabilitation</li> </ul>	
Voluntary Support Services (general / condition specific)	<ul style="list-style-type: none"> <li>Assessment of need and provision of available/ appropriate support services</li> </ul>	

Table 2 Continuum of Care and Service Settings



## 2.2 Competency and Grading Structure

Bossers et al (2002:11<sup>125</sup>) describes professional competency as ‘the behavioural definition of the knowledge, skills, values and personal qualities that underlie the adequate performance of professional activities. Competence taken as the overall integration of knowledge, skills and abilities into professional practice is not static but dynamic and demands that therapists ‘keep abreast with change’ in order to maintain and continually develop competencies. (Alsop and Ryan 1996:187<sup>126</sup>).

The Neurology Programme supports the development of competency frameworks for all HSCP’s working with people with neurological illnesses. Any such undertaking would be conducted in collaboration with all relevant stakeholders.

The Neurology Programme supports further development of the undergraduate curriculum ensuring all HSCP’s have the opportunity to participate in modules reflecting neurological conditions and practice placements working with patients with neurological illnesses.

Preferred characteristics of Health & Social Care Professionals working with people with Neurological conditions

- Postgraduate education is desirable. There is currently no nationally agreed specific competencies for HSCP in relation to treatment/management of patients with neurological conditions. Patients with neurological conditions are treated by those at various levels of qualifications and experience within the professional profile including staff/entry grade, senior, clinical specialist and manager. In scenarios where more junior members of the team are providing the service, a formal supervisory or mentoring process by senior/specialist/managers in their own profession should be in place.
- It is desirable for the majority of patients on their caseload to present with neurological conditions.
- Familiar with specific referral criteria to other health care providers.
- Closely collaborating with other health care providers with neurological expertise.
- Receiving continuous, up-to-date education on neurological conditions from national/international experts.

## 2.3 Grading structure

The majority of HSCPs have a common grading structure across all services. Demand and complexity and role within the continuum of care for neurology patients should determine the appropriate grade required.

---

125 Bossers, A et al. (2002) Competency based fieldwork evaluation for occupational therapists. Albany, NY: Delmar, Thomson Learning

126 Alsop A, Ryan S. (1996) Making the most of fieldwork education: a practical approach. London: Chapman & Hall



Grade	Role in Neurology Services
Graduate / Entry Level Clinician	<ul style="list-style-type: none"> <li>● Rotate between clinical areas within a hospital based on service demand, are initially gaining experience from senior staff specializing in that area</li> <li>● Work in dedicated teams in Primary Care in generalist roles covering all caseloads</li> <li>● Have professional specific knowledge and skills which contribute to neurology services.</li> <li>● Provide assessment and treatment in collaboration with other health and social care professionals</li> <li>● Translate research evidence and use it to implement effective interventions;</li> <li>● Prepare and present appropriate information to the senior health and social care professional to support operational and strategic planning.</li> <li>● Provide under graduate training under supervision of Clinical Tutor and/or senior clinician</li> </ul>
Senior Clinician	<ul style="list-style-type: none"> <li>● Dedicated to specific areas e.g. neurology in patients or out patients to manage the caseload, supervise staff (staff grades/assistants) and liaise with service managers and ensure best use of resources within that area.</li> <li>● Deliver services with higher level of clinical competency in neurology</li> <li>● Lead clinical developments in line with evidence based practice.</li> <li>● apply research outcomes to improve the delivery of service</li> <li>● Provide advanced assessments and interventions in complex cases and as part of a multidisciplinary team approach.</li> <li>● Plan and implement individual and group interventions, discharge, follow up and onward referrals.</li> <li>● Provide training and support to staff and occupational therapy / physiotherapy assistant staff.</li> <li>● Provide under graduate training in collaboration with Clinical Tutors</li> </ul>
Clinical Specialist/ Advanced Practitioners	<ul style="list-style-type: none"> <li>● Provide specialist expertise at advanced level. developing standards of practice;</li> <li>● engaging in research,</li> <li>● evaluating outcomes and effectiveness of services;</li> <li>● contributing to strategic planning and delivery of services;</li> <li>● Provide education and training of health and social care professionals, medical and nursing colleagues.</li> <li>● Work at advanced level in triage clinics providing advanced level assessments to support waiting list management.</li> </ul>
Therapy Assistant Occupational Therapy Assistant/Physiotherapy Assistant	<ul style="list-style-type: none"> <li>● The Expert Group on Various Health Professions (2000)<sup>127</sup> report “the introduction of Assistant health and social care professional has the potential to provide the very necessary practical support for health and social care professionals in the delivery of an efficient and effective service”.</li> <li>● Therapy assistants are employed in occupational therapy and physiotherapy to work under the supervision of appropriate staff grade, senior and clinical specialists</li> <li>● Provide assistance in patient handling, supervision of patients undertaking exercises and daily living skills so therapist’s skills can be appropriately used for patients requiring assessment, diagnosis and initial treatments.</li> </ul>

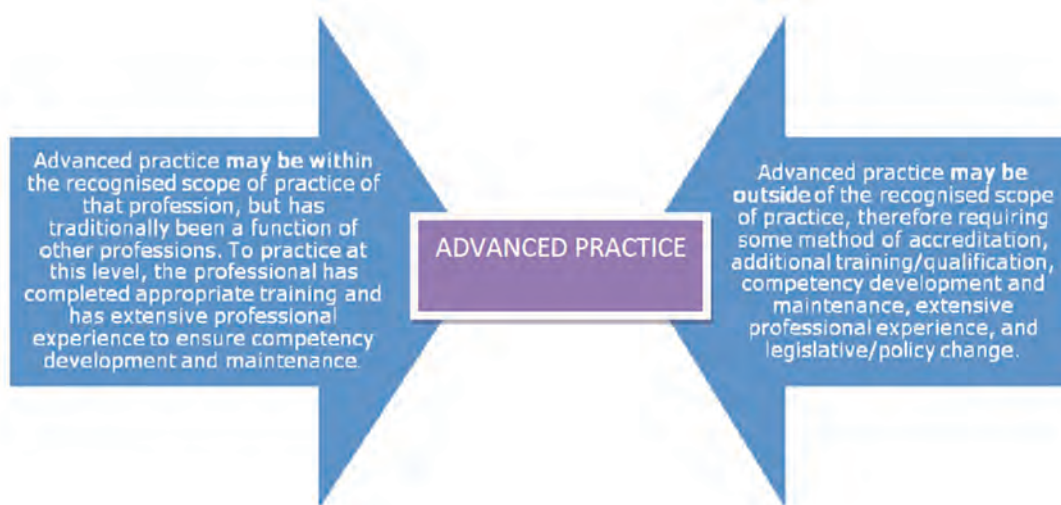
**Table 3; Grading Structures for Health & Social Care Professionals**

127 Report of the Expert Group on Various Health Professions, April 2000. <http://www.hse.ie/eng/staff/Resources/hrstrategiesreports/Report%20of%20the%20expert%20group%20on%20various%20Health%20Professions.pdf>

Neurology centres should be staffed with at least one Clinical Specialist in each discipline whose focus is on management of complex patients, education, research, service development and development of standards of care. The number of HSCPs practicing at clinical specialist level within neurology is relatively low when compared with other specialities.

Currently in Ireland, the role of Advanced Practitioner, as a grade for HSCP's does not exist. In the challenging environment facing health care providers, the development of advanced practice in the HSCPs can bring benefits to the service user and providers in terms of improved access to appropriate healthcare in a timely manner, reduced waiting lists, reducing unnecessary clinical care costs and freeing up other healthcare professionals to focus on the patients, clients and service users who most need their care.

Advanced practice is described as a level of practice rather than a particular role requiring a blend of education and practical expertise, high levels of analysis and critical thinking and the ability to apply in-depth knowledge to clinical decision making. With regard to all HSCPs, advance practice can be defined by considering two aspects, as presented below in Figure 1, and adapted from the Irish Society of Chartered Physiotherapists (ISCP), Scope of Practice (ISCP, 2012<sup>128</sup>)<sup>129</sup>.



**Fig 1 Advanced Practice in Health & Social Care Professions**

## 2.4 Staffing

In order to provide patients with co-ordinated care pathways, delivered by competent HSCP staff, through the continuum of the condition, the current short-fall of HSCP resources with appropriate expertise in neurology must be addressed. Each neurology centre should have access to dedicated multi-disciplinary teams. The national survey carried out by the Neurology Programme has highlighted the fact that very few neurology centres/services have dedicated HSCP for either inpatient or outpatient services. Even those with apparent dedicated staffing exists, those staff report that in reality, due to competing demands and reduced resources across the hospital, the actual hours given to neurology are less than the official whole time equivalent (WTE) assigned.

128 The Irish Society of Chartered Physiotherapists (2012) Scope of Practice. ISCP Dublin

129 Health & Social Care Professions Education & Development Advisory Group. Progressing Advanced Practice in the Health & Social Care Professions, 2014

There are currently no internationally or nationally recognized ratios for HSCP working specifically in neurology. A further challenge is the variance in service delivery sites, i.e. both inpatient acute, acute rehabilitation and ambulatory (outpatient) services. The staffing ratios described in section 12 (requirements) are derived from a review of best practice with respect to acute management of neurological conditions, particularly stroke, inpatient rehabilitation ratios and ambulatory ratios. A national review of HSCP staffing ratios and requirements for neurology services is strongly recommended by the Neurology Programme Working Group.

The HSCP caseload and the number of staff required to provide the service depend on a number of factors which can include the type of patients/case mix; experience of managing a specific condition; and other non-clinical responsibilities such as staff supervision, teaching and research. As described in this model of care, there will be an expectation on specialist HSCP in various settings to provide support and guidance to colleagues. Fulfillment of this role can only be fully achieved if these staff are given dedicated time to deliver this support. This is a particular problem in relation to the recruitment of staff at senior grade who may be appointed to senior positions and not be specialists in the neurology

## 2.5 Recruitment and Retention

To ensure continuity of care, efficient recruitment processes are required. It is also important that these processes facilitate the recruitment and retention of staff with specialist skills and competencies. Delays in recruitment and recruiting from generic panels can be a challenge to the delivery of services.

## 2.6 Managed Clinical Networks

The restructuring of neurology services through proposed managed clinical networks will require health and social care professions to be involved in designing pathways of care between the newly formed Hospital Groups and the Community Health Organisations in each geographical area and between local and tertiary services.

## 2.7 Care Pathways

The delivery of the care pathways as described within this model of care will be dependent on a number of factors. These include;

- Close liaison and integration between hospital and community based service providers including not for profit organisations.
- Financial and budget systems support the delivery of the pathways of care e.g. funding for equipment on discharge and continuation of service should not obstruct the pathway of care and cause delayed discharge or follow up care.
- The need to address the levels of service and competency to ensure access to timely HSCP intervention in line with agreed guidelines and protocols. Staff in both Primary and Secondary care need to work collaboratively to meet the requirement for general and specialist intervention.
- Clearly outlined roles and responsibilities of HSCP across the entire continuum of care from acute assessment at inpatient level to ongoing support and management in the community including specialist outreach services where appropriate.

## 2.8 Education and Training

HSCPs are required to keep their skills up to date and develop skills and competencies as required for service development. Time and resources must therefore be available for

post-qualification education both in-service and external level. In collaboration with all key stakeholders, the Neurology Programme plans to develop a competency framework for all those HSCP working within neurology services. This may be an endorsement or adaptation of existing competency frameworks being utilized across the country. While the framework will include specific competencies in the area or neurology, it will also include more general competencies on;

- Knowledge & skills
- Communication
- Team work

HSCP's working in national Neuroscience centres should provide support and education to those working at regional and local levels where required.

## 2.9 Research

In the document 'Therapy Research – Delivering Best Health A research Strategy for Therapy Professions in Ireland 2008 – 2013'<sup>130</sup> the objectives agreed includes the following

'Objective 6

***The Department of Health and Children, the Health Service executive and the High Education Institutions should work together to develop innovative approaches the creation of clinical, academic and joint academic and clinical research therapy posts. Specific research posts.'***

The Neurology Programme fully supports HSCP engagement in research. As described previously in this model of care, brain research is considered essential, both with respect to development of services & ensuring best practice and for retention of staff through career development opportunities and HSCP's should be supported with dedicated time for research in areas relevant to neurological conditions.

## 2.10 Health & Social Care Professionals (HSCPs) Role

HSCP Role is outlined in summary below for the disciplines listed below. While common indicators for referral and interventions are described, these lists are not exhaustive.

1. Dietitian
2. Medical Social Work
3. Neuropsychology
4. Occupational Therapy
5. Orthoptist
6. Orthotics
7. Pharmacy
8. Physiotherapy
9. Podiatrists
10. Speech and Language Therapy

While the roles of various disciplines are described here in isolation, it is important to note that the interventions described should be provided as per the patient's goals and as one component of a multidisciplinary intervention.

---

130 Department of Health. Therapy Research – Delivering Best Health. A Research Strategy for the Therapy Professions in Ireland 2008-2013

Specialist area	Professionals involved
<p><b>Physical</b></p> <ul style="list-style-type: none"> <li>- Hemiparesis/hemiplegia</li> <li>- Ataxia</li> <li>- Splinting</li> <li>- Muscle weakness</li> <li>- Gait abnormalities</li> <li>- Spasticity/hypertonia</li> <li>- Dystonia</li> <li>- Swallow</li> <li>- Mobility</li> <li>- Balance</li> <li>- Dexterity &amp; coordination problems</li> <li>- Pain management</li> <li>- Dietary management</li> </ul>	<ul style="list-style-type: none"> <li>- Physiotherapy</li> <li>- Occupational Therapy</li> <li>- Speech &amp; Language Therapy</li> <li>- Dietitian</li> <li>- Orthotist</li> <li>- Podiatrist</li> </ul>
<p><b>Cognition</b></p> <ul style="list-style-type: none"> <li>- Standardised cognitive assessment including attention, memory, executive functioning, information processing</li> <li>- Non-standardised cognitive function assessment</li> <li>- Cognitive remediation</li> <li>- Compensatory strategies</li> <li>- Assessment of capacity</li> </ul>	<ul style="list-style-type: none"> <li>- Neuropsychologist</li> <li>- Occupational Therapist</li> </ul>
<p><b>Perception</b></p> <ul style="list-style-type: none"> <li>- Visual perception</li> <li>- Sensory perception</li> </ul>	<ul style="list-style-type: none"> <li>- Occupational Therapist</li> <li>- Orthoptist</li> </ul>
<p><b>Visual</b></p> <ul style="list-style-type: none"> <li>- Investigation and treatment of Diplopia</li> <li>- Assessment and interpretation of visual fields</li> </ul>	<ul style="list-style-type: none"> <li>- Occupational Therapist</li> <li>- Orthoptist</li> </ul>
<p><b>Communication</b></p> <ul style="list-style-type: none"> <li>- Speech</li> <li>- Language</li> <li>- Cognitive linguistic</li> <li>- Assessment for alternative &amp; augmentative communication systems</li> </ul>	<ul style="list-style-type: none"> <li>- Occupational Therapist Speech &amp; Language Therapist</li> </ul>
<p><b>Emotional</b></p> <ul style="list-style-type: none"> <li>- Adjustment</li> <li>- Acceptance</li> <li>- Mood disturbances</li> <li>- Stress management</li> <li>- Depression</li> <li>- Anxiety</li> <li>- Emotional lability</li> </ul>	<ul style="list-style-type: none"> <li>- Neuropsychologist</li> <li>- Medical Social Work</li> <li>- Occupational Therapist</li> <li>- Psychologist</li> <li>- Physiotherapist</li> </ul>



<p><b>Behavioural</b></p> <ul style="list-style-type: none"> <li>- Behavioural management plans</li> <li>- Personal and interpersonal skills</li> <li>- Anger management</li> <li>- Education for patient, family &amp; carer on strategies</li> <li>- Cognitive behavioural therapy</li> </ul>	<ul style="list-style-type: none"> <li>- Medical Social Work</li> <li>- Neuropsychologist</li> <li>- Occupational Therapist</li> </ul>
<p><b>Vocational</b></p> <ul style="list-style-type: none"> <li>- Support returning to work</li> <li>- Vocational exploration</li> <li>- Vocational re-training</li> <li>- Work trials</li> <li>- Vocational assessment</li> <li>- Advocacy</li> </ul>	<ul style="list-style-type: none"> <li>- Occupational Therapist</li> </ul>
<p><b>Social</b></p> <ul style="list-style-type: none"> <li>- information on entitlements</li> <li>- advocacy</li> <li>- family support</li> </ul>	<ul style="list-style-type: none"> <li>- Medical Social Work</li> </ul>
<p><b>Self management</b></p> <ul style="list-style-type: none"> <li>- Advice</li> <li>- Education</li> <li>- Coaching</li> </ul>	<ul style="list-style-type: none"> <li>- Dietitian</li> <li>- Medical Social Work</li> <li>- Neuropsychologist</li> <li>- Occupational Therapist</li> <li>- Orthoptist</li> <li>- Physiotherapist</li> <li>- Speech &amp; Language Therapist</li> </ul>
<p><b>Health Management</b></p> <ul style="list-style-type: none"> <li>- Falls prevention</li> <li>- Medication education</li> <li>- Weight management</li> <li>- Participation in activity/exercise</li> <li>- Secondary prevention</li> </ul>	<ul style="list-style-type: none"> <li>- Dietitian</li> <li>- Occupational Therapy</li> <li>- Pharmacist</li> <li>- Physiotherapist</li> </ul>
<p><b>Environmental Adaptations</b></p> <ul style="list-style-type: none"> <li>- Access</li> <li>- Safety/risk assessment</li> </ul>	<ul style="list-style-type: none"> <li>- Occupational Therapy</li> </ul>
<p><b>Equipment prescription</b></p> <ul style="list-style-type: none"> <li>- Wheelchairs</li> <li>- Mobility aids</li> <li>- Alternative and augmentative communication systems</li> </ul>	<ul style="list-style-type: none"> <li>- Occupational Therapist</li> <li>- Orthotist</li> <li>- Physiotherapist</li> <li>- Speech &amp; Language Therapist</li> </ul>

Table 2; Specialist Roles in Neurology Services

## 2.10.1 Role of the Dietitian

### i) Introduction

Nutritional support is an essential component of care in patients with acute and chronic neurological conditions. A wide spectrum of factors can result in a compromised nutritional status in this patient group. Malnutrition can result in prolonged hospital stays, increased mortality and reduced rehabilitation potential. However, routine nutritional screening can facilitate early identification of those at risk of malnutrition and highlight the need for dietetic intervention both in the community and hospital settings. All dietitians have a scientific and medical background which enables them to give nutritional advice which is specific to the person and the disease. The dietitian is also involved in the decision making process for patients being considered for gastrostomy insertion. In the instances where enteral feeding is indicated, the dietitian is involved with the organisation, planning and follow up for patients receiving home enteral feeding. The dietitian is also key to supporting patients with healthy eating programmes which can then prevent or lessen the burden of potential future co-morbidities. There can frequently be difficulties with referring some patients with neurological conditions to community settings due to lack of capacity for community staff to provide the intensity of support required for this group of patients.

### ii) Indicators for Referral

- Patient is deemed at high risk of malnutrition (using MUST or local screening tool)
- Patient has dysphagia and requires modified consistency diet/thickened fluids
- Additional nutritional co-morbidities present e.g. Coeliac Disease, Chronic Kidney Disease, Diabetes
- Short or long-term enteral feeding is being considered in order to meet full nutrition/ fluid requirements. Parenteral nutrition should be considered if enteral feeding is contraindicated
- Pressure Ulcers
- Ongoing issues with constipation
- For lifestyle modification including: Excess weight gain (BMI >25Kg/m<sup>2</sup>), Hyperlipidaemia
- If ketogenic diet is indicated

### iii) Interventions

- Management of malnutrition

People with neurological conditions can be at increased risk for malnutrition for the following reasons;

- Alterations in resting metabolic rate and increased nitrogen losses. Conditions which may lead to hypermetabolism include Huntington's disease, Gullain Barré Syndrome and Motor Neuron Disease.
- Dysphagia
- Reduced ability to prepare meals/self-feed and fatigue at meal-times
- Gastro-intestinal dysfunction
- Excess weight gain due to reduced mobility

- Other nutritional co-morbidities present which may further restrict intake e.g. Coeliac Disease, Chronic Kidney Disease, Diabetes
  - Medication side-effects
  - Patients opting to follow strict exclusion diets
  - Low mood/depression
  - Incorrect sitting posture and head position during meals
  - Cognitive and/or behavioural issues
- Management of Dysphagia
  - Ketogenic diet
    - The ketogenic diet which is used for the treatment of Epilepsy in childhood has been the focus of renewed interest. There are now an increasing number of these patients transferring to adult services.
    - There is growing evidence that ketogenic dietary therapies can also provide effective seizure control in adults. In addition to this, Ketogenic dietary therapies are increasingly being studied for a variety of other neurological conditions including Parkinson's Disease, Alzheimer's Disease & Amyotrophic Lateral Sclerosis/MND and Narcolepsy
    - Dietitians play a vital role in the education, supervision and treatment of patients on this intensive diet. The dietetic treatment complements and in some case replaces the pharmacological treatment to improve quality of life for some patients.
    - It is crucial that adequate training and resources are made available to ensure that these patients have access to the appropriate dietetic follow up for as long as necessary.

## 2.10.2 Role of Medical Social Work

### i) Introduction

Social workers work to support clients and their families in adjusting to an acquired disability with all the social, practical and emotional implications involved. Social Work focuses on change management and problem solving from a "person within their environment" or systems approach.

The Social Worker engages with patients, families and carers offering practical and counselling supports to assist in the process of coming to terms with an altered future and the transition back to as independent a life as possible.

Using counselling skills to support effective management of a traumatic life event is central to their work. They bring into play as many public, community and voluntary services as possible in order to maximise independence and quality of life.

Social Work Practice is underpinned by training in sociology, social policy and theories of human behaviour. They work within the Irish and European legislative framework of equality and disability, child care and human rights.

## ii) Indicators for referral

Social workers have a particular role in facilitating the process of adjustment for patients, families and carers and in guiding them through what are often unfamiliar and complex social systems. All individuals with the diagnosis of a neurological condition should be considered for referral to medical social work for assessment.

## iii) Interventions

- Specific services offered by Social Work can include:
- Pre-admission planning for complex cases
- Psychosocial assessment of the patient/family situation, resources and goals which supports interdisciplinary team assessments and goal setting
- Counselling services to patients and families, in particular grief and loss and solution focused therapy
- Provision of carer education and training programmes along with other members of the interdisciplinary team
- Extended family/sibling support as appropriate
- Sourcing of and liaison with all possible entitlements and community services such as personal assistants, housing, case management and residential placements
- Post discharge follow up and intervention
- Outreach to schools, community teams and vocational services
- Social Workers in a rehabilitation setting work to support our clients and their families in adjusting to an acquired disability with all the social, practical and emotional implications involved. . Social Work focuses on change management and problem solving from a “person within their environment” or systems approach.

### 2.10.3 Role of the Neuropsychologist

#### i) Introduction

Clinical Neuropsychologists apply an advanced understanding of cognitive and psychological processes to the assessment, diagnosis, treatment and / or rehabilitation of people with neurological, neuropsychiatric, medical or neurodevelopmental conditions. Clinical Neuropsychologists have expertise in the detailed assessment of cognitive functions. This assessment includes areas such as selection of appropriate measures, assessment of cognitive effort and other factors influencing performance. Clinical Neuropsychologists interpret formal assessment data, integrating this with other clinical, premorbid and developmental information, also collateral and observational data, developing detailed formulations of the patient’s situation, which can be meaningfully shared with professional teams, clients and families as appropriate. Clinical Neuropsychologists serve key roles in early diagnosis of cognitive impairment and dementia, aiding in differential diagnosis, guiding prognosis and planning care.

- In the area of neurorehabilitation and in collaboration with multidisciplinary neurorehabilitation teams, Clinical Neuropsychologists coordinate development, delivery and evaluation of appropriate programmes and approaches, supporting optimisation of patients’ rehabilitation potential.
- In the area of Intellectual Disabilities, co-morbid neurological presentations are common. Clinical Neuropsychologists’ assessment can provide diagnosis and

recommendations for appropriate management. Psychological therapies tailored to the individual's needs as necessary.

- Clinical Neuropsychologists often contribute to elective neurosurgical programmes (such as epilepsy surgery and deep brain stimulation for treatment for Parkinson's disease) performing key functions in selecting appropriate candidates for treatment, in evaluating outcome and in supporting adjustment following intervention.
- Clinical Neuropsychologists are uniquely skilled to make objective assessment of the decision making abilities of patients, key when treatment decisions are to be made and decision making capacity is in question.
- The number of Clinical Neuropsychologists in Ireland falls well below international guidelines, which recommend that Clinical Neuropsychologists should be linked with all neurology / neurosurgery services, representing a core neuroscience discipline in acute, community and rehabilitation teams

## ii) Indicators for referral

Any person with a neurological condition with associated cognitive sequelae should be considered for referral to clinical neuropsychology for full assessment and development of a treatment plan.

Those with comorbid difficulties including intellectual disability will require a full cognitive assessment with a clinical neuropsychologist.

## iii) Interventions

Clinical Neuropsychologists have advanced skills in psychological formulation and therapy.

- Therapy can support patients' adaptation to neurological illness and self-management, addressing issues of symptom management and motivation, also promoting engagement with other treatments. Clinical Psychologists' and Neuropsychologists' skill-sets may be applied in developing and evaluating group-based self-management and patient empowerment programmes.
- Clinical Neuropsychologists have expertise in assessment and treatment of people with functional neurological symptoms. These interventions can have marked impacts in reducing health-care utilization and improving quality of life among this group whose care can otherwise prove both costly and unsatisfactory.
- Among clients exhibiting challenging behaviours secondary to neurological injury or illness, following appropriate assessment, Clinical Neuropsychologists design and implement interventions to help the individual and their supporters mitigate the challenges presented.



## 2.10.4 Role of the Occupational Therapist

### i) Introduction

Occupational therapists aim to enable people to participate in activities of daily living (WFOT, 2012<sup>131</sup>). They are skilled in assessment of clients functioning ability and they carry out activity analysis in the areas of self-care, productivity and leisure in order to understand the impact of an illness on an individual and their particular lifestyle.

Occupational Therapists understand the intricate relationship between the person, their environment and their specific occupations and are unique in their role to enable people to maximise their participation in daily life, regardless of the stage of their condition.

Occupational therapy aligns with the core concepts of the International Classification of Functioning, Disability and Health (ICF) framework as it establishes the level of impairment, the degree of participation restrictions which may be present and the environmental factors, all of which interact to influence the functional performance of the individual.

Occupational therapists are instrumental in providing interventions to enable function, maximise independence and maintain participation throughout the course of a neurological condition as it progresses.

Occupational therapists should be involved from diagnosis and should incorporate educating the patient on the role of the occupational therapist in current and future management of their condition (NAI, 2000<sup>132</sup>).

Patients should have access to an Occupational Therapist with specialist knowledge of neurological conditions.

Occupational therapy services for neurology patients should be available in in-patient settings e.g. acute hospital setting, rehabilitation settings, out-patient settings e.g. out-patient clinics and at primary care level e.g. within the home, community based clinics. The type of intervention may be determined by the setting in which the person is being supported.

The role of the acute hospital Occupational Therapist also encompasses assessment of need for further rehabilitation, whether in-patient or out-patient and onward referral to follow-up services e.g. out-patient or primary care. Referrals may also be deemed appropriate for follow-up voluntary services e.g. assistive technology specialist needs, driving assessment. There are many overlaps between stroke and other long term neurological conditions and Early Supported Discharge teams have been successful in reducing the length of stay in stroke patients (Fearon et al, 2012<sup>133</sup>). Occupational therapy treatment in early supported discharge continues the inpatient rehabilitation

131 World Federation of Occupational Therapy (2012), <http://www.wfot.org/AboutUs/AboutOccupationalTherapy/DefinitionofOccupationalTherapy.aspx> [accessed 28.10.14]

132 Neurological Alliance of Ireland, 2000. Standards of Care for people with disabling (progressive and static) neurological conditions in the hospital and community.

133 Fearon P, Langhorne P, Early Supported Discharge Trialists. Services for reducing duration of hospital care for acute stroke patients. Cochrane Database of Systematic Reviews 2012, Issue 9. Art. No.: CD000443. DOI: 10.1002/14651858.CD000443.pub3.

in the persons own environment. Such programmes could prove equally successful if expanded to include other neurological conditions.

In the community setting Occupational Therapists carry out assessments of the patients function in their own home and community. They have a major role to play from the minimal impairment phase through to end of life care (NAI, 2000). Occupational therapists are skilled in cognitive assessment and rehabilitation, seating, positioning and pressure care, upper limb management, moving and handling risk assessment and training. As part of occupational therapy intervention, assistive equipment and technology are prescribed to maximize occupational performance of daily activities. Occupational therapists advise on and compile reports for home modifications and adaptations to facilitate independence.

Occupational therapy rehabilitation is aimed at reducing the impact of disease and maximising the persons' level of participation in all aspects of their lives. At this stage there is emphasis on the person's activity and participation levels and abilities, working with patients to maximise their functional independence to a level where home discharge is feasible. During the rehabilitation process, meaningful goals are set with the individual and an intervention programme designed to meet the person's need.

The Occupational Therapist plays a significant role in vocational assessment and rehabilitation. A specialist vocational assessment is conducted by the occupational therapist to determine the patient's ability to continue working, to return to their job or to alternate work. Utilising their knowledge of surgical and medical interventions and the disease process, the occupational therapist compares the patient's health status, body functions and structures to the demands of a job and a work environment.

Following a comprehensive assessment the occupational therapist focuses on rehabilitating the patient through a process known as vocational rehabilitation or work hardening where the focus is on overcoming the barriers when accessing, remaining or returning to work following illness, injury or impairment. The occupational therapy practitioner simulates the individual's regular work tasks and routine in preparation for their return to work.

Given the close connection between the core principles of occupational therapy and work conditioning or work hardening it is inevitable that occupational therapy is well established in vocational rehabilitation

## ii) Indicators for referral

An occupational therapy assessment is an assessment of a person's functional ability. Any person whose independence is potentially impacted by their neurological condition should be considered for referral to occupational therapy.

An occupational therapy assessment of the patients function takes place and should include screening of components which affect functional performance in many long term neurological conditions. Examples of such components are physical (e.g. tone, sensation, range, power, coordination), cognitive (e.g. attention, memory, executive functioning), perceptual (e.g. vision, inattention, apraxia, agnosia, body scheme) and psychosocial (e.g. mood, behaviour, anxiety).

Functional assessment is an essential part of the occupational therapy process and is inclusive of Personal Activity of Daily Living assessment, Domestic Activity of Daily living assessment e.g. kitchen assessment, home environmental assessment, community based access and Vocational assessment e.g. driving, ergonomics etc.

### iii) Interventions

Occupational therapy treatment interventions within the neurology population may consist of:

- ▲ Environmental assessment e.g. home assessments
- ▲ Housing adaptations assessment and recommendations
- ▲ Seating and positioning e.g. seating assessment, positioning in bed, specialized seating, maintaining optimum postures for function
- ▲ Pressure relief e.g. seating, pressure care equipment.
- ▲ Formal and informal cognitive assessment
- ▲ Perceptual assessment
- ▲ Patient Education e.g. energy conservation, fatigue management.
- ▲ Upper limb treatment e.g. rehabilitation, use of modalities such as splinting
- ▲ Functional transfers e.g. manual handling, education re: safe techniques
- ▲ Compensatory approaches e.g. use of assistive equipment to maintain participation
- ▲ Motorised mobility
- ▲ Specialised treatments such as Neurodevelopmental Treatment (NDT) and Lee Silverman Voice Treatment (LSVT) BIG are used to treat physical elements and are used by Occupational Therapists with specialist training

## 2.10.5 Role of Orthoptist

### i) Introduction

The orthoptist has a crucial role within the multidisciplinary team for patients with neurological visual defects. Orthoptists are experts in diagnosis and management of disorders of ocular motility, binocular vision and visual field defects.

An orthoptic assessment can provide the patient, the medical team and carers with a clear explanation of the visual defects that have arisen and this often aids rehabilitation (Freeman 2003<sup>134</sup>). Assessment and management of patients can be delivered in a variety of settings: on the ward, in acute care or in outpatient clinics for rehabilitation. Best practice states that assessment and management of a patient should be performed as soon as possible. However, access to orthoptic services is not consistent throughout the country with several hospitals not having an orthoptic department. This will obviously impact on patient care, possibly having to travel to a different hospital to receive treatment.

### ii) Indicators for referral

Any person with a neurological condition who has associated visual defects should be referred. Eye movement disorders and visual field defects can impact on the effectiveness of rehabilitation therapy in regaining mobility and activities of daily living (SIGN stroke

---

134 Freeman CF. Collaborative working on a stroke-rehabilitation ward. Parallel Vision (British and Irish Orthoptic Society). 2003

guideline 2010<sup>135</sup>). Orthoptic assessment will help to address this.

### iii) Interventions

- ▲ Orthoptic interventions of patients with neurological visual defects can include:
- ▲ Investigation and treatment of diplopia using:
  - ▲ Prisms
  - ▲ Eye exercises
  - ▲ Occlusion (total or sector)
  - ▲ Assessment of visual field defects
  - ▲ Advice on compensatory strategies for the patient eg. Typoscope to aid reading.
  - ▲ Peli prisms to enhance visual field.
- ▲ Communicating to multidisciplinary team the type of field defect and how best to assess the patient
- ▲ Binocular driving visual field investigation to ensure the patient meets the RSA (Road Safety Authority) driving standards.

## 2.10.6 Role of Orthotist

### i) Introduction

The orthotist is a member of the multidisciplinary team. They measure, design, fabricate and fit orthoses. The orthotist works closely with the physiotherapist and occupational therapist to determine how best to maximise functional mobility.

### ii) Indicators for referral

Commonly treated conditions in patients presenting with neurological conditions include;

- Loss of protective sensation
- Impaired proprioception
- Changes in tone
- Limb paralysis (flaccid and spastic)
- Any of these may be associated with fixed soft tissue or bony deformity.
- From a prosthetic/orthotic perspective, it is of utmost importance to determine if the body segment encompassed by a device has at least “protective” sensation that is the ability to feel excessive pressures that will eventually lead to skin destruction (Bowker 1993)<sup>136</sup>.

### iii) Interventions

The measurement, design, fabrication and fitting of orthoses for patients.

## 2.10.7 The role of the pharmacist

### i) Introduction

Pharmacists aim to maximise the therapeutic effects of drugs to individual patients while minimising associated risks and respecting patient choice. The role of the pharmacist

135 Scottish Intercollegiate Guidelines Network (SIGN). Guidance 118. 2010

136 Bowker, J H. Neurological Aspects of Prosthetic/Orthotic Practice. Journal of Prosthetics & Orthotics. 1993. Vol 5, Num2 p 52-54

is essential throughout all stages of the patients care, with hospital pharmacist involvement in the acute setting through to the community pharmacist in the primary care setting. Many drug related queries relating to the neurological therapies can be answered by pharmacists, e.g. interactions, adverse effects, dosage and administration, dose adjustment of phenytoin levels for patients with low albumin levels

## ii) Indicators for referral

All patients admitted to an acute hospital will be referred to the care of the hospital pharmacy. Particular support may be indicated for patients in the following circumstances;

In patients with swallowing difficulties and/or patients with feeding tubes, pharmacists advise on appropriate administration of the patients required therapies. Management of drug administration may require one or more of the following;

- Modification of the recommended administration, e.g. open a capsule and disperse contents in water
- A change in product formulation, e.g. capsule changed to liquid
- Change in route, e.g. oral to transdermal patch
- Change in choice of agent
- Interaction with enteral feeds and feed break requirements, as applicable

The pharmacist also plays a key role in providing education and support to members of the MDT. This is done both formally and informally as outlined below;

- The major Irish teaching hospitals have Medicines Information Services staffed by pharmacists. These services provide support to neurology services through enquiry answering and providing support and advice to clinical nurse specialists and the Neurology team. Hospital medicines information services are strongly involved in in-house protocol and policy development to ensure drug treatment procedures are safe and standardised within the hospital.
- The National Medicines Information Service, also staffed by pharmacists, answers enquiries arising in the primary care setting. Other examples of local application of such services would be the Medicines Information Service provided by Our Ladies Hospice in Harold's Cross, where staff are given information of medications for patients with palliative care needs.
- Pharmacists also aim to minimise drug safety risks in drug prescribing, administration and supply processes. This is facilitated through medication incident reporting programmes that are in place in community and hospital pharmacies. Analysis of reported incidents and detection of error patterns ensure latent failures in the medication-use system can be identified and ultimately corrected.
- The Irish Medication Safety Network places a clear legal responsibility on pharmacists to clinically review a prescription before they dispense a medicine to ensure it is safe and appropriate for the patient, and to counsel the patient on the correct use and storage of the medicines
- The pharmacist shall ensure that the patient has sufficient information and advice for the proper use and storage of the prescribed medicinal product and shall offer to discuss with the patient, or with the carer of such a patient, all such matters as the pharmacist, in the exercise of his or her professional judgement, deems significant.



### iii) Interventions

For neurology patients, pharmacists have an input in a number of aspects of care;

#### Clinical Review

Pharmacists assess prescriptions for neurology patients to ensure;

- the drugs are being used safely, rationally and cost-effectively
- there are no contra-indications to therapy, i.e. allergies, or significant interactions
- Duplication of pharmacologically similar or identical drugs is avoided
- There are no omissions from drug therapy
- Prescriptions comply with legal requirements
- Resolution of complex medication issues

Potential problems are communicated to the prescriber, preferably before the medicine is dispensed, with advice relating to alternatives offered if appropriate.

The pharmacist is also in an ideal position to counsel patients on appropriate use of their medications, both in the hospital and community setting, with patients commonly counselled on administration, storage, adverse effects and interaction related issues.

#### Supply

One of the primary roles of the pharmacist in the care of the neurology patient is supply of medicines. Pharmacists ensure that medicines are supplied promptly, safely and cost-effectively to all neurology patients. Pharmacists are involved in;

- Ensuring patients have up to date prescriptions for required medications.
- Ensuring the patients medications are available for use by the patients. This can sometimes involve sourcing medicines from other countries.
- Facilitating reimbursement of medicines through community drug reimbursement schemes.
- Ensuring medicines are appropriately stored, e.g. refrigerated goods.
- Business case proposals for high cost therapies in the hospital setting.
- Aseptic compounding of cytotoxic therapies used for selected neurology patients, e.g. mitoxanthrone
- When required, community pharmacists facilitate supply of medicines in user friendly formats, e.g. dosette boxes and blister packs, to facilitate patients with high tablet burdens, compliance issues or if patients have difficulty with the medication dosing regimens.

When patients are initiated on new, complex agents in the secondary care setting, hospital and community pharmacist liaison ensure continuity of supply for patients.

## 2.10.8 The role of the physiotherapist

### i) Introduction

The physiotherapist plays a key role in the management of people with neurological conditions from the time of diagnosis, through ongoing rehabilitation and where appropriate in end of life care. The physiotherapist role is to promote health through exercise, maximize mobility and function, facilitate symptom management and in addition provide emotional and psychological support to promote health and

wellbeing. A physiotherapist with knowledge of neurological conditions is the most appropriate health care professional to advise on physical activity for people with long-term neurological conditions, and the most appropriate setting for this to be achieved, taking into account, stage of the condition. They have the knowledge and skills to advise on the most appropriate type of exercise and setting for exercise, depending on the condition and what stage it is at.

Ongoing continuous professional development in such areas is expected, with postgraduate qualification desirable.

## ii) Indicators for referral

Referral to Physiotherapy with expertise in the management of neurological conditions should be made:

- at time of diagnosis with an emphasis on promoting exercise and healthy lifestyle,
- during an inpatient admission where issues such as, but not limited to, mobility, physical function, pain, dizziness or respiratory compromise are evident
- where deterioration in function is identified by the person or member of the MDT.
- If there is a risk of falls
- where medications influencing physical functioning are introduced or altered

## iii) Interventions

The detailed objective physical assessment provided by the physiotherapist contributes to diagnosis and decision making in the medical management of people with neurological conditions. This detailed assessment is essential to identify which areas to target the physiotherapy intervention to and which goals to set with the client.

Interventions may include but are not limited to the following:

- clinical gait analysis and management of complex gait abnormalities,
- rehabilitation including
  - strengthening,
  - cardiovascular,
  - stretching and
  - balance exercise,
- spasticity and dystonia management,
- Functional electrical stimulation
- management of respiratory symptoms, particularly of neuromuscular respiratory conditions,
- recognising and managing functional movement disorders and
- recognising and managing difficulties such as pain of neurogenic or musculoskeletal origin.
- teaching skills of Self-management support
- falls prevention and advice

In addition to these core interventions, Physiotherapists with appropriate training may work in advanced practice roles such as:

- Botulinum Toxin injection therapy for spasticity management,
- rehabilitation caseload management

- First contact practitioners for patients presenting with difficulties such as vestibular dysfunction and headache.

### 2.10.9 Role of the podiatrist

#### i) Introduction

A Podiatrist is an allied health care professional who specialises in the study, prevention, assessment, diagnosis and comprehensive management of diseases, injuries and disorders affecting the lower extremities with the feet and ankle as the primary foci.

#### ii) Indicators for referral

The Podiatric management may be may be curative, preventative or require long term palliation or health education in high risk patients groups such as those with neurological disorders (Shenton 2009)<sup>137</sup>;

#### iii) Interventions

Role of podiatrist – neurological disorders;

- completion of a comprehensive and holistic neurological and vascular assessment of the lower limb
- Biomechanical assessment for orthotic therapy and footwear
- Regular monitoring appointments and emergency contact provided
- Primary Prevention of ulceration caused by pressure in the neurologically compromised limb
- liaison and collaboration with members of the Multidisciplinary team
- Management of painful lesions and wounds associated with foot deformity and increased pressure.
- Promote foot health education at each episode of care

### 2.10.10 Role of Speech and Language Therapy

#### i) Introduction

The speech and language therapist (SLT) plays a key role within the treating team in the management of patients with neurological conditions. . SLT's are involved in the assessment, diagnosis and management of speech, language, voice and swallowing problems in people with neurological conditions.

As with other disciplines, SLT may be appropriate at many stages along the continuum of care, including end of life. Care can begin in the acute setting and continues through to community and primary care settings. The SLT in the acute setting works as part of the diagnostic team to aid medical assessment and diagnosis including interdisciplinary assessment. Appropriate identification and management of dysphagia by SLT's can reduce complications, length of hospital stay, morbidity and mortality and improve quality of life (RCSLT 2014)<sup>138</sup> In terms of quality of life, the ability of the SLT to develop an adequate communication system has been shown to have a direct impact on improved quality of life (Bush & Scott 2009)<sup>139</sup>. The SLT also plays a role in educating

137 Shenton PA, Baird S, Ashcroft D, (2009) Common Platform for European Podiatry Practice

138 Royal College of Speech and Language Therapists (RCSLT) 2014

139 Bush, M. & Scott, R. 2009. No Voice, No Choice. London: Scope. www.scope.org.uk

the MDT members on identification, monitoring and management of patients with communication and/or swallowing problems (RCSLT 2009)<sup>140</sup>.

## ii) Indicators for referral

Patients who present with Dysphagia and/or communication impairment should be referred for SLT assessment at time of initial diagnosis and for management throughout disease progression, including end of life, as appropriate. The SLT will complete a full assessment of communication and/or eating, drinking and swallowing abilities and complete objective instrumental assessment as appropriate

## iii) Interventions

- Evidence based Therapy to facilitate rehabilitation and/or enable maintenance of communication, eating, drinking and swallowing.
- Prescription of AAC and application to Community agencies for provision of same
- Facilitating patients participation in goal setting with all Team members by maximising communication
- Educating carers and staff in strategies that can support the patient and for making appropriate environmental modifications (e.g. altering diet consistencies or providing information in an aphasia-friendly format)
- Participation in education re the illness and development of a care plan to enable advance decision making where appropriate
- Participation in education programmes for staff, patients and carers on Dysphagia and communication disability in long term neurological illness
- Referring onto and providing mentoring support to Community services
- Management of Dysphagia and communication in the palliative stage of illness

## 3.0 Nursing

The enhancement of nursing roles in neurology facilitates the provision of a timely quality service to the patient promoting and facilitating optimum levels of independence.

