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Feidhmeannacht na Seirbhíse Sláinte Health Service Executive

# REHABILITATION MEDICINE

#### **Clinical Strategy and Programmes Division**

National Clinical Programme for Rehabilitation Medicine (NCPRM)

Model of Care for the Provision of Specialist Rehabilitation Services in Ireland



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The National Clinical Programme for Rehabilitation Medicine (NCPRM) is delighted to present the Model of Care (MOC) for the provision of Specialist Rehabilitation Services in Ireland. This MOC has been developed with input and support from multiple stakeholders but especially we would like to acknowledge the expertise, dedication and commitment of the Rehabilitation Programme Working Group and Rehabilitation Programme Clinical Advisory Group without whom this MOC would not have been developed. A special word of acknowledgement and thanks for the tremendous contribution of our predecessors in the Clinical Programme for Rehabilitation Medicine; Clinical Leads, Dr Aine Carroll and Dr Jacinta Morgan and Programme Manager Dr Valerie Twomey.

Rehabilitation is a dynamic and critical component of any modern health care systems.

Rehabilitation improves health outcomes, reduces disability and improves quality of life. There is a significant and emerging body of international evidence to support the benefit and cost effectiveness of specialist rehabilitation services within a modern health service. The demand for rehabilitation services is growing and is anticipated to continue to grow with changes in populations and with the advances in health care and new interventions and technology. Some of the key drivers for the increasing need include;

- Aproximately 44,000 new neurological conditions are diagnosed annually, and by 2021, it is estimated that there will be approximately 870,000 people in Ireland with a neurological condition and potentially 85,000 will be disabled as a result of that condition.
- Improved immunological therapies has resulted in improved survival and reduced disability of many patients with severe chronic rheumatologic and neurological disorders.
- Life expectancy is improving and the population of older persons is growing with increased demand for specialist rehabilitation services.
- Recent advances in thrombolytic therapy and acute interventional management of stroke has resulted in a 25% drop in the mortality and a reduced burden of disability in many people who survive stroke events.
- Traumatic Brain injury in is the leading cause of death and disability in young persons and internationally development of trauma systems of care has led to improved retrieval and intensive care management of people who have sustained severe injuries as a result of road traffic accidents or other major trauma.
- The proposed development of an effective trauma network in Ireland has the potential to increase survival of those suffering major trauma by up to 30%. Many of these people will have significant specialist rehabilitation requirements. Trauma Networks need to be supported by a well-developed rehabilitation network modelled on international best practice standards if they are to be successful.
- Over 800 people undergo a limb amputation in Ireland each year and these people require specialized integrated multidisciplinary rehabilitation and prosthetic services.

There is a growing body of evidence that rehabilitation in specialised environments is not only effective but cost effective. This has been demonstrated in a variety of settings, such as in-patient units and community teams, and in different diagnostic groups (traumatic brain injury, stroke, multiple sclerosis and Spinal Cord Injury). Specialist rehabilitation may be defined as the total active care of people with a complex, disabling condition by a multi-professional team who have undergone recognised specialist training in rehabilitation, led or supported by a consultant trained and accredited in rehabilitation medicine (RM).

The NCCPRM working group has identified that there are significant resource and delivery gaps in rehabilitation services in Ireland when compared with those in other European countries.

In researching and developing this model of care NCPRM working groups<sup>1</sup> examined in detail the current evidence base and existing recommendations for organisation of specialist rehabilitation services across English-speaking OECD<sup>2</sup> countries.

The three-tier model of complexity-of-need has formed the basis for the commissioning of specialist rehabilitation services in England and Wales since the designation of Brain Injury and Complex Rehabilitation as a specialist service<sup>3</sup>. The model is derived from the Kaiser Permanente illness triangle<sup>4</sup> and was used extensively in the UK in the early years of implementation of the NHS Plan (2000) to convey the conceptual basis for the paradigm shift required to move chronic disease management from hospitals into primary care. The model translates to the Irish rehabilitation context with important adaptations<sup>5</sup>.

In the Rehabilitation MOC there are recognised levels of specialist rehabilitation:-

- Complex specialist service: serves a national population and manages a high proportion of complex cases (60-70% have complex needs).
- Local/Regional specialist rehabilitation service: serves a population of up to 1 million and manages fewer complex cases (up to one third or 25-33% will have complex needs).
- Community rehabilitation services: serves a CHO population (usually ≈500,000) and comprises a wide range of therapy services including specialist and generic, and statutory and voluntary.

Within this framework of specialized rehabilitation care the main premise underpinning all rehabilitation service delivery is

- Person centered approach to patient care
- Development of appropriately resourced interdisciplinary inpatient, outpatient and community based specialist rehabilitation teams across Ireland supported by education and training
- Case management of patients
- Managed Clinical Rehabilitation Networks (MCRN)

This Rehabilitation MOC acknowledges the fact that different service users

- 2 Organisation for Economic Co-operative Development
- 3 Archived web content on the 3rd edition of the Specialised Services National Definition Set 2010; http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/ en/Managingyourorganisation/Commissioning/Commissioningspecialisedservices/ Specialisedservicesdefinition/index.htm
- 4 Archived NHS reference to the KPTriangle accessed 21st November 2014 http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Healthcare/ Longtermconditions/DH\_4130652
- 5 Unlike the UK the base tier of service in the Irish model encompasses community specialist agencies rather than generic, non-specialist services.

I Model of care work stream, multidisciplinary working group and acquired brain injury (ABI) work stream

need different input and different levels of expertise and specialization at different stages in their rehabilitation journey. The critical point of this model is that, although service users may need to access different services as they progress, the transition between services should be facilitated by appropriate communication and sharing of information between services so that they progress in a seamless continuum of care through the different stages<sup>6</sup>.

The successful implementation of the Rehabilitation MOC and the National Strategy & Policy for Neurorehabilitation Services in Ireland is dependent on the investment in strategic development, workforce planning and integration of rehabilitation services across the health care continuum through effective development and implementation Managed Clinical Rehabilitation Networks (MCRN).

An extensive review of population and population needs across a demonstrator pilot project site for testing the feasibility of a Managed Clinical Rehabilitation Network (MCRN) was carried out in recent weeks overseen by the National Steering Group for the Neurorehabilitation Strategy. The demonstration pilot project sites includes the community services within the Community Healthcare Organisations within 2 Community Healthcare Organisations, and inpatient specialist rehabilitation services.

In this preliminary study, if access to rehabilitation was timely and available for these patients, and their average length of stay was reduced by as little as 2 days, this would equate to a 20,474 bed days being released back into the acute hospital system just within this small group of hospitals. On a national scale, there is the potential of releasing many times that amount of bed days back into the acute hospital setting.

It is hoped that the pilot projects, overseen by the National Steering Group will provide proof of concept for managed clinical rehabilitation networks as the mechanism to deliver the Rehabilitation MOC and the Neurorehabilitation strategy. The impact of effective implementation of MCRN should not be underestimated. The resourcing and development of a MCRN will not only improve the access, experience and outcomes for patients, but will improve throughput, improve cost benefit, cost effectiveness and add value back into a health service where there are significant capacity issues within the acute hospital setting.

Reflecting the reality of limited services in Ireland, the NCPRM has necessarily focused on the development of a framework for the delivery of specialist rehabilitation services where it will have the most impact that is initially targeting the most common prevalent acute and chronic disabling conditions affecting adults in Ireland at this time. It is hoped that with sustained development and investment of rehabilitation services that this rehabilitation MOC will support and translate well to the development of specialised rehabilitation services in cancer, cardiac, sports, pain and paediatric rehabilitation.

> Dr Jacinta McElligott, Clinical Lead Edina O'Driscoll, Programme Manager

<sup>6</sup> Model of Care, National Clinical Programme for Rehabilitation Medicine

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#### Introduction

Rehabilitation is a dynamic and critical component of the therapeutic continuum and one that is essential if patients are to regain or maintain their life roles and quality of life after serious illness or injury. It can improve health outcomes, reduce disability and improve quality of life<sup>1</sup>. Specialist rehabilitation is the total active care of patients with a complex, disabling condition by a multi-professional team who have undergone recognised specialist training in rehabilitation, led or supported by a consultant trained and accredited in rehabilitation medicine (RM)<sup>2</sup>.

The objective of the National Clinical Programme for Rehabilitation Medicine (NCPRM) is to describe a framework whereby the ability and societal participation of those affected by complex, life-altering conditions can be maximized by early, timely and life-long intermittent access to specialist rehabilitation. The desired outcomes are improved quality of life, sustainable community independence and improved employability for those treated; and, in the early post-injury stage, reduced length of hospital stay and prevention of unnecessary re-admissions to acute care.

There is a significant body of international evidence to support the benefit and cost effectiveness of specialist rehabilitation services within a modern health service<sup>1</sup>. In Ireland there are profound resource and delivery gaps in rehabilitation services when compared with those in other European countries. Severe underinvestment and the lack, until recently, of a coherent national strategy to guide the development of neurorehabilitation services are the principal contributors to this position<sup>3</sup>.

#### **Background and best practice**

The scope of rehabilitation medicine practice in Ireland is necessarily restricted because of a significant dearth of trained clinicians to lead and deliver specialist rehabilitation programmes for all who can benefit. As more resources are directed towards rehabilitation services it is hoped that the NCPRM's scope of service can be expanded by means of the managed clinical network paradigm.

Emergency trauma and medical care is now more responsive and effective, and more people are surviving catastrophic injuries with complex, life-changing neurological, vascular and orthopaedic effects. This has led to an overwhelming unmet requirement for specialist rehabilitation services particularly for people who have sustained major central nervous system injuries. This is evidenced, for instance, by the inexorable growth in numbers of people with newly acquired complex disability after neurological injury on a national specialist rehabilitation waiting list<sup>a</sup>.

The NCPRM model of care promotes a seamless transition between different care settings and effective identification and management of the patient / service user's rehabilitative needs. It is unlikely that one agency will be in a position to offer all inputs required by an individual and thus interagency co-operation is an essential element of effective rehabilitation provision. It is in this context that case management has emerged as a key strategy in managing lifelong complex effects of severe neurological injuries and illnesses.

Many community residential options for younger severely disabled people do not meet their unique needs where continuing slow functional recovery is possible many years after their injury. Development of more structured community based rehabilitation teams is required to support patients during gradual step-down from tertiary centres and regional units so that they can be supported in reintegrating within their local communities. New funding paradigms that recognise the unique and complex long-term requirements of severely disabled survivors of catastrophic illness or injury require urgent consideration. One suggestion that warrants closer scrutiny is that of ringfenced national funding allocated after detailed needs assessment for the management of longer term rehabilitation and care requirements.

<sup>a</sup> Personal communication, National Rehabilitation Hospital (NRH) waiting list management group

#### Model of care key features

Effective and realistic goal setting, with patient and family engagement, across the continuum of recovery and service delivery, is the cornerstone of the rehabilitation process. Timely access to acute and postacute specialist rehabilitation in facilities equipped to treat patients with complex rehabilitation needs must be realised to optimise the functional recovery of those who survive catastrophic injuries and illnesses. Expansion and standardisation of community based rehabilitation services is essential to ensure that the benefits of post-acute rehabilitation are sustained and reinforced as patients make progress in their new lives.

The NCPRM model of care presents, in line with the National Policy and Strategy for the Provision of Neuro-Rehabilitation Services in Ireland 2011–2015 (DoHC 2011)<sup>a</sup>, an outline for future provision of specialist rehabilitation services in Ireland<sup>b4</sup>. A hub and spoke model is proposed consisting of a tertiary centre linking at least four managed clinical rehabilitation networks (MCRN) each one serving populations of about 1m. The network will connect acute and post-acute rehabilitation units, and community specialist rehabilitation clinicians in a formal governance structure, to allow delivery of coordinated rehabilitative care for patients across all levels of complexity<sup>c</sup>.

#### Model of Care Key Recommendations:

- s Person-centred approach to service delivery
- s Equitable access to services
- s Three level model of service delivery across several managed clinical rehabilitation networks (MCRN)
- s Development of appropriately resourced interdisciplinary inpatient, outpatient and community based specialist rehabilitation teams across Ireland supported by education and training
- s Development of systems to facilitate measurement and data collection

#### Implementation

Clinicians delivering specialist rehabilitation services will, through the framework of the managed clinical networks, define generic and specialist competencies for staff working in rehabilitative care spanning acute, post-acute and community settings. It is hoped that uniform standards of service delivery can be realised in due course across the national, regional and community components of the network.