### 3.1 Advanced Nurse Practitioner (ANP)

The Advanced Nurse Practitioner (ANP) in neurology is an experienced and expert practitioner in this area of practice who is accountable and responsible for an agreed caseload of patients. The advanced nurse practitioner is educated to a master's degree level which includes a major clinical component relevant to neurology. The role of the advanced nurse practitioner may vary depending on the identified service need but should reflect competencies and skills guided by the framework set out by An Bord Altranais. The core components of the advanced nurse practitioner role include autonomy in clinical practice, expert practice, professional and clinical leadership and research. In addition the advanced nurse practitioner role includes practice that enhance patient journey and flow such as nurse prescribing of medicinal products and nurse led discharge.

The advanced nurse practitioner is clinically accountable to the patients named neurologist. They are professionally accountable to the director of nursing in the hospital/service they work within. They will be responsible for the local delivery of high quality care in the hospital and the community. They are also responsible for the safe, efficient and effective management of patient care. The advanced nurse practitioner provides clinical leadership, clinical supervision and support to clinical nurse specialist (CNS), staff nurses and members of the multi-disciplinary team.

### 3.2 Clinical Nurse Specialist (CNS)

The role of the clinical nurse specialist in neurology is to provide for the care and ongoing management of patients within agreed clinical practice guidelines. Clinical nurse specialist roles in neurology can include a range of specialist services to support particular conditions such as Headache, Multiple Sclerosis, and Parkinson's disease. The purpose of the clinical nurse specialist post is to improve and enhance the care of patients and their families by developing services in relation to neurology and to assist overall in optimising quality and continuity of care.

The post holder is required to work as a key member of the multi-disciplinary team in the hospital/service providing physical, psychological and emotional support to neurology patients and their families. They act as a liaison between community services, primary care teams and other agencies. The clinical nurse specialist has extensive knowledge of neurology and holds a relevant post registration qualification care level 8. Core competencies for clinical nurse specialist include clinical focus, patient advocate, education and training, audit and research and consultancy.

### 3.3 Clinical Nurse Manager (CNM)

The Clinical Nurse Manager (CNM) in neurology provides leadership and nursing services to patients at ward level and works with the neurologist and MDT to plan care to meet individual patient needs. The CNM plays a pivotal role in co-ordination and management of activity and resources within the clinical area. The CNM is accountable to the Director of Nursing and core CNM competencies include leadership, change management, staff management and professional development, standards and quality and resource use budgeting and analysis. The CNM should have a relevant nursing management course and also have extensive knowledge of neurology and hold a relevant post registration qualification in care level 8.

### 3.4 Staff Nurse

Staff nurses are integral members of the multi-disciplinary team providing significant clinical care for individuals and their families in a wide range of settings. They provide comprehensive patient assessment to develop, implement and evaluate an integrated plan of care and provide evidence based nursing interventions with specific focus on neurology. The staff nurse engages in monitoring and evaluating the patient's response to interventions and treatment.

#### **Case Management and Key-worker supports**

##### **Key worker role**

The key worker should promote an environment where the patient feels able to discuss and areas of concern/issues and be confident that action will take place as necessary.



The key worker should support diversity and ensure that any needs/preferences are highlighted and care planned around same. While interaction and communication with treating MDT is encouraged, the key worker role is there to further support this communication, including communication between the family (or chosen advocate) and the treating team. A key worker system should not preclude clinical staff from communicating directly with families, carers, external agencies/professions.

### **Case Management**

The model of care for the neurology programme emphasises a seamless transition between different care settings and effective management of the needs of the service user along the service continuum. It is unlikely that one agency will be in a position to offer all the inputs required by an individual and thus interagency co-operation is an essential element of effective rehabilitation provision. For this to happen in practice, it is important that overall responsibility for monitoring and responding to the needs of the service user be assigned to one individual preferably working in a community setting and with a level of training and expertise to enable them to link with a range of health and wider support services. It is in this context that case management has emerged as a strategy in the rehabilitation process.

In this context the role of the case manager can be described as the person who engages with the person served, at whatever stage of their illness they are at, and assists the person in coordinating appropriate environmental interventions and supports in an attempt to improve activity levels or minimise participation restrictions.

The active implementation of the proposed model of care will require further consultation to define and elaborate this role in the context of the delivery of neurological services and supports across the continuum of care.

## Appendix 2 – Headache Pathway

Despite the widespread and incapacitating nature of headache, it can be underestimated in scope and scale. The Scottish Intercollegiate Guidelines Network (SIGN) Guidelines<sup>141</sup> “Diagnosis and management of headache in adults, Nov 2008)” reports that headache has a lifetime prevalence of over 90% of the general population in the United Kingdom. Most of these are non-debilitating episodic tension headaches which do not require access to specialist healthcare. It cites migraine as the most common severe form of primary headache. Up to 17% of the population are thought to have migraine, which amounts to half a million Irish people having this condition.

Headache is the most common cause for referral to a neurology outpatient clinic accounting for 25% of all referrals (Patteson & Esmonde 1993)<sup>142</sup>. It accounts for more than 50% of the disability burden attributed to all neurological disease (Vos et al 2012)<sup>143</sup> and costs €290 million per annum to the Irish Exchequer (Linde et al 2012)<sup>144</sup>.

Primary headache can be defined as a pain felt in the head from a source in the head. Common primary headaches include;

- Tension type headache
- Migraine with or without aura
- Chronic daily headache
- Cluster headache

According to the most recent major World Health Organisation (WHO) global disease burden study published in the Lancet in Dec 2012 migraine is now the 7th most disabling disease overall and 4th amongst women (Vos 2012)<sup>145</sup>. Tension type headaches affects over 40% of the population at any one time. Although less of a burden to the individual sufferer than migraine, its higher prevalence results in a greater societal burden.

Management of headache and migraine can be improved by adopting a multi-disciplinary, coordinated team approach. MDT headache care has been shown to improve headache outcomes leading to fewer hospital appointments (Gaul et al 2011)<sup>146</sup>, increased throughput (Jenson 2013)<sup>147</sup> and reduced outpatient costs by 31.5%<sup>148</sup>.

---

141 Scottish Intercollegiate Guidelines Network, Diagnosis and Management of Headache in Adults

142 Patteson and Esmonde 1993. Comparison of the handling of neurological outpatient referrals by general physicians and a neurologist. *Journal of neurology, neurosurgery, and psychiatry*. 1993; 56(7): 830

143 Vos T, Flaxman AD, Naghavi M, Lozano R, Michaud C, Ezzati M. et al. Years lived with disability (YLD) for 1160 sequelae of 289 diseases and injuries 1990–2010: a systematic analysis for the Global Burden of Disease Study 2010. *Lancet*. 2012, 380(9859): 2163-2196

144 Linde M, Gustavsson A, Stovner LJ, Steiner TJ, Barré J, Katsarava Z. et al. The cost of headache disorders in Europe: the Eurolight project. *Eur J Neurol*. 2012; 19(5): 703-711

145 Vos et al. ' years lived with disability (YLDs) for 1160 sequelae of 289 diseases and injuries 1990-2010: a systematic analysis for the Global Burden of Disease Study 2010. *The Lancet*, Vol 380, Issue 9859, p 2163-2196, Dec 2012.

146 Gaul C, Visscher C, Bhole R, Sorbi M, Galli F, Rasmussen A and Jensen R. Team players against headache: multidisciplinary treatment of primary headache and medication overuse. *J Headache Pain* 2011, 12 (5): 511-519

147 Jenson R. Director of Danish Headache Centre and President of European Headache Federation. Conference Proceedings at Health Professional Conference, Dublin May 13

148 Kiel Headache and Pain Centre: <http://www.schmerzlinik.de/information-in-english/>

### Initial presentation to community pharmacy

Patients with headache are generally seen initially by the community pharmacist. Pharmacists in the community have an important initial role in identifying chronic headache sufferers in the general population. They have the potential to inform, support and generally improve outcomes for anyone with chronic headache, particularly when it is associated with medication overuse.

Other types of headache commonly seen in community pharmacy are episodic tension type headache and migraine.

### Red flags for Pharmacists to indicate referral to GP

It is important that anyone presenting to a pharmacist with signs or symptoms indicating a more sinister headache are not missed. Although relatively rare, headaches can sometimes occur as secondary symptoms of serious underlying conditions. Pharmacists should all be familiar with the following criteria and refer the customer immediately for further investigation should any of these apply;

- Aged <5 or >50 years
- Recent onset headache (< 6 months)
- Unusual or worsening headache symptoms or a recent change in pattern
- Particularly severe or disabling headache
- Headaches associated with other symptoms e.g.
  - Rash
  - Weakness on one side of the body
  - Double or suddenly impaired vision
  - Clumsy/uncoordinated movements
  - Tinnitus
  - Reduced level of consciousness
  - Fits/convulsions
  - Recent accident or head injury
  - Obvious infection
  - Known high blood pressure.

### Initial presentation to a Doctor

Patients with headaches are generally referred initially to doctors in primary or secondary care who may not have a special interest in headache. The NICE headache pathway<sup>149</sup> outlines what is considered best practise for the management of patients with headache once the diagnosis of headache has been confirmed. It is focused primarily on management of headache within the primary care setting.

---

149 National Institute for Health and Care Excellence (NICE) Headaches; Diagnosis and management of headaches in young people and adults [CG150]

## Approach to History - Key to Diagnosis - Top Questions

<ul style="list-style-type: none"> <li>- Past and recent history (travel sickness, sinusitis, recurrent abdominal pain, infection etc)</li> <li>- Medication history (analgesics - frequency, preventative duration &amp; doses)</li> <li>- Frequency &amp; duration of headache (days per month)</li> <li>- Days of mild/moderate or severe headache</li> <li>- Strictly unilateral or bilateral</li> <li>- Aura (present or absent) (visual or sensory)</li> <li>- Worsening/aggravation with head movement</li> <li>- Is headache positional?</li> <li>- Any personal changes?-</li> </ul>	<ul style="list-style-type: none"> <li>- What does patient want to do when they have the headache?</li> <li>- Photophobia, phonophobia, osmophobia, nausea or vomiting</li> <li>- Eyes (conjunctival injection, tearing, ptosis) &amp; vision</li> <li>- Face &amp; limbs (numbness, tingling, weakness etc)</li> <li>- Cognition &amp; speech</li> <li>- Ears (fullness, ringing etc) &amp; nasal congestion or rhinorrhoea)</li> <li>- Neck (stiffness &amp; pain) &amp; unsteadiness ('like on a boat')</li> <li>- Family History</li> </ul>
---	---

**Table 1; Approach to History with the patient with headache**

### Red flags for referral to Neurologist

Referral for further investigations or to a neurologist in cases where the patient presents with the following features;

- A) Worsening headache with fever
- B) Sudden onset headache reaching maximum intensity within 5 minutes
- C) New onset neurological deficit
- D) New onset cognitive dysfunction
- E) Change in personality
- F) Impaired level of consciousness
- G) Recent head trauma
- H) Headache triggered by cough, valsalva or sneeze
- I) Headache triggered by exercise
- J) Orthostatic headache
- K) Symptoms suggestive of giant cell arteritis
- L) Symptoms and signs of acute narrow-angle glaucoma
- M) A substantial change in the characteristics of their headache

### Lifestyle Factors

The initial approach is to look at possible lifestyle factors which may impact on headache. The most common factors include;

- Dietary factors including hydration
- Stress management
- Exercise (moderate)

## Patient's Perspective

Following public consultation with those suffering from headache and migraine, supported by the Migraine Association of Ireland, the following appeared to be recurrent themes with respect to challenges facing those living with headache;

- Lack of neurologists and specialist nursing staff familiar with migraine and headache issues
- Migraine not being treated as a serious issue by health professionals- not seen as a priority as not life threatening despite its prevalence.
- Lack of investment in headache issues i.e. research, access to more innovative treatments such as Botox, high costs incurred on headache sufferers with repeated GP visits and costly medications.
- Limited access to multidisciplinary teams with specialist training/interest in headache
- Excessive waiting times for access to rule out sinister causes and reassure patients
- Lack of education/information on headache for both service users but also clinicians in both hospital and community
- Lack of coordination/integration between hospital based and primary care services
- An emphasis on medications without full consideration of alternative options including self management, pain management etc. For those on prescription medication, there is a lack of support from service providers re: responsiveness to the medication, compliance issues, management of side effects etc.
- Lack of focus on health promotion i.e. Better understanding of this disability/ condition in the workplace, school, GP's surgery, other doctors, neurologist not specialised in migraine and the government, social services etc
- Lack of support regarding applying for Disability Allowance/Medical cards. Medical cards should be given to headache sufferers if condition is chronic and debilitating.

The challenges identified by service users echo the challenges facing all those with neurological conditions nationally as outlined throughout this model of care and previously in the Laffoy review (2007<sup>11</sup>).

The key recommendations of the neurology programme are;

- Optimising service delivery and MDT care
- Staffing & Resources
- Service configuration and Managed clinical networks
- Links to other services
- Medicines management/access to diagnostics
- Education & Training
- Research & programme metrics
- Cross programme collaboration

Implementation of these recommendations detailed throughout this model of care would have a positive impact on the challenges facing service users nationally.

## Acute Treatment

Acute treatment attempts to relieve or stop the progression of an attack. Acute treatment should be taken as early as possible in the headache phase of an attack to prevent its escalation and to increase the drugs' effectiveness.

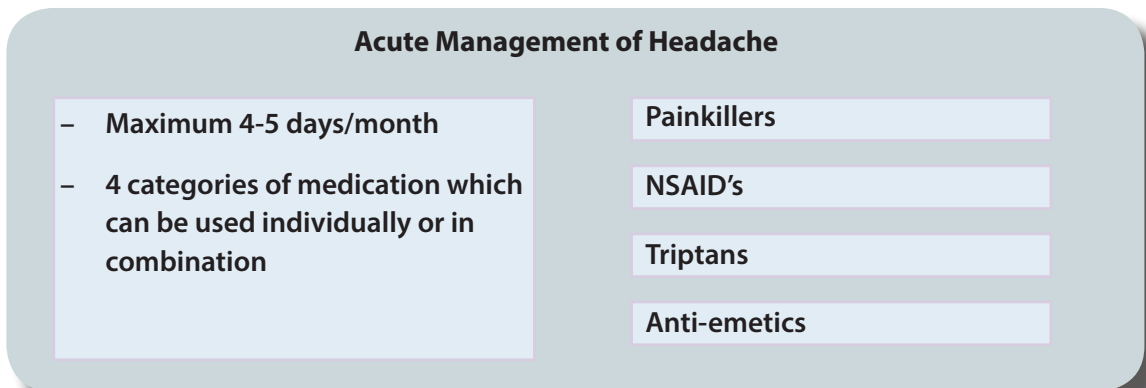


Fig 1; Acute Management of Headache

## Prophylactic Treatment

Prophylactic or preventative migraine medication is used in an attempt to reduce the frequency and severity of anticipated attacks.

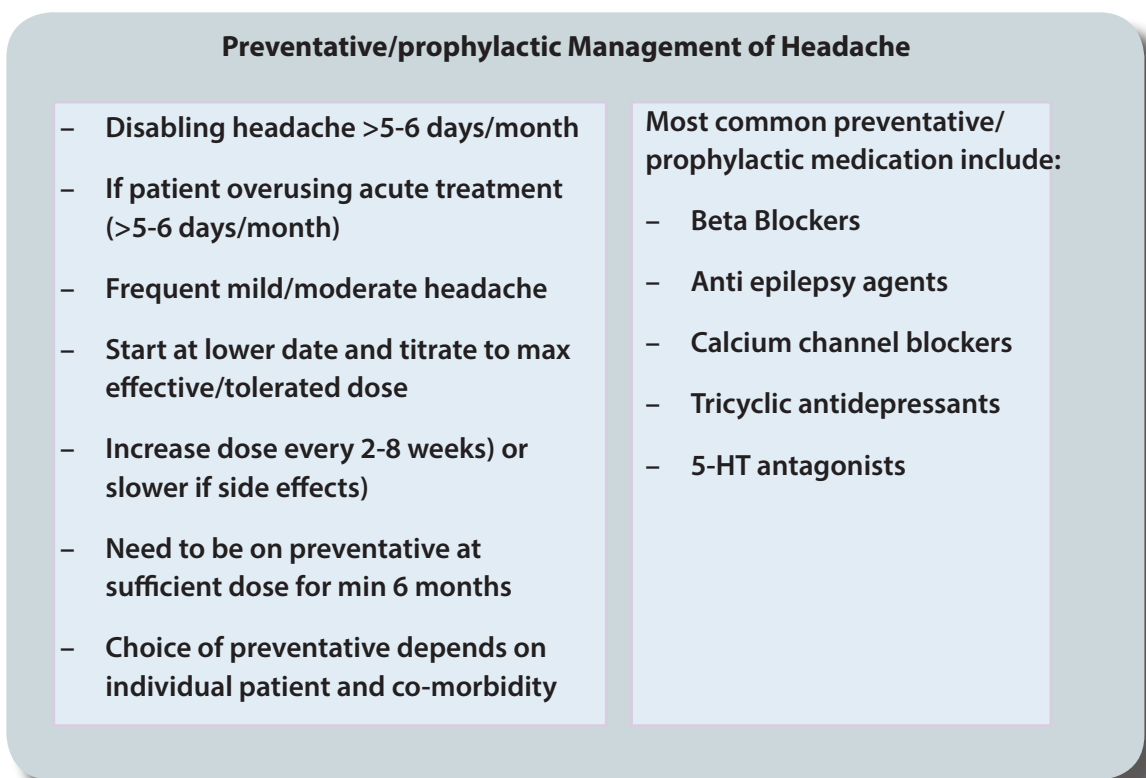


Fig 2; Prophylactic Management of Headache



In the absence of any of the above features, the NICE guideline<sup>149</sup> would recommend the following pathway

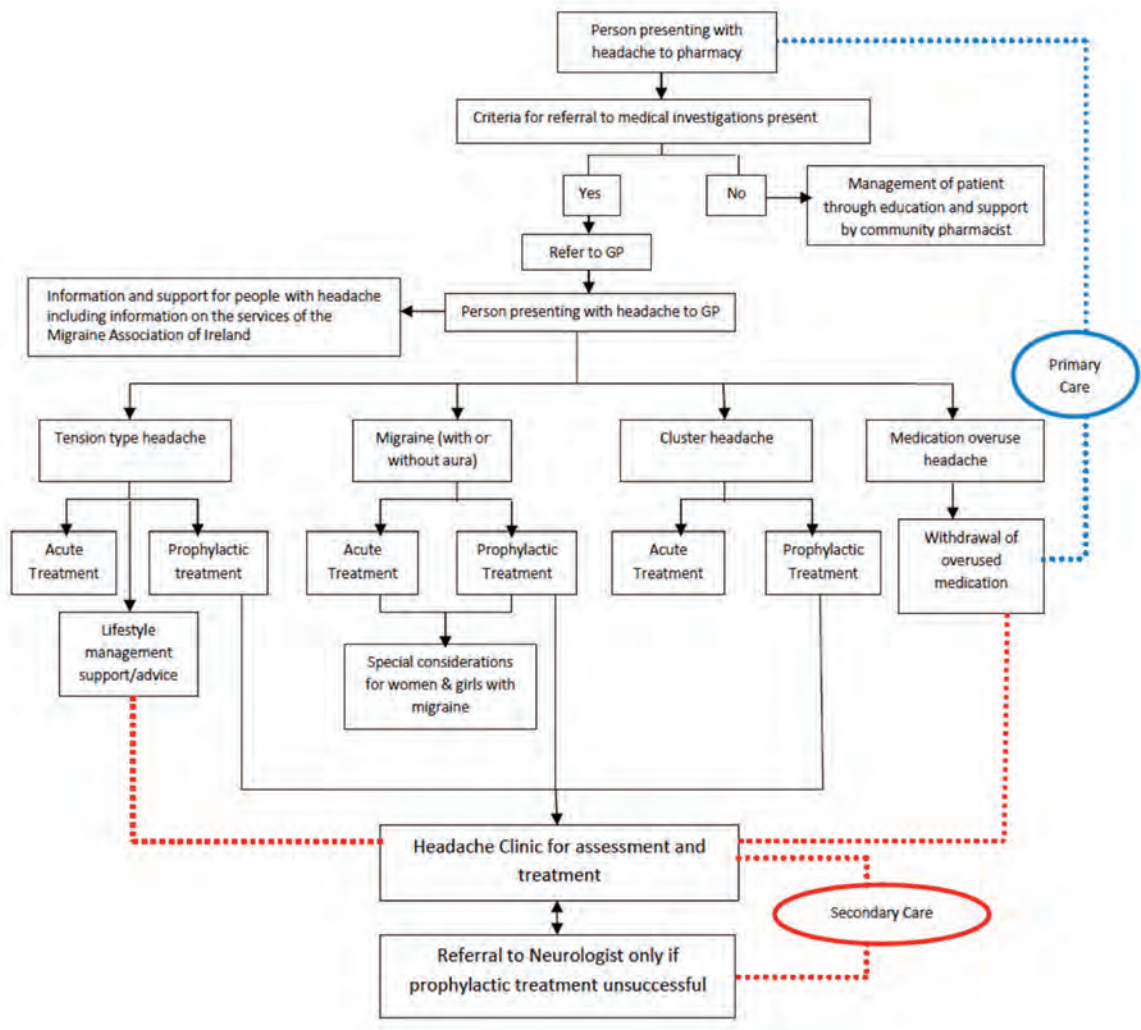


Fig 3; Headache pathway, adapted from NICE headache guideline<sup>149</sup>

It is anticipated that use of these algorithms will support the management of primary headache in primary care. The algorithms are not intended to serve as a standard of care. Use of such an algorithm does not ensure a successful outcome in every case, nor should it be construed as including all proper methods of care or excluding other acceptable methods of care/care pathways. The ultimate judgement must be made by the appropriate healthcare professional responsible for clinical decisions regarding a particular clinical procedure or treatment plan. It would be advised, however, that significant departures from the care pathway should be fully documented in the patient’s notes.

The algorithms are intended as tools for general practitioners, emergency room physicians, acute medical physicians and to a lesser extent, for general hospital physicians.

Non-acute, MDT led headache service which has defined links with group neurology services

are recommended (Gaul 2011),<sup>150</sup> (Gaul 2013)<sup>151</sup>, (Wallasch 2012)<sup>152</sup>. There are currently four specialist clinics for headache and migraine based at Beaumont Hospital, Mater Misericordiae University Hospital, St. Vincent's University Hospital, and Cork University Hospital providing much improved access to new treatments. None of these clinics currently have a full MDT as outlined above.

Headache clinics which are nurse led generally focus on;

- Triage of referrals
- Initial assessment of new patients
- Review of patients current status i.e. levels of disability
- Monitoring drug efficacy and tolerability
- Assisting patients in maintaining their optimum state of health/function
- Information/advice provision on areas such as lifestyle, triggers, withdrawal from overused analgesics
- Promoting patient empowerment which will improve adherence and compliance with treatment recommendations
- Personal support/advocacy
- Psychological support/counselling
- Self-management

The model of nurse led clinics is highly regarded and there has been recent growth in the number of nurse led clinics to meet a variety of health care needs. The most widely reviewed nurse led clinics are epilepsy clinics. A Cochrane review of models of epilepsy care found strong evidence for positive outcomes by the involvement of epilepsy nurse specialists and self-management strategies alone<sup>153</sup>.

Investigations into the effectiveness of epilepsy nurses in primary care and from clinical trials suggest that epilepsy nurse interventions are highly useful and that epilepsy patients cared for by a nurse are well informed and have a high degree of satisfaction<sup>154</sup>. A randomized controlled trial to test the feasibility and effect of nurse run Epilepsy Clinics in primary care has shown that such clinics for patients with epilepsy are feasible, well attended and significantly improve the level of advice and drug management.

Considering the objectives of nurse led epilepsy clinics are comparable to the objectives of nurse led headache clinics, it is reasonable to assume that similar outcomes could be expected in equivalent headache clinic.

It is recommended that each neurology service is supported by a nurse led Headache Clinic. With respect to workforce planning, it would be anticipated that, similar to ratios for Epilepsy Nurse Specialists with out-patient service/outreach remit, 1:140,000 population at a minimum would be required. Given the current population of Ireland, this would equate to 32 WTE CNS in Headache.

---

150 Gaul et al 2011, Team players against headache: multidisciplinary treatment of primary headaches and medication overuse headache. *J Headache and pain* 12(5): 511-519 PMID: PMC3173636

151 Gaul 2013 Efficacy of multidisciplinary rehabilitation of patients with chronic headache. *The Journal of Headache and Pain* 14 (Suppl 1): 09

152 Wallasch TM, Angeli A, Kropp P 2012. Outcomes of a headache-specific cross-sectional multidisciplinary treatment program. *Headache* 52 (7): 1094-1105 doi: 10.1111/j.1526-4610.2012.02189.x. Epub 2012 Jun 15.

153 Cochrane Database Syst Rev. 2008 Jan 23;(1):CD006244. doi:10.1002/14651858.CD006244.pub2.

154 Model of Care, National Clinical Programme for Epilepsy, 2015 Clinical Strategy & Programmes Division, HSE

Investment in this resource would see reductions in the number of patients attending GP's, the number of patients presenting to unnecessarily to Neurologists and indeed reductions in the numbers of patients presenting to ED/AMAU's. It would also provide a more holistic approach to the management of patients with an emphasis on patient education and self-management and the patient themselves at the centre of care pathway.

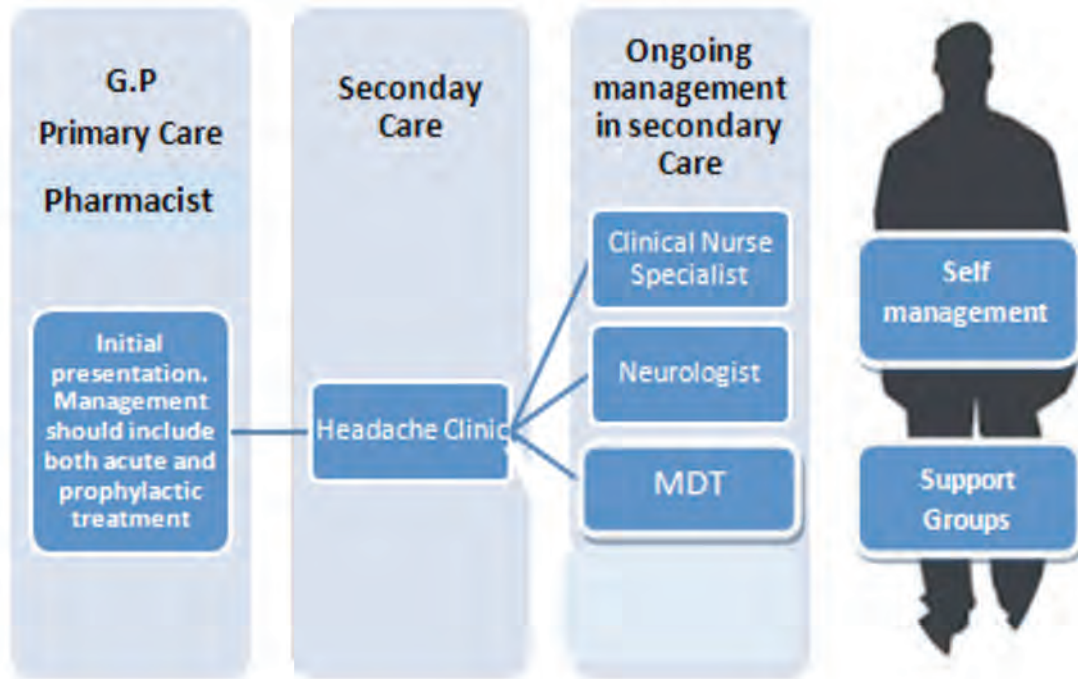


Fig 4; Management of headache across the continuum of care

Specialist area	HSCP Disciplines	Interventions
Headache	Occupational therapy	Self-management/coping strategies (1:1 or in groups) Stress management Pacing techniques Ergonomic Assessment Relaxation
	Physiotherapy	Identification and treatment of potential triggers, in particular cervicogenic & tension headache Postural and Ergonomical advice Education – groups & 1:1 Assessment
	Psychology	Coping strategies Stress management Medication overuse counselling Management of comorbid depression & anxiety

Table 2; The role of the Multidisciplinary team in management of headache

## The role of the physiotherapy

There is a growing body of evidence building for the support of physiotherapy for certain headache subtypes such as cervicogenic headache and tension type headaches.

Additionally there is scope for extending the role of specialist headache physiotherapists in line with successful models such as those described through the National Clinical Programme for Rheumatology and Orthopaedics Musculoskeletal Clinical Care Pathways. With specific training a specialist headache physiotherapist will be able to

- Take comprehensive subjective history and carry out a full neurological screen from appropriate new patients to increase throughput in clinics and reduce waiting lists
- Administer time-consuming interventions such as Botox for appropriate chronic migraine sufferers.

## Occupational Therapy in the Management of Headache

Headache and migraine have an effect on all areas of life and can impact or limit engagement in activities of daily living and roles including home, work and leisure activities.

Occupational therapists are routinely involved in pain management services and facilitate behavioural strategies including stress management, self-management, pacing, and relaxation techniques. The occupational therapists detailed understanding of interactions between the person, environment and occupations are also of value in the management of headache. They can assess physical functioning and apply ergonomic principles in a variety of settings including home, transport modes and the workplace.

## Role of Psychologist

The role of the psychologist within the management of headache varies from patient to patient. For some patients there will be a need for direct intervention i.e. patients with psychiatric comorbidity, difficulties coping with headache, significant problems with sleep and/or stress, medication overuse and if there is a suspected history of misuse. In other situations, such as 'considering patient's beliefs about their readiness and ability to actively manage their headaches, medication adherence and managing triggers' may not necessarily require direct contact with a psychologist 'but all of these involve behavioural/psychological principles'<sup>155</sup>.

Individuals with chronic migraines are also 2 to 5 times more likely to have a diagnosis of depression or anxiety (Jette et al 2008)<sup>156</sup>. The relationship between migraines and depression has been found to be bidirectional, meaning some people develop migraines prior to depression and others have a history of depression that precedes the development of migraines (Breslau et al 1994)<sup>157</sup>.

Additionally, treating depression and anxiety in people who have migraines may lead to better physical outcomes. Research has shown that untreated problems with depression and anxiety can interfere with adherence to medical treatments, diminishing their effectiveness<sup>158</sup>.

155 Nicholson, RA. 'Chronic Headache: the role of the psychologist' Department of Neurology & Psychiatry, Saint Louis University School of Medicine and Ryan Headache Centre/Mercy Health research.

156 Jette, N., Patten, S., Williams, J., Becker, W., Wiebe, S. Comorbidity of migraine and psychiatric disorders. A national population-based study. *Headache*. 2008;48:501-516.

157 Breslau, N., Davis, G.G., Schultz, L.R., Paterson, E.L. Migraine and major depression: A longitudinal study. *Headache*. 1994;34:387-393.

158 <http://www.goodtherapy.org/blog/link-between-chronic-migraines-and-psychological-distress-033114>

## Role of the Pharmacist

Pharmacists are often the first health care professionals to which patients with tension type headache and migraine present to. The importance of a thorough understanding of headache/migraine and its management is essential for pharmacists, because as many as 57% of patients self-treat migraine headaches and inappropriate use of over the counter analgesics can increase the risk of medication overuse headaches<sup>159</sup>. It is important to remember that episodic tension type headache and migraine can both gradually change into chronic daily headache as a result of medication overuse. By advising and appropriately sign-posting patients in the correct use of over the counter medications, the pharmacist can be a valuable addition to the treating team.

The same 'red flags' indicating the potential presence of a more sinister cause of headache are applicable to pharmacists. In addition to this, the pharmacist should consider recommending GP consultation for any new-onset headaches in children or older persons.

## Migraine Association of Ireland

As with other neurological conditions, the role of support organisations should not be underestimated and information provision on the roles and functions of the Migraine Association of Ireland should be routine. MAI provides support, information and reassurance on a range of migraine and other headache disorder issues while promoting awareness on these to migraineurs, health professionals and the general public.

MAI endeavours to foster partnerships and collaborative approaches with all relevant agencies, organisations and other stakeholders to promote the best possible services to migraine sufferers and their families and promotes and supports good self-management practices.

### Services provided by MAI include:

- A confidential Helpline service for sufferers of migraine and other headache disorders to provide on-the-spot information and support.
- A Specialist Nurse Advice Line.
- BrainStorm Newsletter is published 3 times a year circulated to migraineurs and health professionals.( <http://www.migraine.ie/about-the-mai/our-services/>)
- Information leaflets and fact sheets on specific aspects of migraine.
- Migraine Diaries to educate and to assist the migraineur in learning to manage their life with migraine.
- Publications for health professionals.
- Electronic newsletters are produced six times per year for both Health Professionals and migraineurs.
- [www.migraine.ie](http://www.migraine.ie) provides useful up to date on-line information.
- Public information seminars and awareness events
- Migraine Action Week- an annual campaign during September to highlight migraine issues.
- Existing Headache/ Migraine Clinics in the Dublin Neurological Institute, Beaumont Hospital and St Vincent's Hospital in Dublin, in Cork and more recently in Galway have been established. MAI is continuing to promote the development of further clinics and services in other areas of the country.

---

159 DeMaagd, G. Migraine Headache: the pharmacist and the role of OTC medications. Pharmacytimes.com



- Collaboration with others- MAI was a founder member of the Neurological Alliance of Ireland and continues to play an active role in the broader neurological agenda. More recently MAI has established links with the Northern Ireland Headache Network to work together on areas of mutual interest.
- International co-operation- the Association is represented internationally by the President of MAI Audrey Craven who is also the President and a founding member of the European Headache Alliance, an umbrella organisation representing 17 national patient organisations across Europe. She is also President of the European Federation of Neurological Associations.
- Through these contacts MAI attracts the top international experts in the world to its events in Ireland which helps increase the skill levels of professionals working in headache disorders in Ireland.



## Appendix 3 – Multiple Sclerosis Pathway

Multiple Sclerosis (MS) is an acquired chronic immune-mediated inflammatory condition of the central nervous system, affecting both the brain and spinal cord<sup>160</sup> (NICE 2014 guideline). It is the most common cause of serious physical disability in adults of working age with an estimated 2,500,000 people affected worldwide.

Specialist neurological and neurological rehabilitation services should be available to every person with MS. The specific neurorehabilitative needs of people with MS are not detailed in depth in this model of care. While it is wholly acknowledged that patients with this condition require a comprehensive care pathway across all divisions, we are confident that the more specific details in terms of rehabilitation services will be addressed through both the national clinical programme for rehabilitation medicine and through the implementation of the neuro-rehabilitation strategy & policy<sup>16</sup>.

The focus of the care pathway for patients with MS, as per this model of care for neurology, refers to the management of the referral, access to neurology consultant and diagnostic/therapy/social care services and access to appropriate management of the illness.

### Referral Management

An individual who is suspected as having MS should be referred to a neurologist and seen within an audited timeframe. The individual should be seen again after all investigations necessary to confirm or refute the diagnosis have been completed.

The National Institute for Health and Clinical Excellence (NICE 2014) guidelines recommend a timeline of 6 weeks from referral to neurology consultation and then 6 weeks to diagnosis of MS, although it may not always be possible to confirm the diagnosis clinically in this time frame and an additional period of follow-up may be required.

In a recently published audited clinical practise in one Dublin University Hospital (Kelly et al 2011)<sup>161</sup>, timelines from presentation to diagnosis were calculated. In this study the mean time from assessment to diagnosis was 9.5 weeks (median 6 weeks, range 1 day to 80 weeks). The percentage of patients receiving diagnosis within 6 weeks of their first neurology review was 52%. The remaining 48% had a delay of more than 6 weeks from presentation to receiving a diagnosis of MS. Patients who had MRI performed prior to neurology review had a much shorter time to diagnosis than patients who did not.

A number of factors adversely affected a timely diagnosis. Patients who experienced a delay were at times patients referred with atypical presentations or where MS had not been considered as a potential diagnosis by the referring clinician. In these instances delays to MRI, access to a review clinic and lumbar puncture occurred. Deficiencies in administrative support as a resource also accounted for delays in some instances. Overall, 78% of patients were seen in an initial clinic by a neurologist within the 6 week timeframe whereas only 52% received their diagnosis within 6 weeks of initial presentation. This would suggest that many of the challenges of reaching best practise standards are operational in nature including access to diagnostic services.

160 National Institute for Health Care and Excellence, Multiple Sclerosis: management of multiple sclerosis in primary and secondary care 2014 [CG168]

161 SB Kelly, E Chaila, K Kinsella, M Duggan, C McGuigan, N Tubridy & M Hutchinson (Multiple Sclerosis, from referral to confirmed diagnosis: an audit of clinical practise;– Mult Scler 2011 17:1017)

The impact of this should not be underestimated as there is evidence supporting the efficacy of early pharmaceutical treatment with disease modifying therapies (DMT's) in patients with MS. The central premise of early treatment is the belief that by limiting the damage caused by early disease, the impact of the illness on long-term function can be minimised or delayed. (Goodin & Bates 2009)<sup>162</sup>

One possible solution to this challenge is considered in the 'Report and Recommendations on Patient Referrals from General Practice to Outpatient and radiology Services, including the National Standard for Patient Referral Information', HIQA, March 2011<sup>163</sup>.

This report highlights the need to standardise the patient referral pathway and to standardise the information shared between general practitioners and hospital consultant and administrative staff. Implementation of the recommendations presented in the report will lead to a safer, more efficient and effective referral pathway for all patients. Access to services will be improved, information shared between primary and secondary care and with patients will be improved and, when implemented, the recommendations will ensure that all referrals are handled in a timely and efficient manner.

The timely and appropriate referral for a patient between their general practitioner (GP) and specialist consultant or diagnostic service is key to the provision of high quality, safe, effective care for those who use Ireland's health services. By enabling a patient to access diagnostic services which are not provided by their GP, or requesting a consultant's opinion on their condition, patients can be diagnosed more quickly leading to earlier intervention and treatment and ultimately improved health outcomes.

Both nationally and internationally, GPs are recognised as the patient's gatekeeper between primary and secondary care and are usually responsible for the decision to refer a patient to secondary or tertiary care.

The timely and appropriate investigation and assessment of individual cases can be the key to effective and early intervention and treatment. For this reason, improvements in the management of the patient referral pathway are vital.

Within hospitals, significant improvements could be brought about through the use of centralised management of referrals and improved use of information technology systems to support the referral system. Clear accountability for the quality and safety of services delivered is also required.

The recommendations within the HIQA (2011) report<sup>160</sup> which are of specific relevance to the management of referrals of patients with suspected diagnosis of MS include;

- Investigating a direct access service for GP's to radiological services to determine if it may prove a more effective outcome for patients.
- The audit of clinical practice referred to previously (Kelly et al 2011<sup>158</sup>) demonstrated that patients who had MRI completed or referral generated prior to initial clinic appointment with neurologist generally receive their diagnosis within recommended NICE guidelines timeframes.
- Clear referral pathways for outpatient and diagnostic radiological services such that there is consistent and equitable access to services for patients.

162 Goodin DS, Bates D; Treatment of early multiple sclerosis: the value of treatment initiation after a first clinical episode; *Mult Scler* 2009 15: 1175

163 Health Information and Quality Authority 2011. Report and recommendations on patient referrals from general practice to outpatient and radiology serviced including the National Standards for Patient Referral Information.

- A review of waiting times for MRI was undertaken by the neurology programme. Waiting times vary significantly across the country i.e. from 1 month to 23 months. Clear referral guidelines which outline criteria for urgent and routine referrals would be beneficial.
- Hospitals should have processes in place to ensure that patient referrals can be individually and collectively tracked and traced throughout the referral pathway.

Active tracking of referrals would mean that service providers could be alerted if a referral is not progressing in a timely manner.

While there are 26 recommendations within the HIQA 2011 report, it is felt that these examples alone would have a significantly positive impact on the early diagnosis and initiation of treatment for patients with MS. In this instance, the referral pathway for these patients is outlined in figure 1.

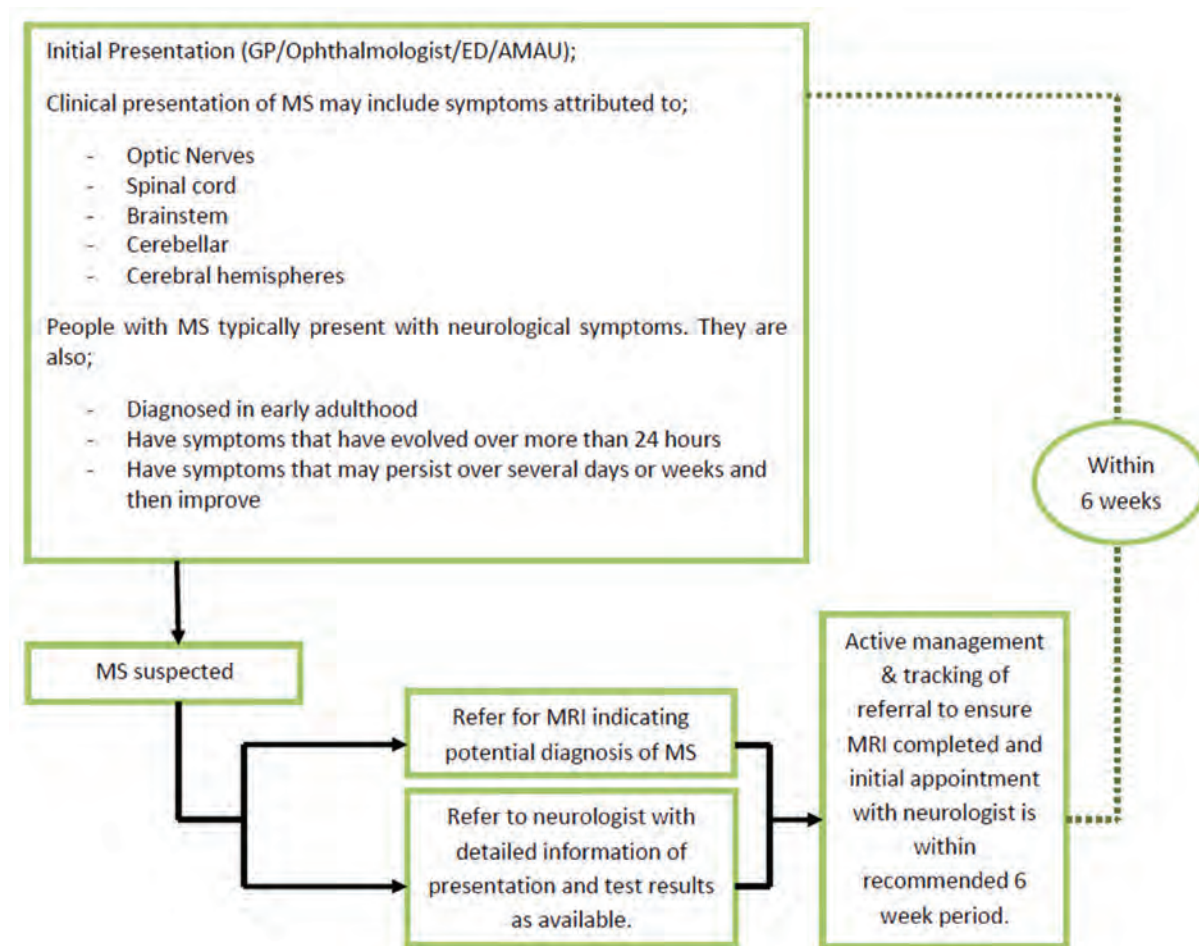
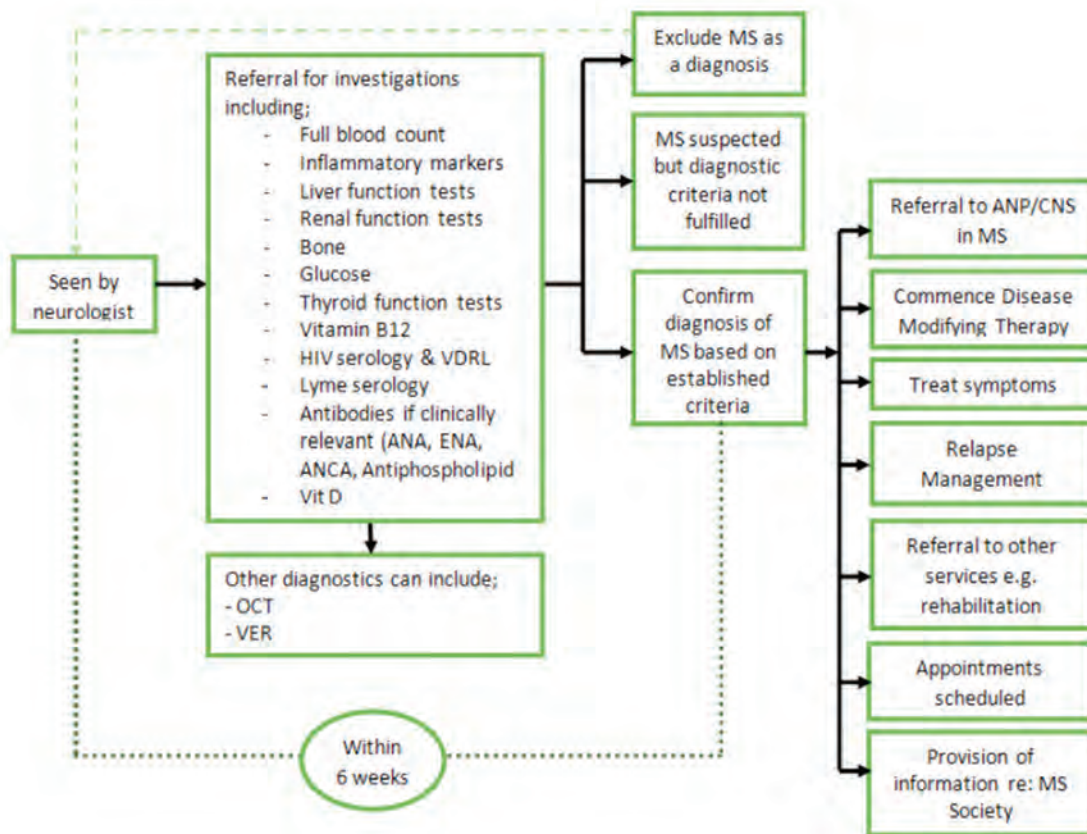


Figure 1; Referral Pathway for patients with suspected diagnosis of MS



**Figure 2 ; referral pathway for patient continued**

The steps outlined above are prompts. Within each step there are a number of requirements to be considered for the pathway to achieve internationally recognised standards of best practise. The requirements outlined below are included as they refer specifically to the role of the neurologist and neurology service. These requirements reference numbered steps in the care pathway above. These requirements are adapted from the Multiple Sclerosis NICE Guideline, 2014<sup>164</sup>

**Confirm diagnosis of Multiple Sclerosis**

A Consultant Neurologist should make the diagnosis of MS on the basis of established up-to-date criteria, such as the revised 2010 McDonald criteria<sup>151</sup> outlined below

Clinical Presentation	Additional Data Needed
<ul style="list-style-type: none"> <li>• <b>2 or more attacks (relapses)</b></li> <li>• <b>Objective clinical evidence of 2 or more lesions, or of 1 lesion with historical evidence of prior attack</b></li> </ul>	<p>None; no additional tests required. However, additional evidence such as imaging or other test (for instance CSF) desirable and must be consistent with MS; if they are not, extreme caution is needed before making diagnosis of MS and alternative diagnosis must be considered.</p>

164 Polman CH, Reingold SC, Banwell B et al. (2011) Diagnostic criteria for multiple sclerosis: 2010 revisions to the McDonald criteria. *Annals of Neurology* 69:292-302





Information provision is also essential at this stage. People with MS and their family members should be offered verbal and written information at the time of diagnosis. The EASE (Education, Adaptation, Support & Enhancement) system ensures all aspects are addressed i.e.

- Education (about the disease, its course, symptom management and psychosocial implications)
- Adaptation (adjustment, modifying lifestyle, setting priorities and promoting self-care)
- Support (counselling, providing information on support groups and help obtaining entitlements)
- Enhancement (self-care, improvement of coping skills and facilitation of communication about needs and concerns)

### **Consultation with service users**

In the development of this pathway, the neurology programme engaged in a number of consultations. While service users were invited to provide feedback on the pathway circulated through the patient organizations, a focus group was also convened to get direct feedback from service users and their families/carers.

When asked about their requirements from their health care service, the attendees at the focus group highlighted the following;

- The need for primary care support
- The need for access to community services, particularly rehabilitation & support groups
- The need for vocational support
- Support in relation to health promotion and keeping healthy
- Access to therapies as needed

When asked about current challenges they face, the following were identified as recurrent themes;

- Lack of knowledge of MS among generalist healthcare staff both at hospital and community level
- Poor links between hospital & community leading to unnecessary duplication of assessments
- Repeated avoidable admissions to hospital through ED
- Neurology clinics under resourced which leads to long waiting times, both for appointments but also within the clinic
- Limited access to respite care
- Limited access to health and social care professionals and neurologists both at hospital level and community level
- Delays in receiving entitlements which leads to unnecessary stress and anxiety and puts families under significant pressure
- Restrictions in access to medical card
- Limited access to equipment, particularly if a medical card has been refused following means testing. Access to equipment should be needs based and not based on means.
- Lack of home help/PA meaning that family members at times have to leave work to fulfill role of carer. This can lead to significant financial burden within a family.

The issues highlighted by users of this pathway echo the difficulties outlined by both the Laffoy Review 2007<sup>11</sup> and reinforced within this model of care. Implementation of the recommendations outlined within this model should begin to address the issues raised. Ongoing engagement with service users will ensure that the programme continues to target areas which would improve patient experience within service delivery plans.



## Referral to Clinical Nurse Specialist

The role of the Clinical Nurse Specialist is highly regarded within the management of MS as being cost effective and highly efficient. The recommended ratio of Nurse Specialist in MS to patient is currently 1: 348.

## MS/ANP Role in Ireland

Currently there are up to 9,000 MS patients attending the public outpatient services in the hospital setting. When surveyed, the majority of nurses working with MS in combination with general neurology patients, stated that the majority of their time was spent working with MS patients due to the increased level of care and support required for this particular group of patients.

There are 9 Clinical Nurse Specialists working either solely with MS patients or combined with other neurological conditions. This means the average current MS caseload is 844 patients for 1 full-time MS Nurse in Ireland. In the UK it is recommended that in order for an MS Nursing service to be sustainable and to give optimum patient care, that there should be a caseload of no more than 358 patients per one full-time MS Nurse Specialist. (MS Specialist Nursing in the UK 2014: The case for equitable provision. November 2014<sup>165</sup>).

Therefore to meet current demand in Ireland at least 13 additional full-time MS nurses are required urgently and then consideration can be given to future demands and development of services. In some centres, in Ireland the caseload is as high as over 1000 patients for 1 MS Nurse Specialist. This is not sustainable and does not allow nurses working in the area to provide quality, satisfactory, safe and patient centred care.

The provision of MS specialist nursing services offers the opportunity of cost saving, admission avoidance and a community model of care. Currently MS nurses spend a large proportion of their time undertaking routine administrative tasks, such as filing, typing letters, answering non-clinical phone enquiries, booking clinics and requesting blood results etc. which represents an inefficient use of their specialist expertise. Nurses working at Specialist and Advanced Practice level need administrative support to free up their time for specialist nursing care.

## MS Nursing Service

MS nurses are vital in providing an understanding of the condition and contributing to a coordinated, interdisciplinary and holistic approach. The MS nurse Specialist role is multifaceted as Multiple Sclerosis is a complex disease and many of the people with MS require support, information and intervention at many different stages of the disease. Neurology including Multiple Sclerosis is an area suitable for the development of Clinical Nurse Specialist and Advanced practice roles. Neurology Departments are faced with increasing demand for their services due to an aging population and increase health care need. There is a need to balance these issues with appropriate skilled and experienced nursing staff at all levels including ward and specialist/advanced level. The CNS/ANP is well defined and available on An Bord Altranais site (<http://www.nursingboard.ie/en/homepage.aspx>).

## Diagnostic Phase

There is an immense need for psychological support and information enabling the person with new diagnosis to adjust to the diagnosis. The MS/ANP Nurse at this stage supports the patient with information on the possible course of the disease, explains the disease process and help to advise on

---

165 MS Specialist nursing in the UK – 2014. Multiple Sclerosis Trust

self- management strategies and plan for the future with support from neuropsychology colleagues. Investment of time at this stage is important as it sets the tone for the client relationship with his/her MS/ANP Nurse and increases a relationship of trust.

### **Disease Modifying Therapy**

Education on treatment options and advice on potential treatment, benefits, risks, common side-effects associated with individual treatments.

In recent years there are a number of newer treatments and second-line treatments that require close monitoring for side-effects and frequent monitoring of blood tests. This has posed as an increased challenge for MS Nurses as more time is invested in monitoring for side-effects and in many centres there are hundreds of patients receiving a variety of treatments with complex side-effects. In one centre the treatment group is as high as 800 patients on treatment for MS.

### **Telephone Support:**

Telephone support provides access to CNS/ANP for expert opinion, advice relating to therapies and their side-effects, symptomatic management and support in challenging times for people with MS and typically the CNS/ANP is the first point of contact.

### **Relapse Management:**

The CNS/ANP is capable of assessing the MS patient for possible relapse or disease progression in the clinical environment or via phone support service. Frequently the MS Nurse through expert opinion or in consultation with the medical team will arrange for rapid assessment, if necessary, in the out-patient environment in order to manage relapse/disease progression symptoms. Clinical relapses may be treated with intravenous steroids (as per Neurology centre protocol) and are given on an out-patient basis preventing numerous hospital admissions on a yearly basis through the intervention of the MS Nurse Specialist.

Irrespective of disability due to a relapse or disability progression, the MS Patient requires a great deal of support. The MS Nurse often assesses if the patient needs support or intervention in order to prevent long-term complications. Whether the person with MS needs acute intervention or additional care support in the community, the MS Nurse often provides prompt referral for appropriate support.

### **Advanced Practice in Multiple Sclerosis Nursing**

Studies show that clinical nurse specialists (CNS) with master's level preparation, demonstrating characteristics of an ANP provide high- quality and cost effective care to patients with chronic diseases (Moore and McQuestion, 2012<sup>166</sup>). CNS's play a critical role in the management of patients with MS with some audits showing that 83% of respondents preferring contact with their MS nurse for MS- related problems rather than any other health care professional (Ward-Abel et al, 2010<sup>167</sup>).

The development of advanced practice level is essential in order to respond to patient and service need at local, national and international level. The ANP Multiple Sclerosis will be an autonomous

---

166 Moore J, McQuestion M. The Clinical Nurse Specialist in chronic diseases. *Clin Nurse Spec* 2012 May-Jun; 26(3):149-63

167 Ward-Abel, Nicki, Kerry Mutch, and Huseyin Huseyin. "Demonstrating that multiple sclerosis specialist nurses make a difference to patient care." *British Journal of Neuroscience Nursing* 6.7 (2010): 319-324.

practitioner with expert clinical skills, who has a vast amount of clinical experience, educated to Masters level who will provide professional and clinical leadership and promote and initiate audit and research in the clinical area (NCNM, 2008<sup>168</sup>).

ANP in Multiple Sclerosis will have the knowledge and skills to provide care to MS making independent and interdependent (in consultation with medical colleagues) treatment decisions in relation to both acute and chronic side effects and be involved in areas traditionally regarded as the sole responsibility of the medical practitioner. The ANP in Multiple Sclerosis is in a unique position to use his/her nursing knowledge and experience in the expanded role to advance the science of nursing in daily clinical practice in caring for patients and their families.

The ANP post holder would be in a position to positively influence the profession of nursing through the provision of education, high quality direct care for patients and their families and as clinical and professional leader highlighting the contribution of nursing to the provision of health care. They will acknowledge the individual needs of each patient and their family and through collaboration and partnership with nursing colleagues, medical, therapy, diagnostic and social care staff to provide a service that combines advanced decision making and an innovative approach to care while retaining the philosophical underpinnings of nursing.

### **Commence Disease Modifying Therapy (DMT)**

It is imperative that people with MS have the opportunity to actively participate in decision making and are fully informed of options available to them. To be a fully active participant in their care, the patient needs to be fully informed of all options available to them. This information should be presented in an unbiased way, with objective information on efficacy of particular treatment courses balanced with predicted side effects and patient autonomy taken into account.

Initiation of therapy is advised as soon as possible following a diagnosis of MS and determination of a relapsing course<sup>169</sup>. DMT's are administered not to manage specific symptoms but with the goal of altering the course of the disease.

Drug treatments can be divided into first line therapies, second line therapies and third line therapies. Once established on therapy it is important that people with MS are reviewed in a specialist clinic at regular intervals for monitoring and assessment of disease activity or progression.

Access to therapy should be equitable and in no way impacted by the patient's demographics. Initiation of DMT's should at all times be a clinical decision made by a neurologist in collaboration with the patient.

While the Neurology Programme recognises that factors such as budgets need to be considered, however consideration of same should again be equitable and transparent so that no individual patients are discriminated against in terms of access to treatment due to the management of the medication budget in the service they are attending.

To support the effective and efficient management of DMT's the Neurology Programme would support the development of a national treatment registry for all MS patients in Ireland. The aim of such a registry would be to encourage regular reviews of MS patients where their clinical progress is assessed. Based on this clinical evaluation, recommendations would be given with respect to

---

168 National Council for the Professional Development of Nursing and Midwifery. Nov 2008

Accreditation of Advanced Nurse Practitioners and Advanced Midwife Practitioners. 2nd Edition.

169 National MS Society, USA

changes in their prescriptions. These changes could be changing medication type, increasing or decreasing doses and indeed discontinuation of treatments which are not proving effective.

### Treat symptoms

There are many symptoms which can be associated directly with the progression of MS. While DMT's address the course of the disease, they do not directly manage many of the symptoms. Symptoms can include;

- Spasticity
- Functional impairment
- Mobility impairment
- Fatigue
- Visual disturbances
- Sensory disturbance
- Pain
- Depression
- Cognitive changes

There are different approaches which can be taken to manage these symptoms i.e. pharmacological management and non-pharmacological management. Treatment options should be made with the individual patient with their personal choice reflected in the decisions made.

While pharmacological treatments will be initiated by the treating neurologist, adherence and success of the treatment can be managed through the MS CNS. The MS CNS and the Multidisciplinary team also have a significant role to play in the non-pharmacological management of symptoms, particularly with people where education is an intervention.

### Relapse in Multiple Sclerosis



**Fig 28; Relapse Pathway**

1. Referral triaged; for those whom it is deemed urgent care is required, they are referred for an urgent appointment to a neurology centre.
2. The CNS in MS is usually the first point of contact therefore if an urgent appointment is required they will facilitate the patient. To expedite a clinic appointment for assessment/review slots should be left available on a weekly basis in OPD to accommodate urgent need for access.
3. A face to face relapse assessment is carried out where relapse is confirmed. Relapse is defined as;
  - New or worsening of symptoms attributable to MS lasting greater than 24hrs in the absence of a temperature and a period of 30 days should be observed between each event to differentiate separate attacks (MS Nurse Specialists 2012)<sup>170</sup>
  - Symptoms should be persistent

170 A guide to best practice – MS nurse specialist nursing in Ireland, 2012

- The pre-requisite for symptoms to last for this period of time is intended to eliminate “pseudo-exacerbations”; which leads to deterioration in neurologic function caused by fever and/or infection which is reversible.
4. The management of relapse may be treated with a short course of Intravenous Methylprednisolone (IVMP) which can hasten recovery from the attack (Menon et al 2011<sup>171</sup>) in the event of impact on ADLs or as per each Neurology center protocol. Oral prednisolone may also be utilized in relapse if the neurologist determines it appropriate. Short-term side & long term side effects should be explained fully to the person with MS.
  5. Admission may be necessary if relapse is considered severe

**Review appointment scheduled**

Regular review appointments should be scheduled taking into account the needs of the person with MS and the course the disease is taking and supports available to the patient i.e. MS CNS etc. While specific recommendations are not given in relation to timeframes between reviews, an annual review would be considered appropriate.

At formal review it is recommended that the following are discussed if applicable;

- Altered mobility
- Bladder/bowel dysfunction
- Cognitive impairment
- Impairment in functional status
- Depression
- Fatigue
- Pain
- Psychological changes
- Social factors
- Spasticity
- Speech and/or language difficulties
- Visual problems

Issues arising should be addressed by the neurologist either directly or through referral to ancillary service.

Condition	HSCP Disciplines	Interventions
Multiple Sclerosis	Clinical Neuropsychology	Neuropsychological assessment Management of cognitive difficulties Support to patients & families Adjustment issues Fatigue management Secondary mood disorders Behavioural management plans Capacity assessment

**Figure 28; Role of the Multidisciplinary team in Management of MS**

171 Menon et al. Management of Optic Neuritis. Indian Journal of Ophthalmology 2011; 59(2): 117-122

	<b>Dietitian</b>	<ul style="list-style-type: none"> <li>Assessment &amp; treatment of malnutrition</li> <li>Modification of diets</li> <li>Nutritional supplementation</li> <li>Advice re: enteral feeding</li> <li>Advice re: weight management and avoidance of constipation, dehydration &amp; pressure sores</li> </ul>
	<b>Occupational therapy</b>	<ul style="list-style-type: none"> <li>Cognitive rehabilitation</li> <li>Insight &amp; awareness training</li> <li>Functional retraining</li> <li>Management of tone</li> <li>Upper limb assessment</li> <li>Sensory/visual rehabilitation</li> <li>Postural management</li> <li>Compensatory strategies for fatigue &amp; pain management</li> <li>Education &amp; emotional support</li> <li>Stress Management</li> <li>Coping Strategies</li> <li>Splinting</li> <li>Assessment and provision of enabling / assistive devices</li> <li>Assessment and prescription of seating systems / positioning devices</li> <li>Home/ Environmental Assessment</li> <li>Ergonomic Assessment</li> <li>Task Analysis Assessment</li> <li>Facilitating Discharge Home from Hospital</li> <li>Vocational Rehabilitation</li> <li>Driving Assessment</li> </ul>
	<b>Orthoptics</b>	<ul style="list-style-type: none"> <li>Manage diplopia</li> <li>Visual field assessment for patient with optic neuritis</li> <li>Screening for macular oedema</li> </ul>
	<b>Physiotherapy</b>	<ul style="list-style-type: none"> <li>Pain management</li> <li>Strengthening</li> <li>Continence</li> <li>Gait &amp; Mobility</li> <li>Tone</li> <li>Fitness</li> <li>Balance and falls prevention</li> <li>Monitoring progress of disease</li> <li>Management of foot-drop</li> <li>Self-management support</li> <li>Respiratory function</li> <li>Fatigue management</li> <li>Management of musculoskeletal issues</li> <li>Spasticity management</li> <li>OP/Bone Health</li> </ul>
	<b>Speech &amp; Language Therapy</b>	<ul style="list-style-type: none"> <li>Communication (language, speech and voice) assessment &amp; management.</li> <li>Eating, drinking and swallowing assessment and management</li> <li>Specialist alternative and augmentative communication evaluation and management</li> <li>Capacity assessment</li> <li>Education, support &amp; counselling</li> </ul>

**Table 2; with title Role of the Multidisciplinary Team in the Management of patients with Multiple Sclerosis**



## Role of Physiotherapist

Physiotherapists are essential in the management of Multiple Sclerosis (MS) as reduced mobility is considered one of the most common impairments affecting People with MS by compromising activity and limiting participation<sup>172</sup> (Sutcliffe 2010). Level 1a evidence has demonstrated the benefits of inpatient and community-based physiotherapy both as an individual discipline and as part of a multidisciplinary team on impairments (strength, continence, pain, tone, fitness), activities (mobility and balance) and participation (the impact of the disease and quality of life) (Rietberg et al. 2004<sup>173</sup>, Garrett and Coote, 2009<sup>174</sup>, Hogan and Coote, 2009<sup>175</sup>, Freeman et al 1999<sup>176</sup>, Cochrane review, Khan et al<sup>177</sup>, Khan et al.<sup>178</sup>).

NICE guidelines (2014) recommend regular access to physiotherapy for people with MS especially at time of relapse or when any sudden increase in disability or dependence. They recommend a specialised neurological physiotherapy assessment and management to help with problems with mobility, spasticity and weakness.

Current guidelines such as the EMSP (European MS Platform, 2012 <http://www.emsp.org/>) guidelines recommend that people with MS have access to physiotherapy at all stages of the condition and that physiotherapy is beneficial and effective in:

- reducing disability and
- increasing participation levels.

They recommend:

- close collaboration between health professionals and non professional care givers at home in order to maximise the successful rehabilitation of people with MS.
- the importance of exercise at all disease stages and
- a combination of strength and endurance training and
- specific exercises to improve activities of daily living.

Canadian physical activity guidelines (2012<sup>179</sup>) recommend that a physiotherapist would be beneficial in determining the appropriate amount of and type of exercise required for the individual concerned. While some of the needs of people with MS may be met in community based exercise

172 Sutliff MH. Contribution of impaired mobility to patient burden in multiple sclerosis. *Current Medical Research And Opinion*. 2010;26(1):109-119.

173 Rietberg MB, Brooks D, Uitdehaag BMJ, Kwakkel G. Exercise therapy for multiple sclerosis. *Cochrane Database Of Systematic Reviews (Online)*. 2005(1 (Electronic)):CD003980.

174 Garrett M, Coote S. Multiple sclerosis and exercise in people with minimal gait impairment : a review. *Physical Therapy Reviews*. 2009;14(3):169-180.

175 Hogan N, Coote S. Therapeutic interventions in the treatment of people with multiple sclerosis with mobility problems: a literature review. *Physical Therapy Reviews* 2009;14(3):160-168.

176 Freeman JA, Thompson AJ. Community services in multiple sclerosis: still a matter of chance. *Journal Of Neurology, Neurosurgery, And Psychiatry*. 2000;69(6):728-732

177 Khan F, Turner-Stokes L, Ng L, Kilpatrick T. Multidisciplinary rehabilitation for adults with multiple sclerosis. *Cochrane Database of Systematic Reviews*. 2008(2). <http://www.mrw.interscience.wiley.com/cochrane/clsysrev/articles/CD006036/frame.html>

178 Khan F, Pallant JF, Brand C, Kilpatrick TJ. Effectiveness of rehabilitation intervention in persons with multiple sclerosis: a randomised controlled trial. *Journal Of Neurology, Neurosurgery, And Psychiatry*. 2008;79(11):1230-1235

179 Canadian Physical Activity Guidelines for adults with Multiple Sclerosis, published by the Canadian Society for Exercise Physiology (CSEP) (2012); available at [www.csep.ca/guidelines](http://www.csep.ca/guidelines)

programmes (Garrett et. al. 2013<sup>180</sup>), it is recommended that advice is sought from a chartered physiotherapist prior to commencing an exercise programme. The role of the physiotherapist may be in tailoring interventions to people with MS with greater limitations in activities and participation and facilitating behaviour change.

### **Role of the Occupational Therapist**

The occupational therapist role explores assisting people to maintain their independence in the face of increasing disability, providing up to date and appropriate assistive technology/equipment/home adaptations where necessary. These compensatory strategies can help people to live with their condition and promote independence and social inclusion.

Occupational therapists set goals with each patient addressing their functional independence including:

- cognitive rehabilitation therapy
- insight and awareness training
- functional re-training
- management of tone
- upper limb assessment
- sensory/visual rehabilitation
- postural management
- fatigue and pain management
- education and emotional support.

### **Role of the Speech and Language Therapist**

Any person with MS should be referred to and assessed by a SLT if there are concerns relating to speech, language, voice, or swallowing problems<sup>181</sup> (NICE, 2003). People with swallowing problems or newly diagnosed or deteriorating communication problems should be assessed by the SLT within 1-10 working days, according to their level of risk (RCSLT, 2006<sup>182</sup>).

Patients with MS should have regular reviews with the SLT to monitor changing communication ability, eating, drinking and swallowing ability as the condition progresses. This is important so that timely and appropriate intervention is given to the patient (RCSLT, 2014, 2009; NICE, 2006).

The SLT's role includes;

- Assessment, diagnosis and management of communication and/or swallowing problems that may result from MS which may also contribute to the differential medical diagnosis (RCSLT, 2014).
- Completion of instrumental speech, voice, and swallowing assessments as appropriate to evaluate communication and/or swallowing problems. Instrumental dysphagia assessments including videofluoroscopy and fiberoptic endoscopic evaluation of swallowing (FEES) improve the accuracy of identifying both the nature of dysphagia and appropriate management (RCSLT, 2014).

---

180 Garrett, M; Exercise in the community for people with multiple sclerosis – a follow-up of people with minimal gait impairment. Multiple Sclerosis (Houndmills, Basingstoke, England), 2013, vol 19 (6), p 790

181 NICE 2003

182 RCSLT, 2006

- Education, counselling, and support of patients and their involved others in respect to communication and/or swallowing function and decisions about care (RCSLT, 2014, 2009<sup>183</sup>).
- Promotion of communication abilities that further the independence and advocacy of patients with MS.
- Onward referral for specialist alternative and augmentative communication evaluation and management to designated assistive technology services as indicated in the care of patients with MS (RCSLT, 2009).
- If long-term alternative feeding is anticipated as being a likely future option, discussions with the person with MS should be commenced at an early stage and their wishes documented.
- Any person with MS whose ability to communicate is affected significantly by
  - dysarthria should be taught techniques to improve and maintain speech
  - production and clarity by an appropriately skilled SLT.
- Where language, speech or voice impacts on communication, the family members, carers and others who regularly communicate with the person with MS should engage with the SLT regarding communication support strategies.
- Contribution to palliative care planning on issues regarding swallow function and/or supporting communication

### **Role of the Dietitian**

Multiple sclerosis is a condition which can present with a range of symptoms, and impacts each individual differently. As the condition progresses a wide range of complications may develop, some of which can compromise nutritional status.

- Support provided by the dietitian may include:
  - Assessment and treatment of patients deemed at risk of malnutrition
  - Ensuring nutritional adequacy of modified consistency diets
  - Nutritional supplementation as indicated
  - Involvement in the decision making process for patients being considered for gastrostomy insertion
  - Organisation and planning of home enteral feeding
  - Provision of appropriate follow up for patients on home enteral feeding
  - Appropriate dietary advice for issues such as constipation, dehydration and pressure sores
  - Weight management/healthy eating programmes thus preventing or lessening the burden of future co-morbidities
  - Dietary management of other nutritional co-morbidities such as diabetes, coeliac disease, chronic kidney disease
  - Advice regarding the importance of nutritional balanced diets and risks involved with restrictive exclusion diets

There can frequently be difficulties referring some of these patient types to community/outpatient settings due to lack of services. Dietetic services need to be made available for all community settings including non-HSE funded nursing homes and for domiciliary visits as needed.

## Role of the Orthoptist

MS patients who have eye symptoms (eg blurred visual acuity (VA), double vision etc..) require orthoptic services to;

- Manage their diplopia
- Visual field assessment for patients with Optic Neuritis
- Screening for macular oedema in MS patients on the new oral DMT Fingolimod
- Referral to Ophthalmologist any patient with ocular defects such as optic neuritis or macular oedema.

Access to orthoptic management is not consistent throughout the country, as not all hospitals have orthoptic departments. Close links need to be established between orthoptics and neurology, to ensure this pathway is available to all MS patients.

## Role of the Neuropsychologist

The unpredictable course may lead to diverse cognitive difficulties (research estimates suggest between 43 and 70% are affected) which can often be best understood and ameliorated once understood fully through detailed neuropsychological assessment, as suggested by NICE (2014). Informed by this assessment Neuropsychologists can support individuals, their families and clinicians to understand and manage these difficulties appropriately. Cognitive difficulties can themselves cause considerable distress – appropriate feedback and recommendations can be an important part of helping people with MS to manage their difficulties more adaptively, potentially reducing their experience of distress.

Fatigue, a common feature of MS, may often lead to subjective experience of cognitive difficulties. Changes in emotional functioning may arise through primary neurocognitive changes, or through the demands of adjusting to what may be suddenly hugely altered circumstances, where a life changing diagnosis has been given

Direct therapeutic interventions can be of great help in supporting some with mood difficulties secondary to their condition. It is vital that teams working with clients with potentially significant psychological distress have access to support from colleagues with specialist training and experience in mental health as it applies to people with neurological illness.

In other cases, where patients may have very significant physical and / or cognitive difficulties, neuropsychological assessment can be invaluable in informing behavioural management plans, in establishing long term care choices and needs or in assessing capacity to make treatment or other decisions.

## Referral to other services

MS is a long term chronic condition and the vast proportion of care and treatment is provided in a non hospital setting. The neurology programme recognises that the effective management of MS is reliant on a range of other services and supports within the health services including:

- an effective response within primary care for the early diagnosis and ongoing management of the needs of people with MS
- access to multidisciplinary neurorehabilitation services within both the hospital and community
- access to respite care and long term care supports
- access to palliative care services and a palliative care approach including at earlier stages

- of the condition, to allow the person with MS and their family to plan effectively
- access to a range of disability and healthcare supports such as equipment, medical cards and personal assistants and home care packages.
- the current system of funding within the health services creates barriers to accessing services and supports based on age. This has significant implications for people with multiple sclerosis once they reach the age of 65. Many of the crucial services they require, for example neurorehabilitation services and PA services, are provided by physical and sensory disability services which are confined to the 18-65 age group. This creates significant challenges for people with MS in transitioning to older peoples services. It is vital that the pathway for MS provides for a smooth transition by ensuring that services continue to be provided once people with MS reach the age of 65.

While the programme focuses on a specific part of the MS pathway, it is recognised throughout this model of care that the effective delivery of neurology services, in common with all other specialisms within the health service, is critically reliant on the capacity of other areas of the health services, particularly community services, to address ongoing patient needs.

Patients with neuro-rehabilitative needs are comprehensively addressed within both the National Strategy & Policy for Neurorehabilitation and the Model of care for the National Clinical Programme for Rehabilitation Medicine (2010<sup>184</sup>).

The National Clinical Programme for Rehabilitation Medicine recognizes three distinct levels of specialization as described by Professor Lynne Turner-Stokes and attempts to address service needs around these three levels.

**Tertiary ‘specialist’ rehabilitation services:** These are high cost / low volume services, which provide for a high proportion of patients with highly complex rehabilitation needs that are beyond the scope of their local and regional specialist services. They provide a higher level of service in terms of specialist expertise, facilities and programme intensity to meet the needs of these patients. Patients attending tertiary specialist rehabilitation services typically require intensive, coordinated interdisciplinary intervention from four or more therapy disciplines.

**Regional specialist rehabilitation services:** These services are typically planned over a regional-level population, and are led or supported by a consultant trained and accredited in rehabilitation medicine, working both in hospital and the community setting. The specialist multidisciplinary rehabilitation team provides advice and support for local non-specialist rehabilitation teams

**Community specialist rehabilitation services:** Local specialist (community based) rehabilitation teams provide general multi-professional rehabilitation and therapy support for a range of conditions within the context of community services.

The largest body of evidence for rehabilitation in progressive or intermittent conditions comes from multiple sclerosis. The strongest recommendations are for:

- Short term intensive inpatient rehabilitation programmes
- Lower-intensity community-based programmes conducted over a longer period. It has been determined that treatment by community based multidisciplinary teams can be cost saving in terms of both bed day usage and reduced need for outpatient services. There is also strong evidence from Cochrane and other systematic reviews that

184 Turner Stokes, L (2010). Specialist neurorehabilitation services: providing for patients with complex rehabilitation needs. Available at: [http://www.bsrm.co.uk/publications/Levels\\_of\\_specialisation\\_in\\_rehabilitation\\_services5.pdf](http://www.bsrm.co.uk/publications/Levels_of_specialisation_in_rehabilitation_services5.pdf)

multidisciplinary rehabilitation can improve the experience of living with a long term neurological condition, both at the level of functional activity and societal participation.

## MS Ireland

MS Ireland provides a wide range of services in the community for people with MS and their families. MS Ireland plays an important role in supporting, educating and advising the person with MS and their families from diagnosis throughout their journey with MS. The role can be multifaceted and can include recognising, promoting and enhancing the person's ability to meet their own needs and solve their own problems and to assist in mobilising the necessary resources to carry out this in a bid to introduce self-management and independence.

Services include:

### 1. Solution focused **Casework/ Case Management**

Ms Ireland offers a Case Work service to people with MS and their families, especially individuals with a recent diagnosis, to navigate the complex services system. Case work supports the person with MS early in the disease course and throughout the transitional changes that MS, as a disease, presents. The Case Work Service is available to any person with MS and their family members in dealing with the many challenges that they face as a family unit.

### 2. **Symptom Management/Educational Programmes**

Community based symptom management and educational programmes are planned to enable people with MS and their carers/families to promote healthy life choices and positive mental health in a supportive environment. Programmes are aimed at supporting people with MS to improve their coping strategies, provide information so that people can better manage their condition and take responsibility for their own health and wellbeing. MS Ireland also run a broad range of tailor made exercise programmes throughout the country. These programmes include physiotherapy led classes, fitness instructor led programmes, yoga classes etc.

### 3. **The MS Care Centre.** This is the only dedicated respite service for people with MS in Ireland. The MS Care Centre is a twelve bedded facility and has a multidisciplinary team which includes MS Clinical Nurse Specialist, physiotherapist and care staff. Services at the MS Care Centre include:

- ◆ Short term respite
- ◆ Multidisciplinary Team Neurological Assessment
- ◆ Referral to local services, e.g. PCCC physiotherapy, occupational therapy etc.

### 4. **MS Information Line:** The Information Line (1850 233 233) provides confidential information and support to those living with MS, their families, health professionals, employers and others affected by or interested in MS.

### 5. **Information Service:** Information is a key aspect of living with MS as it enables and empowers people and families to make decisions about how they live their life. Information assists people to choose where to go for medical advice, who to contact in the community re interventions, how to manage symptoms, how to talk to their family about MS, where to go for support and to meet other people.



- 6. Research:** Research is a key component in improving the health and quality of life for people with MS. Investigations to improve the understanding of the conditions' mechanism, translational research into how this knowledge can be useful and practical, what interventions can be beneficial and how service delivery can positively impact, are all considerations driving the research agenda. MS Ireland has a long history in funding and supporting research in many areas of MS and supports projects as funding becomes available.
- 7. Advocacy Role:** To represent the views and concerns of people with MS at local, national and international levels. Advocating on an individual and collective platform for the improvement in services, resources and policies affecting people with MS. MS Ireland also advocates on MS specific issues e.g. Access to treatments.
- 8. Local Voluntary Branches:** MS Ireland has a network of 39 voluntary Branches nationally that are supported by MS Ireland nationally and regionally. Voluntary Branches are run for people affected by MS by people affected by MS.

## Appendix 4; Parkinson's Disease Pathway

*The fight is not won or lost far away from the witnesses, behind the lines, in the gym, and out there on the road; long before I dance under those lights"*

*Muhammad Ali*

Parkinson's disease (PD) is a progressive neurodegenerative condition resulting from death of the dopamine containing cells of the substantia nigra. There is no consistently reliable test that can distinguish PD from other conditions that have similar clinical presentations. The diagnosis is primarily a clinical one based on the history and examination (RCP 2006)<sup>185</sup>.

### Prevalence of Parkinson's Disease

On the basis of international incidence studies, it is estimated that Parkinson's disease affects 1 in every 500 people. Based on the last census in Ireland (2011) the population size is 4,588,000 (CSO 2011)<sup>186</sup> which would indicate that there could be up to 9,176 people with Parkinson's disease in Ireland. There has been no significant epidemiological study of Parkinson's disease within the Republic of Ireland, and given some of the difficulties in precisely diagnosing Parkinson's disease it is evident that there is a lack of precision in relation to the number of people in the Republic of Ireland who have Parkinson's disease. The Neurology Programme recognizes the need for accurate baseline statistics on the prevalence of Parkinson's disease in Ireland as a necessary first step towards the more effective management of the disease.

People with PD present with a different range of symptoms and responses to treatment. The nature and severity of symptoms, and the rate at which the condition progresses will also be individual. Symptoms may take years to progress to a point where they cause major problems. Drugs are the main treatment to help control the symptoms of Parkinson's disease. These treatments are most effective when supported by access to multidisciplinary input from health and social care professionals. Surgery may be very rarely appropriate in the later stages of PD if drug treatments become ineffective.

### Parkinson's has three main motor symptoms:

**Tremor** – This may begin in one hand or arm and is more likely to occur when the affected part of the body is at rest. Tremor will usually decrease or disappear when the affected part is being used and often becomes more noticeable when a person with Parkinson's disease is anxious or excited. About 70 percent of people with PD have a tremor and it is slightly less common in younger people with Parkinson's disease.

**Muscular rigidity or stiffness** – This is a common early sign in people with Parkinson's disease. Some people find their posture becomes stooped, or that their face becomes stiff, making facial expressions more difficult. Impairment in activities of daily living (ADL)/function becomes apparent.

**Slowness of movement** – People with Parkinson's often find that initiating movements becomes more difficult or that it takes them longer to perform movements. Lack of co-ordination when making movements can also be a problem.

In addition to the above three main motor symptoms, people with Parkinson's may experience a range of other motor symptoms such as freezing of gait, postural instability, stooped posture.

185 The National Collaborating Centre for Chronic Conditions. Parkinson's Disease; National clinical guideline for diagnosis and management in primary and secondary care. London: Royal College of Physicians, 2006

186 Central statistics office : <http://www.cso.ie/multiquicktables/quicktables.aspx?id=cna13>.

## Non-motor features of Parkinson's disease

Non-motor features are of huge importance to patients with PD and have a major impact on quality of life. Overall, non-motor features can be classified under the following headings;

Neuropsychiatric symptoms	Sleep Disorders
<ul style="list-style-type: none"> <li>– Depression, apathy</li> <li>– Anxiety, panic attacks</li> <li>– Hallucinations</li> <li>– Delusions, paranoia</li> <li>– Dementia</li> <li>– Obsessional behaviour</li> </ul>	<ul style="list-style-type: none"> <li>– Restless legs</li> <li>– REM behavior disorder</li> <li>– Excessive daytime somnolence</li> <li>– Vivid dreaming</li> <li>– Insomnia</li> </ul>
Autonomic symptoms	Gastrointestinal symptoms
<ul style="list-style-type: none"> <li>– Bladder disturbances (urgency, nocturia, frequency)</li> <li>– Sweating</li> <li>– Orthostatic hypotension (falls, pain)</li> <li>– Sexual dysfunction (hypersexuality, erectile impotence)</li> </ul>	<ul style="list-style-type: none"> <li>– Dribbling of saliva</li> <li>– Dysphagia/choking</li> <li>– Reflux</li> <li>– Vomiting</li> <li>– Nausea</li> <li>– Constipation</li> <li>– Faecal incontinence</li> </ul>
Sensory symptoms	Other symptoms
<ul style="list-style-type: none"> <li>– Pain</li> <li>– Paresthesia</li> <li>– Olfactory disturbance</li> </ul>	<ul style="list-style-type: none"> <li>– Fatigue</li> <li>– Diplopia</li> <li>– Blurred vision</li> <li>– Seborrhea</li> <li>– Weight loss</li> </ul>

**Table 1; non-motor features of Parkinson's disease**

### Other complex symptoms include;

- Motor fluctuations (on/off, dyskinesia, dystonia)
- Symptoms of wearing off (from medication);
- Increase in motor symptoms (tremor)
- Low mood
- Anxiety/panic attacks
- Irritability/fear
- Sweating
- Cramps/pain
- Peculiar feeling in stomach

### Atypical Parkinson's Disease

Atypical Parkinson's disease (AP) is an umbrella term for a number of parkinsonian syndromes. Being able to differentiate between PD and Atypical Parkinson's (AP) is highly relevant, for several reasons. First, patients find it important to know which specific disease they have. Second, the prognosis varies greatly across the different causes of Parkinsonism. In general, disease progression is slower in PD compared with AP. Third, an accurate diagnosis is important to prompt attention to disease-

specific complications, such as nocturnal inspiratory stridor in MSA patients (which is a cause of sudden death in this disorder), or the ‘motor recklessness’ and concomitant injurious falls seen in patients with Progressive Supranuclear Palsy (PSP). Medication effects are typically much less in AP, with fewer patients that respond, and a more modest and temporary improvement for those that do respond. Fourth, differentiation between PD and AP is important for research purposes, as a correct diagnosis is needed to include the right patients for specific trials.

Once the presence of Parkinsonism has been established, the second step is to search thoroughly for additional symptoms and signs. These additional symptoms– signaling the presence of AP – are commonly referred to as the ‘red flags’ for AP (Aerts et al 2012)<sup>187</sup>.

**Important red flags pointing towards atypical or symptomatic Parkinsonism (Pirker 2014)<sup>188</sup>;**

- Parkinsonism poorly responsive to levodopa
- Rapid disease progression
- Early postural instability and falls (especially within the first year after symptom onset)
- Early, severe postural abnormalities (disproportionate antecollis, camptocormia)
- “Wheelchair sign”
- Early, severe dysarthrophonia or dysphagia
- Respiratory stridor
- Atypical (jerky) tremors and myoclonus
- Cerebellar ataxia
- Pyramidal signs
- Early autonomic failure, especially urinary incontinence
- Early dementia
- Early visual hallucinations, especially in untreated patients
- Vertical gaze palsy
- Apraxia

Types of Atypical Parkinson’s (AP)

- ◆ Progressive Supranuclear Palsy (PSP)
- ◆ Multiple System Atrophy (MSA)
- ◆ Drug-induced Parkinsonism
- ◆ Vascular Parkinsonism
- ◆ Dementia with Lewy bodies (DLB)
- ◆ Corticobasal Degeneration (CBD)
- ◆ Numbness/tingling in fingers

187 Aerts MB et al. Improving the Diagnostic accuracy in parkinsonism. A three-pronged approach. *Pract Neurol*. 2012. 12(2): 77-87

188 Pirker W. Atypical Parkinsonian disorders – a clinical introduction. 4th International Congress of Geriatrics and Gerontology. Venice May 2014

## The Patient Pathway



### Initial presentation

Parkinson's disease should be suspected in people presenting with tremor, stiffness, slowness, balance problems and/or gait disorders. These patients should ideally be referred to a neurologist for confirmation of diagnosis or a geriatrician with a specialist interest in PD. Evidence would suggest that there are discrepancies between the diagnostic ability of experts versus non-experts in relation to PD. The National Clinical Guideline for diagnosis and management of Parkinson's disease in primary and secondary care advises that 'the diagnosis of PD is wrong in around 47% of community ascertained cases, 25% of non-expert secondary care diagnosed cases and 6-8% of cases diagnosed by an expert'.

Since some medications can mask the symptoms and signs of PD, it is recommended that treatment is not initiated prior to assessment by neurologist.