Development of clear referral protocols and pathways by the networks, at the interface between specialist and non-specialist, and community disability services will ensue particularly through the work of the 2011 Neurorehabilitation Strategy Implementation Group. It is important that statutory and non-statutory services should work collaboratively to improve outcomes and experience for service users.

a Referred to as the 2011 Neurorehabilitation Strategy throughout this Model of Care

b http://www.lenus.ie/hse/bitstream/10147/141055/1/Future%20for%20neurological%20conditions%20in%20 Ireland.pdf p.33, accessed 19th November 2014

c http://www.hse.ie/eng/services/publications/corporate/CHOReport.html accessed 19th November 2014

# **02** INTRODUCTION

#### What is specialist rehabilitation?

Rehabilitation is a dynamic and critical component of the therapeutic continuum and one that is essential if patients are to regain or maintain their life roles, status and quality of life after serious illness or injury. Rehabilitation can improve health outcomes, reduce disability and improve quality of life and reduce costs by shortening hospital stays<sup>1</sup>. Specialist rehabilitation is the total active care of patients with a disabling condition, and their families, by a multi-professional team who have undergone recognised specialist training in rehabilitation, led or supported by a consultant trained and accredited in rehabilitation medicine (RM)<sup>2</sup>.

The World Health Organisation (WHO) recommends in its definition<sup>a</sup> that priority is given to ensure access, for those in need, to appropriate, timely, affordable and high-quality rehabilitation interventions consistent with Article 26 of the UN Convention on the Rights of Persons with Disabilities<sup>b</sup>.

Patient / service user	Clinicians	Infrastructure
Health Promotion and Prevention Self-Management Information Provision Vocational Rehabilitation	Key worker & case manager models Education and training Research Appropriate workforce planning	Rehabilitation Database Use of Technology National, regional and community units with • in-patient • out-patient • informal meeting facilities (families and voluntary
Interdisciplinary appr assessmen Ma	organisations) <ul> <li>staff development facilities</li> </ul>	

#### Table 2.1 Elements of specialist rehabilitation services

Patients with complex needs typically present with a combination of medical, physical, sensory, cognitive, communicative, behavioural, psychological and social problems that require specialist input from a wide range of rehabilitation disciplines<sup>c</sup> and consultants trained in Rehabilitation Medicine.

a WHO definition http://www.who.int/topics/rehabilitation/en/ accessed 18th November 2014

b http://www.un.org/disabilities/default.asp?id=286 accessed 19th November 2014

c Rehabilitation nurses, physiotherapists, occupational therapists, speech and language therapists, psychologists, dietitians, orthotists / prosthetists and medical social workers

In researching and writing this model of care NCPRM working groups<sup>a</sup> examined in detail the current evidence base and existing recommendations for organisation of specialist rehabilitation services across English-speaking OECD<sup>b</sup> countries. Policy groups in many of these countries have developed and shared widely their guidelines, pathways of care and experience of service development in general and condition-specific<sup>c</sup> rehabilitation. However only two countries provide service paradigms on which to base an appropriate model for Ireland: England and Wales, and the Victorian Paediatric Specialist Rehabilitation Service.The latter model from Australia has limited application to an adult service but many of its recommendations concerning delivery of intermittent life-long support to those with acquired disability forms the basis of the NCPRM's model of care schema in chapter 4<sup>d</sup>

The three-tier model of complexity-of-need has formed the basis for the commissioning of specialist rehabilitation services in England and Wales since the designation of Brain Injury and Complex Rehabilitation as a specialist service<sup>e</sup>. The model is derived from the Kaiser Permanente illness triangle<sup>f</sup> and was used extensively in the UK in the early years of implementation of the NHS Plan (2000) to convey the conceptual basis for the paradigm shift required to move chronic disease management from hospitals into primary care<sup>5</sup>. The model translates to the Irish rehabilitation context with important adaptations<sup>g</sup>.



Figure 2.1: Complexity levels in Irish Rehabilitation services

#### **Complex Specialist Rehabilitation Services**

These are high cost / low volume services that provide for a high proportion of patients with highly complex rehabilitation needs that are not fully met by their local and regional specialist services. Complex specialist rehabilitation services offer a higher level of specialist expertise, facilities and programme intensity to meet the needs of these patients who typically receive coordinated interdisciplinary intervention from four or more therapy disciplines as well as requiring sub-specialist input from other services such as neuro-urology or neuro-psychiatry.

a Model of care work stream, multidisciplinary working group and acquired brain injury (ABI) work stream

- f Archived NHS reference to the KP Triangle accessed 21st November 2014 http://webarchive. nationalarchives.gov.uk/+/www.dh.gov.uk/en/Healthcare/Longtermconditions/DH\_4130652
- g Unlike the UK the base tier of service in the Irish model encompasses community specialist agencies rather than generic, non-specialist services.

b Organisation for Economic Co-operative Development

c Stroke and traumatic brain injury

d Figure 4.1, page 30

e Archived web content on the 3rd edition of the Specialised Services National Definition Set 2010; http:// webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Managingyourorganisation/Commissioning/ Commissioningspecialisedservices/Specialisedservicesdefinition/index.htm

#### Hospital Group-based Specialist Rehabilitation Services

These services serve a regional or hospital-group population and are led by a consultant trained and accredited in Rehabilitation Medicine working in an in-patient and/or ambulatory setting. The specialist interdisciplinary team provides advice and support for local non-specialist teams. Patients treated in local / hospital group rehabilitation units will typically have a combination of moderate to severe physical, cognitive, behavioural and communication difficulties.

#### **Community Specialist Rehabilitation Services**

Community-based specialist rehabilitation teams provide interdisciplinary rehabilitation, ideally with case managers, and therapy support to patients with stable complex needs usually after single incident neurological conditions, usually in an out-patient or domiciliary setting. The interdisciplinary team case-manages, and coordinates multi-agency referral and on-going care, often on a life-long basis.





#### International Classification of Functioning (ICF)

The World Health Organisation (WHO) model of illness has evolved over the past thirty years (WHO-ICF 2001)<sup>a</sup> and charts the transmission of the impact of the disease pathology through to its effect on the person's ability to perform day to day activities and consequently their ability to participate in their societal roles. ICF belongs to the WHO family of classifications and presents taxonomies of functioning and disability associated with health conditions. Since 2001 it is the recognised framework describing functioning and health<sup>6</sup>.



Figure 2.3: Model of disability forming the basis of the ICF

Diagnosis alone does not predict service needs, length of hospitalization, care requirements or functional outcomes. The ICF provides a more comprehensive model of disability than medical or social models in isolation. It recognizes that disability is an interaction between the features of the person and elements of the overall context in which the person lives. Disability and functioning are viewed as outcomes of interactions between health conditions and contextual factors in the ICF framework.

a WHO International Classification of Functioning 2001 http://www.who.int/classifications/icf/en/

Within this framework, the human experience of functioning is not considered as the consequence of a disease, but the result of the interaction between a health condition and both personal attributes and environmental influences (contextual factors)<sup>7</sup>. The impact of these contextual factors is important, since they can act as facilitators or barriers for functioning.

#### Effectiveness and cost benefit of rehabilitation

There is now substantial proof that intensive rehabilitation in specialised environments, delivered by trained and committed staff, is both effective and cost-effective, in terms of reducing the burden and cost of onward care<sup>8</sup>, and less so in increasing return to work rates. This has been demonstrated in a variety of settings, such as in-patient units and community teams, and in different diagnostic groups (traumatic brain injury<sup>9</sup>, stroke<sup>10</sup>, multiple sclerosis<sup>11</sup> and Spinal Cord Injury<sup>12</sup>).

A recent study<sup>13</sup> examined spending in health services across Europe during recession to determine its affordability. The study evaluated the economic effects of alternative types of government spending by estimating 'fiscal multipliers<sup>a'</sup>. The fiscal multiplier for investment in health was determined as being 43 (2.5-6.1). These findings suggest that investment in health, specifically rehabilitation, contributes to economic health in the long term by creating a healthier labour force.

In Medical Rehabilitation in 2011 and beyond<sup>14</sup> evidence is presented from intervention trials for sudden onset neurological conditions, progressive or intermittent neurological conditions, and limb absence. One such example is a 6 year cohort study of patients with ABI admitted to a tertiary referral centre<sup>15</sup>.

All patients in each of the 3 graded categories of dependency (using the RCS)<sup>b</sup> showed significant reduction in dependency and on-going care costs. The reduction in weekly cost of care was greatest in the high dependency group (at £639 per week); reduced mean costs for the medium-dependency group was about half this amount (£323 per week), and about £111 per week for the low dependency group. Despite their longer length of stay and higher treatment costs the time taken to offset the initial cost of rehabilitation was only 16.3 months in the higher dependency group.

Treatment by community based multidisciplinary teams can be cost-saving. A review of effectiveness of one such community team<sup>16</sup> demonstrated that savings arising from reduced hospital bed usage and reduced out-patient visits with MDT involvement was equivalent to the cost of the team itself thereby rendering the team's work cost neutral. 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<sup>17</sup>.

#### **Clinical Governance within the CSPD**

The NCPRM is one of thirty two clinical programmes within the Clinical Strategy and Programmes Division (CSPD). The division was first developed in 2009 to assist in standardising patient care across service and professional boundaries. It is a clinician-led initiative between the HSE CSPD, Royal College of Physicians of Ireland (RCPI), the Irish Association of Directors of Nursing and Midwifery and the Therapy Professions Committee. It is undergoing a process of reform to allow greater integration with HSE operational divisions and is now established as the systems design authority for the HSE.

a The return on investment for each \$1<sup>a</sup> dollar of government spending; a multiplier greater than 1 corresponds to a positive growth stimulus (returning more than \$1 for each dollar invested)

b Rehabilitation Complexity Scale: low 0 – 7; medium 8 – 11, high 12 – 15 http://www.kcl.ac.uk/lsm/research/divisions/cicelysaunders/attachments/Tools-RCS-Publictaion-Rehabilitation-complexity-scale.pdf



Fig 2.4 HSE Governance Chart including NCPRM \* Correct at time of approval

#### **Governance for Quality Improvement**

Concept	Governance for Quality and Safety			
Domain	Structure	Process	Outcome	
	<ul> <li>X Senior Management Team</li> <li>X Quality and Safety Committee</li> <li>X Clinical Leadership</li> <li>X Accountability spine</li> </ul>	<ul> <li>X Quality and performance indicators</li> <li>X Learning and sharing information</li> <li>X Patient and public involvement</li> <li>X Risk management and patient safety</li> <li>X Clinical effectiveness and audit</li> <li>X Staffing and staff management</li> <li>X Information management</li> <li>X Capacity and capability</li> </ul>	Patient care Patient experience Staff experience, health& wellbeing Service improvement	
Context	Individual Practitioner Service / Department / Division Senior Management Team			

Table 2.2 HSE clinical governance model

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The achievement of good clinical outcomes for patients is dependent on robust clinical governance, a system through which healthcare teams are accountable for the quality, safety and patient experience of the care they deliver across the continuum of care. NCPRM governance is organised and delivered in accordance with the recommendations of the HSE publications on clinical governance<sup>a</sup>. In practice this requires health staff to specify expert clinical standards against which one's practice is benchmarked then compare one's own measurements with the gold standard. Where practice is deficient a quality improvement plan is agreed and implemented.

Use of HSE Clinical Governance assurance check lists<sup>b</sup> within all organisations providing specialist rehabilitation services will assist in establishing baseline compliance and embedding good clinical governance across the continuum of care. This supports the delivery of quality safe patient care, contributing to the readiness to implement regulatory standards and preparing for the introduction of a licensing system<sup>c</sup>.

Ten principles for good clinical practice in the Irish context have been developed by the HSE against which all governance decisions should be tested.