- All patients with suspected PD should be referred immediately without the commencement of medications to a neurologist (or geriatrician with specialist interest) with expertise in the differential diagnosis of this condition. The initial GP referral should be sensitively handled.
- Patients should be seen within 6 weeks of referral as per international guidelines (NICE 2006)<sup>189</sup>.
- The specialist diagnosis should be emphatic and give hope. Feedback from consultation with service user identified this as an area for further development. Subjective reports indicate that people did not feel they were given adequate information at the time of diagnosis. Delivery of such a diagnosis requires sensitivity. The diagnosis should be given in person, ensuring enough time for discussion (suggest 45-60 minutes) with provision of printed materials about the disease, about support and advocacy organisations and informative websites. A copy letter summarizing the discussion can be helpful for patients and carers. When possible, a review within 2-4 weeks follow up/of diagnosis should be scheduled.
- The diagnosis of PD should be reviewed regularly (intervals of 6 to 12 months) and reconsidered if atypical features develop.
- People with PD should have regular access to specialist nursing care who can;
  1. Provide clinical monitoring and adjust medication if indicated
  2. Provide a continuous point of contact for support
  3. Provide information/guidance about clinical and social matters of concern

189 NICE clinical guideline 35 (2006)

- People with PD should have access to up to date and accurate information. This should include information about symptoms, treatment options and what is available to people living with the condition. Information is vital to help patients make informed choices and better manage the condition for themselves. While general information is of benefit, there is a need for patients to be given individualised information, education and support related to their own individual experience and symptoms.
- People with PD should have access to a Multidisciplinary Team for management of their symptoms including mobility, functional independence, effective communication, swallowing assessment etc.
- Maintaining wellbeing in the community setting should be central to the management of the person with PD. Patients with PD in a hospital setting do not do as well as people without PD. The national average hospital stay for a male with PD is 20.2 days which is more than three times greater than the average length of stay of a male without PD (6.3days). The average length of stay for a female with PD is 14.2 days, more than double the average length of stay for a female without PD<sup>190</sup>.
- People with PD and their care partners should be supported with respect to self-management of their symptoms. Self-management is not simply about completing a timebound course but is an ongoing process requiring consistent support through a patient's lifetime to enable effective management of the disease as it progresses and evolves. Self-management programmes for people with PD should include information on medication awareness.
- Palliative care requirements should be considered throughout all phases of the disease. As referred to throughout this document, all staff working with patients with progressive neurological conditions should have competencies in the areas of palliative support appropriate to their grade/discipline.

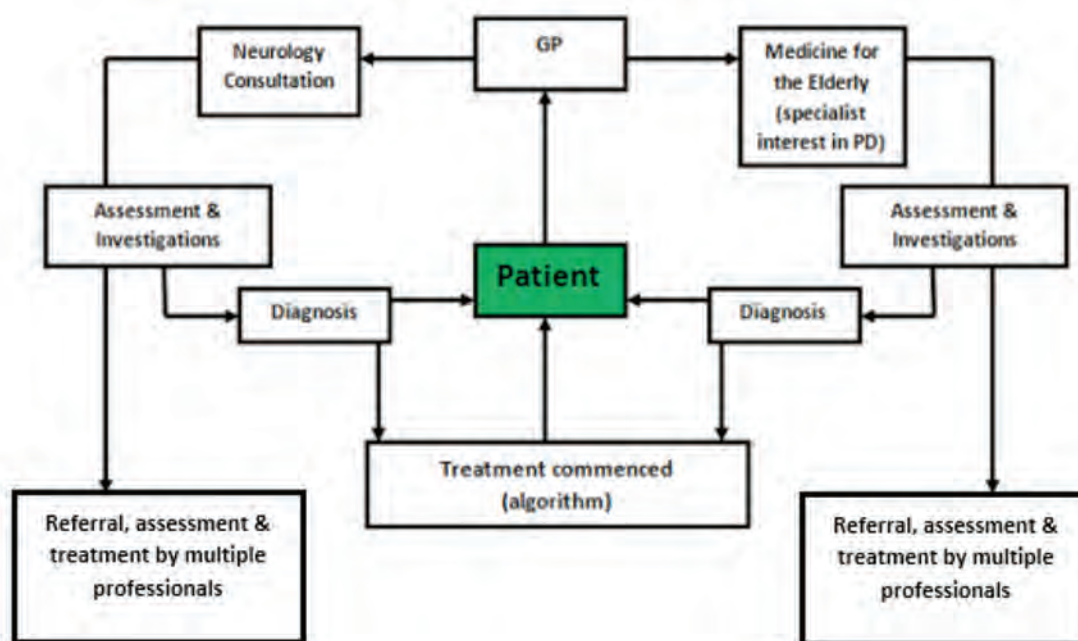


Fig 1; Patient Pathway

190 These Hospital In-Patient Enquiry (HIPE) figures were compiled by the Economic and Social Research Institute on behalf of the HSE in 2012



## Diagnosis & Treatment

It is generally accepted that the diagnosis of PD should be based on clinical findings. The Neurology programme supports the most widely accepted clinical criteria are the UK PDS Brain Bank Criteria (table 17)

<b>UK PDS Brain Bank Criteria for the diagnosis of PDS</b>	
<b>Step 1. Diagnosis of a parkinsonian syndrome</b>	
	<p>Bradykinesia and at least one of the following:</p> <ul style="list-style-type: none"> <li>– Muscular rigidity</li> <li>– Rest tremor</li> <li>– Postural instability unrelated to primary visual, cerebellar, vestibular or proprioceptive dysfunction</li> </ul>
<b>Step 2. Exclusion criteria for PD</b>	
	<p>History of;</p> <ul style="list-style-type: none"> <li>– Repeated strokes with stepwise progression</li> <li>– Repeated head injury</li> <li>– Antipsychotic or dopamine depleting drugs</li> <li>– Definite encephalitis and/or oculogyric crises on no drug treatment</li> <li>– More than one affected relative</li> <li>– Sustained remission</li> <li>– Negative response to large doses of levodopa (if malabsorption excluded)</li> <li>– Strictly unilateral features after 3 years</li> <li>– Other neurological features: supranuclear gaze palsy, cerebellar signs, early severe autonomic involvement, babinski sign, early severe dementia with disturbances of language, memory or praxis</li> <li>– Exposure to known neurotoxin</li> <li>– Presence of cerebral tumour or communicating hydrocephalus on neuroimaging</li> </ul>
<b>Step 3. Supportive criteria for PD</b>	
	<p>Three or more required for diagnosis of definite PD:</p> <ul style="list-style-type: none"> <li>– Unilateral onset</li> <li>– Rest tremor present</li> <li>– Progressive disorder</li> <li>– Persistent asymmetry affecting the side of onset most</li> <li>– Excellent response to levodopa</li> <li>– Severe levodopa-induced chorea</li> <li>– Levodopa response for over 5 years</li> <li>– Clinical course of over 10 years</li> </ul>

**Table 2; UK PDS Brain Bank Criteria**

2.1 Symptomatic therapies for PD treat the symptoms of the disease but do not necessarily slow the rate of progression of the condition.

There is no single drug of choice in the initial pharmacotherapy of early PD. Any decisions regarding treatment should be made in collaboration with the patient with all options clearly and objectively laid presented for the patient to actively participate in joint decision making. Approaches to medication prescription should also be influenced by the age of onset of PD, the severity of symptoms, the symptom control obtained and the degree to which patients tolerate the medications prescribed.

The following algorithm provides a guide for the pharmacological approach to managing patients with Parkinson's disease<sup>191</sup>.

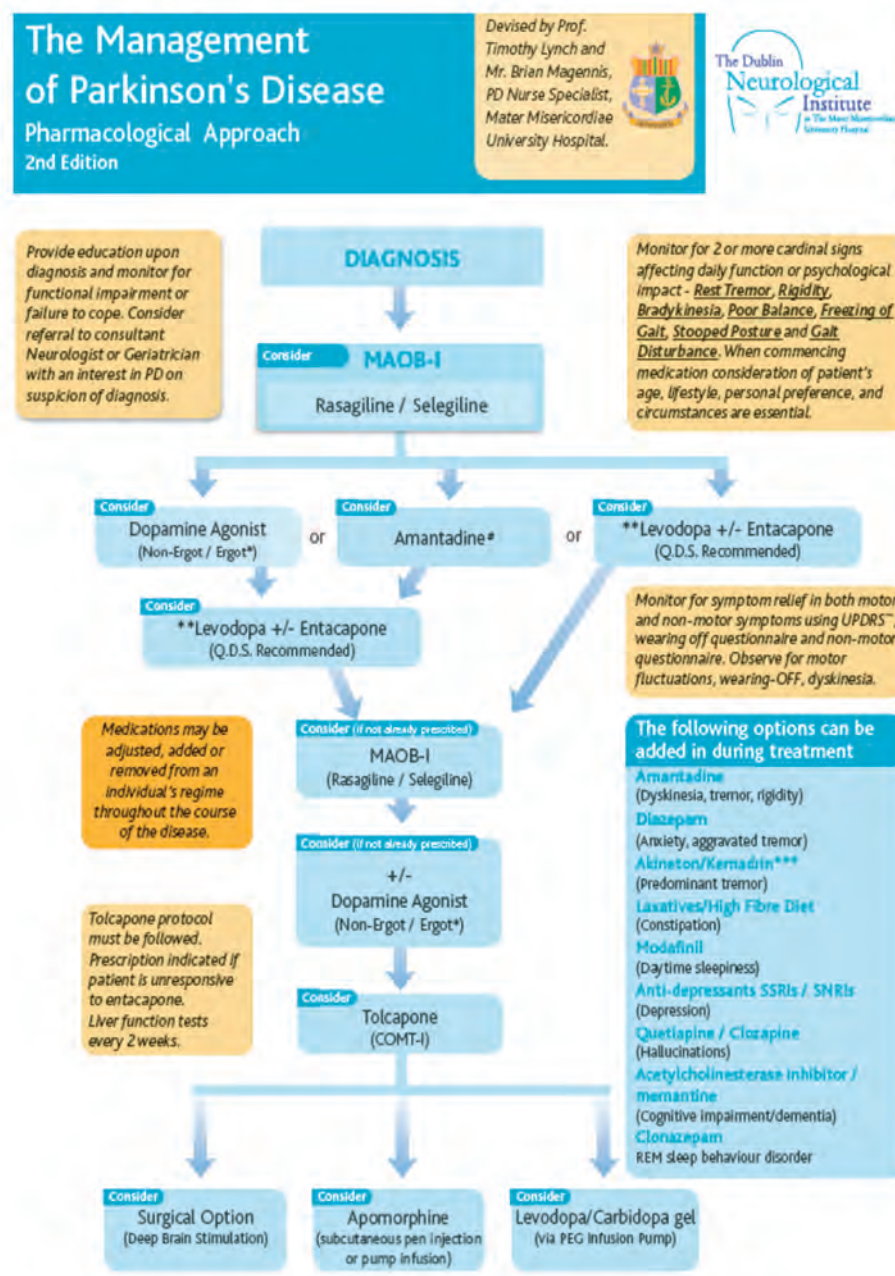


Fig 2; The Management of Parkinson's disease. A pharmacological approach

191 Lynch T, Magennis B. The Management of Parkinson's Disease. A pharmacological approach 2nd Edition

## 2.2 Deep Brain Stimulation (DBS)

DBS is a long term treatment option for adult patients with selected movement disorders including Parkinson's disease, essential tremor and dystonia. Patients with PD account for 77% of the referrals for DBS, which is a surgical procedure aimed at providing relief of motor function symptoms that are no longer controlled by drug therapy.

DBS is a neurosurgical intervention whereby a surgically implanted neurostimulator delivers controlled electrical stimulation to precisely targeted areas in the brain.

As with pharmacological treatments in PD DBS is not curative in nature. The aim of this intervention is to improve quality in life and maximize functional independence.

Both quality of life and efficacy of the treatment should be objectively measured, both in terms of determining suitability of DBS as a treatment option, and indeed measuring its success. The objective measures generally advocated are the Parkinson's disease Questionnaire (PDQ – 39<sup>192</sup>) and the Unified Parkinson's Disease Rating Scale (UPDRS<sup>193</sup>).

DBS is not currently available as a treatment option within Ireland at present, following the recommendations of a HIQA HTA in 2012<sup>34</sup>. Treatment is available through the Treatment Abroad Scheme (TAS).

Currently, patients deemed eligible for DBS are referred by their Neurologist for consideration for treatment through the TAS. On approval, a referral is made for treatment overseas, generally in the UK. Full assessment of suitability is carried out by the center providing the DBS. On meeting the criteria, the patient will be scheduled for the surgical procedure followed by a series of follow up/review appointments in the UK.

Patients receiving DBS through the TAS remain under the clinical management of their Consultant Neurologist in Ireland, and regular reviews with this consultant are also scheduled in tandem with reviews in the UK.

It is acknowledged that the current system is less than ideal for the patient their families and physicians. The difficulty associated with travel, particularly given that individuals who require this treatment have significant difficulties with their movement and function; means that for some patient's access to this treatment is limited and as such the current system is not equitable.

The Neurology programme recommends the establishment of a Deep Brain Stimulation (DBS) service in Ireland to meet the needs of our patients who require this service. Consideration could be given to this service being established on a cross border basis with services in Northern Ireland.

## 3.0 Referral to Parkinson's disease Clinical Nurse Specialist

The particular roles and functions which are performed by Parkinson's Disease Clinical Nurse Specialists (PDCNS) include the following:

- Assessing the person with Parkinson's disease and identifying their needs – they often

192 Available at; [http://isis-innovation.com/wp-content/uploads/2014/07/Final\\_PDQ-39\\_English\\_UK\\_SAMPLE.pdf](http://isis-innovation.com/wp-content/uploads/2014/07/Final_PDQ-39_English_UK_SAMPLE.pdf)

193 Available at; <http://viartis.net/parkinsons.disease/UPDRS1.pdf>

act as key workers linking their patients to professionals and services that can help them. They are the coordinator of the patient's care and a key contact for the patient, family, community nurses, GPs and nursing home staff. In addition, the Nurse Specialist has a key role in educating non-specialist practitioners. This includes creating awareness of the importance of involving family members and carers in the overall management of the patient's condition, educating on medication management.

- Developing care plans.
- Helping with drug management. Medication effectiveness can be prolonged by careful ongoing assessment and review of the patient as the disease progresses. This forms a key component of the PDCNS role.
- Monitoring symptoms; Symptom monitoring is essential throughout the disease but becomes increasingly important when patients commence or change medication, including increasing or decreasing doses. The Nurse Specialist can use a number of Parkinson's-specific assessment tools such as the unified Parkinson's disease rating scale (UPDRS) and the Non-Motor Questionnaire to carry out a thorough assessment
- Providing emotional and lifestyle support.
- Providing support when the person with Parkinson's disease is admitted to hospital.
- Outpatient consultation
- Research

There are only 5 Parkinson's Disease Nurse Specialists in the Republic of Ireland for a population of approximately 4,500,000 (compared to 310 Parkinson's Disease Nurse Specialists in Britain for a population of 64,000,000). There is a clear need to improve the number and range of specialist services which are available to people with Parkinson's disease.

## 4.0 Management of Patients with Parkinson's disease

4.1 Patients with PD should expect regular reviews i.e. every 6-12 months, with their treating neurologist. The purpose of this review should be to monitor and manage the motor and non-motor features of the disease progression, both the motor and non-motor features. The monitoring of medications is also required as is the generation of referrals to any ancillary services.

### 4.2 **An individualised Treatment Plan:**

People with PD should be included in the development of an individualized treatment plan that encapsulates both medicine and non-medicine based treatment for the individual, the effectiveness of which is reviewed at regular intervals, developed by the medical practitioner (be it the neurologist, PD Nurse or GP) in conjunction with the Multidisciplinary Team and with the person with Parkinson's at the centre of this planning team.

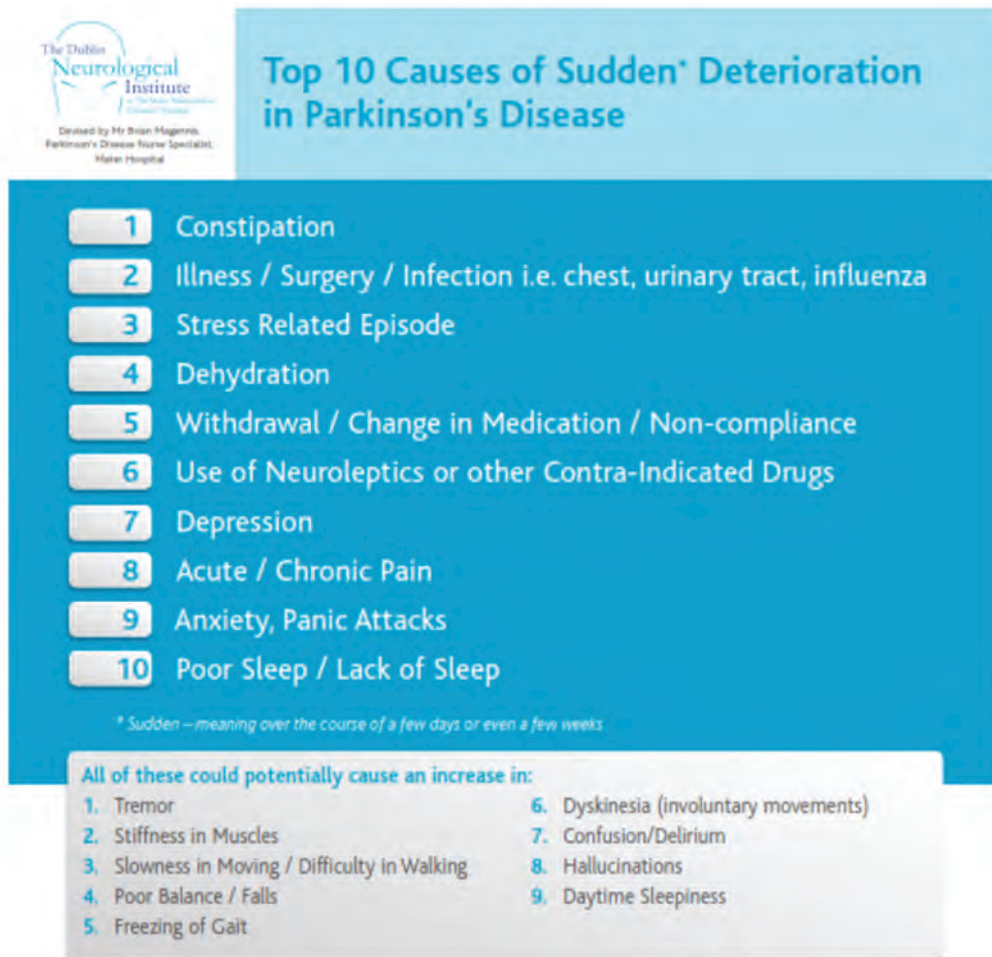
Ideally the plan should include all the appropriate options from an early stage following diagnosis in order to take pre-emptive action with regard to the progression of the disease.

### 4.3 **Avoidance of hospital admissions**

This includes education in relation to the main causes of sudden deterioration in a patient with Parkinson's disease. These causes are generally associated with symptom management as opposed to progression of the disease. As such, education on managing these symptoms is essential. The top 10 causes of sudden deterioration which often lead



to hospital admission are outlined in the table below. (Magennis & Corry 2013)<sup>194</sup>



**Fig 3; 10 causes of sudden deterioration in Parkinson's disease**

Treatment/management of these features should be tailored to the individual with due consideration to current medications and potential interactions/contraindications. Non-pharmacological interventions can also be explored. These are often managed by a clinical nurse specialist and members of the MDT but may require referral to other specialists such as neuropsychiatry, neuropsychology for expert opinion.

#### 4.4 Management in Hospital setting when admission is unavoidable;

As noted above, individuals with PD do not do well in hospital. If a hospital admission is necessary, particular attention needs to be paid to ensuring that the person gets their medication on time. The implications for the person can be very significant if medications are not administered on time with potential motor and non-motor complications. The neurology programme would recommend improved education for both people with PD and indeed healthcare professionals with respect to the importance of optimal delivery of medications. Programmes such as the 'on time, every time' campaign led by

194 Parkinson's disease: top 10 causes of sudden deterioration. Magennis B, Corry M. 234 British Journal of Neuroscience Nursing October/November 2013 Vol 9 No 5

Parkinson's UK<sup>195</sup> should be promoted in Ireland, both in the community and in acute hospital wards. Within the acute hospital setting, grand rounds have proven to be an effective forum for education of staff on this issue (Sathyababu 2012)<sup>196</sup>. Considering the potential for harm to patients, the neurology programme would also recommend hospitals engage in regular audit of untimely administration of medications to patients with PD.

## 5.0 Consultation with service users

In the development of this pathway, the neurology programme engaged in a number of consultations. While service users were invited to provide feedback on the pathway circulated through the patient organizations, a focus group was also convened to get direct feedback from service users and their families/carers.

The recurrent themes emerging from the focus group included but were not limited to;

- Difficulty accessing information from healthcare providers. Range and type of information given appears to vary significantly across the country with some service users reporting that they were given no information at time of diagnosis and had to seek information about their illness independently online.
- Age discrimination – i.e. <65's years unable to access MDT within community setting
- Variance in pathways across services, poor signposting re: what services are available and how to access them
- Access to medical card – should be based on diagnosis, not means tested
- Limited information provided on how to keep healthy i.e. health promotion
- Difficulty accessing neurologist, service users reported that access to neurologist should be at request of service user on an as-needed basis similar to the system currently in operation in the Netherlands. Patient determined reviews have shown to improve attendance rates in outpatient settings.
- Poor sharing of information between service providers & hospitals, resulting in significant duplication of assessments etc
- Concern over hospital admissions in the absence of a 'meds on time' programme in acute hospitals
- Lack of knowledge of PD amongst generalist staff in both hospital and community setting
- Lack of emotional support for patient & family
- Lack of information on what to expect i.e. prognosis
- Poor access to therapy in community, particularly cognitive rehabilitation
- Lack of self management programmes & information on health management i.e. nutrition, medication management etc
- Benefit of support groups and services providing participation support

The issues highlighted by users of this pathway echo the difficulties outlined by both the Laffoy Review 2007<sup>11</sup> and reinforced within this model of care. Implementation of the recommendations outlined within this model should begin to address the issues raised.

195 [http://www.parkinsons.org.uk/sites/default/files/publications/download/english/b104\\_getitontimebooklet\\_0.pdf](http://www.parkinsons.org.uk/sites/default/files/publications/download/english/b104_getitontimebooklet_0.pdf)

196 Sathyababu R. Management of Parkinson's disease medication in acutely admitted patients. BMJ Quality Improvement Reports 2012; 1, No.1 u473.w154



Ongoing engagement with service users will ensure that the programme continues to target areas which would improve patient experience within service delivery plans.

## 6.0 The Multidisciplinary (HSCP) Team

Condition	HSCP Disciplines	Interventions
Parkinson's Disease	Dietitian	<ul style="list-style-type: none"> <li>Management of nutritional complications</li> <li>Assessment for &amp; management malnutrition</li> <li>Self feeding support</li> <li>Management medical side effects</li> <li>Nutritional supplementation</li> <li>Involvement in process for consideration of gastrostomy insertion</li> <li>Planning home enteral feeding</li> <li>Consideration of drug-nutrient interactions</li> <li>Appropriate dietary advice</li> </ul>
	Neuropsychology	<ul style="list-style-type: none"> <li>Assessment of mood &amp; adjustment</li> <li>Psychotherapeutic intervention for depression, anxiety &amp; psychosis</li> <li>Interventions to promote adjustment &amp; cognitive rehabilitation</li> <li>Assessment for DBS</li> <li>Capacity assessment</li> <li>Emotional support</li> </ul>
	Occupational Therapy	<ul style="list-style-type: none"> <li>Occupational Therapy</li> <li>Assessment &amp; management of cognitive skills</li> <li>Assessment &amp; management of physical skills</li> <li>Assessment &amp; management of perceptual skills</li> <li>Optimising functional ability</li> <li>Supporting participation in relationships, roles, work, leisure &amp; driving</li> <li>Positioning &amp; posture</li> <li>Seating assessment</li> <li>Moving and handling techniques</li> <li>Self management</li> </ul>

	Orthoptist	Assessment of blurred vision & diplopia
	Physiotherapy	<b>Maximise quality of movement</b> <b>Improve general fitness</b> <b>Minimise secondary complications</b> <b>Self management</b> <b>Optimising safety</b> <b>Transfer training</b> <b>Gait rehabilitation</b> <b>Balance</b> <b>Falls prevention</b> <b>Manual activities</b> <b>Pain management</b> <b>Respiratory function</b> <b>Compensatory strategies</b>
	Speech & Language Therapy	Communication (speech, voice, language) assessment and management Eating, drinking, and swallowing assessment and management Specialist alternative and augmentative communication evaluation and management Capacity assessment Assessment for Deep Brain Stimulation Education, support, and counselling

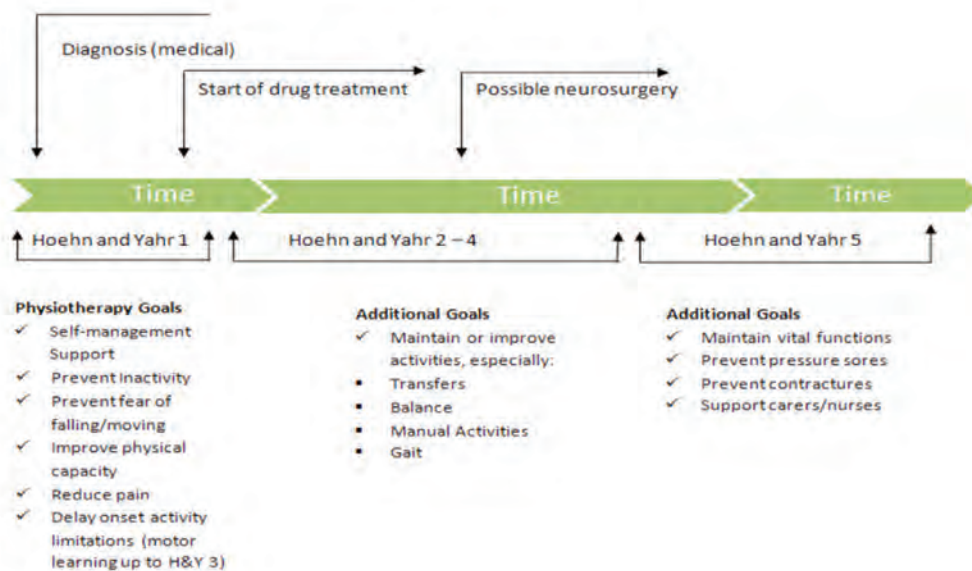
**Table 3; Role of the Multidisciplinary Team in the Management of patients with Parkinson's Disease**

### 6.1 Physiotherapy in Parkinson's disease

Physiotherapists are one of the key personnel in the multi-disciplinary team working with a person with PD, at all stages of the condition. Physiotherapists are expected to treat patients with up-to-date evidence-based methods. The European Physiotherapy Guideline for Parkinson's disease (Keus et al 2014)<sup>197</sup> was developed as a collaboration between the physiotherapy societies of twenty European countries, including the Irish Society of Chartered Physiotherapists (ISCP). It is recommended that all physiotherapists involved in the care of people with PD utilize this guideline (or more up-to-date evidence) to guide their assessment and interventions for people with PD.

197 Keus, S., Munneke, M., Graziano, M., Paltamaa, J., Pelosin, E., Domingos, J., Bruhlmann, S., Ramaswamy, B., Prins, J., Struiksma, C., Rochester, L., Nieuwboer, A. & Bloem, B. (2014) 'European Physiotherapy Guideline for Parkinson's Disease'. [in KNGF/ParkinsonNet, The Netherlands. Available at: <http://www.parkinsonnet.info/euguideline> (Accessed: 1st February 2015).

There are certain times when it is appropriate for a person with Parkinson's disease to be referred to physiotherapist. This can be based on the stage of the disease, specific impairments or limitation in function and in the context of a hospital or nursing home admission. At all stages of the disease a physiotherapist can offer education and advice, and if indicated, a course of treatment. For interventions targeting impairments and activity limitations experienced by people with PD, three modalities of intervention can be identified; exercise, practice and movement strategy training, each of which can be supported by providing information and education. (see figure 31)



**Fig 4; Core areas of physiotherapy related to disease progression –European Physiotherapy guideline for Parkinson's disease (2014)**

## 6.2 Role of the Speech and Language Therapist

Speech and Language Therapists (SLTs) may be part of a multidisciplinary neurology team in both hospital and community settings working with patients at all stages of PD.

The SLT's role includes

- Assessment and diagnosis of communication and/or swallowing problems that may result from PD, which may also contribute to the differential medical diagnosis (RCSLT, 2014).
- Completion of instrumental speech, voice, and swallowing assessments as appropriate to evaluate communication and/or swallowing problems. Instrumental dysphagia assessments including videofluoroscopy and fiberoptic endoscopic evaluation of swallowing (FEES) improve the accuracy of identifying both the nature of dysphagia and appropriate management (RCSLT, 2014).
- Management of communication and/or swallowing problems appropriate to a person's individual presentation, needs, and stage of condition.
- Education, counselling, and support of patients and their involved others in respect to communication and/or swallowing function and decisions about care (RCSLT, 2014, 2009).
- Promotion of communication abilities that further the independence and advocacy of patients with PD.
- Onward referral for specialist alternative and augmentative communication evaluation

and management to designated assistive technology services as indicated in the care of patients with PD (RCSLT, 2009).

- Improvement of vocal loudness and pitch range, with speech therapy programmes including Lee Silverman Voice Treatment (LSVT).
- Teaching strategies to optimise speech intelligibility.

Published guidelines for the role of the SLT in the management of PD have been published by parkinsonnet.nl/<sup>198</sup>

### 6.3 Occupational Therapy in the management of Parkinson's Disease.

The Occupational Therapist addresses the physical, psychological, psychosocial, environmental and occupational needs of this client group.

Occupational therapy services for people with Parkinson's disease should be available when they are needed along the journey of their disease. This includes providing therapy at the various phases of the condition (diagnostic, minimal impairment, moderate disability and significant disability phases) (NAI, 2000).

ParkinsonNet have recently published guidelines for Occupational Therapy in the management of patients with Parkinson's disease<sup>199</sup>. Aragon & Kings (2010<sup>200</sup>) have also published best practice guidelines for occupational therapy for people with Parkinson's disease. The guidelines provide a detailed breakdown of evidence based assessment areas and interventions for occupational therapists. These areas include;

#### Assessment

Occupational Therapists routinely assess physical, cognitive and perceptual skills in patients with Parkinson's disease. Although there is no universally recognized exclusive occupational therapy specific assessment tool specific for Parkinson's disease, there are resources available from standardized measures used in research to measure mobility, functioning and quality of life.

#### Interventions

- ▲ Initiating and maintaining movement

Education and discussion with patients and their families on intrinsic and extrinsic cueing techniques are recommended.

- ▲ Optimising activities
- ▲ Supporting participation
- ▲ End of life care

198 Guidelines for Speech-Language Therapy in Parkinson's disease. Hanneke Kalf, Bert de Swart, Marianne Bonnier-Baars, Jolanda Kanters, Marga Hofman, Judith Kocken, Marije Miltenburg, Bas Bloem, Marten Munneke. Originally published in Dutch as Logopedie bij de ziekte van Parkinson. Een richtlijn van de Nederlandse Vereniging voor Logopedie en Foniatrie. © 2008 NVLF, Woerden 2008/Lemma Publishers

199 Guidelines for Occupational Therapy in Parkinson's disease Rehabilitation. Ingrid Sturkenboom, Marjolein Thijssen, Jolanda Gons-van Elsacker, Irma Jansen, Anke Maasdam, Marloes Schulten, Dicky Vijver-Visser, Esther Steultjens, Bas Bloem, Marten Munneke. Originally published in Dutch as 'Ergotherapie bij de ziekte van Parkinson. Een richtlijn van Ergotherapie Nederland', © 2008 EN, Utrecht 2008/Lemma Publishers.

200 Aragon, A & Kings, J. Occupational therapy for people with Parkinson's, Best practice guidelines. 2010. College of Occupational Therapists in collaboration with Parkinson's UK

### 6.4 Role of the Orthoptist

Patients presenting with Parkinson’s disease (PD) will need to be assessed by an Orthoptist when they develop ocular symptoms such as blurred vision or Diplopia (double vision).

### 6.5 Role of the Dietitian

Parkinson’s disease can result in a wide range of symptoms which can impact each individual differently. As the condition progresses, a number of nutritional complications can arise which places patients at increased risk of malnutrition. Dietetic support is an essential component of care in this patient group both in the hospital and community settings.

Support provided by the Dietitian can include:

- Individualised dietary advice for those deemed at risk of malnutrition
- Nutritional supplementation as indicated
- Involvement in the decision process for patients being considered for gastrostomy insertion
- Organisation and planning of home enteral feeding
- Consideration of drug-nutrient interactions and devising feeding regimens in accordance with same
- Provision of appropriate follow up for patients on home enteral feeding
- Appropriate dietary advice for issues such as constipation, dehydration and pressure sores
- Involvement in community MDT support groups eg. 8 week Living with Parkinson’s

There can frequently be difficulties referring some of these patient types to community/ outpatient settings due to lack of services. Dietetic services need to be made available for all community settings including non-HSE funded nursing homes and for domiciliary visits as needed.

### 5.6 Role of the Neuropsychologist

In the area of Parkinson’s disease, Neuropsychologists deliver direct care to patients and contribute to the work of the multidisciplinary PD team in many ways. Examples areas of input are shown in table below, taken from the excellent document “Psychological Services for people with Parkinson’s’ Disease” (BPS, 2009)<sup>201</sup>.

Assessment of mood and adjustment	Neuropsychological assessment
Psychotherapeutic intervention for depression, anxiety and psychosis	Promotion of long-term psychological adjustment
Interventions to promote psychological adjustment and cognitive rehabilitation	Family based interventions
Dissemination of psychological skills/ understanding of PD issues	Contributions to service developments and to research
Teaching, education and support for clinical and academic staff	

**Table 4 : Neuropsychologists’ contribution in the care of patients with PD (BPS, 2009)**

201 British Psychological Society & Parkinson’s Disease Society (Feb 2009). Psychological services for people with Parkinson’s disease.

Clinical Neuropsychologists are particularly important in clarifying the presence and nature of cognitive syndromes which can accompany Parkinsonism, contributing vital diagnostic information in the identification or outruling of syndromes including CBD, MSA and PSP (Troster, 2008)<sup>202</sup> Further, cognitive assessment can help monitor change and disease progression in such cases. Such assessments can inform treatment decisions, highlighting (for example) compromised executive functioning, which might mean an individual would struggle to use complex treatment delivery devices if unsupported.

In other areas, neuropsychological assessment can be particularly important in assessing decision making capacity of patients with cognitive compromise who may be required to make treatment or other decisions.

There is a significant therapeutic need to support people with PD in their adjustment to the condition and the challenges it brings (which might involve some degree of life review and end of life considerations). This adjustment is often complicated by the neurocognitive changes which may accompany the condition where there may be a greater propensity toward psychological and emotional changes than in other conditions due to dysregulation of dopaminergic, noradrenergic and serotonergic systems, along with the impacts of antiparkinsonian pharmacotherapies. The impulse control difficulties which can arise in PD can prove particularly challenging therapeutically, with often a need to engage with families and supporters, helping them understand the patient's difficulty, as well as how they can best help. Similarly the risk of psychosis can prove particularly challenging for patients and their supporters, requiring significant therapeutic input.

## 6.0 Self-Management

As referred to previously, the focus of managing people with PD in the community should be to enable them to self-manage their symptoms effectively and to avoid hospitalizations as far as possible.

Self-management as an effective strategy is introduced in section 10 where the overall principles are discussed. One of the core principles of a self-management programme is provision of education about the condition (Taylor et al 2014)<sup>203</sup>. Considering this, condition specific programmes may be appropriate. In the case of PD, a PD specific self-management programme has been developed by the support group, Move4Parkinsons. This programme identifies a model which includes 'Five Elements' that they believe draws together the key information on self-management for Parkinson's in one place.

202 Troster, A.I. & Fields, J.A. (2008). Parkinson's disease, progressive supranuclear palsy, corticobasal degeneration, and related disorders of the frontostriatal system. In J.E. Morgan & J.H. Ricker (Eds.), *Textbook of Clinical Neuropsychology* (pp.536–577). New York: Taylor and Francis.

203 Taylor S et al. A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions: PRISMS - Practical systematic Review of Self-Management Support for long-term conditions. Health Services and Delivery Research Volume: 2 Issue: 53. December 2014





Fig 5; The 5 Elements of self-management for people with Parkinson’s disease

### 7.0 The Patient Journey

The patient journey can be complex, with many individuals/services involved as demonstrated in figure below. At all times, the needs of the patient should be central in this journey.



Fig 6; Patient Journey

The flow chart above shows how a patient should progress through the stages of the illness between services. To allow for such a seamless flow through services in an Irish context, the delivery of care for Parkinson's disease needs to be adapted. While the majority of the pieces of the puzzle exist, the gaps in service currently are with respect to consistency across all services, and liaison between service providers.

'Best Care' is identified as being multidisciplinary in nature with management of the patient by specialist healthcare professionals with appropriate training and competencies. Clinical experience suggests that optimal management requires a multidisciplinary approach, with multifactorial health plans tailored to the needs of each individual patient (van der Marck et al 2009)<sup>204</sup>.

A 'person centred approach' needs to be explicitly stated as a cornerstone of the Pathway meaning that it is essential in determining the course of treatment of an individual with PD. Person centeredness requires more than a respectful attitude towards a patient or a personalised style of clinical engagement. Recent studies have identified six dimensions of person centred care;

1. Involvement of the person with PD
2. Provision of tailored information
3. Healthcare accessibility
4. Empathy and PD expertise
5. Collaboration and continuity of care
6. Emotional support (Van der Eijk et al 2011)<sup>205</sup> (Van der Eijk 2012)<sup>206</sup>.

Tailored, disease specific multidisciplinary clinics have been proven to be effective in terms of cost, outcomes and patient experience. For maximum effectiveness, these hospital based services should be complimented by specialist neurorehabilitation teams within the community, and other community/PCCC based services such as nursing management at home, health and social care professionals and palliative care. Robust communication systems should be developed to allow for seamless transition between services for the person with PD.

Support groups for people with PD include Move4Parkinsons and The Parkinson's Association of Ireland. People with PD should be directed towards these groups who play an active role in the management of the condition in the community providing services such as self-management training, peer support, access to accurate, timely and up to date information etc. They can enable patients to be more participative in their environment and play a key role in keeping people with PD healthy and engaged at home.

---

204 Van der Marck, MA, Kalf, JG, Sturkenboom, IHWM, Nijkrake, MJ, Munneke, M, Bloem, BR. Multidisciplinary care for patients with Parkinsons Disease. *Parkinsonism & Related Disorders*, Vol 15, Supplement 3, S219-S223, Dec 2009.

205 M. Van der Eijk, M.J. Faber, S. Al Shamma, M. Munneke, B.R. Bloem "Moving towards patient-centered healthcare for patients with Parkinson's disease" *Parkinsonism Related Disorders*, 17 (5) (2011), pp. 360–364

206 M. Van der Eijk, M.J. Faber, I. Ummels, J.W. Aarts, M. Munneke, B.R. Bloem "Patient-centeredness in PD care: development and validation of a patient experience questionnaire" *Parkinsonism Related Disorders*, 18 (9) (2012), pp. 1011–1016

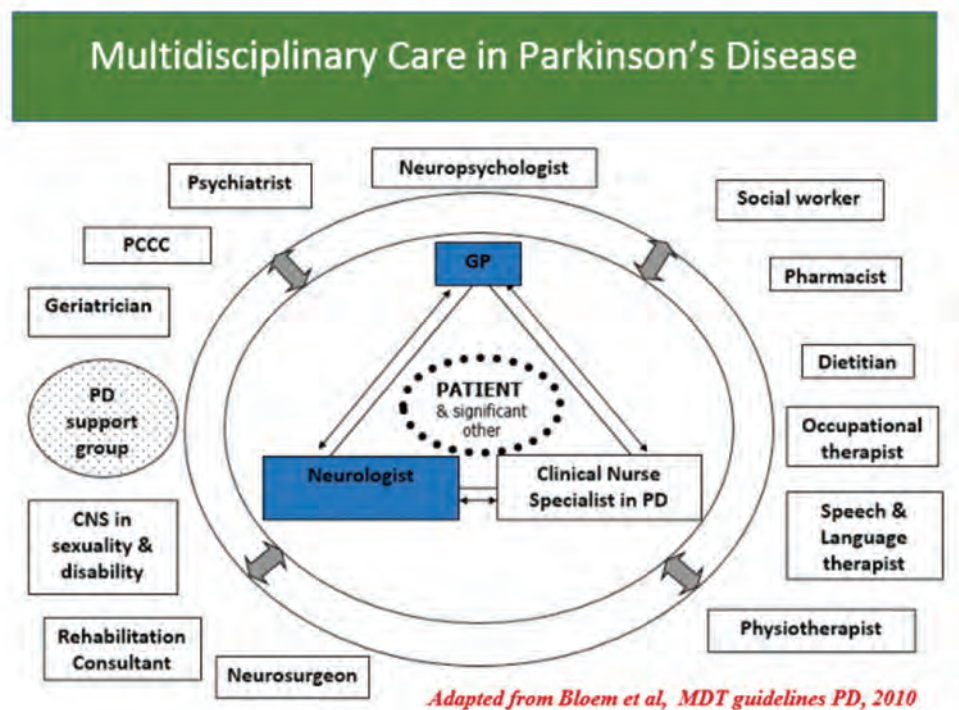


Fig 7; Adapted from Bloem et al, MDT Guidelines PD, 2010

## Appendix 5; Patient Pathway Motor Neurone Disease

### Introduction

Motor Neurone Disease (MND) is a progressive neurodegenerative condition characterised by degeneration of upper and lower motor neurons. There is now considerable evidence that MND is a spectrum of conditions, characterised by distinctive subphenotypes with different disease trajectories and outcomes. 80% of patients present with evidence of combined upper and lower motor neuron involvement- this phenotype is sometimes called Amyotrophic Lateral Sclerosis (ALS), based on original descriptions by Charcot. The international convention is now to refer to the condition as ALS/MND to avoid confusion.

There is now considerable clinical, genetic, imaging and pathology evidence that ALS/MND is a heterogeneous condition. In general, ALS/MND is characterized by progressive decline of all voluntary motor function. Onset is by convention divided into those with progressive decline in limb function (spinal onset), progressive involvement of speech and swallowing (bulbar onset), progressive decline in respiratory function (respiratory onset), and those who present with cognitive or behavioural impairment (cognitive onset). In general the condition progresses, spreading from one region to another and death is generally from respiratory failure. Life expectancy is 3-5 years from the first symptom: 70% of incident cases die within 36 months of onset. There is an acknowledged overlap between ALS and frontotemporal dementia. Over 60% of people with MND exhibit evidence of cognitive or behavioural impairment, and 13% have evidence of a full-blown dementia. Executive impairment is generally progressive and associated with reduced survival. The peak age of onset of ALS is 62 years and the male to female ratio is 1.2:1. Spinal ALS is more common in men and bulbar onset in women.

Up to 15% of ALS is familial. Over 20 genes of major effect have been identified. In Ireland over 50% of all familial ALS is caused by a repeat expansion in the gene C9orf72. The causative gene(s) in the remaining 50% of familial ALS in Ireland remain to be determined as variants in other known genes are extremely rare in the Irish population.

### Restricted Phenotypes

- Progressive Bulbar Palsy (PBP) is a restricted variant of MND, with involvement of the brain stem which contains lower motor neurons needed for swallowing, speaking, chewing, and other functions. Symptoms include pharyngeal muscle weakness (involved with swallowing), weak jaw and facial muscles, progressive loss of speech, and tongue muscle atrophy. Most patients with PBP progress to a more widespread phenotype of ALS.
- Primary Lateral Sclerosis (PLS) is a restricted variant, in which neurodegeneration is confined to the upper motor neuron. The disorder often affects the legs first, followed by the body trunk, arms and hands, and, finally, the bulbar muscles. Speech may become slowed and slurred. When affected, the legs and arms become stiff, clumsy, slow and weak, leading to an inability to walk or carry out tasks requiring fine hand coordination. Difficulty with balance may lead to falls. Speech may become slow and slurred. Diagnosis is by convention restricted to those with the characteristic phenotype for more than 4 years. Respiratory muscles can be affected later in the disease – however progression is slow and PLS is usually associated with a near-normal
- Progressive Muscular Atrophy (PMA) is a restricted phenotype involving the lower motor neurone. Weakness is typically seen first in the hands and then spreads into the lower body, where it can be severe. Other symptoms may include muscle wasting, clumsy hand

movements, fasciculations, and muscle cramps. The trunk muscles and respiration may become affected. Exposure to cold can worsen symptoms. Some patients with PMA evolve to develop a more characteristic ALS.

## Epidemiology

The incidence of ALS/MND in Europe is approximately 2 per 100,000 and the overall lifetime risk is approximately 1:400. ALS/MND is rarer in non-European populations. In Ireland, ALS is more common in males than females by a ratio of 1.4:1. The risk of developing ALS peaks between the ages of 50-75 years and declines thereafter. This suggests that ALS is not a disease of ageing, but a disease for which age is one of a number of risk factors.

## Diagnosis

Early onset of ALS/MND can be insidious, with symptoms ranging from foot drop, weakened grip, fatigue, slurred speech. This can in some way account for the fact that patients with ALS/MND can initially present in a wide range of settings from GPs, EDs, to occupational therapy, physiotherapy, ENT, rheumatology and/or radiology.

Irish Research has shown that the pathway to neurology services for patient with ALS/MND can be convoluted and varies significantly from patient to patient, with some patients being referred to 3 or 4 various services before being assessed by a neurologist. This can lead to unacceptable delays in diagnosis.

Patients with symptoms suggestive of ALS/MND should be assessed as soon as possible by an experienced neurologist. Early diagnosis should be pursued and investigations, including neurophysiology, performed with a high priority (EFNS 2012)<sup>207</sup>. Internationally, 'there is a median delay of 8-16 months from symptom onset to diagnosis, likely due to patients either not being referred or being referred to a specialist other than a neurologist/ALS/MND specialist (Cellura & Spartaro et al 2012)<sup>209</sup>.

Currently there is no single diagnostic test to confirm a diagnosis of ALS/MND, however neurological investigations should include EMG, nerve conduction studies and blood tests. Investigations can also include MRI/CT scanning, lumbar puncture and muscle biopsy to exclude the possibility of any other neurological conditions. Formal diagnosis of ALS is based upon clinical criteria which include the presence of upper motor neuron (UMN) and lower motor neuron (LMN) signs, progression of the disease and the absence of an alternative explanation.

There are 2 sets of criteria for diagnosis of ALS, the El Escorial criteria were developed in 1990 by the World Federation of Neurology (WFN). These guidelines were subsequently revised in Airlie House in April 1998. Both sets of criteria are based on the degree of certainty of diagnosis. These criteria are most helpful with respect to classification of patients for research purposes and are not considered helpful in the day to day management of the patient with the condition<sup>208</sup>.

207 The EFNS task force on Diagnosis and Management of Amyotrophic Lateral Sclerosis. EFNS guidelines on the clinical Management of Amyotrophic lateral Sclerosis (MALS) – revised report of an EFNS task force. European Journal of Neurology 2012, 19:360-375.

208 Hardiman & Doherty. Neurodegenerative Disorders (1st Edition) <http://www.springer.com/gp/book/9781849960106>

209 Cellura, E. R, Spartaro, et al (2012) 'Factors affecting the diagnostic delay in amyotrophic lateral sclerosis'. Clin Neurol Neurosurg 114 (6):550-554



Great care should be taken to rule out diseases that can masquerade as ALS/MND. In specialist practice, 5-8% of apparent patients with ALS have an alternative diagnosis, which may be treatable in up to 50% of cases (EFNS 2012)<sup>207</sup>. There is also a high rate of initial misdiagnosis (27-62%) of those who are eventually diagnosed with ALS (Cellura & Spartaro et al 2012)<sup>209</sup>.

Considering this, it is recommended that diagnosis is reviewed, particularly if there is no evidence of typical disease progression or if the patient develops atypical features.

### **Communicating the diagnosis;**

Imparting a diagnosis of ALS requires both skill and sensitivity. While there have been no controlled trials with respect to informing the patient/family of the diagnosis of ALS, useful strategies have been developed for disclosing a diagnosis of cancer (Mille et al 2009)<sup>210</sup>. In general, the following recommendations from the EFNS task force on management of ALS/MND should be considered<sup>207</sup>;

1. The diagnosis should be communicated by a consultant with good knowledge of the patient.
2. The physician should start the consultation by asking what the patient already knows or suspects
3. The diagnosis should be given in person, ensuring enough time for discussion (suggest 45-60 minutes). Provide printed materials about the disease, about support and advocacy organisations and informative websites. A copy letter summarizing the discussion can be helpful for patients and carers.
4. Assure patients that they will not be 'abandoned' by healthcare services and will be supported by a professional ALS/MND care team (where available), with regular follow up visits to a neurologist. Make arrangements for first follow up visit, ideally within 2-4 weeks.
5. Avoid the following: withholding the diagnosis, providing insufficient information, imposing unwanted information, delivering information callously, taking away or not providing hope (EFNS 2012)<sup>207</sup>.

### **Management of the condition**

A patient presenting with symptoms of MND/MND should be referred to a specialist multidisciplinary ALS/MND service comprising of a neurologist specialising in ALS/MND, a clinical nurse specialist, dietetics & nutrition, gastroenterology, occupational therapy, palliative care, physiotherapy, saliva/secretion management, speech and language therapy, respiratory support. ALS/MND is among the most demanding neurological conditions, is degenerative, often rapidly so, and requires complex anticipatory care.

Whilst there is no cure for MND, the effective and coordinated management of symptoms by a multidisciplinary team has been shown to be effective not just in terms of quality of life, but

---

210 Mille, RG et al, Practice parameter update: the care of the patient with Amyotrophic lateral sclerosis: multidisciplinary care, symptom management, and cognitive/behavioural impairment (an evidence based review). Report of the quality standards subcommittee of the American Academy of Neurology. Neurology 2009; 73: 1227-1233



also in terms of life expectancy. 'Patients who receive their care at a multidisciplinary clinic had a better prognosis than those attending a general neurology clinic' (Traynor et al 2003)<sup>211</sup> (Rooney et al 2014)<sup>212</sup>.

The exact reason for the improvements seen in patients managed by a specialist MND multidisciplinary team is not yet fully known, however it is thought that many factors contribute to improve function, quality of life and prognosis. These factors could include;

- Accumulation of resources and clinical expertise
- A service which combines with existing infrastructure of community service through the Irish Motor Neuron Association (IMNDA)
- An iterative process of multiple decision-making
- Availability of counselling services as ALS patients with psychological distress had a 'significantly greater risk of death' (McDonald et al 1994)<sup>213</sup>

As the optimal treatment for patients with MND has been identified as 'symptom management... provided in a multidisciplinary setting' (Van Groenestijn 2011)<sup>214</sup>, this type of service should be accessible to all patients presenting with the disease.

General Neurology services which do not have the support of a full specialist MDT for patients with ALS/MND should consider referral to a National Centre, or at a minimum, discuss the option of such a referral with their patients as centralized Multidisciplinary clinic is preferable to devolved community based care.

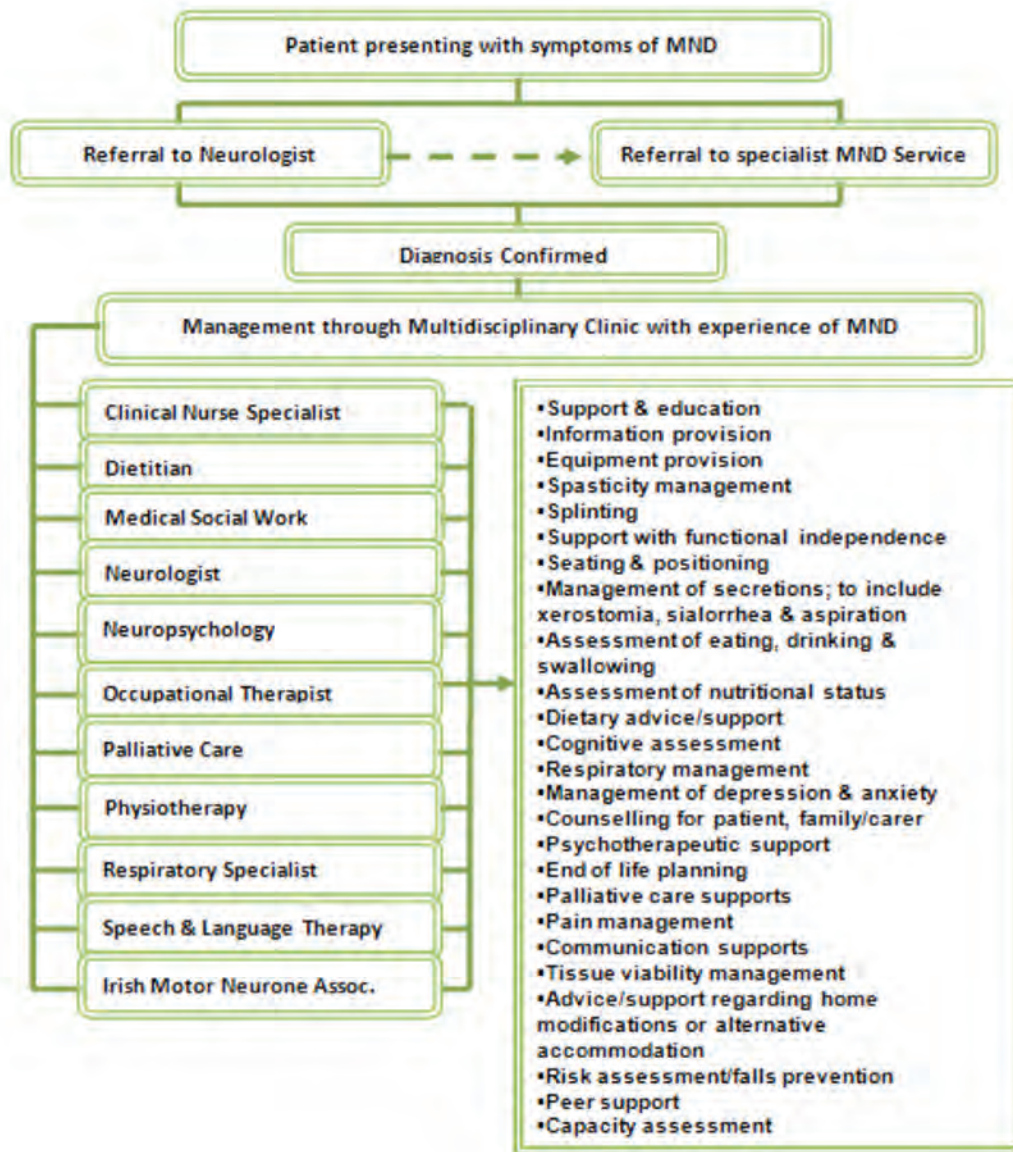
---

211 Traynor BJ, Alexander M, Corr B, Frost E, Hardiman O. Effect of a multidisciplinary amyotrophic lateral sclerosis (ALS) clinic on ALS survival: a population based study 1996- 2000. *J Neurol Neurosurg Psychiatry* 2003; 74: 1258-1261

212 Rooney J, Byrne S, Heverin M, Tobin K, Dick A, Donaghy C, Hardiman O. A multidisciplinary clinic approach improves survival in ALS: a comparative study of ALS in Ireland and Northern Ireland. *J Neurol Neurosurg Psychiatry*. 2014 Dec 30. pii: jnnp-2014-309601. doi: 10.1136/jnnp-2014-309601. [Epub ahead of print] PubMed PMID: 25550416.

213 McDonald ER et al. Survival in amyotrophic lateral sclerosis. The role of psychological factors. *Arch Neurol* 1994; 51. 17-23

214 Van Groenestijn, AC et al. 'Effects of aerobic exercise therapy and cognitive behavioural therapy on functioning and quality of life in amyotrophic lateral sclerosis: protocol of the FACTS-2-ALS trial'. *BMC Neurology* 2011, 11:70



**Fig 1; Pathway for patients with Motor Neurone Disease**

Despite a large number of clinical trials, the anti-glutamate agent Riluzole remains the one evidence based disease modifying drug for ALS/MND. Patients with ALS should be offered this treatment at the time of diagnosis, as clinical trials have demonstrated early treatment with Riluzole can increase survival by a mean of approximately 3 months<sup>208</sup>.

The Multidisciplinary Clinic		
Motor Neurone Disease	Dietitian	Assessment and treatment of malnutrition Modification of diets Nutritional supplementation Advice re: enteral feeding Advice re: weight management and avoidance of constipation, dehydration and pressure sores
	Neuropsychology	Neuropsychological assessment Management of cognitive difficulties Support to patients & families Adjustment issues Fatigue management Secondary mood disorders Behavioural management plans Capacity assessment
	Occupational Therapy	<ul style="list-style-type: none"> <li>- Assessment of seating, posture and functional mobility</li> <li>- Motor Neurone Disease</li> <li>- Specialised wheelchair prescription</li> <li>- Spasticity management</li> <li>- Assessment &amp; recommendations for self-care, feeding, toileting and grooming tasks</li> <li>- Assessment of appropriate transfer aids</li> <li>- Consideration for secondary complications such as shoulder pain, fatigue, subluxation, pressure relief, skin integrity</li> <li>- Review for environmental controls and assistive technology</li> <li>- Assessment of head and neck control</li> <li>- Driving assessment</li> <li>- Assessment and provision of specialist splinting</li> <li>- Housing adaptation and grant advice</li> <li>- Cognitive assessment</li> </ul>
	Physiotherapy	Assessment and monitoring progress of disease Maximising gait and mobility including prescription of orthoses Pain management Exercise advice and prescription Management of tone Management of respiratory dysfunction particularly cough interventions
	Speech and Language Therapy	Referral to specialist assistive technology services for assessment where indicated Screen for language difficulties Assess swallow function and trial strategies to maximise safety and comfort of oral intake Facilitate informed decisions regarding management of communication and/or swallowing difficulties Assist the management of xerostomia and sialorrhoea Assess and diagnosis communication difficulties Maximise speech intelligibility through use of strategies Educate regarding communication aids.

**Table 1; Role of the Multidisciplinary Team in the Management of patients with Motor Neurone Disease**

The primary function of the Multidisciplinary Clinic is symptomatic treatment of the patient. Patients engaged with the Specialist Multidisciplinary ALS/MND clinic can expect the following interventions which are needs led and focus on managing the patients' symptoms as they become prominent and incapacitating;

- Regular reviews which include the following assessments
  - ▲ ALS Functional Rating Scale-Revised (ALSFRRS-R)
  - ▲ Respiratory Assessment (e.g. vital capacity, sniff nasal inspiratory pressure etc)
- Support from CNS which include home visits and provision of medical equipment including NIV
- Splinting/orthoses/seating assessment & spasticity management by the occupational therapist
- Management of sialorrhoea
- Management of secretions
- Cognitive testing using a validated scale for ALS /MND (e.g. the Edinburgh Scale for ALS Assessment ECAS) ([http://www.research.ed.ac.uk/portal/en/publications/validation-of-the-edinburgh-cognitive-and-behavioural-amyotrophic-lateral-sclerosis-screen-ecas\(5bc2b829-825f-4add-82a3-59e6479bd809\).html](http://www.research.ed.ac.uk/portal/en/publications/validation-of-the-edinburgh-cognitive-and-behavioural-amyotrophic-lateral-sclerosis-screen-ecas(5bc2b829-825f-4add-82a3-59e6479bd809).html))
- Respiratory therapy including physiotherapy
- Management of depression and anxiety/counselling
- End of life planning
- Palliative care supports
- Pain management
- Support from IMNDA

The multidisciplinary team will also liaise closely with local services who will also have a role in managing the patient's symptoms, particularly when travel to the MDT becomes more challenging.

Each discipline specific team member enriches the knowledge base of the team as a whole, and over time, the multidisciplinary team composition can change to reflect the changes in the person's need<sup>215</sup>.

### Role of the Dietitian

Malnutrition is a common finding in ALS/MND and it can negatively affect prognosis and quality of life. Early assessment and appropriate individualised nutritional intervention is essential for this patient group. The European Federation of Neurological Societies (EFNS) task force guidelines on the clinical management of amyotrophic lateral sclerosis recommend that bulbar function and nutritional status, including body weight should be checked at each visit to MDT clinic and that patients should be referred to a dietitian as soon as dysphagia appears.<sup>216</sup>

Swallowing problems and malnutrition can be a huge source of anxiety for patients and their carers. The neurology Dietitian works in close partnership with the Speech & Language Therapist in order to give appropriate and individualised dietary advice. All patients being considered for gastrostomy

215 [http://www.mndnsw.asn.au/index.php?option=com\\_content&view=article&id=228:multidisciplinary-care-team&catid=106:living-better-for-longer&Itemid=214](http://www.mndnsw.asn.au/index.php?option=com_content&view=article&id=228:multidisciplinary-care-team&catid=106:living-better-for-longer&Itemid=214)

216 Anderson PM, Abrahams S, Borasio GD, De Carvalho M, Chio A, Van Damme P, Hardiman O, Kollewe K, Morrison KE, Petri S, Pradat PF, Silani V, Tomik B, Wasner M & Weber M. EFNS guidelines on the clinical management of Amyotrophic Lateral Sclerosis (MALS) – revised report of an ENFS task force. *European J Neur*. 2012;19(3):360-375

insertion should be referred to a Dietitian. Pre-gastrostomy education is essential so that the patient and their carers can make an informed decision as to whether or not to proceed with the procedure. As the condition progresses patients may no longer be able to attend their multidisciplinary clinic. Adequate training and resources should be available to ensure that this patient group can be offered dietetic follow up in all community setting including their domiciliary homes.

Risk factors or causes of malnutrition in ALS/MND include:

- dysphagia
- prolonged meal times
- difficulty self-feeding
- breathing difficulties
- taste changes
- hypermetabolism
- constipation
- cognitive changes

Refer ALS/MND patients to dietetics if:

- The patient is deemed at high risk of malnutrition (using MUST of local screening tool)
- Dysphagia symptoms are present
- The patient is being considered for gastrostomy insertion (even if weight stable and bulbar symptoms absent)
- Admitted for gastrostomy insertion
- Ongoing issues with constipation
- Pressure ulcers

### **Role of the Neuropsychologist**

In the care of people with MND, given the high incidence of cognitive impairment (up to 40%, with 15% meeting criteria for FTD), early cognitive assessment to identify the initial features of this can guide clinical decision making (Phukan et al 2012)<sup>217</sup> Such information can allow appropriate preparation of patients and carers, but can also inform decisions around planning for management of PEG feeding, for example, where this might be independently managed far less successfully by someone developing an FTD syndrome, with implications for survival. It has been identified that early executive dysfunction in MND patients is a negative prognostic indicator for life expectancy (Elamin et al, 2013)<sup>218</sup>(Elamin et al 2011)<sup>219</sup> and such functions should be evaluated at the earliest opportunity. Furthermore, patients have been shown to benefit from attendance at a full multi-disciplinary team including psychology compared to those that do not attend such teams (Rooney et al 2015).<sup>220</sup>

---

217 Phukan, J., Elamin, M., Bede, P., Jordan, N., Gallagher, L., Byrne, S., . . . Hardiman, O. (2012, Jan). Cognitive Impairment in Amyotrophic Lateral Sclerosis: A Population-based Study. *Journal of Neurology, Neurosurgery and Psychiatry*, 83(1), 102-8

218 Elamin, M., Bede, P., Byrne, S., Jordan, N., Gallagher, L., Wynne, B., . . . Hardiman, O. (2013). Cognitive changes predict functional decline in ALS: A population-based longitudinal study. *Neurology*, 80(17), 1590-1597.

219 Elamin, M., Phukan, J., Jordan, N., Pender, N., & Hardiman, O. (2011, April). Executive Dysfunction Is a Negative Prognostic Indicator in ALS: A Population Based Study. *Neurology*, 76(14), 1263-9.

220 Rooney, J., Byrne, S., Heverin, M., Tobin, K., Dick, A., Donaghy, C., & Hardiman, O. (2015, May). A multidisciplinary clinic approach improves survival in ALS: a comparative study of ALS in Ireland and Northern Ireland. *J Neurol Neurosurg Psychiatry. Journal of Neurology, Neurosurgery and Psychiatry*, 86(5), 496-501



Where communication is compromised, as may be the case in patients with MND, through individually tailored assessment (and appropriate interpretation of the resultant data) neuropsychologists can reliably assess the cognitive abilities and compromises of patients with communicational or motor deficits. Specialised assessment by a neuropsychologist can be of particular importance where an individual's premorbid cognitive level is unclear (so where there is less clarity as to whether their current functioning reflects actual decline). In relation to similar issues, neuropsychologists can serve a vital function in determining whether a person with MND lacks capacity to make treatment or care decisions – while these decisions are ultimately the responsibility of the treating Consultant Neurologist, the evidence based, functional approach to such assessments taken by Neuropsychologist can be particularly important in less clear-cut cases.

The rapid progression and decline characteristic of the condition requires patients and their supporters to accommodate quickly to the diagnosis and all it brings. For patients and families this represents an enormous set of challenges, testing their coping resources to the very limit. Many in this situation require emotional support as described earlier in the pathway description. In most cases generic counselling and support may be sufficient supplements to existing support systems to enable people to manage, however some may need specific psychotherapeutic interventions to enable them to manage the psychological challenges brought by the diagnosis and its implications. Further, Neuropsychologists working alongside other clinicians delivering less specialist counselling and therapeutic interventions may be well placed to provide consultation or supervision, supporting the work of their colleagues.

### **Role of the Occupational Therapist**

The Occupational Therapist (OT) is an integral part of the neurology MDT and should be involved in the assessment and treatment of patients on initial diagnoses of MND (Corr 1998<sup>221</sup>). The OT role is to maintain and promote the patients independence and quality of life in all activities of daily living at home and in the community throughout the different stages of their disease.

An understanding of the stage and syndrome of disease will be key for the therapist to make recommendations and advise around appropriate compensatory strategies or environmental changes. The OT will assess the patient's physical, cognitive, psychosocial and environmental needs to optimise participation in their chosen occupations and to encourage optimal function. "alleviating activity limitations and participation restrictions across social, domestic, work, leisure and community roles that result from impairments of body function" (Morris et al, 2006<sup>222</sup>). The OT also plays a specific role in the provision of equipment with the therapeutic focus on maximising residual function and, by altering the environment and educating key people around the client, ensuring the patient with MND has the opportunity to function optimally" (Morris et al, 2006)

### **Role of the Physiotherapist**

The physiotherapist plays an essential role in the management of MND from diagnosis to death. Physiotherapists work as members of the specialist MND multidisciplinary team in the tertiary setting and are also key members of community and palliative care teams. Physiotherapists in the tertiary setting require a range of specialist skills and provide support as required to colleagues working at primary care level.

---

221 Corr, B. et al(1998) Service Provision for patients with ALS/MND: A cost effective multidisciplinary approach. *Journal of Neurological Sciences* 160:141-145

222 Morris M.E. et al (2006) Outcomes of Physical Therapy, Speech Pathology and Occupational Therapy for People with Motor Neuron Disease: A Systematic Review. *Neurorehabilitation and Neuronal Repair* 20 (3) 424-434



One of the key issues addressed by the physiotherapist is maximizing mobility and preventing falls through timely and appropriate prescription of aids and appliances. As their condition progresses, the mobility needs of MND patients can change quite rapidly and therefore regular review and efficient changes in prescription of walking aids, orthoses and other equipment is required. Timely access to funding for such equipment is essential.

Pain and in particular shoulder pain, is common in MND and physiotherapy is a useful component of pain management through conventional therapies or with injection therapy. Rapid access to shoulder injection therapy is currently provided by Physiotherapists with advanced training.

The physiotherapist also plays a key role in managing the respiratory dysfunction associated with MND, in particular managing weak cough. In the tertiary clinic equipment such as breath stacking or mechanical insufflation/exsufflation 'cough assist' devices are prescribed. Evidence based Irish Guidelines for the management of MND have been published,<sup>223</sup> which aim to support physiotherapists in providing the best possible care to patients with MND.

### **Role of the Speech and Language Therapist**

Speech and Language Therapists (SLTs) are a key member of the specialist MND multidisciplinary team in the tertiary setting and are also key members of community care teams. SLTs in the tertiary setting provide support as required to colleagues working at primary care level.

A significant role of the SLT is to facilitate an adequate communication system for the person with MND throughout the course of their disease. The absence of an adequate communication system or equipment affects a person's ability to make choices. It also negatively affects their quality of life.<sup>224</sup> If the patient loses effective communication, it can also have an isolating affect on carers. Due to the time required for assessment and provision of electronic assistive communication devices, it is important to plan to have an alternative communication system in place before the patient becomes anarthric. As the patient's presentation can change rapidly, it is necessary to regularly review the efficiency of assistive technology especially if alternative access such as switch or eyegaze is required.

The SLT also has a key role in the management of dysphagia and should work closely with MDT colleagues; dietetics regarding weight management, Occupational Therapy for assistive devices / feeding utensils and postural management including head supports, physiotherapy for managing weak cough when penetration and/or aspiration is suspected.

Objective swallow assessments such as videofluoroscopy are not routinely recommended as most symptoms of dysphagia are predictable according to the usual course of disease progression and are evident on clinical assessment. The SLT also has a role in educating patients about alternative feeding options. The EFNS taskforce for ALS states that 'suitability' for gastrostomy insertion is based on an individual approach taking into account bulbar symptoms, malnutrition (weight loss of over 10%), respiratory function and the patient's general condition' therefore recommendation for gastrostomy should be made by a medical consultant. Early insertion of a feeding tube is recommended.

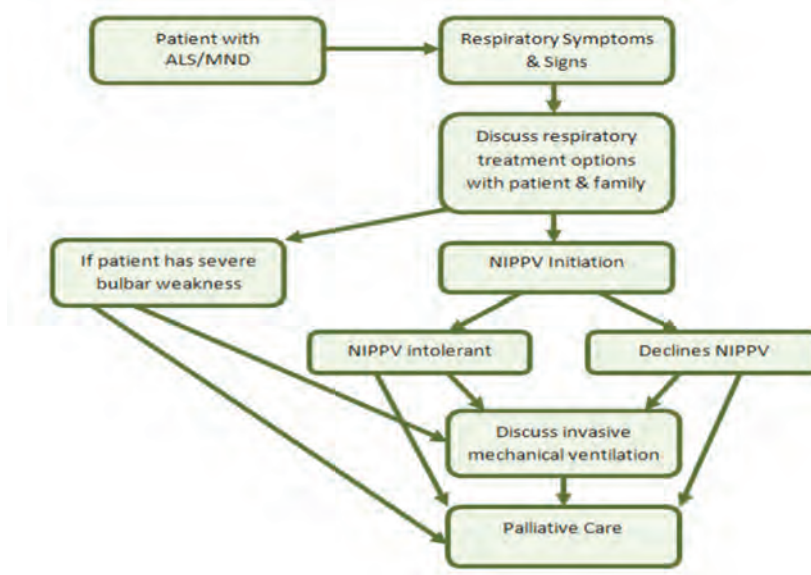
### **Respiratory Management in patients with ALS**

Respiratory complications are the main cause of death in ALS primarily as a consequence of diaphragmatic weakness combined with aspiration and infection. Non-invasive and less frequently,

223 Guidelines for the management of MND, September 2014 <http://imnda.ie/wp-content/uploads/2014/09/MND-guidelines-on-Physiotherapy.pdf>

224 Bush & Scott 2009, Hamm & Miranda 2006

invasive mechanical ventilation (IMV) are used to alleviate symptoms of respiratory insufficiency and prolong survival.



**Fig 2; Flow chart for the management of respiratory dysfunction in ALS. Adapted from EFNS task force on Management of ALS 2012<sup>207</sup>**

### **Palliative care options/end of life planning**

Currently there is curative treatments for patients with ALS/ MND and the aim of many if not all interventions is to maximise the quality of life from the time the patient is first diagnosed right through to the end of life. A palliative approach should be incorporated into the care plan for each patient and their family/carer.

The option to discuss end of life planning should be given to all patients. Discussions and decisions relating to end of life care generally cover preferences for symptom management and in the end stages, nutritional and respiratory support. Appropriate timing will vary between individual patients, however the following times are proposed (NICE 2010)<sup>225</sup>;

- Around the time that ALS/MND is first diagnosed (but only if requested by the patient explicitly, or of the patient's clinical condition indicates that ventilator support will be needed in the immediate future)
- When non-invasive ventilation is accepted or declined
- When the patient is becoming increasingly dependent on non-invasive ventilation
- If the patient asks for information.

Effective communication is essential to ensure that the individual is able to;

- Understand as much as they want to know about their disease
- Be aware of what may happen as their disease progresses
- Feel empowered to make informed choices over their future care
- Be part of a two-way process – with the person feeling that their views and preferences have been heard and understood<sup>226</sup>.

225 Motor Neuron Disease. The use of non-invasive ventilation in the management of motor neurone disease. London (UK): National Institute for Health and Clinical Excellence (NICE); 2010 Jul. 127p. (Clinical Guideline; no 105)

226 End of life care in neurological conditions: a framework for implementation'. The National Council for Palliative Care, the Neurological Alliance & NHS National End of Life Care Programme. 2010

Discussions about end-of-life care should include:

- Planning end of life care
- Considering advance decisions to refuse treatment (Advance Directives/Living Wills/ Advance decisions currently have no legal standing in Ireland)
- Considering what to do if non-invasive ventilation fails because of either;
  - An acute or, but potentially reversible, deterioration in health or
  - Irreversible disease progression
- Strategies to withdraw non-invasive ventilation if the patient wishes
- The involvement of family and carers in decision making (with the patient's consent if they have the capacity to give it)

Advance care planning is considered an important part of care, particularly when only palliation can be offered. According to MND Scotland 'At its simplest the doctor and patient should try to 'future-gaze' and agree which actions should be taken if certain common or predictable circumstances occur'<sup>227</sup>.

Failure to discuss these issues or a delay in discussing them may lead to such decisions having to be made in a crisis situation when the patient suffers life threatening complications. In these instances patients/families may have to make decisions under stressful situations and may not be afforded the opportunity to reflect on all issues. In its most extreme, crisis situations can lead to the initiation of full mechanical ventilation via a tracheostomy with lack of prior informed consent (Heritier 2013)<sup>228</sup>

Palliative care provision is the responsibility of the whole healthcare team and uses a team approach to planning and providing care tailored to meet the individual needs of the person and their family. Within a healthcare team are three levels of palliative care provision with increasing specialisation from level 1 to level 3 as previously referred throughout this model of care.

It is recommended that all members of the MDT working with patients with MND should have competencies in the provision of level 1 and level 2 palliative care provision.

### **Support Organisation**

The role of support organisations such as the Irish Motor Neurone Association (IMNDA) should be fully utilized as their services provide telephone support, advocacy and information and offer actual treatment and management of patients' conditions in collaboration with their Multidisciplinary MND Clinic. Other services provided include;

- Financial assistance to increase home care packages as appropriate
  - Provision of specialist medication equipment
  - Information/education to patients and families/carers
  - Peer support
  - Research support
  - All patients should be given information and/or referral to IMNDA, not only for themselves but for their families and carers also.

227 MND Scotland. Integrated Care Pathway

228 Heritier Barras, A-C et al. 'Is tracheostomy still an option in amyotrophic lateral sclerosis? Reflections of a multidisciplinary workgroup, Swiss Med Wkly. 2013; 143:w13830

## Appendix 6; Transition Checklist

Area	Objectives	Achieved
<b>Self-advocacy</b>	1. Patient able to describe their neurological condition	
	2. Patient asks appropriate questions in clinic	
	3. Patient is able to access information about their condition	
	4. Patient can describe available adult care options	
	5. Patient understands differences between paediatric and adult care.	
<b>Independent Health care behaviour</b>	1. Patient understands what medication they are on and is able to discuss potential side effects etc	
	2. Patient knows how to access help in an emergency situation	
	3. Patient understands principles of confidentiality	
	4. Patient maintains a personal health care record book to keep track of appointments, health information, medication, treatments and health care providers	
	5. Patient has met with a consultant/specialist nurse who works with adult patients	
<b>Sexual health</b>	1. Patient understands changes associated with puberty and the implication of their condition on pubertal development	
	2. Patient's parents have been given information about puberty, sex and sexuality	
	3. Discussion regarding patient's sexual capability, fertility, safe sex and any associated genetic issues.	
<b>Psychosocial support</b>	1. Parent's given an opportunity to discuss any concerns regarding transition or the future	
	2. Patient understands benefits of friends and supportive relationships	

Area	Objectives	Achieved
	3. Patient able to set positive goals for their future	
	4. Any assistance for personal care identified	
	5. If patient's condition is potentially life-shortening, support for help in dealing with this identified.	
<b>Educational and vocational planning</b>	1. Patient understands restrictions that may affect educational and recreational activities	
	2. Discussion regarding employment and/or educational options, vocational assessment etc	
	3. Information regarding available health care benefits	
<b>Health &amp; lifestyle</b>	1. Patient understands health implications of smoking, alcohol and recreational drug use	
	2. Discussion regarding body image and any concerns about weight gain or loss	
	3. Patient has had opportunity to discuss any feelings of low mood, depression, or problems adjusting to or managing their condition	
	4. Patient is aware of contact information for any help or advice needed going forward.	

## Appendix 7 – Neurology subspecialties

\*Adapted from NHS England – Service Specifications

### Neuropsychiatry

It is notoriously difficult to separate disease processes in psychiatry but “organic” conditions have been described as those in which a cerebral or systemic pathological process lead or contribute to the psychiatric condition (Lishman, 1998<sup>229</sup>). On the other hand, the term “neuropsychiatry” is at the interface between neurology and psychiatry and refers to disorders, which are clearly caused by a brain dysfunction. Lishman’s original description would exclude disorders due to toxic, endocrine or metabolic disorders. However, “functional” disorders e.g. conversion disorders, may also present initially suggesting neurological or organic origins with neurological signs or symptoms, but may actually have psychological or psychosocial contributions.

Currently there is a severe shortage of Neuropsychiatrists in Ireland. Services are generally delivered in a consultation liaison model of care within general hospitals e.g. Beaumont Hospital where there are 2 Psychiatry Consultants with half time clinical commitments. Consultation Liaison colleagues around the country may provide an ad hoc service where possible.

Consultants in the voluntary sector e.g. Bloomfield Health Services may also contribute with a cognitive disorders clinic and specialised services for those with Huntington’s disease, early onset cognitive disorders and their caregivers and family members. Regionally based Neuropsychiatry posts should be developed and filled alongside specialist training SpR rotations within the Irish College of Psychiatry to educate future Consultants. Expanded access to experienced neuropsychology colleagues is vital to the development of best practices.

Access to specialist psychiatry services with multidisciplinary team members for those with early onset cognitive disorders is vital to decrease the psychiatric burden in this population, provide education and support to caregivers and family members and to support colleagues in the general adult services who may be struggling to care for these individuals. Multidisciplinary teams should include dietetics/nutrition, neuropsychology, nursing/clinical nurse specialists, occupational therapy, physiotherapy, social work, speech and language therapy who help these individuals and their families navigate their difficult journey to finding locally based, specialised services if possible. Academic and research activities must be encouraged and supported to develop best practices and to provide access to international based research efforts e.g. in Huntington’s disease.

There is considerable overlap between the two medical disciplines of neurology and psychiatry and below is a brief outline of various disorders that may be included in the domain of neuropsychiatry. Patients may be referred from one specialty to another as clinical symptoms develop; best practice would be for a collaborative model of care with joint clinical commitments e.g. outpatient clinics or consult service teams.

Recent updates in the Diagnostic and Statistical Manual of Mental Disorders Fifth edition (DSM V) released in 2013 introduced the term Neurocognitive Disorders (NCDs).

229 Lishman WA 1998. Organic Psychiatry: the Psychological Consequences of Cerebral Disorder



This is considered to be a broader term than the previous term of dementia and is not tied to age. In these disorders pathology can potentially be determined and several NCD's may co-exist with each other e.g. Alzheimer's Disease or Vascular Dementia or mixed pathologies. Amnesic disorder with decline in one single domain, are no longer considered dementia.

#### **Neurocognitive domains include:**

- 1) Attention (complex, sustained, selective and divided)
- 2) Executive function (planning, decision making, working memory, feedback error utilization, inhibition and cognitive flexibility)
- 3) Learning and Memory (Immediate memory span, recent memory and very long term memory)
- 4) Language (Expressive, grammar and syntax and receptive language)
- 5) Perceptual-motor (visual perception, visuoconstructional, perceptual-motor, praxis and gnosis)
- 6) Social Cognition (recognition of emotions and theory of mind)

#### **Neurocognitive disorders**

##### **Delirium**

- A disturbance of consciousness with impairment in attention and awareness. Difficulties focusing, sustaining or shifting attention and reduced orientation to time and place. Usually develops over a short period of time with a change from baseline functioning and fluctuates during day. There is evidence from the history, exam or labs that there is a causal medical condition or substance and may have multiple etiologies. Delirium may be acute or persistent and may present in a hypoactive (lethargy or somnolence) or hyperactive manner (agitated, excited, tremulous or with psychotic phenomena).
- Prevalence: 1-2% in the community population but this increases with age to 14% in those over 85 years. Delirium is reported in 10-30% of those older patients in Emergency Departments, in 14-24% of those admitted to hospital and may occur in 6-56% of patients during admission with rates of 70-87% of those in an ICU. Delirium is reported in up to 60% in Nursing Home residents and in 83% of those at the end of life.

##### **Major Neurocognitive disorder** (previously termed dementia)

- There is a significant decline in 1 or more domains from a previous level of functioning based on the concern of the individual informant or clinician and substantive impairment in cognitive performance. These deficits interfere with independence in activities of daily living (IADLs)
- Prevalence is related to age and etiology with rates of 1-2% of individuals at 65 years of age and 30% by 85 years.

##### **Mild Neurocognitive Disorder**

- Here there is evidence of a modest decline (1-2 Standard Deviations) from an

individual's previous level in 1 or more domains based on collateral information or self-concern and modest impairment on testing. Substantially congruent with previous definitions of mild cognitive impairment. Such impairments do not interfere with IADLS. It may be a sign of a developing major neurocognitive disorder in the future.

- Prevalence rates of 2-10% of those aged 65 years and 25% at 85 years.

### **Other Neuropsychiatric Disorders**

#### **Traumatic Brain Injury (TBI)**

- Neurocognitive disorder may present with difficulties with complex attention, executive ability, learning, memory and slowed information processing and disturbances in social cognition. If there is severe injury with brain contusion, intracranial hemorrhage or penetrating injury, then additional deficits e.g. aphasia, neglect and constructional dyspraxia may occur. Diffuse axonal injury may lead to enlargement of the ventricles. Posttraumatic epilepsy occurs in about 2-5% of closed head injuries and in over 30% of open head injuries.
- Individuals with TBI may have changes in emotional function, reduced control over aggression, mood disorders, anxiety, personality changes, physical disturbances and reduced tolerance to medications. The highest prevalence rates are reported in males, those less than 4 years, and teenagers and in those over 65 years. Other risk factors may include use of alcohol, illicit substances and a past psychiatric history. Repeated concussions may lead to persistent NCD and traumatic encephalopathy.

#### **Cerebral Tumours**

- These may include primary cerebral tumours or more commonly brain metastases (often from lung or breast)
- Presenting symptoms of brain tumours may include headaches, papilloedema, focal neurological deficits, seizures, personality or cognitive changes. Symptoms are related to the location and nature of the tumour and the presence of raised intracranial pressure. Treatment includes chemotherapy, immunotherapy, radiation therapy and surgery.

#### **Epilepsy**

- Seizures may present as classic motor events or comprise complex behavioural changes or subjective experiences. Psychotic disorders, cognitive disorders and disturbances in personality have all been described in individuals. The majority of those with epilepsy have little or no psychiatric difficulties.
- Psychiatric symptoms may be related to the underlying disorders causing the seizures e.g. learning disabilities. Disorders that may be temporally related to the seizures include: pre-ictal, ictal (aura, automatisms, non-convulsive status) and post ictal (delirium or psychosis). Interictal disorders may include mood disorders, schizophrenia like psychosis, personality disorder, neurocognitive disorders or dissociative seizures. This latter type of seizure requires careful consideration to differentiate them from epileptic seizures.

### Intracranial Infections

- Acquired immunodeficiency syndrome: opportunistic infections include toxoplasmosis, cytomegalovirus, herpes simplex, progressive multifocal leucoencephalopathy (JC polyomavirus), Cryptococcus neoformans, candida, tuberculosis and syphilis. Neurocognitive disorders and other psychiatric disorders may occur including acute stress reactions and more chronic disorders of anxiety, depression, suicide, psychosis and obsessive compulsive disorder
- Syphilis: Although primary syphilis this has generally declined the meningovascular subtype now accounts for most new cases. It may occur with HIV co infection. Syphilis of the CNS can present with almost any psychiatric disorder

### Cerebrovascular disorders

- Vascular neurocognitive disorders: the etiology ranges from large vessel stroke to microvascular disease. Many individuals present with multiple infarctions with acute step-wise or fluctuating decline in cognition. Individuals may have periods of stability or even improvement but presentations may vary. A gradual onset with slow progression is generally due to small vessel disease with lesions in white matter, Basal ganglia +/- thalamus. Psychiatric sequela of stroke includes neurocognitive disorders, changes in personality, depression and bipolar disorders. Similar symptoms can occur after sub arachnoid haemorrhage.
- Migraine sufferers are at increased risk of anxiety and depression
- Subdural haematoma
- Systemic lupus erythematosus (SLE)
- Vasculitis of the CNS

### Endocrine and metabolic disorders

#### Substance related disorders

- Alcohol: intoxication, blackouts, tremor, hallucinosis, withdrawal syndromes (include delirium tremens), Wernicke's encephalopathy and Korsakoff's syndrome
- Barbiturates,  $\gamma$  hydroxybutyrate, benzodiazepines, opioids, cannabinoids, psychostimulants, hallucinogens, solvent abuse, heavy metals

#### Sleep disorders

- Primary dyssomnias: insomnia, circadian rhythm disturbances, narcolepsy, idiopathic hypersomnia, sleep apnoea syndromes, restless leg syndrome and periodic limb movement syndrome, somnambulism, night terrors

#### Movement disorders

- Medication induced disorders: acute dystonia, akathisia, parkinsonism and tardive dyskinesia, Parkinson's disease, Wilson's disease, Progressive supranuclear palsy, Corticobasal degeneration, Striatonigral degeneration, Primary dystonias, Tourette's syndrome
- Psychogenic movement disorder: tremor, dystonia, myoclonus

### Other

- Multiple sclerosis, Schilder's disease, Tuberos sclerosis, Neurofibromatosis, Freidrich's ataxia, Motor neuron disease, Myasthenia gravis, Progressive muscular dystrophies, Normal pressure hydrocephalus

**Somatic Symptom and related disorders** (replaces previous somatoform disorders)

#### **Conversion disorder (functional neurological symptom disorder) (ref)**

- One or more symptoms of altered voluntary motor or sensory function
- Evidence of incompatibility between the symptom and recognized neurological or medical conditions
- Diagnosis supported by a history of multiple somatic symptoms and onset may associated with stress/trauma
- Often associated with dissociative symptoms e.g. depersonalization, derealization or dissociative amnesia
- May be related to maladaptive personality traits, history of abuse or neglect in childhood, co morbid neurological disorders
- Co-morbid psychiatric disorders include anxiety and depression. Personality disorders more common than in general population. May have co-morbid neurological or medical disorders

### **Inflammatory Diseases of the Nervous System\***

- Inflammatory disease of the central nervous system (CNS) is where the brain and/or spinal cord become inflamed. Inflammatory brain diseases are due to primary processes in which inflammation occurs without a normal trigger. For example, immune system malfunction leads to unnecessary inflammation and continues with no resolution if not treated.
- Examples of primary inflammation in the brain include:
  - CNS vasculitis
  - Antibody-mediated inflammatory brain diseases
  - Demyelinating conditions, such as multiple sclerosis (MS) and acute disseminated encephalomyelitis (ADEM).
- Very rare inflammatory diseases of the CNS, such as Rasmussen's encephalitis and neurosarcoidosis, are caused by particular immune cells functioning abnormally.