Patient first	Based on a partnership of care between patients, families, carers and healthcare providers in achieving safe, easily accessible, timely and high quality service across the continuum of care
Safety	Proactive identification and control of risks to achieve effective efficient and positive outcomes for patients and staff
Personal responsibility	Where staff, patients and the population take personal responsibility for their own and others health needs. Defined authority The scope given to staff at each level of the organisation to carry out their responsibilities
Clear accountability	A system whereby individuals, functions or committees agree accountability to a single individual Leadership Motivating people towards a common goal and driving sustainable change to ensure safe high quality delivery of clinical care.
Inter- disciplinary working	Work processes that respect and support the interdependence and unique contribution of all staff members in the provision of clinical care. Supporting performance Managing in a supportive way, in a continuous process, taking account of clinical professionalism and autonomy in the organisational setting.
Open culture	A culture of trust, openness, respect and caring where achievements are recognised; discussion of error is embedded in everyday practice and communicated openly to patients
Continuous quality improvement	A learning environment with a comprehensive programme of quality improvement programmes. Clinical governance is not a separate function but an integral component of governance arrangements

 Table 2.3 Descriptors for Guidance principles

a http://www.hse.ie/eng/about/Who/qualityandpatientsafety/resourcesintelligence/Quality\_and\_Patient\_ Safety\_Documents/clingov.html

b An assurance check is intended as a guide for reviewing the structures and processes used in achieving good clinical outcomes.

c Adapted from Report of the Quality and Safety Clinical Governance Development Initiative; Sharing our Learning, QPSD,2014

**HIQA Guidance** 



#### Figure 2.5 HIQA (2012) Themes for Quality and Safety

The Health Information and Quality Authority (HIQA) published guidance in its National Standards for Better Safer Health Care in June 2012<sup>13</sup>. Eleven standards are applicable under Theme 5 'Leadership, Governance and Management' to all services offering patient care, inclusive of in-patient, out-patient and community services:

T	Clear accountability arrangements to achieve the delivery of high quality, safe and reliable healthcare
2	Formalized governance arrangements for assuring the delivery of high quality, safe and reliable healthcare
3	Publicly available statement of purpose that accurately describes the services provided, including how and where they are provided
4	Clear objectives and plans for delivery of high quality, safe and reliable healthcare services
5	Effective management arrangements to support and promote the delivery of high quality, safe and reliable healthcare services
6	Culture of quality and safety promoted
7	Personal and professional responsibility for the quality and safety of services provided promoted
8	Systematic monitoring arrangements for identifying and acting on opportunities to continually improve the quality, safety and reliability of healthcare services
9	Formal monitoring of services provided
10	Compliance with relevant Irish and European legislation
Ш	Adherence to standards, alerts, recommendations and guidance as issued by regulatory bodies

 Table 2.4
 Standars under Theme 5, Safer, Better Healthcare

#### Context and objectives of the NCPRM



Fig 2.6 NCPRM governance within the HSE CSPD

A short account of roles (below) within the programme and a schematic representation (above) of its context in HSE governance structure are presented.

The National Clinical Lead is a Consultant in Rehabilitation Medicine and has accountability and responsibility for strategic development and liaison with HSE operational divisions (especially social care).

The Clinical Advisory Group (CAG) is a physician group representing the Royal College of Physicians of Ireland (RCPI) and its Chair is a Consultant in Rehabilitation Medicine. The CAG 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 NCPRM as being the nationally agreed strategic model. Regional Lead Physicians are consultants from within the CAG who provide local / hospital group-based leadership in developing and implementing national strategy.

The NCPRM Working Group comprises representatives from all rehabilitation-related professional bodies and patient advocacy groups, and is 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). This group includes representatives from medical, nursing, and health and social care professions.

Each HSCP and lead has direct access to expert advisory groups within their professional bodies who can contribute to surveys, audits, requests for submissions and feedback. Similarly, Nurse Leads on Working Groups establish advisory sub-groups for input from expert nurses in the subspecialties.

Cross Programme collaboration with related clinical programmes within the CSPD and with Primary and Social Care Divisions is central to the design and delivery of a service which delivers patient focused, evidenced based rehabilitation. This document is consistent with other relevant models of care developed through the National Clinical Programmes and Strategy Division, in particular those of the Neurology, Older Persons, Stroke, Critical Care, and Rheumatology clinical programmes. The publications of the National Clinical Programme for Palliative Care such as their needs assessment and competency framework are also highly relevant (Department of Health 2001<sup>a</sup> and HSE CSPD 2014)<sup>b</sup>. Together these documents cover the continuum of care for patients with rehabilitative needs 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.

#### Neurology

The NCPRM is liaising with the Neurology Clinical Programme particularly with reference to scope and programme synergies. The role of rehabilitation medicine in the management of patients with neurological conditions is wide ranging. Both programmes are advocating for managed clinical networks with national complex specialist services, regional specialist services and community or local services. Implementation of both models of care will be reliant on the development of adequately resourced community specialist and primary care teams to support patients in the right setting at the right time.

#### **Paediatrics**

Although paediatric specialist rehabilitation services are outside the NCPRM scope the programme has promoted the development of a hub and spoke model to address the needs of children with acquired disability from serious illness. The NCPRM is engaging on an ongoing basis with the development board for the new National Paediatric Hospital, the National Rehabilitation Hospital and the Paediatric Clinical Programme in this regard and has contributed a chapter on specialist rehabilitation to the 2015 Paediatric and Neonatology Programme's Model of Care.

#### Stroke

Patients with stroke who have complex and enduring specialist rehabilitation needs are considered within the scope of the NCPRM. Links are being forged with the national Stroke Programme, particularly in relation to their TRASNA telemedicine programme<sup>c</sup> which has the potential to enhance clinical and educational links between clinical teams in hospital groups and managed clinical networks.

#### Trauma and orthopaedics and emergency medicine

The NCPRM national clinical lead has recently joined a DoH / HSE Steering Group to develop a Trauma Network Policy for Ireland which includes the National Clinical Leads of the Trauma and Orthopaedic, and Emergency Medicine Programmes.

#### **Mental Health**

The NCPRM recognises the high prevalence of psychiatric illness in patients with neurological disease/ injury and that many patients presenting with specialist rehabilitation needs require input and support from colleagues in mental health services.

These patients can present with;

- a) premorbid mental health condition
- b) mental health condition secondary to their disability
- c) dual diagnosis

a 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

b Palliative Care Competence Framework Steering Group. (2014). Palliative Care Competence Framework. Dublin: Health Service Executive. Accessible on www.hse.ie/palliativecareprogramme

c http://www.hse.ie/eng/about/Who/clinical/natclinprog/strokeprogramme/trasna/ (accessed 26th May 2015)

It is also recognised that individuals with neuropsychiatric needs are often referred to general adult psychiatric community mental health teams (CMHT). Due to the complex nature of these conditions, these referrals place an ever increasing burden on already overstretched services. While specific inputs from neuropsychiatry are described in this document, particularly for those with complex specialist needs, the NCPRM would also recognise the requirement for patients to be able to access psychiatry teams, with the appropriate skills and resources at each level across the continuum of care.

#### **Objectives**

QUALITY	ACCESS	VALUE
Reduction of inappropriate patient discharges to nursing homes	Access to early specialist rehabilitation assessment within 2 weeks of referral for 80% of those referred	Reduce length of stay in acute hospitals by 5 days
Rehabilitation in the most appropriate care setting to meet patient needs	Admission to specialist rehabilitation inpatient beds, if clinically indicated, within 60 days for 80% of those referred	Reduce length of stay in complex specialist rehabilitation inpatient beds by 5 days
Specialist rehabilitation provided by interdisciplinary teams	Reduction of 20% in the number of patients waiting to access complex specialist rehabilitation	Reduction in days lost to delayed discharge in specialist rehabilitation services
Appropriate, earlier transfer of care between rehabilitation settings	Reduction in delayed discharges from complex specialist rehabilitation in- patient beds	10% reduction in acute hospital readmission rate of treated specialist rehabilitation patients, for index condition or complications
National defined and tracked outcome measures	Equitable access to specialist rehabilitation services regardless of geography	Discharge to appropriate care facilities

#### Table 2.5 NCPRM programme objectives

The NCPRM's objectives have been developed over the past 4 years and reflect the expressed aspirations and needs of current and former service users, and rehabilitation clinicians. Achievement of these objectives is dependent on implementation of the recommendations within this model of care across the care continuum i.e. acute hospitals, social care & primary care.

#### The Scope of the NCPRM

Specialist rehabilitation has thrived in the US, mainland Europe and the Antipodes for more than 50 years and so a wide range of sub specialties have evolved in those countries to serve the needs of patients with disabilities and long-term conditions whatever their primary diagnosis. In the US the following PRM<sup>a</sup> sub-specialties are recognised for certification<sup>b</sup>: Brain Injury Medicine, Hospice and Palliative Medicine, Neuromuscular Medicine, Pain Medicine, Paediatric Rehabilitation Medicine, Spinal Cord Injury Medicine and Sports Medicine.

The UEMS-PRM<sup>c</sup> Section and Board represent the interests of Rehabilitation Medicine physicians in Europe. The abundance of PRM specialists in all other European countries, excluding the UK and Ireland, allows the European PRM section to invite, and receive, requests for accreditation of programmes of care from specialist rehabilitation teams treating an eclectic and diverse range of medical conditions<sup>d</sup>.

In Ireland and the UK management of (i) spinal injured patients in the post-acute phase, (ii) patients with previously disabling inflammatory arthritides and (iii) those with limb absence has been the mainstay of specialist rehabilitation for more than 50 years. Programmatic delivery of brain injury rehabilitation is a relatively recent development in Ireland (1994). The dearth of capital and human resource expansion in specialist rehabilitation over the past 20 years has limited the potential, as yet, to offer programmes in cancer, cardiac, sports and pain rehabilitation.

The Trauma Network Policy Steering Group is committed to supporting the development of specialist rehabilitation services and in that regard it is a priority for the NCPRM that patients with complex multiple system consequences of trauma will be treated in the current tertiary centre (NRH) and any new regional / satellite rehabilitation units. The report of the Trauma Steering Group was published in Feb 2018 with 'rehabilitation services' included in 'recommended designation criteria' for Major Trauma Centres and Trauma Units.

Reflecting the reality of restricted services in Ireland the NCPRM is therefore focused on development of a framework for the delivery of specialist rehabilitation services to adults over the age of 18 with limb loss, a range of neurological conditions and the effects of major trauma.

CATEGORY	EXAMPLE
Sudden onset conditions	Brain injury, spinal cord injury, limb absence
Intermittent conditions	Relapsing remitting Multiple Sclerosis (MS)
Progressive conditions	Parkinson's disease, progressive MS
Stable conditions	Cerebral palsy, post-polio syndrome

#### Table 3.1: long-term neurological conditions

**Sudden onset:** In studies of patients with acquired brain injury (ABI), predominantly stroke, and spinal cord injury (SCI) the greatest benefit for patients is demonstrated in (i) early intensive rehabilitation programmes starting soon after onset of the medical condition, (ii) specialist programmes for all those with complex needs and (iii) specialist vocational programmes for those with potential to return to work.

a Physical and Rehabilitation Medicine

b https://www.abpmr.org/candidates/subspecialties.html accessed 21st April 2015

c European Union of Medical Specialists – Physical and Rehabilitation Medicine

d http://www.euro-prm.org/index.php?option=com\_content&view=article&id=45&Itemid=194&Iang=en accessed 21st April 2015

**Progressive or intermittent conditions:** The largest body of evidence for rehabilitation in progressive or intermittent conditions is observed in multiple sclerosis patients<sup>18</sup>. The strongest recommendations are for (i) short term intensive inpatient rehabilitation programmes and (ii) lower-intensity community-based programmes delivered over a longer period.

**Limb absence conditions:** Patients who lose lower limbs account for 92% of those who undergo amputation. Those with upper limb amputations are a much smaller population and account for 5% of those with limb loss. People with congenital limb absence are the smallest group representing just over 2%.



#### Fig 3.1: Amputee and Prosthetic numbers (BSRM)

Specialist services for those with limb loss deliver better outcomes when groups of services establish formal affiliations and when complex prosthetic management (e.g. congenital upper limb) is accessible from one tertiary referral centre<sup>19</sup>.

#### **Epidemiology of disability**

Accurate information on incidence<sup>a</sup> and prevalence<sup>b</sup> of a disease, and the numbers disabled by it, is essential in planning services particularly around workforce skill mix and numbers, and the geographical location of those services. For instance, there are more than 30,000 people living in Ireland with the effects of an acquired brain injury<sup>20</sup>.