Secondary inflammation occurs second to another disease in the body. For example, inflammation occurs as part of the immune response to infection of the meninges in meningitis.

Treatment of inflammatory disease of the nervous system should be provided as described in National Institute for Health and Clinical Excellence (NICE) guidelines. Specialised services for inflammatory disorders of the nervous system will include; multi-professional care including involvement of: Specialist nurses, health & social care professionals, continence and pain relief services, services provided jointly with specialists in rehabilitation medicine, spasticity management services and clinics for the assessment for and monitoring of disease modifying therapies.

### Epilepsy and related disorders\*

Epilepsy is a chronic disease characterized by unpredictable, sometimes lifelong, often dangerous seizures which result in involuntary alterations in behaviour and consciousness. The condition affects about one in every 100 people. Of the 40,000 sufferers in Ireland only about 70% are well controlled on medication, leaving about 12-15,000 people who have breakthrough seizures, and are in regular contact with secondary and tertiary hospital services.

Specialised services for epilepsy will include multi professional care including epilepsy nurse specialists, pre-surgical assessment services, clinics providing care for those with seizures resistant to treatment and arrangement for transitional care between paediatric and adult clinicians.

### Movement disorders\*

Movement disorders are neurological conditions that affect the speed, fluency, quality, and ease of movement. Abnormal fluency or speed of movement, **dyskinesia**, may involve excessive or involuntary movement (**hyperkinesia**) or slowed or absent voluntary movement (**hypokinesia**).

Movement disorders include the following conditions:

- Ataxia
- Dystonia
- Huntington's disease
- Multiple system atrophies
- Myoclonus
- Parkinson's disease
- Progressive supranuclear palsy
- Restless legs syndrome (RLS) and reflex sympathetic dystrophy/periodic limb movement disorder (RSD/PLMD)
- Tics
- Tourette's syndrome
- Tremor (e.g., essential tremor, resting tremor)
- Wilson disease

Treatment for movement disorders depends on the underlying cause. In most cases, the goal of treatment is to relieve symptoms, however where this is not possible, the goal is to lessen the functional impact of the disorder on the patients' life.

### Neuromuscular Disorders (NMD)\*

A neuromuscular disease is a disorder that affects the peripheral nervous system. The peripheral nervous system includes muscles, the nerve-muscle (neuromuscular) junction, peripheral nerves in the limbs, and the motor-nerve cells in the spinal cord. Other spinal cord or brain diseases are not considered "neuromuscular" diseases.

Patients with neuromuscular diseases can have weakness, loss of muscle bulk, muscle twitching, cramping, numbness, tingling, and a host of other symptoms. Problems with the nerve-muscle junction can also cause droopy eyelids, double vision, and weakness

that worsen with activity. Some neuromuscular disorders can also cause difficulty with swallowing and sometimes with breathing<sup>230</sup>.

There are more than 60 different types of muscular dystrophy and related (NMD). NMD can be genetic or acquired;

Inherited NMD include;

- Muscular dystrophies
- Spinal muscular atrophy (SMA)
- Congenital and syndromal neuropathies
- Inherited neuropathies
- Congenital myopathies
- Metabolic myopathies
- Genetic myasthenic syndromes
- Mitochondrial disorders
- Channelopathies
- Myotonias

Acquired disorders include;

- Myasthenia gravis
- Autoimmune neuropathies
- Inflammatory myopathies

There are few curative treatment options for most of these diseases. A number, such as Duchenne Muscular Dystrophy, are aggressive and cause progressive muscle wasting and weakness, orthopaedic deformity, cardiac and respiratory compromise, dependency on others for day-to-day care and usually premature death. Others cause life-long disability without limiting lifespan.

Some neuromuscular disorders can present in childhood or young adult life. Others can be late onset conditions in adulthood.

### **Neurogenetic Diseases\***

Neurogenetic disease is an umbrella term used to describe inherited conditions which affect the nervous system. Neurogenetic diseases are primarily caused by an alteration – or mutation – in the individual's DNA. These disorders are typically chronic and debilitating, often degenerative and life limiting. Diseases with a mutation in a single gene are referred to as "monogenetic diseases". These include;

- Huntington's disease
- Myotonic dystrophy
- Rett syndrome
- Fragile X syndrome.

In these cases, the single-gene mutation causes certain neurons in the central and/or peripheral nervous system to develop abnormally and/or function poorly.

230 [http://www.neurology.upmc.edu/neuromuscular/patient\\_info/what.html](http://www.neurology.upmc.edu/neuromuscular/patient_info/what.html)



Some neurogenetic diseases are referred to as “complex diseases”, since multiple genes and environmental factors can contribute to the development of the disease. These include;

- Parkinson’s disease
- Alzheimer’s disease.

Diagnoses are established by reviewing medical records, studying the family history, interviewing and examining affected individuals, and obtaining additional testing as needed (such as genetic testing and neuro-imaging). Treatment should be coordinated and multidisciplinary and focused on supporting independence and maximising function. Genetic counselling should also be available as requested.

### **Neuro-oncological diseases\***

Neuro-oncological disease include brain and spinal cord neoplasms, which include;

- astrocytoma
- glioma
- glioblastoma multiforme
- ependymoma
- pontine glioma
- brain stem tumors

Among the malignant brain cancers, gliomas of the brainstem and pons, glioblastoma multiforme, and high-grade (highly anaplastic) astrocytoma are considered the most severe.

Treatment of these conditions includes radiation treatment, chemotherapy and/or surgery. While treatments may be curative, however malignant brain cancers tend to regenerate and emerge from remission early. Where curative treatment is not an option, the goal of treatment is to preserve vital functions and cognitive abilities for as long as possible.

### **Psychogenic disorders**

Psychogenic neurologic disorders account for a small minority of categories of neurologic illness. Also known as ‘functional’ neurological disorders, they are thought to account for approximately 16% of patients referred to neurology clinics (Edwards et al, 2012)<sup>231</sup>.

Such disturbances represent, on some level of awareness, the intentional (but generally inaccurate) simulation of usually familiar, common neurologic disorders that have involuntary etiologies, yet their contrived basis may not be realised by patient and they are not considered to be fictitious or malingering, as the symptoms are not intentionally produced or feigned.

Despite their psychogenic basis, such disturbances are generally truly disabling. Psychogenic neurologic disturbances respond best to empathetic concern by the clinician; demonstration that the disorder lacks a structural or permanent etiology,

231 Edwards, MJ, Kailash, PB. Functional (psychogenic) movement disorders: merging mind and brain. The Lancet Neurology, Vol 11, issue 3, p250, March 2012

communication of the lack of understanding of the mechanism of the disturbance, and praise for the gradual improvement by means of patients guided attempts to reduce sources of distress (Victor, 2012)<sup>232</sup>.

In psychogenic neurologic disorders, the disturbance is essentially psychologic, that is, rather than a neurophysiologic alteration that is not modelled by the patient after a familiar neurologic disorder. Hence, in psychogenic disorders there are characteristically no electroencephalographically convulsive, inflammatory or structural disturbances (as are usually found in conventional neurologic diseases). Instead, the disturbance causes mentally regulated skeletal muscle contractions, complaints of altered sensation (including vision, hearing or pain) or alterations of speech or other behaviours that resemble well-described cognitive disturbances (e.g. impaired language, attention or memory) (Edwards et al, 2012<sup>231</sup>).

While there are several competing theories, PMD is hypothesized to have a basis in faulty inhibitory circuits of motor control. Additionally, the intensity of the psychogenic movements worsen when patients are exposed to stressful and/or emotionally-charged situations<sup>233</sup>. There has been an influential historical emphasis on causation by emotional trauma, which is not supported by epidemiological studies. The similarity between physical signs in functional disorders and those that occur in feigned illness has also raised important challenges for pathophysiological understanding and has challenged health professionals' attitudes towards patients with these disorders (Edwards et al, 2012<sup>231</sup>).

### Diagnosis

There is no single test which can confirm a psychogenic condition and as such they can be difficult to diagnose. A psychogenic disorder can mimic almost any organically based disease. A thorough history and neurologic examination are the most important aids to the clinician in distinguishing organically from psychologically based disease (Shaibani & Sabbagh, 1998)<sup>234</sup>. The following are identified as 'clues' which may assist the physician in identifying potential psychogenic syndromes;

- Precipitated by stress
- Occurs or worsens in the presence of others
- Signs of other psychiatric illness (panic attacks, depression, schizophrenia)
- Histrionic personality
- History of multiple surgeries (e.g. appendix, gallbladder, adhesion, nerve entrapment)
- No serious injuries sustained despite falls or 'seizures'
- Denies psychologic etiology of symptoms
- Normal reflexes, muscle tone, papillary reaction etc
- Symptoms persist despite specific medical treatment
- Alexithymia, inability to describe feelings in words
- Vague, bizarre, inconsistent description of symptoms

232 Victor W Mark MD. Psychogenic neurologic disorders. April 2001; med link Neurology

233 <http://www.ninds.nih.gov/jobsandtraining/summer/2008student/minwuabstract.htm>

234 Shaibani, A, Sabbagh MN; Pseudoneurologic syndromes: recognition and diagnosis Am Fam Physician. 1998 May 15; 57 (10): 2485-2494

- Striking inconsistencies on repeated examination
- Nonanatomic distribution of abnormalities

Although these clues do not rule out organically based disease, they should raise the clinician's suspicion for pseudoneurologic syndrome. In particular, objective findings such as normal reflexes, muscle tone and pupils are rarely altered in psychogenic causes, and pseudoneurologic syndrome often does not follow neuro-anatomic (e.g. dermatomal) patterns (Shaibani & Sabbagh, 1998<sup>234</sup>).

### **Treatment**

A multi-therapy approach to treating psychogenic conditions can include;

- Psychotherapy
- Placebo
- Suggestion
- Antidepressants for symptoms related to depression or anxiety
- Cognitive- behavioural therapy to identify and alter thoughts and feelings that may be causing the psychological illness
- Physical therapy
- Occupational therapy to improve performance of activities of daily living<sup>235</sup>

### **Prognosis**

The severity of the condition and prognosis varies among individuals. Prognosis is considered poor when the disorder continues for many years. Outcome appears to be better in younger people with a shorter duration of symptoms than in older persons with more chronic symptoms. Also, people with few and mild symptoms that have an acute onset tend to have a more favourable outcome, particularly if the duration of symptoms is relatively short and preceded by a stressful or traumatic event.<sup>235</sup>

235 <http://www.ninds.nih.gov/disorders/psychgenicmovemtn.htm>

## Appendix 8 – Neurology centre survey

### National Survey of Neurology Services

#### Preliminary Report prepared by the Neurological Alliance of Ireland & Neurology Clinical Programme For Neurology

##### **Executive Summary**

The neurology clinical programme, with the support of the umbrella of patient organisations, the Neurological Alliance of Ireland carried out an online survey of eleven neurology centres in early 2015. The limitations of a small scale unstandardised measure relying on self report are recognised. Respondents were requested to provide information from each centre in relation to staffing resources, current bed complement and bed needs, the number and range of outpatient clinics, outreach to other hospitals, access to neurodiagnostic tests and provision of ED cover and stroke services. Centres were also asked to rate their access to a range of support services such as neurorehabilitation, palliative care and other supports in the community. Each centre was invited to highlight changes and innovative practices which have been introduced within the centre to improve service delivery and patient care. Finally, each centre was asked to identify priority issues which represent a particular ongoing challenge for the service.

The findings highlight an array of resource issues which continue to impact significantly on neurology services. Deficits in staffing are apparent across all disciplines and in all centres. There is a particular issue in relation to staffing in the small regional centres of Limerick, Sligo and Waterford. The lack of protected neurology inpatient beds also emerges as a critical issue. Waiting times and access for diagnostic testing highlight that these issues also requires attention in the context of the important and increasing role of neuroimaging in the diagnosis and ongoing treatment of neurological conditions. Neurology services are reliant on effective supports in the community for the long term management of neurological conditions. Each centre highlighted significant challenges in accessing neurorehabilitation, home care support and nursing home care for their patients.

This survey represents only a very limited and initial attempt to examine resourcing and other issues affecting neurology services in Ireland. However, the findings are important in informing key priority areas for the neurology programme going forward.

##### **Foreword**

A preliminary survey was carried out by the neurology clinical programme in January and February 2015 with additional information collected in May 2015. The aim of the survey was to gather information on current resourcing within neurology services to inform the model of care for the neurology programme and to guide the work of the programme in terms of priority objectives and work areas. There are some important caveats to be issued. The survey is not intended as a comprehensive overview of neurology services. There remain significant gaps in our information, both within the areas addressed and in relation to a wide range of areas not examined in the current survey. The survey is intended as a preliminary overview which, it is recommended, should inform the design of a much needed comprehensive audit of neurology services including current and future needs. Assessments of resourcing and resource needs are based on self reports as perceived by Neurologists in relation to their service within each centre and have not been cross checked with other data sources.

The programme acknowledges the support of all the neurology centres which took the time from extremely busy workloads to complete and return their responses. The programme would also

like to thank the Neurological Alliance of Ireland, the national umbrella of neurological charities, which helped to design the survey, analysed the responses and prepared this preliminary report for the programme team. The Working Group and Clinical Advisory Group of the National Clinical Programme of Neurology will interpret the findings of this survey. Recommendations emanating from the survey will be made by the Neurology Programme under its key objectives which are to;

- Improve access to appropriate services
- Improve safety and quality in the delivery of patient centred care
- Improve value of services

### **Format of this Report**

This report has been prepared by the Neurological Alliance of Ireland as a preliminary overview of the findings of the survey of neurology centres, carried out by the neurology clinical programme between December 2014 and January 2015 with further information collated in April 2015. As part of its commitment to supporting the work of the neurology programme, the NAI has been happy to provide staffing support to assist in the initial design of the survey and in preparing this initial analysis of the results. There remains a considerable task for the programme team to further interpret and review these findings in the context of the implications for service delivery and priorities for the neurology programme going forward.

As well as reporting the basic findings of the survey to date, this report will identify areas where further information could be gathered to improve the quality of the information available and recommendations for further areas of service provision and resourcing that need to be examined. The report will also review existing information available within the health services which is important in the context of interpreting these findings.

The Neurological Alliance of Ireland has welcomed the opportunity to work in partnership with the programme on this project and would like to take this opportunity to pay tribute to the positive working relationships established by the neurology programme manager, Edina O Driscoll, with the Neurological Alliance that has supported this collaboration.

### **Introduction**

There has been no systematic attempt to examine, document and publish current resourcing and resource needs within each of the neurology centres in Ireland. The Strategic Review of Neurology Services (200711) carried out a series of site visits of each of the main neurology centres but with a view to documenting overall issues within the service, rather than an audit of resources available. The outcome of the individual consultations was not published as part of the final report. Both of the Comhairle na nOspidéal reports on neurology services reviewed a number of aspects of current service provision and future need, principally in relation to consultant staffing in the areas of neurology and neurophysiology.

## **Part A: A Review of Information Available from HSE Information Systems in relation to neurology services**

### **(i) Neurology Activity in Irish Hospitals**

For the purposes of this report, the NAI requested the most up to date information available from the HSE business intelligence unit and other sources in relation to neurology services.

The data is presented below:

**(i) Activity within Neurology Centres**

There are 17 hospitals that provide neurology care in Ireland. However, the health services considers there to be 10 main neurology centres across Ireland. These are identified in bold in Table 1a.

**Table 1a – Neurology Activity\* in Irish Hospitals 2014\*\***

	In-patient	Daycase	New OPD	Return OPD	Total OPD
<b>Cork University Hospital</b>	1,131	3,282	2,030	6,143	8,173
<b>Beaumont Hospital</b>	859	696	1,695	6,683	8,378
<b>Galway University Hospitals</b>	375	1,723	1,461	5,155	6,616
<b>Tallaght Hospital</b>	332	935	1,443	3,185	4,628
<b>Mater Misericordiae University Hospital</b>	316	579	2,035	2,620	4,655
<b>St. Vincent's University Hospital</b>	266	2,170	2,315	6,130	8,445
Mercy University Hospital Cork	222	211	258	871	1,129
<b>Sligo Regional Hospital</b>	140	679	401	1,353	1,754
<b>University Hospital, Limerick</b>	20	9	704	1,294	1,998
<b>University Hospital Waterford</b>	2	13	661	1,041	1,702
<b>St. James's Hospital</b>	170	166	1,291	3,226	4,517
Kerry General Hospital			202	724	926
St. Luke's Hospital Kilkenny			186	385	571
Letterkenny General Hospital			155	348	503
Connolly Hospital - Blanchardstown			182	179	361
Cavan General Hospital			107	184	291
Our Lady of Lourdes Hospital Drogheda		42	46	9	55
<b>Total</b>	<b>3,663</b>	<b>10,505</b>	<b>15,172</b>	<b>39,530</b>	<b>54,702</b>

\* It is important to note that Table 1 excludes activity related to paediatric neurology, neurosurgery and clinical neurophysiology specialities. Some neurology services are offered in some hospitals (e.g. maternity hospitals) but this is mostly as an adjunct to the obstetric care within those hospitals.

\*\* Source – Business Intelligence Unit HSE



**Table 1b – New to Return Ratio for Neurology Out-patients across Neurology Centres \***

	New	Return	Total OPD	OPD N:R Ratio
Mater Hospital	2,035	2,620	4,655	1:1.3
University Hospital Waterford	661	1,041	1,702	1:1.6
University Hospital, Limerick	704	1,294	1,998	1:1.8
Tallaght Hospital	1,443	3,185	4,628	1:2.2
St. James's Hospital	1,291	3,226	4,517	1: 2.5
St. Vincent's University Hospital	2,315	6,130	8,445	1:2.7
Cork University Hospital	2,030	6,143	8,173	1:3**
Sligo Regional Hospital	401	1,353	1,754	1:3.4
Galway University Hospitals	1,461	5,155	6,616	1:3.5
Beaumont Hospital	1,695	6,683	8,378	1:3.9**
<b>Total</b>	<b>14,036</b>	<b>36,830</b>	<b>50,866</b>	<b>1:2.6</b>

\* Source – Business Intelligence Unit HSE

\*\* New:Return ratios are expectedly higher in both of CUH and Beaumont. This is reflective of the complexity of patients seen in both these national centres. Patients with a higher degree of complexity require regular review and monitoring through OPD services.

A comparison with information from 2009 in Table 1c and graphic Fig 1 below indicates the significant increase in OPD activity across neurology centres (2009 v 2014).

**Table 1c Comparison of Neurology OPD activity and New Return Ratios 2009/2014**

	Total OPD activity 2009	New Return Ratio 2009	Total OPD activity 2014	New Return Ratio
<b>Cork University Hospital</b>	7007	1:5.3	8173	1:3
<b>Beaumont Hospital</b>	7677	1:5.5	8378	1:3.9
<b>Galway University Hospitals</b>	4002	1:1.9	6616	1:3.5
<b>Tallaght Hospital</b>	3681	1:1.7	4628	1:2.2
<b>Mater Misericordiae University Hospital</b>	3613	1:0.9	4655	1:1.3
<b>St. Vincent's University Hospital</b>	5555	1:2.7	8445	1:2.7
<b>Mercy University Hospital Cork</b>	1291	1:3.9	1129	1: 3.4
<b>Sligo Regional Hospital</b>	1552	1:1.9	1754	1:3.4
<b>University Hospital, Limerick</b>	571	1:1.2	1998	1:1.8
<b>University Hospital Waterford</b>	1224	1:0.8	1702	1:1.6
<b>St. James's Hospital</b>	3274	1:1.9	4517	1: 2.5

Table 1d Comparison of Neurology OPD activity 2009/2014

	Total OPD activity 2009	Total OPD activity 2014	% increase
Cork University Hospital	7007	8173	16.64%
Beaumont Hospital	7677	8378	9.13%
Galway University Hospitals	4002	6616	65.32%
Tallaght Hospital	3681	4628	25.73%
Mater Misericordiae University Hospital	3613	4655	28.84%
St. Vincent's University Hospital	5555	8445	52.03%
Mercy University Hospital Cork	1291	1129	-12.55%
Sligo Regional Hospital	1552	1754	13.02%
University Hospital, Limerick	571	1998	249.91%
University Hospital Waterford	1224	1702	39.05%
St. James's Hospital	3274	4517	37.97%
<b>Total</b>	<b>39,447</b>	<b>51,995</b>	

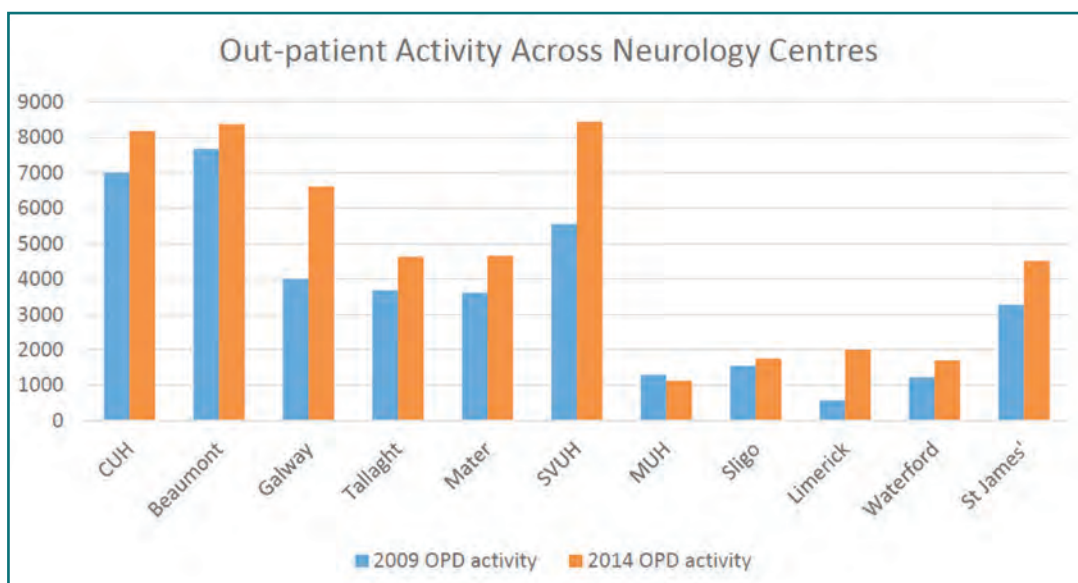


Fig 1: OPD activity 2009 and 2014 (total new and return)

## (ii) Neurology Waiting Lists

Table 2 outlines the recent waiting list information for neurology. It shows:

- Compared to other specialities, there are only small numbers of patients waiting for in-patient and daycase. This reflects the significant out-patient basis and treatment approach within neurology. Only 17% of neurology admissions are day cases (Source: Strategic Review of Neurology and Neurophysiology Services 2007). The relatively low number of those waiting on in-patient services is also reflective of the minimal number of elective neurology beds available throughout the country, those requiring inpatient admission currently tend to present to ED (1 in 5 admissions) in the absence of elective inpatient services.
- 54% of all Out-patient waiting lists are in 4 hospitals (Beaumont, Tallaght, Galway, Mater).
- Neurology patients represent approximately 2.1% of all out-patient visits to hospitals nationally each year. However, in contrast, neurology patients represent 3.8% of all adults waiting for out-patients nationally.

**Table 1d– Neurology Waiting Lists in Irish Hospitals 2014\***

	Inpatient	Day Case	OPD
Beaumont Hospital	39	13	2,084
Tallaght Hospital		14	2,082
Galway University Hospital			1,785
Mater Misericordiae University Hospital	2		1,072
University Hospital Waterford			910
University Hospital Limerick			853
St. Vincent's University Hospital	6		810
Cork University Hospital	11	2	642
St. James's Hospital	170	1	397
Cavan General Hospital			342
Letterkenny General Hospital			322
Kerry General Hospital			301
Connolly Hospital			298
Mercy University Hospital			282
Sligo Regional Hospital		30	176
Total	58	60	12,356

\* Dec 2014 Source – Business Intelligence Unit HSE

- (iii) Challenges associated with the information on neurology services currently collated by existing information systems within the health services

There are a number of challenges in relation to the information collected on neurology services by the current information management systems within the HSE.

- **The data does not capture all neurological activity:** There were 3,663 in-patient discharges from the speciality of neurology in 2014. Of these, 1,990 (54%) were from two centres (Cork and Beaumont). It should be noted that many more patients will be admitted to hospital requiring neurological care. However, in such circumstances the patient may be admitted by a general physician or another speciality with neurologists providing appropriate support care as required. Similarly, there are many conditions which have a significant neurological basis to them (e.g. pain management, falls, spinal injuries, etc) which are not categorised specifically as “neurological”. The Strategic Review of Neurology and Neurophysiology Services (2007) notes that “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”.
- **Neurology provides support to other specialities which is not captured:** Evidence from the UK shows that 7% of all admissions to hospitals have a neurological component to them. It further shows that of all admission episodes mentioning a neurological condition, only 43% had a primary diagnosis of a neurological condition. This suggests that much neurological related work focuses on collaborative and multi-disciplinary working with other specialities.

**The requirement to provide on call services represents a significant part of the activity, particularly for specialist centres such as CUH and Beaumont.**

- **The New: Return ratio should be interpreted with care.** The new : return OPD ratio nationally was 2.6. Table 1b shows the new: return ratio for OPD across neurological centres. Care should be exercised in interpreting the variation in ratios due to differences in the complexity of patients across centres, the infra-structural and organisational differences within hospitals and the availability of primary care services for neurology patients. As can be seen, the Mater, Waterford and Limerick demonstrate a low return ratio. Beaumont (which also has an associated neurosurgical service) has a higher return ratio of 3.9.

**NOTE: The role of Beaumont and Cork University Hospitals as specialist centres is a significant factor in new:return ratios for these centres. Note the comment at the end of this section in relation to return OPD visits per episode of care which is of particular relevance for specialist centres managing complex cases.**

**New: return ratios do not capture nurse led clinics**

- (iv) **Current Information Systems do not capture information which is of critical importance to neurology services**

**Presentation of Neurological Cases in Emergency Departments**– Currently no national information on ED presentations is available on a speciality basis. We cannot determine the current demand and presentation level within ED. Estimates from the UK reiterated in the Strategic Review of Neurology and Neurophysiology Services (2007) are that one in five presentations to emergency department is for a neurological condition.

**Diagnostic Activity:** Diagnostic activity information is not routinely collated in Ireland so we cannot at this point profile the diagnostic activity associated with neurological conditions. However, given the high diagnostic requirements within neurology, it is expected that diagnostic related activity (particularly MRI and CT) would be high for these categories of patients. Data from the UK Compendium of Neurological Statistics 2012-2013<sup>236</sup> indicates that for this period:

- one third of all CT scans in the public health service were for inpatients with a diagnosis mention of a neurological condition
- 28% of MRIs for the same period were for outpatients with a diagnosis mention of a neurological condition
- nearly half of all CT and MRI were for inpatients and outpatients with a diagnostic mention of a neurological condition.

**Total number of return Out-patient visits per episode of care** – Currently at national level, only single attendance data for out-patients is available. We cannot determine the total patient based activity for neurology patients nationally. The UK compendium of neurological statistics 2012-2013 showed that while 45% of outpatient attendees with a neurological condition had one appointment per year, 11.3% of patients with a neurological condition attending outpatient services had ten or more appointments per year, indicating the chronic nature of many of these conditions requiring multiple presentations.

## **Part B: Findings of the Current Survey: Providing a Vital Context to Neurology Service Provision in Ireland**

This section will outline the findings of the national survey of neurology centres carried out by the neurology programme in collaboration with the Neurological Alliance of Ireland.

### **Rationale**

The clinical programme is very conscious of the need to provide a context in which to understand current neurology service provision in Ireland. Activity within neurology takes place against a backdrop of significant challenges within the service. Each of the existing reports on neurology services, and the current draft model of care for the neurology programme, point to the historical underdevelopment of neurology services in Ireland. A nationwide survey of people with neurological conditions and family members undertaken by the Neurological Alliance of Ireland in 2014 with over five hundred respondents highlighted significant issues in relation to accessing services for people with neurological conditions and a perceived deterioration in access to many services over the past three years 2011-2014.

The aim of the current survey of neurology centres was to examine a number of areas of resourcing within neurology services that provide a key, and to date unavailable, documented context for the programme in which to understand current neurology service provision and prioritise areas where resources are critically needed.

---

236 Compendium of Neurology Data England 2012 -2013. Health and Social Care Information Centre (March 2014)

## Methodology

A draft survey was designed and circulated to two pilot centres for their comments. Following a number of changes, the survey was then distributed to eleven neurology centres. The survey was made available on a survey monkey link for ease of completion. The survey was also available in a Word pdf to allow respondents to collate data before completing online. A contact person was identified for each centre to allow the survey administrators to revisit or query any particular set of responses.

Survey responses were completed between December 2014 and January 2015. Additional information was sought from individual centres in April/May 2015.

For the purposes of the current survey, eleven neurology centres are identified as follows:

- Beaumont Hospital
- Tallaght Hospital
- Galway University Hospital
- Mater Misericordiae Hospital
- University Hospital Waterford
- University Hospital Limerick
- St Vincent's University Hospital
- Cork University Hospital
- St James Hospital
- Sligo Regional Hospital
- Mercy University Hospital

These are the only sites within Hospital groups which have a consultant neurologist on site. The survey was not circulated to hospitals who are in receipt of outreach as this information was provided by the centre from which outreach was being delivered.

The survey examined current resourcing for each neurology centre across a number of categories including:

- (a) staffing
- (b) inpatient beds, number, need and configuration
- (c) access to neuroimaging and other diagnostics
- (d) stroke services and ED cover
- (e) clinics including outreach to other hospitals
- (f) access to step down, rehabilitation and palliative care services
- (g) opportunity to identify ongoing challenges facing the neurology centre
- (h) innovative practices and improvements to service delivery that have been developed within the centre.

### Efforts of this Survey to Profile Resources Specifically Dedicated to the Neurology Service

The survey findings exclude, as far as possible, specific dedicated resources which were obtained through the National Clinical Programme for Stroke in terms of dedicated AHP posts and dedicated beds. Resources which are dedicated to epilepsy and were secured through the National Clinical Programme for Epilepsy are specifically highlighted in italics in the reports from each individual centre. This step has been taken in order to provide a clearer insight into resources that are specifically dedicated to the neurology service, as distinct from resources obtained specifically for the management of stroke and epilepsy through the national clinical programmes.



Profiles of staffing resources from each of the neurology centres include epilepsy nurses and these are highlighted in italics. These nurses are dedicated to epilepsy services and not available to general neurology patients. OPD clinics and outreach services also highlight epilepsy services in italics. In relation to outreach, with the exception of consultant outreach to Cavan, Monaghan, Drogheda, Letterkenny and Kilkenny, all other outreach listed in the survey findings is carried out by Epilepsy cANP's and available only to epilepsy patients. The resounding success of the ANP service within epilepsy is a model which could potentially be considered for other conditions within neurology where similar returns on investment would be possible.

The national clinical programme for Epilepsy is a stand alone clinical programme. This programme has secured significant resources, particularly with respect to the development of the Advanced Nurse Practitioner role. To date there are 15.75 WTE currently working in adult Epilepsy services with 2.5 WTE in paediatric epilepsy services. Staff nurse posts have also been secured for the Epilepsy Monitoring Units. Specialist Epilepsy Nurse WTE now totals 25 nationally. The impact of additional resourcing to epilepsy services has led to radical improvements in service delivery with over 70% of new patients seen in under 4 weeks of referral and 80% of patient referrals receiving telephone contact in under 10 days of receipt of referral. Waiting times for OPD for neurology are being impacted by this reduction in OPD waiting times for epilepsy which would otherwise be higher.

## Survey Findings

### Section 1.Staffing

In relation to dedicated staffing, Whole Time equivalents, current vacancies and posts covered by locum/agency were addressed for a range of disciplines in each neurology centre. The results for each centre are outlined separately below. It should be noted that these are based on self report from each of the neurology centres and have not been compared with other data sources. They also include locum posts which are not permanent. Note that ongoing challenges were reported in many centres in relation to ensuring that posts funded for neurology were actually available to the service in practice.

### Centre by Centre Staffing Review

Table 1.1: Tallaght Hospital

	Total WTE dedicated to your neurology service	Total WTE vacancies*	Total WTE that is typically covered off by agency/locum staff
Consultant Neurologist	4	0	1 of 4
NCHD	5	0	0
Occupational Therapy	1.5	0	0
Speech & language therapy	1	0	0
Dietician	.4	.4	.4
Medical Social Work	1	0	0
Physiotherapy	2.1	0	0
Neuropsychology	1	0	0

Staff Nurse	0	0	0
Clinical Nurse Specialist	*2.5 (1 WTE Epilepsy)	0	0
Advanced Nurse Practitioner	0	0	0
Podiatry	0	0	0
Orthoptics	0	0	0
Admin/secretarial support	6.5	0	0

\*.5 Pharma funded

**Table 1.2: Galway University Hospital**

	Total WTE dedicated to your neurology service	Total WTE vacancies*	Total WTE that is typically covered off by agency/locum staff
Consultant Neurologist	4.4	0	0
NCHD	5.4	0	0
Occupational Therapy	0.4*	0	0
Speech & language therapy	1.0*	0	0
Dietician	0	0	0
Medical Social Work	.5WTE	0	0
Physiotherapy	*0	0	0
Neuropsychology	0	0	0
Staff Nurse	0	0	0
Clinical Nurse Specialist	2.4	0	0
Advanced Nurse Practitioner	2.0 (epilepsy only)	0	0
Podiatry	0	0	0
Orthoptics	0	0	0
Admin/secretarial support	4.0	0	0

\*SLT post was originally designated neurology but is used to cover general medical/surgical and is not dedicated to the neurology service. OT also covers other disciplines and is not dedicated to neurology

\*Physiotherapy is a medical rehab post and is not dedicated to neurology

**Table 1.3: St Vincent's University Hospital**

	Total WTE dedicated to your neurology service	Total WTE vacancies*	Total WTE that is typically covered off by agency/locum staff
Consultant Neurologist	3	0	0
NCHD	2	1	0
Occupational Therapy	0.2	0	0
Speech & language therapy	.5	0	0
Dietician	0	0	0
Medical Social Work	.8	0	0
Physiotherapy	1	0	0
Neuropsychology	0	0	0
Staff Nurse	5	0	0
Clinical Nurse Specialist	3	0	0
Advanced Nurse Practitioner	0	0	0
Podiatry	0	0	0
Orthoptics	0	0	0
Admin/secretarial support	2	0	0

**Table 1.4: Waterford Regional Hospital**

	Total WTE dedicated to your neurology service	Total WTE vacancies*	Total WTE that is typically covered off by agency/locum staff
Consultant Neurologist	2	0	0
NCHD	1	1	0
Occupational Therapy	1	0	0
Speech & language therapy	0	0	0
Dietician	0		
Medical Social Work	0	0	0
Physiotherapy	0	0	0
Neuropsychology	0	0	0
Staff Nurse	0	0	0
Clinical Nurse Specialist	0	0	0

Advanced Nurse Practitioner	0	0	0
Podiatry	0	0	0
Orthoptics	0	0	0
Admin/secretarial support	2	0	0

**Table 1.5: Mid Western Regional Hospital Limerick**

	Total WTE dedicated to your neurology service	Total WTE vacancies*	Total WTE that is typically covered off by agency/locum staff
Consultant Neurologist	2	0	0
NCHD	3	0	
Occupational Therapy	0	0	0
Speech & language therapy	0	0	0
Dietician	0	0	0
Medical Social Work	0	0	0
Physiotherapy	.4	0	0
Neuropsychology	0	0	0
Staff Nurse	0	0	0
Clinical Nurse Specialist	2 (1 is Epilepsy *cANP)	1	0
Advanced Nurse Practitioner	0	0	0
Podiatry	0	0	0
Orthoptics	0	0	0
Admin/secretarial support	1 (currently on sick leave) Additional support of 2× .2 WTE for typing Total: 1.4		1 (locum starting 11th May)

\*cANP refers to candidate Advanced Nurse Practitioner

**Table 1.6: Mercy University Hospital Cork**

	Total WTE dedicated to your neurology service	Total WTE vacancies*	Total WTE that is typically covered off by agency/locum staff
Consultant Neurologist	1 WTE	0	0
NCHD	3 WTE	0	0

Occupational Therapy	None assigned to neurology	0	0
Speech & language therapy	0	0	0
Dietician	0	0	0
Medical Social Work	0	0	0
Physiotherapy	0	0	0
Neuropsychology	0	0	0
Staff Nurse	0	0	0
Clinical Nurse Specialist	1 WTE	0	0
Advanced Nurse Practitioner	0	0	0
Podiatry	0	0	0
Orthoptics	0	0	
Admin/secretarial support	1 WTE	0	0

Table 1.7: Cork University Hospital

	Total WTE dedicated to your neurology service	Total WTE vacancies*	Total WTE that is typically covered off by agency/locum staff
Consultant Neurologist	5	0	0
NCHD	9	0	0
Occupational Therapy	1	0	0
Speech & language therapy	.5	0	0
Dietician	.3	0	0
Medical Social Work	0	0	0
Physiotherapy	.5	0	0
Neuropsychology	0	0	0
Staff Nurse	30 WTE approx		
Clinical Nurse Specialist	3* -(1 cANP epilepsy)	.5	
Advanced Nurse Practitioner	0	0	0
Podiatry	0	0	0
Orthoptics	0	0	0
Admin/secretarial support	2		
*1 WTE pharma funded			

**Table 1.8: St James Hospital**

	Total WTE dedicated to your neurology service	Total WTE vacancies*	Total WTE that is typically covered off by agency/locum staff
Consultant Neurologist	3	0	0
NCHD	4	0	0
Occupational Therapy	1	0	0
Speech & language therapy	0	0	0
Dietician	0	0	0
Medical Social Work	.8	0	0
Physiotherapy	1	0	0
Neuropsychology	0	0	0
Staff Nurse	0	0	0
Clinical Nurse Specialist	5 ( 1.75 WTE Epilepsy cANP; 1.75 WTE Epilepsy CNS)	0	0
Advanced Nurse Practitioner	0	0	0
Podiatry	0	0	0
Orthoptics	0	0	0
Admin/secretarial support	3	0	0

**Table 1.9: Sligo Regional Hospital**

	Total WTE dedicated to your neurology service	Total WTE vacancies*	Total WTE that is typically covered off by agency/locum staff
Consultant Neurologist	1	1	0
NCHD	2	Applied for intern	0
Occupational Therapy	0	0	0
Speech & language therapy	0	0	0
Dietician	0	0	0
Medical Social Work	0	0	0
Physiotherapy	0	0	0
Neuropsychology	0	0	0



Staff Nurse	0	0	0
Clinical Nurse Specialist	*1	0	0
Advanced Nurse Practitioner	2 candidate ANP epilepsy	0	0
Podiatry	0	0	0
Orthoptics	0	0	0
Admin/secretarial support	1	0	0

\*Pharma funded Post

**Table 1.10 Beaumont Hospital**

	Total WTE dedicated to your neurology service	Total WTE vacancies*	Total WTE that is typically covered off by agency/locum staff
Consultant Neurologist	4.4	5	1 (covering sick leave)
NCHD	14	TBC	TBC
Occupational Therapy	1	0	0
Speech & language therapy	.8 WTE neurology	0	0
Dietician	.5 neurology	0	0
Medical Social Work	1	0	0
*Physiotherapy	3	0	0
Neuropsychology	3	1 new post approved	
Staff Nurse	26 (5 WTE Epilepsy Video EEG)	3.29 WTE	2 WTE
Clinical Nurse Specialist	5 WTE **	0	0
Advanced Nurse Practitioner	1.5WTE (2.5 candidate ANP) All epilepsy		0
Podiatry	TBC		0
Orthoptics	1 WTE		0
Admin/secretarial support	***5.9	.5 neurology	0

\*Physiotherapy: 1 senior grade across neurosciences, 1 senior neurology and 1 staff grade neurology

\*\* CNM2 Epilepsy Surgery Co Ordinators x 1 WTE

CNS Community Liaison funded by Epilepsy Ireland x 1 WTE. Note one of the remaining 3 CNS posts (non epilepsy) is funded by pharma

\*\*\*Admin/secretarial support: Note that particular deficits in relation to admin support were highlighted by this centre

**Table 1.11: Mater Misericordiae Hospital and Dublin Neurological Institute**

	Total WTE dedicated to your neurology service	Total WTE vacancies*	Total WTE that is typically covered off by agency/locum staff
Consultant Neurologist	2.8	0	0
NCHD	8	0	0
Occupational Therapy	.5	0	0
Speech & language therapy	.5	0	0
Dietician	.3	0	0
Medical Social Work	.5	0	0
Physiotherapy	1 WTE approx. *	0	0
Neuropsychology	0	0	0
Staff Nurse	0	0	0
Clinical Nurse Specialist	2 **	0	0
Advanced Nurse Practitioner	1 candidate ANP epilepsy	0	0
Podiatry	0	0	
Orthoptics	0	0	0
Admin/secretarial support	***3 WTE	0	0

Note: \*1 additional physiotherapy post funded privately by Dublin Neurological Institute (DNI)

\*\*Additional posts funded by pharma: 3 CNM2 funded by pharma.

\*\*\*A further 3 admin posts are funded privately through the Dublin Neurological Institute

### **Dedicated Allied Health Professional Staffing within individual neurology centres**

The table below highlights the availability of dedicated allied health professional staffing within individual neurology centres.

**Table 1.12 Availability of Dedicated Allied Health Professional and other Neurology Staffing within Specific Centres**

	OT	SLT	Dietician	Medical	Physiotherapy	Neuropsychology	Podiatry	Orthoptics
Mater	.5WTE	.5WTE	.3WTE	.5WTE	1WTE	0	0	0
Sligo	0	0	0	0	0	0	0	0
St. James	1WTE	0	0	.8	1	0	0	0
Waterford	0	0	0	0	0	0	0	0
Tallaght	1.5WTE	1WTE	.4WTE	1WTE	2.1 WTE	1	0	0
Limerick	0	0	0	0	.4	0	0	0
Cork	1WTE	.5WTE	.3 WTE	0	.5WTE	0	0	0
Galway	.4WTE	1WTE	0	.5WTE	0	0	0	0
Beaumont	1WTE	.8WTE	.5WTE	1WTE	3WTE	3WTE	0	1WTE
Mercy Hospital	0	0	0	0	0	0	0	0
St. Vincent's	.2 WTE	.5WTE	0	.8WTE	1WTE	0	0	0

Overall observations in relation to these findings are:

- Three of the 11 hospitals have no dedicated OT for neurology patients.
- Five neurology centres have no dedicated speech and language therapist for neurology patients.
- Five neurology centres have no dedicated medical social worker for neurology patients, including CUH which is one of two national neuroscience centres in Ireland.
- Only Beaumont and Tallaght Hospital have dedicated neuropsychology services available to patients, which means that the second main neuroscience centre in the country in CUH has no dedicated access to neuropsychology (with the exception of contracted hours for Neuropsychological assessment of potential candidates for epilepsy surgery).
- Sligo hospital has no dedicated posts for any of the core supporting therapies of occupational therapy, speech and language therapy, physiotherapy and neuropsychology. The regional centres of Limerick and Waterford also have very limited access to dedicated allied health professional staffing.
- Podiatry and Orthoptics availability is extremely limited across neurology centres with only the Beaumont centre having dedicated staffing in this area.

### Access to AHP services for centres without dedicated posts: WTE available for neurology patients

Table 1.13 below reflects the estimated WTE available to the neurology service from elsewhere in the hospital where there is NO dedicated post within the neurology service.

**Table 1.13: Access to AHP services for centres without dedicated access: WTE available for neurology patients**

	Mater	Beaumont	Sligo	Waterford	James
Occupational Therapy	*DS	DS	<1 WTE	<1 WTE	
Speech & Language	DS	DS	<1 WTE	<1 WTE	<1 WTE
Dietician	DS	DS	<1 WTE	<1 WTE	<1WTE
Medical Social Work	DS	DS	Service not available	Service not available	available
Physiotherapy	DS	DS	<1 WTE	<1 WTE	
Neuropsychology	Service not available	DS	Service not available	Service not available	Service not available
Podiatry	Service not available	Info not available	<1 WTE available	<1 WTE	Service not available
Orthoptics	<1 WTE	DS	Service not available	<1 WTE	Service not available

**Table 1.13 contd: Access to AHP services for centres without dedicated access: WTE available for neurology patients**

	Galway	Vincent's	Mercy	CUH	Limerick
Occupational Therapy	DS	DS	< 1 WTE (5-10 sessions)	DS	Service not available
Speech & Language Therapy	DS	DS	<1 WTE (5-10 sessions)	DS	<1 WTE
Dietician	<1 WTE	<1 WTE (5-10 sessions)	Service not available	DS	<1 WTE
Medical Social Work	DS	DS	<1 WTE (2-5 sessions)	<1 WTE (1-2 sessions)	Service not available
Physiotherapy	<1 WTE	DS	<1 WTE (5-10 sessions)	DS	<1 WTE
Neuropsychology	Service not available	Service not available	Service not available	<1 WTE (1-2 sessions)	<1 WTE
Podiatry	Service not available	Service not available	Service not available	<1 WTE (1-2 sessions)	Service not available
Orthoptics	Service not available	<1 WTE (1-2 sessions)	Service not available	<1 WTE (1-2 sessions)	<1 WTE

\*(No response for Tallaght Hospital)

DS refers to dedicated staffing (even if only partial WTE) within the centre for that discipline  
 The data from Table 1.13 indicates that, even when resources available elsewhere in the hospital to support the neurology service are factored in:

Neuropsychology is not available in a majority of centres

Medical social work is not available in the regional centres of Limerick, Waterford, Sligo

Podiatry and Orthoptics are not available in the majority of centres.

It should be noted that the option of stating the exact proportion of the WTE available to the neurology service was not available for this question. The proportion of WTE available to neurology and for disciplines where there is no dedicated staffing for neurology is likely to be very low (as indicated by information provided by some centres on the number of ring fenced sessions for neurology patients per month (e.g CUH)

Table 1.14 highlights the staffing ratio within each hospital group for consultant neurology based on the recommended level of staffing. Each group significantly exceeds the recommended ratio of 1 neurologist to 70,000 population (Association of British Neurologists).

**Table 1.14: Neurology Resourcing Across Individual Hospital Groups**

Hospital Group	Neurology Centers	No. of Neurologists (including locum's & backfill for CSPD clinical leads)	Ratio neurologist: population Recommended 1:70,000	Beds available	Provide outreach to...
Dublin North East 1 center Pop 800,000	Beaumont	4.4	1:181,818	34 (Inclusive of EMU and 16 stroke beds accessible to medEl)	Connolly Drogheda Monaghan
Dublin Midland 2 Centers Pop 800,000	St James Hospital	3	1:114,285	No Dedicated Beds	Telephone support to midlands hospitals. Epilepsy outreach
South/South West 3 centers Pop 850,000	Tallaght Hospital	4	1:106,250	No dedicated beds	0
	Cork University Hospital	5		21 (inclusive of EMU)	Kerry
	Waterford Regional Hospital	2		No dedicated beds	Kilkenny
	Mercy University Hospital	1		5	0

West/North West 2 centers 700,000	University Hospital Galway	4.4	1:185,185	5-10	0
	Sligo Regional Hospital	1 (+1 vacant post)		No dedicated beds	Letterkenny
Mid-West 1 center Pop 400,000	Mid-Western Regional Hospital Limerick	2	1:200,000	No dedicated beds	0
East 2 centers Pop 1,000,000	Mater Misericordiae University Hospital	2.8	1:147,158	2 elective neurology beds	Cavan
	St Vincent's University Hospital	3		7	0



## Section 2: Neurology Beds

### Profile of Neurology Beds

It is not possible to fully profile the neurology bed capacity for a number of reasons. Not all hospitals will fully designate beds to specialities and it is likely that given the current bed occupancy level that neurology patients will be admitted to in-patient beds in other wards within hospitals and that non-neurology patients may be admitted to neurology specific beds. However, the survey provides an indication that the availability of dedicated neurology beds is a critical issue facing neurology services with only five neurology centres having access to dedicated beds.

**Table 2.1 – A profile of neurology beds across neurology centres**

	In Patient - Total Available	In patient - Current Neurology Beds Occupied by a Delayed Discharge	In patient - Current Neurology Beds Closed	Daycase - Total Available	Additional Inpatient Beds Required	Additional Daycase Beds Required
Beaumont	16 (exclusive of the Epilepsy Monitoring Unit)	9	0	2	12	
Cork University Hospital (CUH)	21 (inclusive of epilepsy monitoring unit)	8	0	1-5		2 additional 5 day beds
Galway University Hospitals	5-10	0	0	5-10	1-5	1-5
St. Vincent's University Hospital	7	3	0	4 (not dedicated)	5	4
Mater	2 (+ 11 stroke beds)	Info not available	0	1-2	26 and 6 stroke	
Sligo	0	0	0	0	0	20
St. James's Hospital	0	0	0	0	6	2
University Hospital Waterford	0	0	0	0	6	6
Tallaght Hospital	0	0	0	0	24	6
Mercy Hospital	5	2	0	2	5	2
University Hospital Limerick (UHL)	0	0	0	0	Exact requirement currently unclear	Exact requirement currently unclear

### Bed Configuration and Staffing by Neurology Nurses

For centres that had dedicated beds, items were included in the survey in relation to: (a) whether neurology beds available are staffed by neurology nurses and (b) are they configured into a single wards or distributed throughout the hospital. It is preferable to have beds cohorted in a single ward (s) it is of concern that this is not the case even in a main neuroscience centre such as Cork University Hospital.

**Table 2.2–Profile of Dedicated Inpatient Neurology Beds within specific centres**

	Staffed by Neurology Nurses	Cohorted within one ward
Beaumont	Yes (inclusive of Epilepsy nurses for EMU)	Cohorted (with stroke patients)
Cork University Hospital (CUH)	Yes (inclusive of Epilepsy Nurses for EMU)	Cohorted (with Stroke patients)
Galway University Hospitals	no	Cohorted
Mater	yes	Cohorted
Mercy	no	yes
St. Vincent's University Hospital	yes	Cohorted

**Table 2.3 Profile of Dedicated Daycase Neurology Beds within specific centres**

	Staffed by Neurology Nurses	Cohorted within one ward
Beaumont	yes	Cohorted in one ward
Cork University Hospital (CUH)	no	Cohorted
Galway University Hospitals	no	Cohorted
Mercy	no	Info not available
St. Vincent's University Hospital	No dedicated	No day beds day beds
Mater	3 DNI	Cohorted DNI

## Section 3 Outpatient Services

The table below indicates the number of consultant led, nurse led and MDT led clinics in each centre per month in relation to condition specific and general neurology clinics.

**Table 3.1: Outpatient Clinics per month**

Neurology Centre	No. of Consultant led clinics	No. of Nurse led Clinics	No. of MDT led Clinics
Mater	43	28 (inclusive of Epilepsy cANP clinics)	4
Sligo	7 + 7 outreach	0	0
St James'	30	8 (inclusive of Epilepsy cANP clinics)	0
Waterford	36	0	0
Tallaght	53	10-20 (inclusive of epilepsy cANP clinics)	2-5
Cork	62	0	1-2
Galway		1-2 (inclusive of epilepsy cANP clinics)	1-2
Beaumont	38	5-10 (inclusive of epilepsy cANP clinics)	5-10
Mercy	8	0	0
St Vincent's	52	2-5	0

Nurse led clinics appear to be a routine form of practice where these professionals are in place, in most cases their absence appears to be due to limited or nonexistent CNS staffing in those centres, for example Mercy Hospital (Less than one CNS post) and Waterford (no CNS post).

The range of condition specific clinics provided by individual centres is detailed below, with additional specialist clinics listed for specific centres. It should be noted that currently, there is not agreed defining criteria for what is considered a 'specialist' clinic. The model of care for Neurology provides descriptors within the care pathways as to best practice within condition specific clinics, but only for the 4 conditions specifically addressed.

**Table 3.2: Condition Specific Clinics Provided by Individual Neurology Centres**

Neurology Centre	Parkinson's Disease	Dystonia	Motor Neurone Disease	Movement Disorders	Epilepsy	Multiple Sclerosis	Migraine
Mater	✓	✓	✓	✓	✓	✓	✓
Sligo					✓	✓	
St James'	✓	✓			✓	✓	
Waterford		✓	✓		✓		
Tallaght	✓	✓			✓		
Limerick	✓				✓		
Cork	✓	✓	✓	✓	✓		✓
Galway	✓		✓		✓	✓	✓
Beaumont	✓	✓	✓	✓	✓		✓
Mercy	✓				✓		
St Vincent's	✓	✓				✓	✓

**Additional clinics:**

- Beaumont provides neurogenetics, Huntington's disease, Stroke & Neuromuscular clinics
- Tallaght provides peripheral neuropathy, ataxia, movement disorders, DBS and rapid access stroke prevention
- CUH provides neuromuscular and neurovascular clinics and TIA clinics
- MMUH also provides clinics for Myasthenia Gravis, neuromuscular clinic, neurogenetics, deep brain stimulation, hypertension and neurovascular

## Section 4: Profile of Outreach Services to Other Hospitals

Table below profiles the outreach services provided by individual neurology centres to other hospitals and units such as residential care services etc

This table is useful in providing an initial insight into those areas of the country which do not have access to a neurology service.

**Table 4.1: Profile of Outreach Services to Other Hospitals**

Neurology Centre	Outreach provided to	Consultant Led Clinics per month	Nurse Led Clinics per month
Mater	Cavan	4	0
Sligo	Letterkenny	5-10	0
St. James	Liaison service to Midlands hospitals (telephone) for consult advice and acceptance of inpatient transfers <i>Epilepsy outreach to Tallaght and Cheeverstown</i>	1-5	1-5
Waterford	St Lukes Kilkenny	5-10	0
Tallaght	No outreach		
Limerick	No outreach		
Cork	<i>Residential care unit for people with ID &amp; epilepsy</i> <i>Cork University Maternity Hospital (consult and acute emergency referrals)</i> Referrals and transfers from: Mallow General Hospital Bantry General Hospital Kerry General Hospital St. Joseph's Hospital Clonmel Waterford University Hospital	1-5	0
Galway	No outreach		
Beaumont	<i>St Josephs (ID) centre</i> Connolly Hospital Monaghan Hospital <i>Rotunda (CNS clinics)</i> <i>National Maternity Hospital (CNS clinics)</i> Drogheda (CNS clinics) <i>Drumcar (ID service)</i> Mater & Connolly (CNS migraine clinics)	1-5	5-10
Mercy Hospital	No outreach		
St. Vincent's	Accept inpatients and outpatients from centres such as St Michael's House, Wexford General, St Luke's Kilkenny, St Colmcillles, St John Of Gods.		

Currently it appears that the following regional hospitals do not have access to onsite consultations from a neurologist:

**Table 4.2 : Hospitals that do not have not access to onsite consultations from a neurologist**

Group /	Group Members	Group	Group Members
Dublin North East	Louth County Hospital	South/South West	South Tipperary General Hospital South Infirmity Victoria University Hospital Bantry General Hospital Mallow General Hospital
Dublin Midland	Midlands Regional Hospital, Tullamore Naas General Hospital Midlands Regional, Portlaoise Mayo General Hospital	West/North West	Merlin Park Hospital Portiuncula Hospital Roscommon County Hospital
East	Midlands Regional Hospital, Mullingar Wexford General Hospital Hollis Street Hospital Our Lady's Hospital, Navan St Columcilles Hospital St Michael's Hospital Dun Laoghaire	Mid-West	Ennis General Hospital Nenagh General Hospital St John's Hospital Limerick Mid Western Regional Maternity Hospital



## Section 5: Access to Neurology Diagnostics

The programme was keenly conscious that access to a range of diagnostic services is a critical issue for neurology services.

The survey examined:

- (a) Availability of diagnostic services within each neurology centre
- (b) Waiting times within each neurology centre

### (a) Availability of diagnostic services within each neurology centre

Table 6.1: shows the range and arrangements of diagnostic availability across neurology centres nationally. It shows the in-house / external referral to another hospital availability of these tests and whether neurology patients have dedicated access or not. It also shows where diagnostic services are not available. The survey results demonstrate:

- MRI – In-house access to MRI is available in all neurology centres but with only 4 centres only having dedicated access for neurology patients.
- Neuroradiology – only 3 centres have in house dedicated access to neuroradiology, of note the main neuroscience centre in Beaumont Hospital does not.
- Interventional neuroradiology – a similar pattern to neuroradiology, 3 centres have in house dedicated access to interventional neuroradiology, 5 centres do not have onsite interventional neuroradiology while the service is not available in Galway. Waterford, Limerick and Galway do not have access to either neuroradiology or interventional neuroradiology within the centre.
- 7 of the 11 neurology centres have no in-house access to PET scanning.
- All neurology centres have access to CT with the majority (10) centres having no dedicated CT access for neurology patients.
- All neurology centres have access to fluoroscopy.
- Discography, for the relief of pain, is not available in 3 centres.
- Dedicated access for Electroencephalography (EEG) for the recording of electrical activity is available in 7 centres.

### Table 5.1: Availability of diagnostic services that are important to the diagnosis and treatment of neurological conditions

Legend for interpretation of Table 6.1

- 1: Service available in house with protected slots for neurology patients
- 2: Service available in house but without protected slots for neurology patients
- 3: Referral to external hospital for this service
- 4: Service not available to the neurology centre
- 5: Other arrangement provided to access this service

	MRI	Neuro radiology	Interventional Neuro radiology	PET scanning	CT	Fluoroscopy	Discography	EEG	EMG	Ultra Sound	Myelo graphy
Mater	1	1	2	2	2	2	3	1	1	2	2
Sligo	2	2	3	3	2	2	4	2	5	2	5
St. James	2	2 & 3	2&3	2	2	2	2	2	2	2	2
University Hospital Waterford	1	5	3	3	1	1	3	3	3	1	3
Tallaght Hospital	2	2	3	3	2	2	1	1	1	2	2
University Hospital Limerick	2	3	3	3	2	2	4	1	1&3	2	5
Cork University Hospital	1	1	1	2	2	2	2	1	1	2	1
Galway University Hospitals	1	4	4	3	1	1	4	1	1	2	2
Beaumont	2	1	1	3	2	2	2	1	1	2	2
Mercy Hospital	1	3	3	3	2	2	4	1	1	2	3
St. Vincent's Hospital	2&3	2	2	2	2	2	2	2&3	2&3	2&3	2&3

### (b) Waiting Times for Diagnostic Services

Table 6.2 below shows the current access times for routine neurology referrals for these diagnostic tests. Waiting times of more than 6 months are highlighted in red, 2-6 months in amber and those less than 2 months are shown in green.

Waiting times for neurodiagnostics confirm reports from individual neurology centres and patient representative organisations of significant and growing problems in this area.

- MRI – no centre has MRI access for routine referrals in under 2 months and 7 of the ten neurology centres cannot get access within 1 year of referral. MRI is becoming increasingly required in not only the diagnosis of neurological conditions, but also in the appropriate management of condition, in particular Multiple Sclerosis. Fig 2 clearly highlights the lengthy waiting periods for MRI across neurology services.
- CT Scanning – access to CT scanning has a typical wait of between 2-6 months. Tallaght Hospital has extended waiting times for routine referrals.
- Electroencephalography - Only the Mater hospital has less than a 2 month waiting list for EEG monitoring. All other centres have waiting times of at least two months with 4 hospitals having waiting times over 6 months.

### Out of hours access for CT and MRI

Out of hours access for CT and MRI was examined in all centres

Only 1 centre, Beaumont, had out of hours access for MRI. All centres had out of hours access for CT except Sligo. MRI and CT represent essential diagnostic tools to support the modern neurology service and it is critical that there is access to these diagnostic tests on a twenty four hour basis.

**Table 5.2: Waiting times for diagnostic services for neurology patients**

**Waiting times of more than 6 months are highlighted in red, 2-6 months in amber and those less than 2 months are shown in green.**

	MRI	Specialist radiology	PET scanning	CT	Fluroscopy	Discography	EEG	EMG	Ultra sound	Myelo graphy
Mater Hospital	> 1 year	< 1 mth	< 1 mth	2-6 mths	2-6 mths		1-2 mths	6-12 months	2-6 mths	2-6 mths
Sligo	2-6 mths	2-6 mths		2-6 mths	2-6 mths	Service not available			2-6 mths	Service not available
St. James's Hospital	2-6 mths	1-2 mths	2-6 mths	1-2 mths	2-6 mths	2-6 mths	1-2 mths	12-14 mths	2-6 mths	2-6 mths
University Hospital Waterford	> 1 year			2-6 mths	1-2 mths		> 1 year	> 1 year	1-2 mths	
Tallaght Hospital	> 1 year		Service not available	6-12 mths	No waiting	No waiting	2-6 mths	2-6 mths	2-6 mths	
University Hospital Limerick (UHL)	> 1 year			2-6 mths			2-6 mths	2-6 mths	2-6 mths	
Cork University Hospital (CUH)	> 1 year	2-6 mths	< 1 mth	2-6 mths			2-6 mths	> 1 year	2-6 mths	
Galway University Hospitals	6-12 mths	2-6 mths	2-6 mths	1-2 mths	No waiting		2-6 mths	1-2 mths		
Beaumont	> 1 year		Service not available	< 1 mth	< 1 mth		4-6 mths	4-6 mths	< 1 mth	
Mercy	2-6 mths	Info not available	1-4 weeks	Less than 1 week	Info not available	Service not available	2-6 mths	6-12 mths	Less than 1 week	Info not available
St. Vincent's Hospital	> 1 year	> 1 year	2 weeks	2-6 mths	1-2 mths	Info not available	6-12 mths	6-12 mths	2-6 mths	Info not available

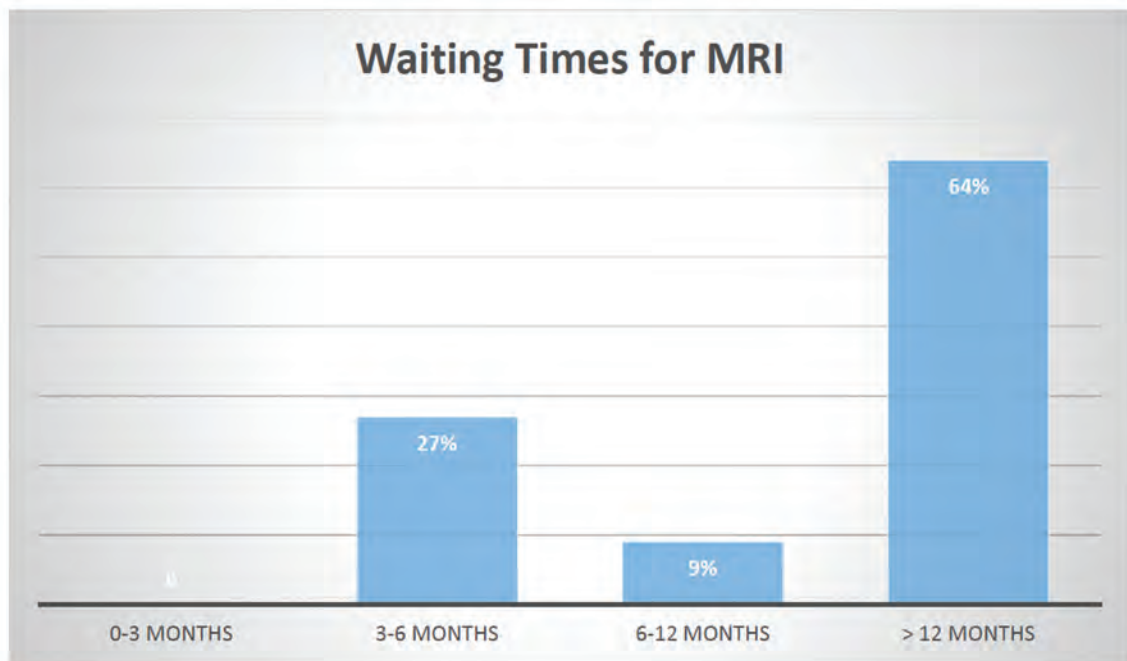


Fig 2: Waiting times for MRI access across neurology centres

## Section 6: ED Cover and Stroke Services

Table 7.1 below indicates the provision of ED cover and stroke services within each of the neurology centres. Only 4 of the 11 centres provide 24 hour access to emergency department neurology cover. Given that it is estimated that one in five presentations to ED has a neurological component this is of note in terms of access to a neurological opinion within the emergency department with patients being managed under the care of consultants including general surgeons, rheumatologists, emergency & orthopaedic physicians, cardiologists etc. Speciality specific referral in neurology has been shown to expedite diagnosis and treatment and leads to a significantly reduced length of stay in hospital<sup>237</sup>. In hospitals served by a single handed consultant neurologist, consultation services in addition to in-patient and out-patient case load is frequently unmanageable.

The demands on neurologists are likely to increase with advances in critical care management of patients. Improved survival rates can lead to new complications secondary to both illness and treatment. Neurological complications double both the length of stay in hospital and the likelihood of death; the mortality rate for patients with neurological complications is 55% compared to 29% for those without<sup>238</sup>.

The role of neurologists in the management of stroke is outlined with four of the centres leading on the stroke/thrombolysis service within their hospitals. This represents a significant increased factor in the workload of these neurology services. One of the important reports coming from individual centres of an increase in workloads and pressure on neurology beds and other resources due to the need to provide stroke cover.

Of those centres with dedicated stroke units, (10 centres) 4 of these lack appropriate step down facilities to prevent these beds becoming blocked. This is an important issue for this service going forward.

---

237 Ali E, Chaila E, Hutchinson M, Tubridy N. The 'hidden' work of a hospital neurologist: 1000 consults later. *European Journal of neurology* 2010; 17: e28-e32

238 Saif S M Razvi, Bone I. Neurological consultation in a medical intensive care unit. *J Neurol Neurosurg Psychiatry* 2003; 74 (suppl III):iii 16-iii23

**Table 6.1: ED cover and Stroke Services provided by each of the neurology centres**

	24 hour ED specialist neurology cover	Dedicated stroke unit with protected beds exclusively for acute stroke patients	Step down facilities from the stroke unit so that new acute stroke patients can access beds	Neurology led stroke/ thrombolysis service in the neurology centre	Joint (neurology and other specialism) stroke/ thrombolysis service	Stroke/ thrombolysis service in the hospital led by another speciality	Additional Notes
Mater Hospital	Yes (stroke cover only)	Yes	Yes	Yes	Yes	No	Stroke thrombolysis cover provided by neurology and medicine for the elderly
Sligo	No	Yes	No	Yes	No	Yes	Stroke service led by Geriatrician. Access to rehabilitation centre, St John's, but no specific SLA/ protected beds within this centre
St. James's Hospital	No	Yes	Yes	Not applicable	Yes		
University Hospital Waterford	No	Yes	Yes	No	No	Yes	
Tallaght Hospital	No	Yes	No (access to early support discharge team)	Not applicable	Yes	Not applicable	
University Hospital Limerick (UHL)	No	Yes	Yes	No	No	Yes	The stroke unit is sometimes (and more often in recent times) used to accommodate non-stroke patients, although the majority of stroke beds are occupied by stroke patients. Non - stroke patients are usually medical, but have occasionally been surgical too.



Cork University Hospital (CUH)	Yes	Yes	Yes	Yes	Yes	No	Neurology manage patients <65 years; Geriatrics manage patients >65 years
Galway University Hospitals	No	Yes	Yes	No	Yes	No	
Mercy Hospital	No	Yes	No	No	Yes	No	
Vincent's Hospital	No	No	No	For under 65 only	Yes	No	
Beaumont	Yes	Yes	No	Yes	Yes	No	

## Section 7:

### Access to Hospital Based Rehabilitation Services

Each of the neurology centres were invited to comment on access to hospital based rehabilitation services (a) within the hospital where the neurology centre is based and (b) within hospitals to which sessional commitments are provided.

Access to rehabilitation services is a critical support for the effective delivery of neurology services, meeting a critical need of neurology patients as well as enabling discharge from neurology services to appropriate rehabilitation facilities. 5 of the centres reported limited or very limited access to rehabilitation services, only one centre reported very good access.

7 of the centres have sessions from a Consultant in Rehabilitation Medicine, however currently, none of the centres have on-site 'specialist' 226 rehabilitation in-patient services.

**Table 7.1: Access to hospital based rehabilitation services (in the hospital where the neurology service is based)**

	Very good access	Moderately good access	Limited access	Very limited access	No access	Information not available
Mater		✓				
Sligo			✓			
St. James		✓				
Waterford				✓		
Tallaght		✓				
Limerick					✓	
Cork			✓			
Galway				✓		
Beaumont				✓		
Mercy Hospital			✓			
St. Vincent's			✓			

**Table -7.2: Access to hospital based rehabilitation services (in hospitals to which sessional commitments are provided)**

	Very good access	Moderately good access	Limited access	Very limited access	No access
Mater			✓		
Sligo					✓
St. James					
Waterford				✓	
Tallaght					
Limerick					✓
Cork					✓
Galway			✓		
Beaumont				✓	
Mercy Hospital				✓	
St. Vincent's					

## Section 8: Access to Palliative Care Services

Each of the neurology centres were invited to comment on access to a range of palliative care supports

Access to palliative care services was positive overall, with access described as moderately good or very good for most centres in relation to hospital based palliative care teams and community specialist palliative care teams. Specific issues in certain centres should be noted, i.e. Cork and Waterford in relation to palliative care services.

### (a) Access to hospital based specialist palliative care teams

**Table -8.1: Access to hospital based specialist palliative care teams**

	Very good access	Moderately good access	Limited access	Very limited access	No access	Information not available
Mater				✓		
Sligo	✓					
St. James		✓				
Waterford	✓					
Tallaght	✓					
Limerick					✓	
Cork		✓				
Galway	✓					
Beaumont	✓					
Mercy Hospital	✓					
St. Vincent's	✓					

### (b) Access to community based specialist palliative care teams

**Table -8.2: Access to community specialist palliative care teams**

	Very good access	Moderately good access	Limited access	Very limited access	No access	Information not available
Mater		✓				
Sligo						✓
St. James		✓				
Waterford		✓				
Tallaght	✓					
Limerick	✓					
Cork			✓			
Galway	✓					
Beaumont	✓					
Mercy Hospital		✓				
St. Vincent's		✓				

### (c) Access to hospice/specialist inpatient units

**Table -8.3: Access to hospice/specialist inpatient units**

	Very good access	Moderately good access	Limited access	Very limited access	No access	Information not available
Mater		✓				
Sligo	✓					
St. James			✓			
Waterford				✓		
Tallaght		✓				
Limerick	✓					
Cork	✓					
Galway	✓					
Beaumont	✓	✓				
Mercy Hospital			✓			
St. Vincent's		✓				

## Section 9: Access to a range of step down facilities in the community

Access to a range of step down and support services is in marked contrast to the positive situation for palliative care.

For general rehabilitation services in the community, the majority of centres report limited or very limited access. Only one centre, Tallaght reported very good access.

For specialist neurorehabilitation services in the community, the situation portrayed is worse, with 5 centres reporting very limited access and three reporting limited access. Again the positive experience in Tallaght is of note and would be of interest for further investigation. It is of significant concern that one of the two main national neuroscience centres, CUH reports no access to specialist neurorehabilitation services in the community. In their comment, CUH notes very long waiting times to access specialist neurorehabilitation services, giving the example of 4-6 month wait for young stroke patients to access the National Rehabilitation Hospital.

### (a) General rehabilitation services in the community

**Table 9.1: Access to general rehabilitation services in the community**

	Very good access	Moderately good access	Limited access	Very limited access	No access	Information not available
Mater		✓				
Sligo			✓			
St. James		✓				
Waterford				✓		
Tallaght			✓			
Limerick			✓			
Cork				✓		
Galway			✓			
Beaumont				✓		
Mercy Hospital			✓			
St. Vincent's			✓			

### (b) Specialist neurorehabilitation services in the community

**Table 9.2: Access to specialist neuro-rehabilitation services in the community**

	Very good access	Moderately good access	Limited access	Very limited access	No access	Information not available
Mater			✓			
Sligo			✓			
St. James			✓			
Waterford				✓		
Tallaght			✓			
Limerick				✓		
Cork					✓	
Galway				✓		
Beaumont				✓		
Mercy Hospital				✓		
St. Vincent's			✓			

Access to nursing home care and home care packages is vital to support discharge and appropriate referral from neurology services. Limited access to nursing home care was reported in six centres, with very limited access in two centres. A majority (eight centres) reported limited or very limited access to home care packages suitable to meet the needs of people with neurological conditions.

Responses in this section indicate the dearth of crucial neurorehabilitation and other community services to support effective delivery of neurology services.

### (c) Nursing Home Care

**Table 9.3: Access to nursing home care**

	Very good access	Moderately good access	Limited access	Very limited access	No access	Information not available
Mater		✓				
Sligo			✓			
St. James			✓			
Waterford				✓		
Tallaght			✓			
Limerick		✓				
Cork			✓			
Galway		✓				
Beaumont				✓		
Mercy Hospital			✓			
St. Vincent's			✓			

### (c) Home Care Packages appropriate for the needs of neurological patients

**Table 9.4: Access to home care packages appropriate for the needs of neurological patients**

	Very good access	Moderately good access	Limited access	Very limited access	No access	Information not available
Mater			✓			
Sligo			✓			
St. James		✓				
Waterford				✓		
Tallaght		✓				
Limerick			✓			
Cork			✓			
Galway		✓				
Beaumont				✓		
Mercy Hospital			✓			
St. Vincent's				✓		



## Section 10: Service Innovations

### Summary of Areas of Change/Innovation across Neurology Services

This section indicates the range of innovations and changes put in place by individual neurology centres. Innovations can be grouped under a number of themes including:

1. *Encouraging and developing the role of multidisciplinary care within the neurology centre. This includes training opportunities for specific HSCP, developing guidelines for HSCP management of specific conditions, development of advanced nurse practitioner posts in epilepsy.*
2. *Development of specialised and subspecialised clinics for specific conditions*
3. *Development of pathways for specific conditions such as stroke and dementia with other disciplines within the hospital*
4. *Development of rapid access and outreach clinics for specific conditions to improve access to services.*
5. *Improving access to the neurology service for GPs and other disciplines within the hospital through online referral and information systems. Improving access for patients through outreach clinics, telephone services and "one stop shop" clinics combining same day access to neurodiagnostics and neurophysiology.*
6. *Addressing the need for information management systems for neurology services through developing their own databases within the service.*

The changes introduced across the centres highlight the energy and commitment within the neurology services to expand and develop their range of services in response to patient need and the need from other disciplines. They also highlight the problem focused approach that is actively taking place within neurology services to address specific centre based concerns. There should be an opportunity to recognise and reward innovative practice which promotes efficiency and effective management of neurological conditions and mechanisms put in place to translate the learning across centres.

#### Centre by Centre Outline of Changes/Innovations

<b>Mercy</b>	
1.	Reorganised OPD into disorder based clinics
2.	Keeping a database of patients attending neurology to estimate different disease burden on service
3.	Specialist nurse is doing advanced practitioner course, aiming to have nurse led clinics,
4.	Helped devise protocols for management of patients in AMAU with neurology issues for rapid assessment and management and avoidance of admission to general hospital where possible,
5.	Working with OT to try and increase funding for OT available to neurology, possibly clinic based,
6.	Worked with dietician services re developing diet guidelines for stroke patients & avoid delays in d/c

**Mater**

1. Developed Dublin Neurological Institute model: independent company with well-developed governance and flexibility to meet the needs and demands of neurological patients. MDT approach
2. Close working relationship with between old-age medicine and neurology to develop acute stroke service
3. Use of Alternative services - acupuncture, caring for carer advice
4. Nurse-led clinics

**St James'**

1. New inpatient and outpatient spasticity/therapeutic botulinum toxin service.
2. New Movement Disorders Outpatient service.
3. Development of DEMPATh (pathways for a dementia-friendly hospital experience) and cognitive clinic.
4. Development of epilepsy service with outreach clinics to other Dublin and regional centres.
5. Development of new hyperacute stroke pathways and significant new infrastructure to provide stroke unit care throughout hospital journey for stroke patients.
6. Establishment of new OT services for driving assessment and adjustment to neurological diagnoses.

**Beaumont**

1. Opening of Neurology Day Unit (July 2013)
2. Development of nurse led clinics in Epilepsy and Migraine

**Tallaght**

1. Development of sub-specialty clinics: We have a dedicated Rapid Access Stroke Prevention clinic (co-directed by Dr McCabe with our ARHC colleagues since 2006), and since 2012, have subspecialty clinics in peripheral nerve disorders / neuromuscular disease (Dr Murphy), movement disorders (Dr Walsh), and run the only Inherited Ataxia Clinic in the country (Dr Murphy /Walsh). These Consultant-led clinics clearly offer greater efficiency and ensure that high quality expert care is delivered to patients in the locality, region and nationally. Dr Walsh has also set up a specialist clinic to deliver Botulinum toxin injections to suitable patients with dystonia and e.g. spasticity
2. With the reduction in NCHD staffing and working hours, we have made changes to team structure which will hopefully lead to greater efficiency of use of both NCHD and consultant time, maintain the positive Neurology training experience for our NCHDs in the face of hugely challenging human resource issues.
3. We have encouraged the direct involvement of dedicated members of the Neurology HSCP team and Nurse Specialists in the assessment of patients with the medical staff in our clinics. This allows for more comprehensive assessment of patients at a single visit. Our Candidate Advanced Nurse Practitioner in Epilepsy works alongside us in clinic, reviews

and facilities treatment of patients, and provides Nurse-led education to our patients with seizure disorders. We are also fortunate to have dedicated, expert Clinical Nurse specialists in Multiple sclerosis and Parkinson Disease who assess and advise patients re treatment options in close collaboration with the Neurology team on site. In the movement disorders clinic, the involvement of our Speech and Language therapist offers great potential for both enhancement of the clinical service, but also for research and training

4. Dr McCabe has secured access to same day screening lab tests, colour Doppler ultrasound, CXR, ECG, CT scanning and 24 hour Holter monitoring to facilitate the delivery of a highly-efficient daily Rapid Access Stroke Prevention service with our ARHC colleagues that facilitates early accurate diagnosis and treatment of patients with suspected TIAs, prevents unnecessary admissions, and expedites admission in high-risk cases, when required. This service represents a model of efficient urgent care delivery, and has a strong evidence base for the reduction of stroke related morbidity and mortality. In collaboration with our ARHC colleagues, we have also supported the development of a Clinical Stroke Nurse Specialist-delivered 'Secondary Prevention Clinic' where advice re secondary prevention, lifestyle issues and medication adherence etc. are emphasised to optimise secondary prevention of recurrent vascular events after TIA or stroke.
5. Dr McCabe has chaired a weekly Neurovascular MDT since 2006 in collaboration with colleagues in Neurology, Vascular Surgery and Age Related Health Care. At this meeting, the Consultants reach an evidence-based consensus decision regarding the suitability of carotid endarterectomy or endovascular treatment for patients presenting with symptomatic or asymptomatic carotid and other arterial stenoses. This MDT meeting expedites appropriate neurovascular investigation and treatment of suitable cases, prevents unnecessary investigations, admission and interventional treatment of some patients, and facilitates urgent identification of patients who need to be referred for a further expert outpatient neurovascular opinion
6. In collaboration with Dr Mike Alexander, Dr Murphy has secured same day access to neurophysiological investigations at the specialist Peripheral Nerve Clinic, thus allowing delivery of a 'one-stop clinic' for selected new patients with suspected peripheral neuropathy. This model facilitates expedited accurate diagnosis, efficient same-day neurophysiological investigations, and avoids unnecessary return appointments in some cases.
7. Despite the absence of any protected academic time, Dr McCabe, Dr Murphy and Dr Walsh are actively involved in translational, clinical and epidemiology research at AMNCH and TCD. As a Departmental group, we are currently involved in 23 different local, national or international collaborative studies. Patient participation in research has been clearly shown to enhance patient care overall and provide access to optimised evidence-based medicine, and our externally-funded clinical research staff have been integral to the delivery of our out-patient clinical services at no direct cost to the Hospital.

**Limerick**

1. We have gradually accumulated junior medical staff, which makes seeing inpatient consultations (and the occasional inpatient) more efficient. Two neurology-specific CNSs (epilepsy and PD), as well as a stroke CNS, have improved efficiency of patient care in these areas.
2. The stroke service (not specifically neurology, but led by PB) has gradually accumulated specific SLT, OT and CNS staff, as well as the stroke unit being recognised as important and hopefully, soon, seen as a specific high-dependency area on par with CCU.
3. Limited NCS service for screening CTS and neuropathy cases.

**Cork University Hospital**

1. Combined OPD wait lists
2. Consultant and/or Registrar-led clinics (no SHOs or Interns in OPD)
3. Recent establishment of Stroke CNS and Epilepsy cANP posts
4. Rapid access clinics (RASP, 1st seizure, General)
5. Establishment of dedicated Neurology ward with embedded stroke unit and epilepsy monitoring unit
6. Establishment of outreach Epilepsy clinics for people with ID
7. Consultant-led teaching on weekly basis

**Galway**

1. Clinical Nurse specialist phone service (epilepsy, movement, MS)
2. ANPs in MND, Movement disorders

**St Vincent's**

1. Three clinic sessions per day instead of 2.
2. Online referral system for hospital consults
3. Online GP referral system for advice and referrals.

## Section 11: Priority Issues

### Summary of Issues

This section provides insight into a set of common themes across centres which will be critical in informing the key priorities for the neurology clinical programme going forward

1. Critical staffing issues across all disciplines within the neurology service which impact on workloads as well as on patient care with many centres having limited access to multidisciplinary care due to staffing shortages.
2. Dedicated ring fenced neurology beds is identified as a critical issue as well as dedicated clinical space for the neurology service within the hospital
3. Consultant neurology staffing in relation to the smaller regional neurology centres in particular, creating significant issues in relation to sick/holiday cover, vacant posts and long waiting lists. There needs to be a plan for the future of these centres.
4. Access to critical supports for neurology such as neurodiagnostic services and neuropsychology are outlined across centres
5. Physical issues facing neurology services, including inadequate or inappropriate space and facilities within the hospital
6. The need for guaranteed dedicated administrative support is identified across centres.

### Part C: Summary and Recommendations

The programme recognises the time and commitment of individual neurologists in agreeing to complete and return the survey within their individual centres and extends sincere appreciation to all those involved.

This survey attempts only a very limited and initial overview of neurology centres with the aim of highlighting the context in which neurology services in this country are operating in terms of resources and challenges.

The limitations of the survey are clearly recognised. Many of the items rely on self report rather than an objective measure, for example access to community based services, nursing home care etc. Numbers on resources available (staffing, beds), are based on self report from each neurology centre and have not been cross checked with other data sources. In this regard, it is important to note that the programme recognises the limitations involved in the interpretation of the data and the generation of recommendations from the findings.

The initial section of the report sets out some of the information that is currently available within existing health information systems on neurology services, i.e. neurology activity and OPD waiting lists. The NAI acknowledges the support of the Business Intelligence Unit HSE in relation to providing this information. The increase in activity over the past five years is apparent. However it is important to recognise that there are important gaps in the information currently collected in relation to activity within neurology services. The profile of activity does not capture the full workload of the neurology service and does not reflect the demand represented by the complex chronic nature of many neurological conditions.

The remainder of the report outlines the findings of a nationwide survey of eleven neurology centres. The section on staffing highlights workforce shortages across neurology services, within all centres. The problem is most acute in regional centres which lack sufficient access to many of the key elements of multidisciplinary care, even when resources within the hospital available to the neurology service are considered. Such staff shortages impact significantly on patient care, workloads and waiting lists. There are clear implications for the neurology clinical programme in

addressing overall staff shortages within the service, as well as targeting specific critical shortages impacting on individual centres. The overall summary of neurology staffing across centres highlights the critical nature of staffing shortages in this area. Even where dedicated staffing is available, it is inadequate to meet current need and is under pressure from increasing demand and to meet the requirements of other services within the hospital. In terms of access to multidisciplinary care, lack of dietician, neuropsychology and medical social work services are identified as issues across a majority of centres while prosthetics and orthoptics services are unavailable within a majority of centres. The recommendations of the Strategic Review of Neurology and Neurophysiology Services (2007) that all externally funded clinical AHP posts should be mainstreamed has not been addressed. A number of clinical nurse specialist posts in particular are still being funded by pharmaceutical companies.

The section on neurology beds aims to provide an overview of current bed provision and need within the service, based on self reports from each centre. The lack of dedicated inpatient beds continues to have a critical impact on neurology services and patient care and needs to be urgently addressed.

Important measures such as having beds staffed by neurology nurses and cohorted within single ward(s) were not uniformly available in all centres. Where centres do have dedicated beds, these are inadequate to meet current needs within the service and almost all centres which had dedicated beds reported that these are frequently used by other services within the hospital (stroke, general medicine) and retaining beds for the neurology service in the medium to long term was a struggle. According to the findings from this survey, current dedicated neurology beds available to the neurology service nationwide is far below what is required in the view of those working in the services to operate effectively. This represents a significant discrepancy that has to be a key priority area for the programme to address going forward.

Outpatient capacity reflects the volume of activity and range of clinics provided across centres. The section on outreach services indicates that a number of hospitals still do not have access to a neurology service. It is not possible to gauge from the current survey how existing outreach services are coping with demand. A further piece of work by the programme in this area should specifically address the capacity of existing outreach services as well as determining the resourcing required to ensure equity of access to a neurology service across the nation's hospital network. This will be an important area of recommendation for the model of care.

Information on access to and waiting times for neuroimaging are not collected by the HSE and represent an important issue for neurology services and this area was therefore a subject of focus in the current survey. The section on access to diagnostics highlights the range of problems facing existing centres, with the lack of dedicated sessions for routine diagnostic tests in many centres. The waiting times are also of significant concern. This survey represents the first attempt to collate this information across neurology centres and the findings highlight a priority area for the neurology programme going forward. A working group on MRI access has been developed with the support of the programme which will be collating further detailed information in this area and highlighting the issue within the HSE.

Demands on neurology services are increasing with a number of centres now leading the stroke thrombolysis service within their hospitals, including 24 hour cover. It is important that the programme monitor capacity issues in this area on an ongoing basis in collaboration with the stroke programme. There were reports from a number of individual centres of increased workloads and pressure on resources, including beds, due to the need to provide stroke cover. The neurology programme will need to review resourcing within neurology if there are recommendations from the model of care for greater availability of neurological opinion within emergency departments. Many ED presentations will have a neurological component to them and these include cerebrovascular events, headache disorders and seizures.