In addition not all patients are disabled by their condition at all times and accurate information indicating the numbers that are can be difficult to ascertain. Good estimates of the numbers of individuals living with and disabled by a neurological illness are presented in the same paper extrapolated from the UK Neuro Numbers report from 2003, also from the UK Neurological Alliance<sup>21</sup>. At any one time, 17% of the Irish population (726,000) is living with a neurological illness such as acquired brain injury, epilepsy, multiple sclerosis, stroke, Parkinson's disease, dementia, and other progressive, intermittent or disabling conditions of the brain or spinal cord. Neurological conditions can impact the physical, intellectual, emotional, social and economic life of the person and their family<sup>22</sup>. It is estimated that 85,000 are disabled by the condition defined as needing the help of another person to perform most of their activities of daily living, including personal care, meal preparation, housework and shopping.

a Incidence refers to the number of new cases of a disease occurring annually in a given population.

b Prevalence refers to the total number of individuals living with a disease in a given population, at a given time.

Over 700 000 with a sural start	100000.00			
- Over 700,000 with neurological	900000.00			
conditions in Ireland		/	-	
an estimated 131 820 will be	800000.00			With Neurological
- an estimated 191,020 win be	700000.00			Condition
significantly disabled by				
Neurological condition by the year	600000.00		_	With significant disability
and the second condition by the year	500000.00			
2021.				
- over 50.000 new diagnoses	400000.00			Newlydiagnosed
annually avaasted by 2021	300000.00			in the second seco
annually expected by 2021.	200000.00			
<ul> <li>75,000 caring for person with</li> </ul>	200000.00			
neurological condition by 2021	100000.00			Laring for person with
neurological conultion by 2021.				rear orogreat condition

Fig 3.2: epidemiology of neurological conditions in Ireland

Many factors have contributed to a substantial and enlarging number of disabled individuals: certainly, diagnostic accuracy has improved. Over the past 20 years sustained improvements in retrieval and intensive care management of those who have sustained severe brain injuries have yielded a group of patients, mostly of working age, who demonstrate slow and incomplete recoveries. Improved immunological therapies and other high-cost treatments have ensured the survival of many more patients.

The process of rehabilitation after such injuries and illnesses, given the degree of nervous system damage, can be of indefinite duration. Recovery may result in limited functional gains for the injured individuals and wider society, in terms of the patients' ability to re-engage in their former life roles. In addition, their care needs impact hugely on the lives of their families or carers, many of whom are forced to abandon their own educational and work activities.

Assessing the level of need for specialist rehabilitation services is constrained by absence of epidemiological research and the lack of a single comprehensive data source for recording and monitoring this information within the health services. This section outlines an estimate of the need based on consideration of the data sources that are available. There is an approximate prevalence of 4,000 people with limb absence and prosthetic requirements in Ireland, and an incidence of 500 people with primary major limb loss.

The incidence of new SCI (traumatic and non-traumatic) is approximately 120 per annum<sup>23</sup> and more than 2500 people are living with the consequences of those injuries.

According to Hospital Inpatient Enquiry Scheme (HIPE) data from 2010 more than 30,000 individuals were discharged from an acute hospital in Ireland with a neurological condition or amputation. Based on international comparisons about 50% will require access to specialist rehabilitation services to reduce complications. They require assessment and triage towards appropriate services in hospital or community settings. There are significant gaps in provision of specialist rehabilitation across all levels of complexity.

#### **Guiding policy documents in Ireland**

The development of the NCPRM model of care draws from key policy developments and reforms within the Irish health services with detailed consideration of the following:

 National Policy and Strategy for the Provision of Neuro-rehabilitation Services in Ireland 2011-2015 (2011)<sup>a</sup>. This strategy 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 being led by HSE disability services in collaboration with the NCPRM.

a 2011 Neurorehabilitation Strategy

- Department of Health and Children's Value for Money Review of Disability Services, 2012<sup>24</sup> has resulted in significant restructuring of disability services following the recommendations of the review. There are also recommendations for further restructuring and policy development in the areas of reconfiguration of therapy services (recommendation 5.10), formal outcome measurement based on the assessment of person-centred plans (recommendation 6.6); establishment of a primary care network (recommendation 7.12) and cross-sectoral working (recommendation 7.17).
- Health (Amendment) Act 2005<sup>a</sup>; Disability act 2005<sup>b</sup> The Disability Act is designed to advance and underpin the participation of people with disabilities in society by supporting the provision of disability specific services and improving access to mainstream public services. It places significant obligations on public bodies to make buildings and services accessible to people with disabilities, provides for sectoral plans in key service areas, requires public bodies to take positive actions to employ people with disabilities and provides for the establishment of a Centre for Excellence in Universal Design.
- HSE Procurement Policy<sup>c</sup>: this policy refers to the purchasing of supplies, works and services and is governed by core values which include; patient focus, dealing with quality suppliers who comply with all relevant legislation and government guidelines and managing risk. Considering the needs of patients requiring specialist rehabilitation and their requirements for aids/appliances/prosthetics, this policy will guide development of any national guidelines with respect to aids & appliances.
- National Standards for Safer Better Healthcare 2012<sup>d</sup>: by incorporating national and international best available evidence, these standards from the Health and Information Quality Agency (HIQA) promote healthcare that is up to date, effective and consistent. The standards provide a sound basis for anyone planning, funding or providing healthcare services to work towards achieving and maintaining high quality, safe and reliable care. They also determine the characteristics of high quality and safe healthcare and what patients and clinicians should expect from a well-run service.
- National Healthcare Charter, National Advocacy Unit, Quality and Patient Safety Directorate<sup>e</sup>, HSE 2012<sup>f</sup>. This charter, involving contributions from service users and patient advocacy organisations, is designed to involve service users in influencing the quality of healthcare in Ireland. It is used to support the implementation of the National Standards for Safer Better Healthcare.
- Key policies on prevention and public awareness campaigns e.g. Road safety Authority (RSA) and smoking cessation
- Future Health: A Strategic Framework for Reform of the Health Service 2012-2015<sup>g</sup> launched in November 2012 provides an overarching policy framework for the establishment of hospital groups. At the time of writing the six hospital Group CEOs and their boards had been appointed.
- HSE Chronic illness framework 2008<sup>h</sup>: the goal of this framework is to provide individuals, groups and carers with early diagnosis, education, optimum clinical and social care in the most appropriate setting and achieve stable control of their condition. Self-management support, avoidance of complications and improved outcomes are also addressed.

e Now the HSE Quality Improvement Division

a http://www.hiqa.ie/standards/health/safer-better-healthcare accessed 20th November 2014

b http://www.irishstatutebook.ie/2005/en/act/pub/0003/index.html accessed 19th November 2014

c http://www.oireachtas.ie/documents/bills28/acts/2005/a1405.pdf accessed 20th November 2014 d http://www.hse.ie/eng/about/Who/Procurement/ accessed 20th November 2014

f http://www.nmh.ie/\_fileupload/Patient%20Services/HSE%20It's%20Safer%20to%20Ask.pdfaccessed 20th November 2014

g http://health.gov.ie/blog/publications/future-health-a-strategic-framework-for-reform-of-the-healthservice-2012-2015/ accessed 20th November 2014

h http://www.lenus.ie/hse/bitstream/10147/65295/1/Chronicillness08.pdf accessed 20th Nov 2014

- Review of Neurology and Clinical Neurophysiology Services (Laffoy report, submitted December 2007 to the National Hospitals' Office)<sup>a</sup>: Dr Marie Laffoy carried out a strategic review of these services in 2007 and her recommendations were revisited at the request of the HSE in March 2009 by external experts Professors Charles Warlow and Jan Van Gijn. The report recommended that more resources be allocated to specialist personnel and facilities to improve access to diagnostic facilities for patients with neurological conditions.
- Prosthetics and Orthotics Review 2012<sup>b</sup>: A recent review of prosthetic and orthotic services<sup>g</sup> undertaken by the National Clinical Programme for Rehabilitation Medicine contains recommendations on the following best practice: development of clear clinical pathways for the care of patients; provision of service as close as possible to the patient's home; treatment by expert staff and RM consultant involvement in prescription of a prosthetic device being prescribed for that patient. Regarding orthotic services, it is recommended that complex cases should be referred to a specialist rehabilitation team with appropriate experience. Third party suppliers must have demonstrated compliance with appropriate HSE National Standards (under development) and supply arrangements must comply with the HSE's requirements for value for money, transparency and management of risk.
- Progressing Children's Disability Services is a national project established by the Health Service Executive (HSE) to change the way services are provided. The aim of the 'Progressing Disability Services for Children and Young People' programme is to achieve a national unified approach to delivering disability health services, so that there is a clear pathway to the services they need for all children regardless of where they live, what school they go to or the nature of their disability or delay. The programme's objectives are based on the recommendations of the Report of the Reference Group on Multidisciplinary Services for Children aged 5 to 18 Years completed in 2009 and approved by the HSE in 2010.
- Towards Earlier Discharge, Better Outcomes, Lower cost: stroke rehabilitation in Ireland (ESRI 2014)<sup>25</sup> The report's summary suggests that

...more than 3,000 people every year who sustain a stroke could benefit from Early Supported Discharge (ESD), yielding net savings estimated at  $\notin 2$  million to  $\notin 7$  million each year. ESD could save more money in reduced length of hospital stay –  $\notin 12$  million– than would need to be reinvested in developing community rehabilitation ( $\notin 5 - 10$  million). ESD could free up over 24,000 hospital bed days, the equivalent of 67 hospital beds, annually. These findings provide the economic justification for the rapid development of Ireland's community rehabilitation and care services for the benefit of people who have been deprived of vital services to boost their quality of life.

 Vision for Change, Department of Health and Children, 2006. The current National Mental Health Policy has clarified the case of unmet need for clinical Neuropsychiatry services in Ireland. A year after traumatic brain injury, approximately 20% of people will have diagnosable mental disorders and 40% will have neurobehavioral problems. These figures estimate a neuropsychiatry need in traumatic brain injury of approximately 80 cases per 100,000 population.

a Report to the National Hospitals' Office 2007; unpublished

b Prosthetic & Orthotics and Specialised footwear supply project, HSE, Dec 2012 (pending release)

#### Interdisciplinary team working

The complex challenge of enabling an individual to achieve their rehabilitation potential requires the involvement of many professionals from a variety of disciplines. The interdisciplinary team (IDT) model of care is widely recognised as the gold standard for rehabilitation provision using a holistic, collaborative and patient focused approach.

Traditional multidisciplinary team (MDT) models involve professionals working independently in order to achieve discipline specific goals. Individual team members may not communicate directly with all other team members in care planning. Members working independently often lack a common understanding of issues that can influence interventions<sup>26</sup>.

The key factors distinguishing the IDT from the MDT is that team members work together closely in goal setting, treatment, decision making and ongoing problem solving to ensure continuity of care and a more holistic approach<sup>27</sup>. From the time of admission, and in some cases from the time of referral, to the point of discharge the patient, family and the team are working on mutually agreed goals to achieve the optimum outcome.

There is good evidence that IDT working creates efficiencies in healthcare services. IDT collaboration improves patient compliance and satisfaction, reduces costs, lowers mortality, reduces length of stay and increases team members' satisfaction<sup>28</sup>. It appears that the "value added" element of the interdisciplinary model is in the IDT use of combined skills to meet the complex rehabilitative needs of patients, to ensure optimal outcomes at the lowest cost in the shortest length of stay<sup>29</sup>. Effective IDT working should have more impact than the sum of its members working individually.

Working within an IDT requires commitment from all members. Collaborative team work and discussion require communication and negotiation skills, demonstration of respect for all team members with a willingness to put aside views of differing status of members and a readiness to blur professional boundaries.

#### **Case management**

Intensive, ongoing and personalised case management can improve quality of life and outcomes for individuals with complex or ongoing needs and those who care for them. Case management can enable patients to return home after hospital admission for a life-changing illness more quickly with a coordinated support package. An account of how case management can be implemented is presented in chapter 5.

#### **Guidelines and care pathways**

Consensus standards for the provision of in-patient and community rehabilitation<sup>30</sup>, rehabilitation after traumatic brain injury<sup>31</sup> and organisation of stroke services and clinical management of stroke<sup>32</sup> have been in routine use across all areas of the UK (Scotland<sup>33</sup>, Northern Ireland<sup>34</sup>) for much of the last decade. They contain evidenced-based recommendations regarding the organization of the services, minimum staffing levels and skill mix, clinical interdisciplinary work processes such as referral and discharge practices, and minimum weekly therapy interventions. More recently, health departments in the devolved territories of Wales and Northern Ireland have commissioned external reviews of their neurosciences<sup>35</sup> and brain injury rehabilitation<sup>36</sup> services respectively.

Clinical guidance is becoming more specific and explicit with clear and all-inclusive algorithms available to ensure logical and comprehensive management of patients throughout the course of their illness. Examples include the Scottish and Multiple Sclerosis Society care pathways for multiple sclerosis the excellent management handbook from the UK Parkinson's Disease Society and NHS Scotland National Patient Pathways.

Interdisciplinary pathways for the rehabilitative management of those with acquired brain injury, spinal cord injury and limb absence in Ireland are presented in the appendices of this model of care. Minor variations from the pathways may occur as clinical freedom is exercised to meet the often complex and varying needs of individual patients.

#### **Current Service Configuration**

The ambitious mapping and gapping exercise which informed the 2011 Neurorehabilitation Strategy is the principal source of information regarding service provision up to 2011 for those with neurological disability and long-term neurological conditions in Ireland. Services for those with limb absence of all ages were surveyed in the 2012 HSE Prosthetics and Orthotics review. When compared with international norms these two reports identified a significant shortage of specialists in all clinical areas, in addition to a significant shortage of in-patient rehabilitation beds, out-patient post-acute rehabilitation and community specialist rehabilitation.



Fig 3.3 visualisation of current service configuration in some areas

#### In-patient specialist rehabilitation

In Ireland, in-patient complex specialist rehabilitation for children and adults, who have acquired disability related to sudden neurological injury / illness and acquired limb absence is delivered in the National Rehabilitation Hospital (NRH). The NRH provides a comprehensive range of specialist rehabilitation services to patients who, as a result of an accident, illness or injury have acquired a physical or cognitive disability and require specialist rehabilitation<sup>a</sup>. Services delivered by the National Rehabilitation Hospital (NRH) are predominantly high-cost and low volume, and provided to patients with highly complex conditions.

Specialist rehabilitation is delivered through specialty programmes whose scope comprises brain injury (including stroke), spinal cord system of care, prosthetic, orthotics and limb absence (POLAR) and paediatric and family centred. All clinical programmes are accredited by CARF<sup>b</sup>. The NRH has developed a full continuum of care which includes rehabilitation programmes in comprehensive integrated Inpatient care (CIIRP), outpatients, home and community care, and vocational services (the Rehabilitative Training Unit).

Many patients treated in the NRH are seen and treated initially in one of the two neurosurgical units in Ireland. The larger unit is within the Neuroscience centre in Beaumont Hospital, Dublin serving a population of more than three million and the other in Cork University Hospital providing services to approximately I million people living in Munster<sup>41</sup>. Many of the most severely disabled patients treated in

a Adapted from www.nrh.ie (accessed 10th July 2015)

b Commission for Accreditation of Rehabilitation Facilities (www.carf.org)

the two neurosurgical centres wait for up to a year for a suitable bed in the NRH with many transferred back to their initial treating hospitals to acute surgical or medical wards.

Three Consultants in Rehabilitation Medicine have dedicated liaison sessions in the two neurosurgical centres and other consultant colleagues carry out liaison consultations in the National Spinal Unit (Mater Hospital), St James's, Tallaght and St Vincent's University Hospitals with another Consultant post in the South/Soutwest Hospital Group.

Significant work has been invested by the NRH and NCPRM in helping the former HSE regions, now the new hospital groups and CHO's recognise the overwhelming unmet need for specialist in-patient and community rehabilitation services outside Dublin.

#### **Out-patient specialist rehabilitation**

Out-patient (also called ambulatory care) services allow continuation of structured rehabilitation programmes following in-patient treatment in acute or sub-acute health facilities. Out-patient specialist rehabilitation programmes can result in earlier transfer of care or discharge from in-patient settings. When employed de novo these services can allow patients avoid hospitalisation. Early Supported Discharge stroke rehabilitation programmes are obvious examples of ambulatory care and their efficacy and benefit have been endorsed in a 2005 meta-analysis<sup>a</sup>.

#### **Community Based specialist rehabilitation**

A number of community based rehabilitation teams are in operation around the country, however the current geographic spread means that access to these services is patchy and inequitable. These teams, where they do exist, are generally led by senior Health & Social Care Professionals.

Non-statutory organisations offer many innovative services that ensure effective and durable rehabilitation outcomes including work retention and retraining, social inclusion, carer support and long term management of neurological sequelae. In the area of community specialist neurological rehabilitation the principal agencies are Acquired Brain Injury Ireland (www.abiireland.ie) and Headway (www.headway.ie).

ABI Ireland and Headway Ireland have secured accreditation for several of their programmes from the international accreditation agency CARF<sup>b</sup>. Details of services are available through their websites.

ABI Ireland, Headway Ireland and Multiple Sclerosis Ireland (www.mssociety.ie) and many other voluntary organisations also provide a range of supports for the individual and their family working closely with statutory specialist services to provide information, peer support and guidance critical to enabling personal goal attainment.

#### **Ongoing Care for Highly Dependent Patients**

A growing number of adult patients survive major trauma, extensive vascular and hypoxic brain injury, and exacerbation of long-standing neurological illness with complex needs, including a requirement for ventilatory support through permanent tracheostomies. They require 24-hour care and ideally should be engaged in 'slow-stream' multi- or interdisciplinary rehabilitation over a period of many years to facilitate their optimal recovery.

The only option currently available to these patients is long term care in nursing homes. Funding of these placements is through the HSE Nursing Home Support Scheme (fair deal). A small number of nursing homes around Ireland provide maintenance levels of occupational and physiotherapy if appropriate 'top-up' funding is agreed before transfer with the disability manager in the patient's local HSE area. Lean budgets and competing funding requests may result in these highly dependent patients losing their scant rehabilitation input in the absence of perceived progress inmeeting functional goals.

a Nursing Home Support Scheme http://www.hse.ie/nhss/ (accessed 25th September 2015)

b Commission for Accreditation of Rehabilitation Facilities

#### Introduction

The NCPRM Model of Care shares a common purpose with the framework outlined in the 2011 Neurorehabilitation Strategy. The model and terminology is adopted from other published rehabilitation models of care and adapted to the Irish context.

Fundamental to the development of specialist rehabilitation services is the appreciation that different service users need different input and different levels of expertise and specialisation at different stages in their rehabilitation journey. The critical point of this model is that, although patients may need to access different services as they progress, the transition between services should be facilitated by appropriate communication and sharing of information between services so that they progress in a seamless continuum of care.



Figure 4.1: Adapted from Neurorehabilitation Strategy

#### **Rehabilitation process**

**Referral**: Early referral and rehabilitation intervention minimises complications of severe injury and immobility. For instance, early referral and rehabilitation assessment within 48 hours of injury is recommended in all hospitals in England and Wales admitting major trauma<sup>43</sup>

Guidance is required to support patients and clinicians who are not rehabilitation specialists to explain what it means to be 'ready for rehabilitation'. This information establishes the benefit of continuing assessment and review by a senior rehabilitation clinician - particularly in relation to preventing complications and establishing readiness for active rehabilitation. 'Readiness' considers the patient's ability to endure the daily duration and intensity of therapies, and their medical stability. In addition waiting list management systems<sup>44</sup> are required to ensure equitable and transparent access to rehabilitation facilities and services. Ready for rehabilitation should be decision made based on clinical judgement.

**Assessment**: Standardised assessment by specialist rehabilitation IDT members is holistic covering physical, cognitive, psychological & social domains of function. For instance in the management of major trauma in England and Wales a senior rehabilitation clinician generates a rehabilitation prescription/ rehabilitation needs assessment for each patient that is reviewed at pre-determined intervals after reiterative assessment. Goal setting is recognised as a central component of specialist rehabilitation yet there is no consensus on the optimum mode of goal setting. Current practices (SMART or domain-based goal-setting, and GAS<sup>a</sup>) adopt a pragmatic and empirical approach that may not always capture the

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a Goal Attainment Scale
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complexity of the person's disability or required interventions. Goal setting should also be informed by the Rehabilitation Consultant's prognosis to ensure that goals are realistic and achievable.

**Rehabilitation intervention**: Specialist rehabilitation, whether in hospital or community settings, is delivered by interdisciplinary rehabilitation teams comprised of a range of professionals presented in chapter 5. Their common attributes include specialist training and competence in integrated assessment and goal setting. Team members interface during regular meetings where goals, explored with the patient during therapeutic meetings, are discussed and agreed, often using the framework of a validated outcome measure such as FIM FAM. An overview of the range of treatments deployed by all rehabilitation clinicians is alluded to in chapter 5.

**Transfer of care, follow-up and re-entry**: Discharge planning begins on or before admission to the post-acute rehabilitation facility where all community support options are considered in the context of a patient's altered function in physical, cognitive, emotional and vocational domains. In the absence of existing formal service agreements between hospital and community specialist rehabilitation teams in 2015 it is best to avoid prescriptive advice about future practices. It is envisaged that clinicians in all settings, through the proposed managed clinical networks, will develop joint pathways to promote seamless care and optimum patient rehabilitation.

#### **Rehabilitation setting**

#### Acute rehabilitation

Timely acute rehabilitation exploits plasticity and reduces the potential for complications. There is grade A evidence that acute rehabilitation leads to reduced length of stay (LOS) in hospital and improved outcomes<sup>1,</sup>. Acute rehabilitation is required by all patients admitted to hospital with severe injury or illness that may result in disability. Rehabilitation services can be delivered in acute hospital settings using a range of models outlined in table 4.2

Model	Activity	Clinical	Advantages
Rehabilitation beds in acute (tertiary) hospitals	Transfer of patients to rehabilitation beds within the acute hospital	<ul> <li>Early exposure to RM clinical activity and rehabilitation principles</li> <li>RM clinicians integrated into acute hospital governance systems</li> </ul>	<ul> <li>Early access to acute beds maintained only if post-acute bed capacity is sufficient and well-managed</li> </ul>
Mobile rehabilitation medicine (RM) team within the acute hospital	RM team working solely within the acute hospital consulting on patients	<ul> <li>Possible to consult on larger numbers of patients with a wider range of conditions</li> <li>Effective liaison between team and acute clinicians</li> </ul>	<ul> <li>Reduced clinical control for RM team</li> <li>No RM team available out of hours</li> </ul>
RM consults to acute wards in acute hospitals	RM physician from stand-alone RM centre reviews patients in acute beds	<ul> <li>Larger numbers of patients with a wider range of conditions reviewed</li> </ul>	<ul> <li>Reduced clinical control for RM team • No dedicated RM team</li> <li>RM physician not on site or on-call</li> </ul>

Table 4.2 Models of acute rehabilitation: adapted from RCP Medical rehabilitation in 2011 and beyond

In recent years clinicians and commissioners in the UK have recognised the importance of early, timely and intensive specialist rehabilitation in ensuring an optimal functional outcome for people who experience major trauma. When Prof Keith Willett was appointed as the National Trauma Tsar in 2009 he stated that "Rehabilitation for the severely injured patient in the UK is poor. Historically we have under invested in rehabilitation. There is a lot of important work to be done".

Trauma networks are now fully implemented and all patients attending the trauma centres or trauma units must have a 'rehabilitation prescription' completed within 48 hours of presentation and reviewed at regular intervals. Below is a proposed pathway for management of such patients in the Irish context.



#### Fig 4.2: Pathway for trauma patients Adapted from BSRM SPECIALIST REHABILITATION Core Standards (2013)

#### **Post-Acute Specialist Rehabilitation**

Post-acute specialist services comprise two types of facility: (i) complex specialist rehabilitation services (Tertiary Specialist Centre) and (ii) Local (hospital group-based) units. Both provide intensive in-patient and out-patient (capacity-dependent) services but differ in case mix. It is the proportion of complex patients that chiefly distinguishes these two levels of service<sup>a</sup>. In a local specialist rehabilitation service it could be expected that, at any one time, up to one third (25-33%) will have complex needs. In a tertiary specialist service 60-70% of patients are likely to have complex needs.

#### **Tertiary Specialist Centre**

In all post-acute specialist rehabilitation settings team members work in an interdisciplinary manner and have specialist training and competency to provide this level of rehabilitation. Services are led a Consultant in Rehabilitation Medicine and ideally a key worker (often the medical social worker) is identified for each patient and their families. Patient goal-setting and review drives all interventions usually accompanied by measurement of validated outcome scores discussed at weekly IDT meetings. Individual therapy interventions are delivered typically by more than one therapist.