Many neurological conditions are chronic, often progressive, requiring a range of long term supports in the community to enable effective management of the needs of the person with a neurological condition. This survey attempted to develop some level of insight into the availability of these supports in individual neurology centres. The survey examined access to hospital and community based rehabilitation services, palliative care, nursing home care and home care packages. While access to palliative care was good in general, the lack of access to rehabilitative and other supports in the community was significant across the majority of centres. While the scope of the neurology programme is hospital based neurology services, it is important to recognise the effect of the dearth of community services and its impact in terms of delayed discharges, pressure on outpatient capacity to provide more frequent reviews and most importantly, on patient care overall. For example, delayed discharges represented up to a quarter of bed occupancy in some centres at the time the data was collected.

The final section of the survey examined innovations and changes that have been put in place by each individual centre to improve service delivery as well the priorities and challenges facing each centre. The section on innovation provides important scope for the neurology programme to examine and develop mechanisms to support and drive innovation in practice across neurology services. Individual centres demonstrate significant drive and creativity in developing pathways to improve care and improving access to neurology services by GPs, other disciplines within the hospital and patients themselves. Individual centres have also taken important steps to develop and improve multidisciplinary care within their centres in recognition of best practice in neurology services.

The priorities for each centre highlight basic resource needs again and again within the service. Staffing, space including dedicated beds and access to diagnostic imaging are issues raised in common across a majority of centres. There are important implications for the programme in seeking to address these critical requirements of the service in order to cope with current and future demand. There is a considerable task involved to ensure that the model of care for neurology services is implemented in full with the resources required. With the findings of this survey, the programme has an important body of evidence to support the concerns of neurology personnel and patient representative organisations in relation to the need for investment in and development of neurology services.

### **Use of the Findings**

The findings from this survey will be directly incorporated into the model of care for neurology services, through informing the section on requirements to support service delivery. Specific findings will be used to support the recommendations of the model of care in key areas such as staffing, neurology beds and access to neurodiagnostics. A review of the priority issues across neurology centres indicates that these areas should also represent key priorities for action for the programme going forward, both at national level and in addressing immediate and critical problems within individual centres.

The programme acknowledges the support of the Neurological Alliance of Ireland in preparing this report. The findings represent a key tool to this umbrella organisation in continuing to advocate for the development of neurology services nationwide and the programme continues to be supportive of the work of the NAI in this regard.

The Neurological Alliance of Ireland is conscious that an important voice is absent in this report, that of the person with a neurological condition accessing these services. The NAI will work with the neurology programme in the coming months to examine the experiences of service users in relation to neurology services by designing and conducting the first patient experience survey of neurology services in Ireland.

## Version Control

<b>Final Draft</b>	<b>June 2015</b>	<b>Post CAG &amp; Working group review for submission to Clinical Strategy &amp; Programmes Division</b>
Substantive Draft 4.0	May 2015	For CAG to review in advance of sign off and submission to CSPD
Substantive draft 3.0	April 2015	Amendments post public consultation for working group
Substantive Draft 2.0 for Public Consultation	Feb 2015	Submitted to CSPD for public consultation
Substantive Draft 1.0 for Public Consultation	Jan 2015	Amendments following working group meeting
Substantive Draft 0.2 for working group	Dec 2014	Amendments made relating to both content and presentation at CAG. Significant edit undertaken by members of working group.
Substantive Draft 0.1 for CAG	Nov 2014	Review by CAG for review prior to public consultation
Version 5	Oct 2014	Circulated to CAG for review and comment prior to meeting of CAG in November
Version 4	Sept 2014	Circulated to working group for comment following proposed amendments at previous working group meeting
Version 3 MND headache	July 2014	Decision made by working group to include pathway. Work progressing on MS, PD & pathways.
Version 2	June 2014 meeting	Amendments made following working group
Version 1	May 2014	Amendments made following working group meeting
Version 0.1	April 2014	Amendments made following working group meeting

## References

1. National Clinical Programme for Epilepsy 2015, *Model of Care*, Clinical Strategy & Programmes Division, HSE
2. National Clinical Programme for Rehabilitation Medicine, *draft Model of Care 2014*, Clinical Strategy & Programmes Division, HSE
3. National Clinical Programme for Older People July 2012, *Specialist Geriatric Services, Model of Care, Part 1: Acute Service Provision*. Clinical Strategy & Programmes Division, HSE
4. National Clinical Programme for Stroke, *Model of Care July 2012*. Clinical Strategy & Programmes Division, HSE
5. National Clinical Programme for Critical Care. Oct 2014. *Right Care, Right Now. Model of care for Adult Critical Care*. Clinical Strategy & Programmes Division, HSE
6. Department of health (2001) *report of the national advisory committee on palliative care*, Dublin: Dublin Stationary office.
7. Palliative Care Competence Framework Steering Group. (2014). *Palliative Care Competence Framework*. Dublin: Health Service Executive. Accessible on [www.hse.ie/palliativecareprogramme](http://www.hse.ie/palliativecareprogramme)
8. Craig J & Patterson V (2005) 'Introduction to the Practice of Telemedicine', *Journal of Telemedicine and Telecare*, 11(), pp. 3-9.
9. Department of Health and Children (2001) *Report of the National Advisory Committee on Palliative Care*. Dublin Stationary Office. <http://www.dohc.ie/publications/pdf/nacpc.pdf?direct=1>
10. Palliative Care Competence Framework Steering Group. (2014). *Palliative Care Competence Framework*. Dublin: Health Service Executive
11. Neurosciences in Ireland 2007. *Strategic Review of Neurology and Clinical Neurophysiology services*. [http://www.nai.ie/go/resources/guidance\\_policy\\_standards/guidance\\_poicy\\_standards\\_ireland/strategic-review-of-neurology-and-neurophysiology-services-in-ireland](http://www.nai.ie/go/resources/guidance_policy_standards/guidance_poicy_standards_ireland/strategic-review-of-neurology-and-neurophysiology-services-in-ireland)
12. Royal College of Physicians. *Local adult neurology services for the next decade*. Report of a working party. London: RCP, 2011
13. Sweeney B et al. 2010 *Neurology OPD services – supply, demand and capacity*
14. Albrecht G, Higginbotham N, Freeman S (2001) Transdisciplinary thinking in health and social science research: definitions, rationale and procedure. *Health Social Science: A transdisciplinary and complexity perspective*, 4, 78-89
15. The Medical Research Charities Group (MRCG) & Irish Platform for Patients' Organisations Science and Industry (IPPOSI) Oct 2011 '*Towards a National Strategy for Patient Registries in Ireland: Considerations for Government*'
16. Department of Health & Health Service Executive 2011. *National Policy and Strategy for the Provision of Neuro-rehabilitation Services in Ireland 2011-2015*
17. Health Information and Quality Authority, June 2012. *National standards for better safer healthcare*,
18. National Advocacy Unit, *National Healthcare Charter*. Quality and Patient Safety Directorate, HSE 2012
19. Gustavsson, A et al, Cost of disorders of the Brain in Europe 2010; *Eur Neuropsychopharmacol*. 2011 Oct; (10): 718-79
20. Julian, Laura J., et al. "Employment in multiple sclerosis." *Journal of neurology* 255.9 (2008): 1354-1360.

21. WHO 2006 - *Neurological Disorders, public health challenges*
22. Loneragan R, Kinsella K, Fitzpatrick P, et al. Multiple Sclerosis prevalence in Ireland: relationship to Vitamin D status and HLA phenotype. *J Neurol Neurosurg Neuropsychiatry* 2011;82:317-322
23. World Health Organisation, March 2000. *Headache disorders and public health*,
24. NHS Standard Contract for Neurosciences 2013: *Specialised Neurology (Adult)*. NHS Commissioning Board
25. Department of Health 2014. *The Irish National Dementia Strategy*
26. NHS. March 2005. *Action on Neurology; Improving Neurology Services – a practical guide*
27. NHS October 2009. *Neurological health services; clinical standards*
28. UK Department of Health March 2005. *National Service Framework for Long-term Conditions'*
29. Ali E, Chaila E, Hutchinson M, Tubridy N. The 'hidden' work of a hospital neurologist: 1000 consults later. *European Journal of neurology* 2010; 17: e28-e32
30. Saif S M Razvi, Bone I. Neurological consultation in a medical intensive care unit. *J Neurol Neurosurg Psychiatry* 2003; 74 (suppl III):iii 16-iii23
31. SDU Technical Guidance, Scheduled Care 2013. Out-patient Waiting Times. NTPF 2013
32. Llewelyn Gm Kinton L. ABN: *Job Planning for NHS consultant neurologists and clinical academic neurologists* 29/5/14. ABN Services and Standards Committee.
33. Department of Health 2013. *The Establishment of Hospital Groups as a transition to Independent Hospital Trusts*. A report to the Minister for Health, Dr James Reilly, TD. Published Feb 2013
34. Health Information and Quality Authority Oct 2012. *Health technology Assessment of a national deep brain stimulation service in Ireland*
35. Connell, P; Pringle, D/ Population Aging in Ireland – projections 2002-2021, *Report No 81, National Council on Ageing and Older People*.
36. SB Kelly, E Chaila, K Kinsella, M Duggan, C McGuigan, N Tubridy and M Hutchinson. Multiple Sclerosis, from referral to confirmed diagnosis: an audit of clinical practice. *Multiple Sclerosis Journal*, 17(8) 1017-1021 (2011)
37. Craig, J, Patterson V. Introduction to the practise of telemedicine. *Journal of telemedicine and telecare* 2005; 11:3-9
38. Greene A et al. Do Managed clinical networks improve quality of diabetes care? Evidence from a retrospective mixed methods evaluation. *Qual Saf Health Care*. 2009 Dec. 18 (6):456-61. Doi: 10.1136/qshc.2007.023119
39. Comhairle na hOispidéal, 2005. *Committee to review neurosurgical services*,
40. Skelly, R, Brown, L, Fakis, A et al. 'Does a specialist unit improve patients outcomes for hospitalized patients with Parkinson's Disease?' *Parkinsonism and related Disorders* 2014. <http://dx.doi.org/10.1016/j.parkreldis.2014.09.015>
41. Sun, Y, Paulus, D et al. A systematic review and meta-analysis of acute stroke unit care: what's beyond the statistical significance? *BMC Medical Research Methodology* 2013, 13:132
42. Royal College of Physicians. *Local adult neurology services for the next decade*. Report of a working party. London: RCP, 2011.
43. Health Information & Quality Authority March 2011. *Report and recommendations on patient referrals from general practice to outpatient and radiology services, including the national standard for patient referral information*.
44. Royal College of Physicians, National Council for Palliative Care, British Society of Rehabilitation Medicine. Long term neurological conditions: *management at the interface*

- between neurology, rehabilitation and palliative care*. National Guidelines. Concise guide to good practise series No 10. London RCP 2008
45. Weafer JA 2014. *The Palliative Care needs of People with Advancing neurological Disease in Ireland*. A Report prepared for the Neurological Alliance of Ireland and the Irish Hospice Foundation.
  46. Health Service Executive & Irish Hospice Foundation 2008. *Palliative care for all. Integrating palliative care into disease management frameworks*. Dublin.
  47. Adapted from; The National Council for Palliative Care, the Neurological Alliance & NHS National End of Life Care Programme. 2010 '*End of life care in neurological conditions: a framework for implementation*'.
  48. Comhairle na nOspideal. Report of the Committee to review Neurology and Neurophysiology Services, April 2003.
  49. Rooney J, Byrne S, Heverin M, Tobin K, Dick A, Donaghy C, Hardiman O. A multidisciplinary clinic approach improves survival in ALS: a comparative study of ALS in Ireland and Northern Ireland. *J Neurol Neurosurg Psychiatry*. 2014 Dec 30. pii: jnnp-2014-309601.
  50. British Society of Rehabilitation Medicine 2009. *Standards for rehabilitation services mapped on to the national service framework for long-term conditions*
  51. Neurological Alliance of Ireland 2010. *The Future for Neurological Conditions in Ireland: a challenge for healthcare; an opportunity for change*
  52. Health Service Executive. April 2014. *Preventing Chronic Disease: Defining the Problem. Report from the Prevention of Chronic Disease Programme*.
  53. Gutenbrumer C, Ward CB & Chamberlain M A. White book on physical and rehabilitation medicine in Europe. *Journal of rehabilitation medicine*. January 2007. Supplement No 45.
  54. Ory, MG et al. The impact of Chronic Disease Self-Management Programmes: Healthcare Savings through a Community Based Intervention. *BMC Public Health*. 2013; 13 (1141)
  55. Lorig, K etc al. Effect of a self management programme on patients with chronic disease. *Effective Clinical Practice*, Nov/Dec 2001
  56. [www.chcf.org.documents/chronicdisease](http://www.chcf.org.documents/chronicdisease)
  57. <http://www.ncbi.nlm.nih.gov/pubmed/22234713>
  58. Department of Health, UK, 2006. *A guide to developing local strategies and good practice*.
  59. *Improving the Health and Wellbeing of People with Long Term Conditions in Scotland: A National Action Plan*, Dec 2009
  60. MacKinnon, N. Safe and Effective: the eight essential elements of an optimal medication-use system. *Canadian Pharmacists association* 2007.
  61. Galt, K. Rule, M. Clark B E. Bramble, JD. Taylor, W. Moores, KG. Best Practices in Medication Safety: Areas for Improvement in the Primary Care Physician's Office.
  62. *National Dementia Strategy in Ireland* 2014
  63. *Patient Empowerment – Living with Chronic Disease; the European Network on Patient Empowerment*.
  64. [www.patientsorganizations.org](http://www.patientsorganizations.org)
  65. Institute on Medicine. "*Crossing the Quality Chasm: A New Health System for the 21st Century*
  66. Leigh, E. Teaching Patients about their Medications: *The keys to decreasing non-compliance*
  67. Gleason, KM. Groszek, JM. Sullivan, C. Rooney, D. Barnard, C. .Noskin, GA. Reconciliation of discrepancies in medication histories and admission orders of newly hospitalized patients.



- Am J Health-Syst Pharm.* 2004; 61:1689-95
68. Strull, WM. Lo, B. Charles, G. Do patients want to participate in medical decision making? *JAMA* 1984; 252 (21): 2990-2994
  69. Guadagnoli, E. Ward, P. Patient participation in decision-making. *Social Science & Medicine.* Vol 47, Issue 3. 1998; 329-339
  70. *NHS standard contract for Neurosurgery (Adult)*, NHS Commissioning Board, 2013
  71. *Report of the committee to review Neurosurgical services in Ireland*, Comhairle na nOspideal, Dec 2005. Health Service Executive
  72. *Model of Care for Acute Surgery*, 2013, National Clinical Programme for Surgery Clinical Strategy & Programmes Division, HSE
  73. *Model of Care for Neonatal Services in Ireland*, Draft 2015, National Clinical Programme of Paediatrics and Neonatology, Clinical Strategy and Programmes Division, HSE
  74. Joint faculty of Intensive care medicine of Ireland, 2011. *National Standards for adult critical care services.* Dublin: JFICMI..
  75. Findlay, G et al, 2007. Trauma: who cares? *A report of the National Confidential Enquiry into patient outcome and Death* (NCEPOD)
  76. National Institute for Health and Clinical Excellence (NICE), 2014. *Head Injury: Triage, assessment, investigation and early management of head injury in infants, children and adults.* London: NICE
  77. Phillips, J, 2008. *Phillips report: national report on traumatic brain injury in the Republic of Ireland 2008.* Dublin: Traumatic Brain Injury Research Group
  78. Harrison, DA et al, 2013. *Risk Adjustment in Neurocritical Care (RAIN) – prospective validation of risk prediction models for adult patients with acute traumatic brain injury to use to evaluate the optimum location and comparative costs of neurocritical care: a cohort study.* London: NIHR
  79. <http://www.radiologyinfo.org/en/careers/index.cfm?pg=understanding> (accessed 30.1.15)
  80. Amon Y Liu, MD 'Update on Interventional Neuroradiology'. *Perm J.* 2006 Spring; 10(1): 42–46. Published online Spring 2006. PMID: PMC3076983
  81. Goyal M et al. Randomised assessment of rapid endovascular treatment of ischaemic stroke. *New England Journal of Medicine* Feb 11, 2015.
  82. <http://www.experts.com/content/articles/Simmons-Grab-Visual-Dysfunction-Neurological-Event.pdf>
  83. West S K et al. Functional and visual impairment in a population based study of older adults. The SEE Project. *Investigative Ophthalmology & visual science*, January 1997, Vol 38, No 1
  84. <http://pathology.duke.edu/anatomic-pathology/subspecialties/neuropathology>
  85. Christodoulou, M. Neurological nurse specialists: a vital resource under threat. *The Lancet Neurology*, Vol 11, No3, p210-211, March 2012
  86. Mudge, A. Laracy, S. Richterm K & Denaro, C (2006) Controlled trial of multidisciplinary care teams for acutely ill medical inpatients: enhanced multidisciplinary care. *Internal Medicine Journal*, 36:558-563.
  87. Cartmill, L. Comans, T. Clark, M. Ash, S. Sheppard, L. Using staffing ratios for workforce planning: evidence on nine allied health professions. *Human resources for Health* 2012, 10:2
  88. National Clinical Programmes Model of Care Development Checklist Governance for Quality and Safety. Quality and Patient Safety Division, Oct 2014
  89. HSE Quality and Risk Management Standard 2007
  90. Royal College of Physicians of Ireland 2014. *Medical Workforce Planning Report*



91. Royal College of Physicians of Ireland. *Higher Specialist Training in Neurology*, July 2012
92. Guidelines for Occupational Therapy in Parkinson's Disease Rehabilitation, Ingrid Sturkenboom, Marjolein Thijssen, Jolanda Gons-van Elsacker, Irma Jansen, Anke Maasdam, Marloes Schulten, Dicky Vijver-Visser, Esther Steultjens, Bas Bloem, Marten Munneke, <http://www.parkinsonnet.nl/>
93. <http://parkinsonnet.info/news/the-european-physiotherapy-guideline-for-parkinson's-disease>
94. <sup>1</sup>[http://parkinsonnet.info/media/14829977/dutch\\_slp\\_guidelines-final.pdf](http://parkinsonnet.info/media/14829977/dutch_slp_guidelines-final.pdf)
95. The Neurological Alliance of Ireland 2013: *Navigating Neurology services: helping strategic clinical networks to be a success story*.
96. The Medical Research Charities Group (MRCG) & Irish Platform for Patients' Organisations Science and Industry (IPPOSI) 2011 '*Towards a National Strategy for Patient Registries in Ireland: Considerations for Government*'
97. Blum et al, 1993, cited by DH/Child Health and Maternity Services, 2006)
98. Viner, R. Transition from paediatric to adult care. Bridging the gaps or passing the buck? *Arch Dis Child* 1999; 81:271-275
99. <http://www.hse.ie/palliativecareprogramme>
100. Inclusion Ireland National Association for people with intellectual disability, *Annual report 2009*
101. Straetmans JMJA, Van Schrojenstein Lantman-de Valk HMJ, Schellevis FG, et al. Health problems of people with intellectual disabilities: the impact for general practice. *Br J Gen Pract* 2007; 57:64-66
102. <http://www.welfare.ie/en/downloads/protocol4.pdf>
103. Bernarl, J. (1995) 'Epilepsy' in Learning about intellectual disabilities and health accessed at [http://www.intellectualdisability.info/complex\\_disability/epilepsy.htm](http://www.intellectualdisability.info/complex_disability/epilepsy.htm) accessed August 2009
104. Prasher V (1995) Age-specific prevalence: Thyroid dysfunction and depressive symptomology in adults with down syndrome and dementia. *International Journal of Geriatric psychiatry* 10, 25-31
105. Kerr D. Down Syndrome and dementia. Voice, Winter 2009. *Down Syndrome Victoria Members Journal*
106. Armon, C. *Neurologic Disease and Pregnancy*. <http://emedicine.medscape.com/article/1149405-overview>
107. WK To, Cheung RTF. Neurological disorders in pregnancy. *HKMJ* Vol 3 No4 December 1997
108. <http://www.hse.ie/eng/about/Who/clinical/natclinprog/epilepsyprogramme/>
109. Menken, M 'Alzheimer's disease and the modified role of the neurologist in today's healthcare environment' + doi: 10.1212/WNL.51.1\_Suppl\_1.S61 *Neurology* July 1998 vol. 51 no. 1 Suppl 1 S61-S64
110. Kelley et al. Rapidly Progressive Young-onset Dementia. *Cogn Behav Neurol* 2009 Mar; 22(1): 22-27
111. Cahill S, O'Shea E, Pierce M. *Creating Excellence in Dementia Care. A research review for Ireland's national dementia strategy*. DSIDC's Living with dementia research programme. School of Social work & Social Policy, TCD. Irish Centre for Social Gerontology. National University of Ireland, Galway. 2012
112. Harvey RJ, Skelton-Robinson M, Rossor M N. The prevalence and causes of dementia in people under the age of 65 years. *J Neurosurg Psychiatry* 2003; 74: 1206-1209

113. Bickel et al 2005 – get full reference
114. Samson EL, Warren JD, Rossor MN. Young onset dementia. *Postgrad Med J* 2004; 80:125-139
115. Mendez, Mario F. "The accurate diagnosis of early-onset dementia." *The International Journal of Psychiatry in Medicine* 36.4 (2006): 401-412.
116. Beattie AM, Daker-White G, Gilliard J, Means R. Younger people in dementia care: a review of service needs, service provision and models of good practice. *Ageing and Mental Health*, Vol 6, Issue 3, 2002
117. Roach P, Keady J, Bee P et al. Subjective experiences of younger people with dementia and their families: implications for UK research, policy and practice. *Reviews in Clinical Gerontology* May 2008; 8(2), pp 165-172
118. Svanberg E, Spector A, Stott J. the impact of young onset dementia on the family: a literature review. *International psychogeriatrics*. Vol 23, issue 03, April 2011, pp 356-371
119. Beattie et al 2008 – get full reference
120. Freyne, Aideen, et al. "Burden in carers of dementia patients: higher levels in carers of younger sufferers." *International journal of geriatric psychiatry* 14.9 (1999): 784-788.
121. UK college and AS 2006 – get full reference
122. Duarte RA, Fishman O. The Role of the Neurologist in assessment and management of individuals with acquired brain injury. *Acquired brain injury*. 2007 pp 39-63. ISBN 978-0-387-37574-8
123. Gutenbrunner C, Ward AB, Chamberlain MA. White book on physical and rehabilitation medicine in Europe. *Journal of rehabilitation medicine*. Supplement No 45, Jan 2007.
124. <http://www.coru.ie>
125. Bossers, A et al. (2002) *Competency based fieldwork evaluation for occupational therapists*. Albany, NY: Delmar, Thomson Learning
126. Alsop A, Ryan S. (1996) *Making the most of fieldwork education: a practical approach*. London: Chapman & Hall
127. Report of the Expert Group on Various Health Professions, April 2000. <http://www.hse.ie/eng/staff/Resources/hrstrategiesreports/Report%20of%20the%20expert%20group%20on%20various%20Health%20Professions.pdf>
128. The Irish Society of Chartered Physiotherapists (2012) *Scope of Practice*. ISCP Dublin
129. Health & Social Care Professions Education & Development Advisory Group. *Progressing Advanced Practice in the Health & Social Care Professions*, 2014
130. Department of Health 2013. *Therapy Research – Delivering Best Health. A Research Strategy for the Therapy Professions in Ireland 2008-2013*.
131. World Federation of Occupational Therapy (2012), <http://www.wfot.org/AboutUs/AboutOccupationalTherapy/DefinitionofOccupationalTherapy.aspx> [accessed 28.10.14]
132. Neurological Alliance of Ireland, 2000. *Standards of Care for people with disabling (progressive and static) neurological conditions in the hospital and community*.
133. Fearon P, Langhorne P, Early Supported Discharge Trialists. Services for reducing duration of hospital care for acute stroke patients. *Cochrane Database of Systematic Reviews* 2012, Issue 9. Art. No.: CD000443. DOI: 10.1002/14651858.CD000443.pub3.
134. Freeman CF. *Collaborative working on a stroke-rehabilitation ward*. Parallel Vision (British and Irish Orthoptic Society). 2003
135. Scottish Intercollegiate Guidelines Network (SIGN). Guidance 118. 2010
136. Bowker, J H. Neurological Aspects of Prosthetic/Orthotic Practice. *Journal of Prosthetics &*

- Orthotics*. 1993. Vol 5, Num2 p 52-54
137. Shenton PA, Baird S, Ashcroft D, (2009) *Common Platform for European Podiatry Practice*
  138. Royal College of Speech and Language Therapists (RCSLT) 2014
  139. Bush, M. & Scott, R. 2009. *No Voice, No Choice*. London: Scope. www.scope.org.uk
  140. Royal College of Speech & Language Therapists (RCSLT) 2009
  141. Scottish Intercollegiate Guidelines Network 2008, *Diagnosis and Management of Headache in Adults*. Guideline No 107
  142. Patteson and Esmonde 1993. Comparison of the handling of neurological outpatient referrals by general physicians and a neurologist. *Journal of neurology, neurosurgery, and psychiatry*. 1993; 56(7): 830
  143. Vos T, Flaxman AD, Naghavi M, Lozano R, Michaud C, Ezzati M. et al. Years lived with disability (YLD) for 1160 sequelae of 289 diseases and injuries 1990–2010: a systematic analysis for the Global Burden of Disease Study 2010. *Lancet*. 2012, 380(9859): 2163-2196
  144. Linde M, Gustavsson A, Stovner LJ, Steiner TJ, Barré J, Katsarava Z. et al. The cost of headache disorders in Europe: the Eurolight project. *Eur J Neurol*. 2012; 19(5): 703-711
  145. Vos et al. 'years lived with disability (YLDs) for 1160 sequelae of 289 diseases and injuries 1990-2010: a systematic analysis for the Global Burden of Disease Study 2010. *The Lancet*, Vol 380, Issue 9859, p 2163-2196, Dec 2012.
  146. Gaul C, Visscher C, Bholra R, Sorbi M, Galli F, Rasmussen A and Jensen R. Team players against headache: multidisciplinary treatment of primary headache and medication overuse. *J Headache Pain* 2011, 12 (5): 511-519
  147. Jensen R. Director of Danish Headache Centre and President of European Headache Federation. Conference Proceedings at Health Professional Conference, Dublin May 13
  148. Kiel Headache and Pain Centre: <http://www.schmerzlinik.de/information-in-english/>
  149. National Institute for Health and Care Excellence (NICE) 2012 *Headaches; Diagnosis and management of headaches in young people and adults* [CG150]
  150. Gaul et al 2011, Team players against headache: multidisciplinary treatment of primary headaches and medication overuse headache. *J Headache and pain* 12(5): 511-519 PMID: PMC3173636
  151. Gaul 2013 Efficacy of multidisciplinary rehabilitation of patients with chronic headache. *The Journal of Headache and Pain* 14 (Suppl 1): 09
  152. Wallasch TM, Angeli A, Kropp P 2012. Outcomes of a headache-specific cross-sectional multidisciplinary treatment program. *Headache* 52 (7): 1094-1105 doi: 10.1111/j.1526-4610.2012.02189.x. Epub 2012 Jun 15.
  153. Cochrane Database Syst Rev. 2008 Jan 23;(1):CD006244. doi:10.1002/14651858.CD006244.pub2.
  154. Model of Care 2015, National Clinical Programme for Epilepsy, Clinical Strategy & Programmes Division, Health Service Executive
  155. Nicholson, RA. '*Chronic Headache: the role of the psychologist*' Department of Neurology & Psychiatry, Saint Louis University School of Medicine and Ryan Headache Centre/Mercy Health research.
  156. Jette, N., Patten, S., Williams, J., Becker, W., Wiebe, S. Comorbidity of migraine and psychiatric disorders. A national population-based study. *Headache*. 2008;48:501-516.
  157. Breslau, N., Davis, G.G., Schultz, L.R., Paterson, E.L. Migraine and major depression: A longitudinal study. *Headache*. 1994;34:387-393.

158. <http://www.goodtherapy.org/blog/link-between-chronic-migraines-and-psychological-distress-033114>
159. DeMaagd, G. *Migraine Headache: the pharmacist and the role of OTC medications*. Pharmacytimes.com 2007. <http://www.pharmacytimes.com/publications/issue/2007/2007-03/2007-03-6318>
160. National Institute for Health Care and Excellence 2014 *Multiple Sclerosis: management of multiple sclerosis in primary and secondary care* [CG168]
161. SB Kelly, E Chaila, K Kinsella, M Duggan, C McGuigan, N Tubridy & M Hutchinson Multiple Sclerosis, from referral to confirmed diagnosis: an audit of clinical practise; – *Mult Scler* 2011 17:1017)
162. Goodin DS, Bates D. Treatment of early multiple sclerosis: the value of treatment initiation after a first clinical episode; *Mult Scler* 2009 15: 1175
163. Health Information and Quality Authority 2011. *Report and recommendations on patient referrals from general practice to outpatient and radiology serviced including the National Standards for Patient Referral Information*.
164. Polman CH, Reingold SC, Banwell B et al. (2011) Diagnostic criteria for multiple sclerosis: 2010 revisions to the McDonald criteria. *Annals of Neurology* 69:292-302
165. Multiple Sclerosis Trust 2014. *MS Specialist nursing in the UK*
166. Moore J, McQuestion M. The Clinical Nurse Specialist in chronic diseases. *Clin Nurse Spec* 2012 May-Jun; 26(3):149-63
167. Ward-Abel, Nicki, Kerry Mutch, and Huseyin Huseyin. "Demonstrating that multiple sclerosis specialist nurses make a difference to patient care." *British Journal of Neuroscience Nursing* 6.7 (2010): 319-324.
168. National Council for the Professional Development of Nursing and Midwifery. Nov 2008. *Accreditation of Advanced Nurse Practitioners and Advanced Midwife Practitioners. 2nd Edition*.
169. National MS Society, USA
170. A guide to best practice – MS nurse specialist nursing in Ireland, 2012
171. Menon et al. Management of Optic Neuritis. *Indian Journal of Ophthalmology* 2011; 59(2): 117-122
172. Sutliff MH. Contribution of impaired mobility to patient burden in multiple sclerosis. *Current Medical Research And Opinion*. 2010;26(1):109-119.
173. Rietberg MB, Brooks D, Uitdehaag BMJ, Kwakkel G. Exercise therapy for multiple sclerosis. *Cochrane Database Of Systematic Reviews (Online)*. 2005(1 (Electronic)):CD003980.
174. Garrett M, Coote S. Multiple sclerosis and exercise in people with minimal gait impairment : a review. *Physical Therapy Reviews*. 2009;14(3):169-180.
175. Hogan N, Coote S. Therapeutic interventions in the treatment of people with multiple sclerosis with mobility problems: a literature review. *Physical Therapy Reviews* 2009;14(3):160-168.
176. Freeman JA, Thompson AJ. Community services in multiple sclerosis: still a matter of chance. *Journal Of Neurology, Neurosurgery, And Psychiatry*. 2000;69(6):728-732
177. Khan F, Turner-Stokes L, Ng L, Kilpatrick T. Multidisciplinary rehabilitation for adults with multiple sclerosis. *Cochrane Database of Systematic Reviews*. 2008(2). <http://www.mrw.interscience.wiley.com/cochrane/clsysrev/articles/CD006036/frame.html>
178. Khan F, Pallant JF, Brand C, Kilpatrick TJ. Effectiveness of rehabilitation intervention in persons with multiple sclerosis: a randomised controlled trial. *Journal Of Neurology, Neurosurgery, And Psychiatry*. 2008;79(11):1230-1235



179. Canadian Physical Activity Guidelines for adults with Multiple Sclerosis, published by the Canadian Society for Exercise Physiology (CSEP) (2012); available at [www.csep.ca/guidelines](http://www.csep.ca/guidelines)
180. Garrett, M; *Exercise in the community for people with multiple sclerosis – a follow-up of people with minimal gait impairment*. Multiple Sclerosis (Houndmills, Basingstoke, England), 2013, vol 19 (6), p 790
181. NICE 2003
182. Royal College of Speech and Language Therapy 2006
183. Royal College of Speech and Language Therapy 2009
184. Turner Stokes, L (2010). Specialist neurorehabilitation services: providing for patients with complex rehabilitation needs. Available at: [http://www.bsrm.co.uk/publications/Levels\\_of\\_specialisation\\_in\\_rehabilitation\\_services5.pdf](http://www.bsrm.co.uk/publications/Levels_of_specialisation_in_rehabilitation_services5.pdf)
185. The National Collaborating Centre for Chronic Conditions. *Parkinson's Disease; National clinical guideline for diagnosis and management in primary and secondary care*. London: Royal College of Physicians, 2006
186. Central statistics office: <http://www.cso.ie/multiquicktables/quicktables.aspx?id=cna13>.
187. Aerts MB et al. Improving the Diagnostic accuracy in parkinsonism. A three-pronged approach. *Pract Neurol*. 2012. 12(2): 77-87
188. Pirker W. *Atypical Parkinsonian disorders – a clinical introduction*. 4th International Congress of Geriatrics and Gerontology. Venice May 2014
189. NICE clinical guideline 35 (2006)
190. Hospital In-Patient Enquiry (HIPE) figures were compiled by the Economic and Social Research Institute on behalf of the HSE in 2012
191. Lynch T, Magennis B. *The Management of Parkinson's Disease. A pharmacological approach* 2nd Edition
192. PDQ-39; Available at; [http://isis-innovation.com/wp-content/uploads/2014/07/Final\\_PDQ-39\\_English\\_UK\\_SAMPLE.pdf](http://isis-innovation.com/wp-content/uploads/2014/07/Final_PDQ-39_English_UK_SAMPLE.pdf)
193. UPDRS; Available at; <http://viartis.net/parkinsons.disease/UPDRS1.pdf>
194. Magennis B, Corry M. Parkinson's Disease: top 10 causes of sudden deterioration. 234 *British Journal of Neuroscience Nursing* October/November 2013 Vol 9 No 5
195. [http://www.parkinsons.org.uk/sites/default/files/publications/download/english/b104\\_getitontimebooklet\\_0.pdf](http://www.parkinsons.org.uk/sites/default/files/publications/download/english/b104_getitontimebooklet_0.pdf)
196. Sathyababu R. Management of Parkinson's Disease medication in acutely admitted patients. *BMJ Quality Improvement Reports* 2012; 1, No.1 u473.w154
197. Keus, S., Munneke, M., Graziano, M., Paltamaa, J., Pelosin, E., Domingos, J., Bruhlmann, S., Ramaswamy, B., Prins, J., Struiksmā, C., Rochester, L., Nieuwboer, A. & Bloem, B. (2014) 'European Physiotherapy Guideline for Parkinson's Disease'. [in KNGF/ParkinsonNet, The Netherlands. Available at: <http://www.parkinsonnet.info/euguideline> (Accessed: 1st February 2015).
198. Guidelines for Speech-Language Therapy in Parkinson's Disease. Hanneke Kalf, Bert de Swart, Marianne Bonnier-Baars, Jolanda Kanters, Marga Hofman, Judith Kocken, Marije Miltenburg, Bas Bloem, Marten Munneke. Originally published in Dutch as *Logopedie bij de ziekte van Parkinson. Een richtlijn van de Nederlandse Vereniging voor Logopedie en Foniatrie*. © 2008 NVLF, Woerden 2008/Lemma Publishers
199. Guidelines for Occupational Therapy in Parkinson's Disease Rehabilitation. Ingrid Sturkenboom, Marjolein Thijssen, Jolanda Gons-van Elsacker, Irma Jansen, Anke Maasdam, Marloes Schulten, Dicky Vijver-Visser, Esther Steultjens, Bas Bloem, Marten Munneke.

- Originally published in Dutch as 'Ergotherapie bij de ziekte van Parkinson. Een richtlijn van Ergotherapie Nederland', © 2008 EN, Utrecht 2008/Lemma Publishers.
200. Aragon, A & Kings, J. *Occupational therapy for people with Parkinson's, Best practice guidelines*. 2010. College of Occupational Therapists in collaboration with Parkinson's UK
  201. BPS. (2009, February). *Psychological Services for people with Parkinsons disease* . Retrieved April 13, 2015, from [http://www.bps.org.uk/sites/default/files/documents/psychological\\_services\\_for\\_people\\_with\\_parkinsons\\_disease.pdf](http://www.bps.org.uk/sites/default/files/documents/psychological_services_for_people_with_parkinsons_disease.pdf)
  202. Troster, A. e. (2008). Parkinson's disease, progressive supranuclear palsy, corticobasal degeneration, and related disorders of the frontostriatal system. In J. E. Morgan, & J. H. Ricker, *Textbook of Clinical Neuropsychology* (pp. 536-577). New York: Taylor and Francis.
  203. Taylor S et al. A rapid synthesis of the evidence on interventions supporting self-management for people with long-term conditions: PRISMS - Practical systematic Review of Self-Management Support for long-term conditions. *Health Services and Delivery Research* Volume: 2 Issue: 53. December 2014
  204. Van der Marck, MA. Kalf, JG. Sturkenboom, IHWM. Nijkrake, MJ. Munneke, M. Bloem, BR. Multidisciplinary care for patients with Parkinsons Disease. *Parkinsonism & Related Disorders*, Vol 15, Supplement 3, S219-S223, Dec 2009.
  205. M. Van der Eijk, M.J. Faber, S. Al Shamma, M. Munneke, B.R. Bloem "Moving towards patient-centered healthcare for patients with Parkinson's disease" *Parkinsonism Related Disorders*, 17 (5) (2011), pp. 360–364
  206. M. Van der Eijk, M.J. Faber, I. Ummels, J.W. Aarts, M. Munneke, B.R. Bloem "Patient-centeredness in PD care: development and validation of a patient experience questionnaire" *Parkinsonism Related Disorders*, 18 (9) (2012), pp. 1011–1016
  207. The EFNS task force on Diagnosis and Management of Amyotrophic Lateral Sclerosis. EFNS guidelines on the clinical Management of Amyotrophic lateral Sclerosis (MALS) – revised report of an EFNS task force. *European Journal of Neurology* 2012, 19:360-375.
  208. Hardiman & Doherty. *Neurodegenerative Disorders* (1st Edition) <http://www.springer.com/gp/book/9781849960106>
  209. Cellura, E. R, Spartaro, et al (2012) 'Factors affecting the diagnostic delay in amyotrophic lateral sclerosis'. *Clin Neurol Neurosurg* 114 (6):550-554
  210. Mille, RG et al, Practice parameter update: the care of the patient with Amyotrophic lateral sclerosis: multidisciplinary care, symptom management, and cognitive/behavioural impairment (an evidence based review). Report of the quality standards subcommittee of the American Academy of Neurology. *Neurology* 2009; 73: 1227-1233
  211. Traynor BJ, Alexander M, Corr B, Frost E, Hardiman O. Effect of a multidisciplinary amyotrophic lateral sclerosis (ALS) clinic on ALS survival: a population based study 1996-2000. *J Neurol Neurosurg Psychiatry* 2003; 74: 1258-1261
  212. Rooney J, Byrne S, Heverin M, Tobin K, Dick A, Donaghy C, Hardiman O. A multidisciplinary clinic approach improves survival in ALS: a comparative study of ALS in Ireland and Northern Ireland. *J Neurol Neurosurg Psychiatry*. 2014 Dec 30. pii: jnnp-2014-309601. doi: 10.1136/jnnp-2014-309601. [Epub ahead of print] PubMed PMID: 25550416.
  213. McDonald ER et al. Survival in amyotrophic lateral sclerosis. The role of psychological factors. *Arch Neurol* 1994; 51. 17-23
  214. Van Groenestijn, AC et al. 'Effects of aerobic exercise therapy and cognitive behavioural therapy on functioning and quality of life in amyotrophic lateral sclerosis: protocol of the FACTS-2-ALS trial'. *BMC Neurology* 2011, 11:70



215. [http://www.mndnsw.asn.au/index.php?option=com\\_content&view=article&id=228:multidisciplinary-care-team&catid=106:living-better-for-longer&Itemid=214](http://www.mndnsw.asn.au/index.php?option=com_content&view=article&id=228:multidisciplinary-care-team&catid=106:living-better-for-longer&Itemid=214)
216. Anderson PM, Abrahams S, Borasio GD, De Carvalho M, Chio A, Van Damme P, Hardiman O, Kollewe K, Morrison KE, Petri S, Pradat PF, Silani V, Tomik B, Wasner M & Weber M. EFNS guidelines on the clinical management of Amyotrophic Lateral Sclerosis (MALS) – revised report of an ENFS task force. *European J Neur.* 2012;19(3);360-375
217. <sup>1</sup>Phukan, J., Elamin, M., Bede, P., Jordan, N., Gallagher, L., Byrne, S., . . . Hardiman, O. (2012, Jan). Cognitive Impairment in Amyotrophic Lateral Sclerosis: A Population-based Study. *Journal of Neurology, Neurosurgery and Psychiatry*, 83(1), 102-8
218. <sup>1</sup>Elamin, M., Bede, P., Byrne, S., Jordan, N., Gallagher, L., Wynne, B., . . . Hardiman, O. (2013). Cognitive changes predict functional decline in ALS: A population-based longitudinal study. *Neurology*, 80(17), 1590-1597.
219. <sup>1</sup>Elamin, M., Phukan, J., Jordan, N., Pender, N., & Hardiman, O. (2011, April). Executive Dysfunction Is a Negative Prognostic Indicator in ALS: A Population Based Study. *Neurology*, 76(14), 1263-9.
220. <sup>1</sup>Rooney, J., Byrne, S., Heverin, M., Tobin, K., Dick, A., Donaghy, C., & Hardiman, O. (2015, May). A multidisciplinary clinic approach improves survival in ALS: a comparative study of ALS in Ireland and Northern Ireland. *J Neurol Neurosurg Psychiatry. Journal of Neurology, Neurosurgery and Psychiatry*, 86(5), 496-501
221. Corr, B. et al (1998) Service Provision for patients with ALS/MND: A cost effective multidisciplinary approach. *Journal of Neurological Sciences* 160:141-145
222. <sup>1</sup>Morris M.E. et al (2006) Outcomes of Physical Therapy, Speech Pathology and Occupational Therapy for People with Motor Neuron Disease: A Systematic Review. *Neurorehabilitation and Neuronal Repair* 20 (3) 424-434
223. Guidelines for the management of MND, September 2014 <http://imnda.ie/wp-content/uploads/2014/09/MND-guidelines-on-Physiotherapy.pdf>
224. Bush & Scott 2009, Hamm & Miranda 2006
225. Motor Neuron Disease. The use of non-invasive ventilation in the management of motor neurone disease. London (UK): National Institute for Health and Clinical Excellence (NICE); 2010 Jul. 127p. (Clinical Guideline; no 105)
226. The National Council for Palliative Care, the Neurological Alliance & NHS National End of Life Care Programme. 2010 'End of life care in neurological conditions: a framework for implementation'.
227. MND Scotland. Integrated Care Pathway
228. Heritier Barras, A-C et al. 'Is tracheostomy still an option in amyotrophic lateral sclerosis? Reflections of a multidisciplinary workgroup, *Swiss Med Wkly.* 2013; 143:w13830
229. Lishman WA 1998. Organic Psychiatry: the Psychological Consequences of Cerebral Disorder
230. [http://www.neurology.upmc.edu/neuromuscular/patient\\_info/what.html](http://www.neurology.upmc.edu/neuromuscular/patient_info/what.html)
231. Edwards, MJ, Kailash, PB. Functional (psychogenic) movement disorders: merging mind and brain. *The Lancet Neurology*, Vol 11, issue 3, p250, March 2012
232. Victor W Mark MD. Psychogenic neurologic disorders. April 2001; med link Neurology
233. <http://www.ninds.nih.gov/jobsandtraining/summer/2008student/minwuabstract.htm>
234. Shaibani, A, Sabbagh MN; Pseudoneurologic syndromes: recognition and diagnosis *Am Fam Physician.* 1998 May 15; 57 (10): 2485-2494
235. <http://www.ninds.nih.gov/disorders/psychogenicmovemtn.htm>