With such a complex patient group the tertiary centre would be expected to deliver programmes such as (i) detailed global assessment and family support for patients with prolonged disorder of consciousness (PDoC), (ii) management of patients with complex polytrauma, (iii) high cervical spinal cord injuries including patients requiring ventilator support, (iv) complex spasticity management requiring advanced medical or surgical intervention<sup>b</sup>, (v) oro-pharyngeal and tracheostomy management, (vi) neurobehavioural management and vii)pre-prosthetic and prosthetic rehabilitation.

a Summarised in appendix I

b Such as regional nerve blocks, intrathecal baclofen pump and tendon-release surgery

Access to additional services including but not limited to;

- Assistive technology
- Neuropsychiatry
- Audiology
- Orthotics
- Wound care
- Rehabilitation engineering
- Sexual counselling

- Vocational rehabilitation
- Addiction counselling
- Driving assessment
- Parenting skills

- Ophthalmology

#### Local (hospital Group-based) Units (INpatient SPECIALIST REHABILITATION)

Clinical services are provided by trained rehabilitation staff led by a Consultant in Rehabilitation Medicine. Units are ideally situated on the campus of acute hospitals so that access to all acute clinical and support services can allow early immersion in rehabilitative care while ensuring patient safety. It is envisaged that when developed many of the more rapidly improving and less dependent lower limb prosthetic and neurological patients (with stroke, TBI or less severe polytrauma) will be treated in these units. As a minimum the team should include rehabilitation nurses, physiotherapists, occupational therapists, speech therapists, dietitians, medical social workers and clinical psychologists; appropriate staffing ratios to deliver the required treatment intensity are detailed in chapter 5. While these units can be considered a step in the continuum of care as people progress and require less intensive rehabilitation supports, they should not be considered a discharge destination for those who may have ongoing care needs but who have been deemed to have achieved maximum potential benefit with respect to rehabilitation needs.

#### **Community-based Specialist Rehabilitation**

Goal-directed therapy within the community is typically focused on restoration of function and independence, and coordinated discharge planning with a view to continuing rehabilitation within primary care teams. The development of community specialist rehabilitation teams within each community healthcare organisation, as described in the National Strategy & Policy for Neurorehabilitation Services in Ireland (2011-2015) is supported strongly by the NCPRM.

Therapeutic programmes are typically interdisciplinary and of moderate intensity for patients requiring two or more therapies. In some instances, complexity and intensity of services can be determined by impact of disability on the individual i.e. they may require intensive intervention from a single discipline. Requiring two or more disciplines should not be the sole determinant for access to these teams.

Community specialist rehabilitation teams form a critical link in the care pathway by facilitating early discharge and continuity of therapy from acute and post-acute rehabilitation facilities; assessing and making recommendations on vocational options such as returning to work, educational and occupational activities, and liaison with rehabilitative training services.

Complex specialist rehabilitation members require a degree of specialisation and training that enables them to provide services to people with complex presentations requiring a degree of specialist input beyond that available from a primary care team. Typically these people do not require in-patient facilities and benefit from supported transition from hospital to home. These teams play a pivotal role in supporting primary care teams through consultation and in delivering shared care to the affected person indefinitely.

Community specialist rehabilitation teams will include a range of health and social care professionals, and a case manager, with support from a rehabilitation medicine specialist, and prosthetic and orthotic expertise. This configuration will ensure strong links with local and tertiary hospitals and will in turn support ongoing care provision through primary care teams.

- Vestibular assessment
- Orthoptics

Currently there are a number of community based specialist rehabilitation teams providing excellent services to patients. Replicating these services nationally would be considered a priority for the NCPRM.

#### Vocational rehabilitation

Vocational rehabilitation (VR) is a specialist rehabilitation service which support return to work, vocational retraining or withdrawal from work through the medium of interdisciplinary assessment and interagency intervention. This process returns patients to meaningful occupation which can include productive roles such as parenting, education, training and volunteering.

The NCPRM recognises that its role in promoting return to work is limited to supporting the delivery of focused vocational training and support by a range of statutory and non-statutory service providers. The programme recognises the importance of common standards for assessment, delivery and outcomes for vocational rehabilitation.

Ideally, vocational assessment/evaluation forms part of the total evaluation process in the rehabilitation continuum – medical, physical and functional, psychological, cognitive and perceptual, speech and language evaluations. It must be a collaborative process to facilitate the patient in gaining insight into their strengths and weaknesses, assessing their aptitude for work (including transferable skills), exploring the demands of suitable jobs with suitable employers and exploring alternative work or training options taking into account vocational interests.

Successful vocational rehabilitation programmes for adults seldom focus on the treatment of 'impairment', instead their success has been with addressing workplace access, tailoring work patterns and demands to match the attributes of the employee and providing information on health conditions, rights and resources to both employers and employees<sup>46</sup>.

The societal and personal value associated with employment should not be underestimated. Being employed influences life satisfaction positively. Those who return to work, in general, can be seen to have a higher level of activity, fewer medical treatments, fewer depressive symptoms and better overall adjustment.

#### Transition of children to adult services

The NCPRM is working with the New Children's Hospital Group and National Paediatric Hospital Board with respect to pathways for complex specialist rehabilitation services.

Transition is the planned move of a patient's care from a paediatric to an adult health care provider. Transition is a step necessary to achieve the best outcomes possible for patients and their families in areas of health, independence and adulthood.Transition can be defined as 'a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-orientated healthcare systems<sup>47</sup>.

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

Transferring care to adult physicians should be 'a guided educational and therapeutic process, rather than an administrative event'<sup>48</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. While some of the literature would advocate a 2 phased approach, others would propose a 3 phased approach. Irrespective of age or number of phases, all agree that the concept of transition should be introduced in early adolescence, with the young person becoming aware of their own health and care needs, and the full implications of their medical condition.

Progression through phases should be based on the assessment of the young persons' understanding and their confidence in their own autonomy. Six key areas should be addressed including self-advocacy, independent health care behaviour, sexual health, psycho social support, educational and vocational planning, and health and lifestyle.

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.

The NCPRM advocates the use of a transition checklist<sup>a</sup> to guide transition from paediatric to adult services. The NCPRM recommends that each site serving paediatric patients with specialist rehabilitation needs refer to the checklist, even when paediatric and adult services are in the same hospital as evidence would suggest that geographic co-location does not always translate into smooth transition services.

#### **Primary care**

Within a network model the longer-term needs of people with neurological and limb absence disability can be best met through shared arrangements between specialist and local health services in partnership with social services and other statutory authorities such as housing, employment, education and transport. Many individuals continue to require specific supports in the community with respect to personal care and activities of daily living' these needs are best met through PCCC services and Public Health Nursing.

#### **Not-For-Profit Providers**

The role of not for profit providers is crucial in the rehabilitation and long term management of neurological conditions and is acknowledged in the 2011 Neurorehabilitation Strategy thus:

...the integral role played by the community and non-statutory sector in service delivery is acknowledged from the outset (of this report)

The NCPRM recognises that not for profit providers are integral to the provision of community based rehabilitation services aimed at meeting the many and complex needs of people with neurological conditions. Not for profit organisations provide direct services that ensure effective and durable outcomes from the rehabilitation process to allow the individual to pursue goals that are meaningful to them and their families. In addition, they play a vital role in supporting the needs of the individual in the community around a range of health and social care services as well as access to other vital supports such as transport, housing, employment and social inclusion.

Not for profit organisations have developed innovative and comprehensive responses to address these critical gaps in the provision of services required by people with neurological conditions and their families living in the community. Many not for profit organisations have applied for and secured internationally-recognised accreditation standards for the programmes they provide.

a Appendix 4

Services provided by not for profit organisations lie outside the scope of the NCPRM programme as these organisations are subject to separate contractual arrangements with the HSE. However, the NCPRM acknowledges the critical role of these supports in the rehabilitation process and recommends that the implementation plan for the national neurorehabilitation strategy engage directly with these organisations in the implementation process, including in developing a framework for the composition and operation of community based neurorehabilitation teams.

The table below indicates the range of services and supports provided by the not for profit sector around the delivery of neurorehabilitation services.

#### **Direct Service Provision**

- Residential, home care and respite services
- Rehabilitation assessment and structured training and education support programmes through specialist day services and one to one support
- Supported employment and back to work training and assistance
- Provision of neuropsychological assessment and individualised and group rehabilitation services
- Provision of specialist services for people with specific neurological conditions that require neurobehavioural and other supports
- Specialist case management services
- Direct provision of nurse specialist, occupational therapy, speech and language and physiotherapy and neuropsychology services
- 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
- Specialised support, education and counselling for family members
- One to one support services for people with neurological conditions around the impact
  of their diagnosis and ongoing management of their condition. Many organisations have
  specialised programmes for symptom management, adjustment to the condition, family
  support and information and social inclusion. These specialised programmes focus on
  self-management and supported self-care adapted for the specific needs of people with
  neurological conditions
- Provision of trained advocates working directly with people to identify and access the services they require
- Peer support for people with the condition and their families.
- Providing accessibility through provision of transport services, this is a vital requirement in supporting the delivery of neurorehabilitation and long term care.
- Provision of specialist aids and appliances which are critically required and are often unavailable or face lengthy delays within the statutory health services.
### Awareness Promotion and Education around specific neurological conditions

- A wide range of education programmes aimed at employers, health professionals, schools and community services aimed at promoting greater awareness of neurological conditions.
- Promoting, commissioning and funding research on neurological conditions and keeping up to date with developments in research and treatment and disseminating this information to people with neurological conditions, their families and health professionals
- Preparation and regular updating of information resources such as websites, newsletters, leaflets and information booklets and manuals, videos, CDs, press releases etc.
- Developing training programmes and partnerships with health professionals which are particularly critical in improving the management of neurological conditions in non-specialist settings, including in primary care
- Developing programmes and initiatives to support further specialist training for health professionals

### **Consultation and Policy Development**

- Consultation at policy and planning level in all areas of health and social services to inform and drive the development of policy to meet the needs of people with specific neurological conditions.
- Identifying gaps and resource needs in relation to neurorehabilitation services and advocating at local, national and individual level around these needs.
- Development and pioneering of innovative approaches to the needs of their client group.

#### **Managed Clinical Rehabilitation Networks**

The NCPRM recommends the establishment of managed clinical rehabilitation networks (MCRNs) through which specialist neurological and limb absence rehabilitation services will be delivered.

Managed clinical networks facilitate re-design, quality improvement, strategy and planning across pathways. Teams work across department boundaries, teams, units and divisions. They achieve their results through consensus and collaboration by enabling clinicians with differing levels of expertise, patients and service managers to work together to deliver safe, effective and person-centred care<sup>49</sup>. The essential components of a MCN are:

- n Excellent clinical governance and quality assurance structures<sup>a</sup>.
- n Access to specialised, competent clinical and managerial staff
- n Clear referral protocols and pathways at the interface between specialist and non-specialist rehabilitation, and disability services
- n Collaborative working between statutory and non-statutory agencies
- n Responsive and needs-led services at all levels of complexity

(NHS HDL (2007) 21; Scottish Executive Health department)

a ...Achieved through integrated teamwork, development and sharing of agreed protocols benchmarking against agreed standards, identification of good practice and supporting innovation and clear measurement of efficiency, effectiveness and value for money. 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"

MCNs for a wide range of medical conditions have been established in Scotland and England, and consist of linked groups of health professionals and organisations from primary, secondary and tertiary care working in a coordinated manner. At best the MCNs can encourage all service providers that when they work together they deliver more than the individual parts when working in isolation<sup>50</sup>.

### Structure

There will be a number of population-based MCRNs, taking consideration of areas covered by Hospital Groups, CHOs<sup>a</sup>, tertiary centres and the forthcoming trauma networks<sup>b</sup>. There will be an additional specialty network for Prosthetics/Orthotics & Limb Absence Rehabilitation. Clinical leadership will be from a designated rehabilitation medicine consultant who will have formal links to the NRH.

The structure of a network derives from defined points of entry to care, points of care delivery and their connections. All professionals involved with care delivery will be de-facto members of the network.

A national steering committee will support and guide the work of each regional network. Membership of the steering group will include representatives from all relevant stakeholders. Supporting the role of the steering committee are subgroups, including public and patient involvement, quality assurance, education/training.

MCRN Lead Clinicians will be drawn from the ranks of senior, experienced rehabilitation clinicians within the network and will exhibit clinical authority, ability to inspire the interdisciplinary team and to work in partnership across professional boundaries and with colleagues from other sectors.

Each MCRN will include

- Acute rehabilitation facilities (i.e. units or teams within acute hospitals)
- Population based rehabilitation units as individual network hubs
- Specialist community rehabilitation teams (CRTs) that will meet the needs of the patient groups who need specialist rehabilitation care
- Primary care teams proving non-specialist rehabilitation services

a Community Health Organisations

b Trauma Network Policy under development by DoH and HSE; expected pub'n date March 2016



Figure 4.3 National MCRN MODEL

# **MCRN** Operation and Governance

MCRNs will be fully integrated and embedded within HSE planning, operational service delivery and governance structures (fig 4.3). MCRNs will be involved in discussions on the prioritization of services and resource re-allocation in their region. The MCRN will plan and manage resources to deliver high quality, safe and reliable rehabilitation services. Each region will determine the precise resources available to the area and work with the different service providers to ensure that these resources are reconfigured in teams that retain specialist and disease-specific expertise.

The MCRNs will ensure their service providers have robust recruitment and workforce planning procedures allowing them to recruit staff with the relevant competencies and registration to treat particular levels of complexity. All service providers within the network will have adequate supervision, support, reporting arrangements and clinical accountability systems for their staff. Interdisciplinary audits will be encouraged to nurture team learning.



Figure 4.4 MCRN MODEL

Patient and carers / family involvement, formal and informal, will be facilitated at all points on the continuum of care and feedback will inform service development. Systems will be in place to ensure information delivery to patients and families as well as feedback, complaints procedures and self-management.

The regional hubs will have clinical and consultant leadership from a designated specialist in rehabilitation medicine. MCRNs will ensure that all professionals involved in the network are participating in appropriate appraisal systems that assess competence to carry out roles. Systems will be developed to ensure consistent policies on training, competencies and CPD. MCRNs educational and training potential will be exploited in particular through exchanges among clinicians working across the rehabilitation continuum in community and primary care, and in hospitals or specialist centres.

Pathways between hospital networks, voluntary agencies and community providers (statutory and voluntary) will be developed within regional network taking note of the on-going mapping of disability services as part of the Neurorehabilitation Strategy Implementation plan.

Specialist rehabilitation services in the provider organisations within the MCRNs will take heed of the HSE's Risk Management Policy. The MCRN will ensure that there are mechanisms in place to develop, implement and monitor patient safety initiatives around critical areas including essential mechanisms such as robust incident management, effective risk registers and complaints and ensure they are managed effectively and in line with relevant policies.

MCRNs will develop systems to ensure gathering and reporting of high quality information on clinical effectiveness and outcomes. MCRNs will develop and implement an annual clinical audit plan. Services within the network should reflect contemporary evidence of what is known to achieve best patient outcomes.

# **Patient involvement and empowerment**

Chronic diseases are now the biggest cause of death and disability worldwide causing a fundamental shift in health systems and health care and, as a consequence, in roles and responsibilities of patients<sup>51</sup>.

The International Association Patient Organisations (IAPO) Declaration on Patient-Centred Healthcare<sup>a</sup> outlines five key principles against which models of care can be measured to determine the degree to which they are patient-centred. In clinical practice, the rehabilitation cycle of assessment, collaborative goal-setting, treatment plan and intervention, and goal review attempts to mirror these 5 principles



Figure 5.1 Five principles of 'patient-centredness'

Patient involvement in Health Policy: The importance and benefits of patient involvement within healthcare is widely accepted and there is a wealth of available evidence confirming the unique perspective of patients when it comes to determining what constitutes good quality care<sup>52</sup>. The World Health Organisation's international conference in primary care in 1978 explicitly stated that "people have a right and a duty to participate individually and collectively in the planning and implementation of their healthcare".

Information provision: The 2011 Neurorehabilitation Strategy's consultation exercise made frequent reference to the need for clear information for patients and families at each stage of the rehabilitation process in a clear format. Levels of anxiety among family members and cognitive issues among patients mean that information provided at one stage of the rehabilitation process will need to be repeated at further stages.

The NCPRM 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-centred care model.

a www.patientsorganizations.org accessed 15th October 2014

Access and Support: 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. Access refers not only to diagnostics and hospital based services but includes access to all the relevant required professions, information and services that enhance the short and long term management of their condition

**Respect**: Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions is recommended by the NCPRM

**Choice and Empowerment**: Patients should be encouraged to participate in decision making on a partnership basis when desired. For this to be effective, appropriate information on their condition is essential. The benefits of adequate education can not only reduce the symptoms of illness, but increase self-esteem, autonomy and independence.

Little is known about the degree of participation in decision making that patients prefer or about clinicians' appreciation of these preferences. Evaluating a patient's level of "readiness" to share in decision-making can increase participation<sup>53</sup>.

#### **The Patient Journey**

This section will examine the issues that impact on the patient journey and how they can be addressed. Specific issues in relation to accessing rehabilitation services for people with specialist rehabilitation needs include:

- Long waiting lists for specialist rehabilitation services
- Limited access to specialist rehabilitation services for those who need them
- A dearth of community based specialist rehabilitation services and support services within the community to manage the longer term needs of people with neurological conditions. This includes:
  - (a) Specialist community neurorehabilitation teams to support people with neurorehabilitation needs in the community, including following discharge from hospital based specialist rehabilitation services.
  - (b) Adequate home care packages for patients with a high level of need and public health nursing input when required.
  - (c) supports to enable people to live in the community including transitional living units, respite centres and appropriate residential settings for people with neurological conditions
  - (d) aids, appliances, specialist equipment and home adaptation to support independent living
  - (e) specialist supports for rehabilitative training, day services and vocational training for people with neurological conditions
  - (f) specialist support and intervention around managing challenging behaviour and dealing with mental health issues
  - (g) supports around palliative rehabilitation for those with progressive neurological conditions
  - (h) lack of co-ordinated care at all stages resulting in a range of unmet needs, delays in accessing services and inappropriate services.

The patient journey through specialist rehabilitation services is characterised by the following

- I. Not all those who need specialist rehabilitation services will be able to access them
- 2. There are long delays in waiting for a bed to become available for specialist inpatient rehabilitation in the national tertiary centre with a varied level of access to rehabilitation across the acute hospital network.
- 3. Rehabilitative gains may not be maintained once the person is discharged from specialist rehabilitation services because there is an inadequate framework of specialist service provision to meet the longer term needs of people living with neurological conditions in the community.
- 4. Specialist rehabilitation in the community, through services provided by both statutory and nonstatutory providers is inadequate to meet the need.
- 5. Many people with neurological conditions will have complex needs through all stages of their condition. A seamless, co-ordinated system of care including case management is only available to a minority of people who need it.

The NCPRM aims to address specific issues in relation to the patient journey by:

- s Making recommendations for the development of specialist rehabilitation to address the unmet need and long waiting lists for this service
- S Working in partnership with other stakeholders to develop a plan for the national neurorehabilitation strategy which will require the development of inpatient rehabilitation services within acute hospitals, further development of the national tertiary centre and establishment of a network of community based neurorehabilitation teams
- S Recommending a framework for service provision within specialist rehabilitation services aimed at improving co-ordination of care, involvement of people with neurological conditions and their families in the rehabilitation process and improved referral and discharge systems to and from specialist rehabilitation services.
- s The NCPRM recognises the increased use of patient experience surveys to identify and respond to the needs of service users and will work with the Neurological Alliance of Ireland to design and carry out a survey among those currently accessing specialist rehabilitation services.
- s As an initial effort to gather information on patient experience, the NCPRM facilitated a 'WorldCafé Conversation' with a view to drawing on the knowledge and opinions of many key stakeholders including service users and service user representative groups in a collaborative way.
- S The programme recognises that specialist rehabilitation services are part of a continuum of service need that extends throughout the lifetime of a person with a neurological condition. There is a critical need to address the lack of a service framework to support the long term needs of people with neurological conditions living in the community.

#### Health promotion and prevention

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.

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>54</sup>.



Figure 5.2 Proposed model of continuum of health care

Health promotion and preventive strategies (tables below) have an important role to play in the primary and secondary prevention of some conditions requiring rehabilitation. A significant proportion of health promotion will be delivered in the context of the primary care / patient interaction though raising awareness in schools, workplaces, accessible local community, leisure and primary care centres.

High-quality antenatal, obstetrics and paediatric care – to reduce risk factors for cerebral palsy, including prematurity, very low birth weight and infection

Injury prevention in relation to road safety and occupational health to reduce the risk of acquired brain injury and spinal cord injury such as cyclists wearing helmets and car drivers using seatbelts<sup>55</sup>

Promotion of a healthy lifestyle, management of atrial fibrillation and hypertension – to reduce the risk of stroke

Road Safety Strategy, the HSE Falls Prevention Strategy and the National Cardiovascular Health Strategy<sup>56,57</sup>

#### Table 5.1 primary prevention strategies

Within rehabilitation, 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<sup>58</sup>. Examples of same are outlined in the table below.

Prevention	Characteristics	Setting in which preventative measures are undertaken	Examples
Primary	Avoid Disease or injury	Political & societal arenas Primary care	Reduction of risk for cerebrovascular disease & head trauma
Secondary	Avoid effect & complications of disease or injury	Acute Hospital & early rehabilitation	Prevention of falls, immobility & contractures
Tertiary	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 5.2: Adapted from White Book of PRM in Europe

### Self-management

Central to the population health approach is a commitment to develop the personal skills and selfmanagement 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 chronic 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 analysing 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<sup>59</sup>.

A recent systematic review related to neurological conditions found evidence of a beneficial effect in the domains of functional ability and quality of life associated with a number of self-management programmes for patients with multiple sclerosis, Parkinson's disease and traumatic brain injury<sup>60</sup>.

The Population Risk Pyramid Model<sup>a</sup> conveys clearly the reality that a proportion of people 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<sup>61</sup>.

Self-management support (SMS) in rehabilitation practice enables individuals and their carers to take an active role in caring for and managing their own condition with professional guidance when required. Transformation of the traditional patient- health professional /caregiver relationship into a collaborative ongoing partnership is a pre-requisite for successful expression of self-management<sup>b</sup>.

Self-management support allows individuals with chronic conditions to access the information and skills they need to manage their own condition confidently and to make daily decisions that improve their health and well-being. This is achieved by provision of information, education and other supportive interventions to increase the person's knowledge, skills and confidence in managing their condition.

a Improving the Health and Wellbeing of People with Long Term Conditions in Scotland: A National Action Plan, Dec 2009

b www.chcf.org.documents/chronicdisease (last accessed in September 2012)

An implementation plan for the NCPRM model of care needs to be developed to ensure selfmanagement programmes are planned and delivered in an integrated manner across the clinical networks and that patients get access to the most appropriate self-management programmes at alllevels of the model of care. This implementation plan should review the efficacy of various models, outline the staffing requirements and training needs, and contain proposals for the number of programmes to be delivered per annum in each clinical network. While there are a number of varying self-management programmes, the Stanford Model (Stanford School of Medicine) has significant research supporting its efficacy.

The NCPRM is aware of a number of specific initiatives focused on supporting patients to self-manage aspects of their condition. These include the chronic disease self-management programme in Beaumont Hospital (for numerous conditions) the self-management toolkit developed by Epilepsy Ireland, the five elements programme developed by Move4Parkinsons and condition specific self-management workshops run by a range of not for profit neurological organisations. The programme recognises the value of these initiatives, particularly when they are integrated into a coordinated programme of patient centred care.

# Implementation of the 2011 Neurorehabilitation strategy

Patients with neurorehabilitative needs are managed across the spectrum of health care facilities from acute rehabilitation, post-acute complex rehabilitation services, regional specialist rehabilitation and community-based rehabilitation through to primary care settings.

The National Primary Care Strategy<sup>a</sup> identifies primary care 'as a key vehicle in addressing the majority of health needs'. The 2011 Neurorehabilitation Strategy supports the enhancement of primary care teams' capacity through the reconfiguration and development of existing resources. This move is designed to allow regional and national facilities concentrate their efforts on treating patients with more complex needs. Non-specialist services provided through primary care teams are outside of scope of the NCPRM.

The realization of the managed clinical rehabilitation networks will be dependent on the mobilization of resources and enhancement of service structures as outlined in the neurorehabilitation strategy.

The National Clinical Programme for Rehabilitation Medicine will be one of the primary reference points for the implementation of the Neuro-Rehabilitation strategy, given the importance in ensuring consistency and clarity in pathways to and across services. The model of care of the NCPRM will provide a framework for the design and delivery of specialist rehabilitation services in the context of a strategy that addresses the broad continuum of services and supports required by those with neurorehabilitative needs.

The NCPRM will provide guidance on clinical matters critical to many elements of the framework for neuro-rehabilitation services whilst the wider stakeholders involved in implementation will be key in emphasising and developing services that ensure the range of supports people require are understood and appropriate to individual needs. There are two overarching goals that support the policy and strategy objective.

a Primary Care: A New Direction (Department of Health and Children 2001b)

Goal I to provide a service that is:

1 1 1 1

Goal 2 is the creation of a flexible, responsive and accountable system that will fully support the realisation of Goal 1.

These goals are reflected in this model of care which aims to support people with neurorehabilitative needs in accessing the most appropriate service at the most appropriate time.

### Personnel and workforce planning

Specialist Rehabilitative care should be provided by a Consultant in Rehabilitation Medicine working with a team of specialist nurses, Health and Social Care Professionals including dietitians, medical social workers, neuropsychologists, occupational therapists, orthoptists, orthotists, speech and language therapists, podiatrists, pharmacists and physiotherapists. Interfaces with other related services including neurology, neuropsychiatry, orthopaedics, neurosurgery, neuroophthalmology and neuroradiology are also essential as well as others such as psychiatry, palliative care and care of the elderly.

### **MEDICAL**

# **Rehabilitation Medicine**

Rehabilitation Medicine as a specialty is concerned with the prevention, diagnosis and rehabilitation management of people with disabling medical conditions. It was developed primarily to meet the needs of young adults and those of working age, but the specialty, particularly relating to impairment management, technical aids, provision of wheelchairs, orthotics or prosthetics, is relevant to people of all ages.

The principal aims of RM specialist practice are to identify, as team lead or contributor to an IDT, impairments that limit activity and daily tasks, optimise physical and cognitive functioning and modify personal and environmental factors to enable greater participation and quality of life. Rehabilitation medicine consultants also have specialist expertise in assistive rehabilitation technology, including environmental control equipment, wheelchairs and orthotics; these are not disease specific and cover a wide range of complex disabilities.

The scope of rehabilitation medicine practice in Ireland includes in-patient and liaison management of patients with acquired neurological disability from single incident injury arising from various aetiologies. Patients with limb loss/deficiency and progressive neurological conditions such as multiple sclerosis, and disabling musculoskeletal conditions can also benefit from a co-ordinated rehabilitation approach. Congenital conditions or those arising in childhood, such as cerebral palsy, muscular dystrophies and limb deficiency, will continue into adulthood and benefit from ongoing support from RM consultants who contribute to the work of community specialist rehabilitation teams.

	France	Germany	Sweden	ltaly	UK	Ireland
Number of RM Consultants	1760	1571	160	2200	152	П

Table 5.3 adapted from BSRM Neurological rehabilitation; a briefing paper for commissioners of clinical neurosciences

Undergraduate training in Ireland in RM is limited to 3 of the 6 Irish medical schools who have formal teaching agreements with the NRH. All three Dublin Medical Schools (UCD,TCD and RCSI) place more than 400 medical students each year in the NRH for formal tuition in structured clinical and research modules.

Regarding post-graduate training, higher specialist training positions in Rehabilitation Medicine are governed by agreements between the HSE National Doctor's Training and Planning Unit and the Irish Committee for Higher Medical Training (ICHMT) within the Royal College of Physicians of Ireland (RCPI). The number of those positions is limited practically by the availability of training in only one specialist centre in Ireland.

There are 11 Consultants in Rehabilitation Medicine in Ireland; 10 are working in the area of direct clinical practice. The UK benchmark for the ratio of RM Consultants to population is 1.5 per 250,000. The target number for Ireland on this basis is 27-28 RM Consultants requiring 15 – 16 more consultants. This is a modest target given that the average number of PRM physicians for all European countries is 2.8 per 100,000. The target for Ireland on that basis would be 129 RM.

### Neurology

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.

There are currently 34 approved neurologist posts across the country. For the current population Ireland requires 64 neurologists (1:70,000) (Association of British Neurologists) with corresponding multidisciplinary and nursing teams are needed as determined by international best practice standards.

### **Psychiatry**

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.

There is considerable overlap between the medical disciplines of neurology, rehabilitation medicine and psychiatry. At present patients are referred from one specialty to another as clinical symptoms develop. A collaborative model with joint clinical commitments e.g. outpatient clinics or consult service teams would offer.

### Neuropsychiatry

Neuropsychiatry is the specialty that provides for the mental health needs of persons with brain and Nervous system disorders. Clinical neuropsychiatry is a subspecialty of psychiatry devoted to the assessment and management of mental and behavioural problems in nervous system as well as unexplained neurological symptoms'

Typical clinical presentations requiring the specialist skills of neuropsychiatry services include brain injury sequelae, early-onset dementia, psychological morbidity related to epilepsy and other neurological disorders and psychogenic non-epileptic seizures. A key role of Neuropsychiatry services is the assessment of these complex cases, which are often beyond the skills and service remit of general adult mental health services.' (Vision for Change, Department of Health and Children, 2006)

Neuropsychiatry services work closely with other neuroscience and mental health services and have expertise provided by neither service alone. Neuropsychiatry services see patients with conditions such as young onset dementia including Huntington's disease, movement disorders, neuro-developmental

disorders, epilepsy, sleep disorders, and acquired brain injury for example from head injury, cerebral tumours or a cerebrovascular accident. These patients are usually seen because of cognitive, behavioural or psychiatric symptoms. Other patients are seen because of neurologically unexplained symptoms or altered states of consciousness or mental symptoms of uncertain aetiology. Specialist neuropsychiatric activity includes: inpatient and outpatient assessment for complex conditions presenting with psychiatric symptoms; access to clinical and nursing expertise, including neuropsychological assessment and brain scanning facilities and assessment of physical function; intensive nursing care in specialist units and within community teams; links with neuropathological centres; access to detailed genetic investigations and counselling.' (Manual for prescribed specialised services.' Specialised Services Commissioning Transition Team, NHS Commissioning Board; November 2012)

### **Orthopaedic Spinal Surgery**

Most patients with traumatic SCI and some with non-traumatic SCI are referred to the national spinal injuries unit (NISU) Mater Misericordiae University Hospital (reference spinal pathway in appendices), for acute surgical management. In the interest of improved rehabilitation outcomes, clear pathways both into and out of the NSIU are required.

### **Ophthalmology**

Neuro-ophthalmology straddles the fields of neurology and ophthalmology, often dealing with complex systemic diseases that have manifestations in the visual system. Some of the common problems evaluated by neuro-ophthalmologists include, but are not limited to, optic nerve problems (such as optic neuritis and ischemic optic neuropathy), visual field loss, permanent or transient visual loss, other visual disturbances such as double vision, abnormal eye movements, thyroid eye disease, myasthenia gravis, unequal pupil size, and eyelid abnormalities<sup>62</sup>.

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>62</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.

### Nursing

Rehabilitation nursing training is required in addition to general nursing qualification to practice in the rehabilitation setting. Staffing ratios for nursing differ depending on the rehabilitation setting and should reflect the level of dependency of patients as opposed to numbers of patients on a ward. There are currently no guidelines with respect to ratios of general nursing and rehabilitation nursing staff in the rehabilitation setting, however international standards for in-patient rehabilitation services requires that rehabilitation nursing services are available 'twenty four hours per day, seven days a week' (the CARF medical rehabilitation standards, section 3A). Higher proportions of rehabilitation nurses have been shown to have a direct impact on patient outcomes in both acute and longer term care facilities<sup>63</sup>.

The enhancement of nursing roles in rehabilitation medicine facilitates the provision of a timely quality service to the rehab patient promoting and facilitating optimum levels of independence.

# Nursing professional grading

Advanced Nurse Practitioner (ANP): The ANP in rehabilitation patient care is an experienced and expert practitioner in this area of practice who is accountable, responsible for an agreed caseload of patients; and competent in and practices rehabilitation care under locally agreed protocols. The ANP should be educated to a master's degree level which includes a major clinical component relevant to rehabilitation. The role of the ANP 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 ANP role include autonomy in clinical practice, expert practice, professional and clinical leadership and research. In addition the ANP role includes practice that enhance patient journey and flow such as nurse prescribing of medicinal products, nurse facilities and nurse led discharge<sup>64</sup>.

The ANP is clinically accountable to the patients named rehabilitation consultant and to the regional lead. They are professionally accountable to the Director of Nursing in the rehabilitation centre. They will be responsible for the local delivery of high quality rehabilitation care in the hospital and the community. They are also responsible for the safe, efficient and effective management of patient care. The ANP is responsible for case management of rehabilitation patient group which includes comprehensive patient assessment and management of specific needs. The ANP provides clinical leadership, clinical supervision and support to CNS, staff nurses and members of the interdisciplinary team.

Recommendation: Each SPECIALIST REHABILITATION services, particularly at complex specialist level, developing the role of the ANP in rehabilitation as a key role that can provide autonomous nursing care and lead on development of rehabilitant nursing - in response to service needs.

**Clinical Nurse Specialist (CNS)**: The role of the CNS in rehabilitation is to provide for the care and ongoing management of patients requiring rehabilitation within agreed clinical practice guidelines. CNS roles in rehabilitation can include a range of specialist services to support the brain injury, spinal and POLAR programmes. The purpose of the CNS post is to improve and enhance the care of patients and their families by developing services in relation to rehabilitation 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 and rehabilitation centre providing physical, psychological and emotional support to rehabilitation patients and their families. They act as a liaison between community services, primary care teams and other agencies. The CNS has extensive knowledge of rehabilitation and holds a relevant post registration qualification in rehabilitation (Brain injury, Spinal injury, POLAR) care level 8. Core competencies for CNS include clinical focus, patient advocate, education and training, audit and research and consultancy.

Recommendation: Each rehabilitation service (in-patient / community) should have within its clinical team a CNS with specialist knowledge and experience in rehabilitation. The potential for the role to evolve into a key worker or case manager may also be explored in the future.

**Clinical Nurse Manager (CNM)**: The Clinical Nurse Manager (CNM) in rehabilitation provides leadership and nursing services to patients at ward level and works with the rehabilitation consultant and MDT to plan care to meet individual patient needs. The CNM play a pivotal role in co-ordination and management of activity and resources within the clinical area. The CNM in 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 rehabilitation CNM has a relevant nursing management course and also have extensive knowledge of rehabilitation and hold a relevant post registration qualification in rehabilitation (brain injury, spinal injury, POLAR) care level 8.

*Recommendation:* Each rehabilitation ward should be managed by a CNM with specialist training and experience in rehabilitation. The CNM may also progress in role to CNM 3 or Director of Nursing level in a view to manage regional rehabilitation units as they develop.

**Staff Nurse**: Rehabilitation staff nurses are core members of the interdisciplinary 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 rehabilitation care. The staff nurse monitors and evaluates the patient's response to interventions and treatment, and reinforces therapeutic strategies throughout the 24-hour care cycle.

Recommendation: The NCPRM recommends and supports the provision of systematic high-quality education and professional development in all aspects of rehabilitation nursing. This will support the progression of nurses along a clinical (CNS and ANP) and managerial (CNM) career pathway within rehabilitative care.

### **Nursing education**

An experienced, dedicated nursing workforce with competencies in caring for patients with specialist rehabilitation 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.

Post graduate training in rehabilitation is advised. In advance of this, at a minimum, a competency framework for nurses working in rehabilitation should be implemented. Existing competency frameworks such as the Association of Rehabilitation Nurses Competency Model for Professional Rehabilitation Nursing should be considered for implementation. This framework considers four domains of competency;

- Domain I: Nurse led evidence-based interventions
- Domain 2: Promotion of Health and successful living
- Domain 3: Leadership
- Domain 4: Interprofessional care

Appropriate continuing medical education (CME) and continuing professional development (CPD) training must be encouraged to promote provision of safe and effective care for patients presenting with specialist rehabilitation needs.

### **Health and Social Care Professions**

Health and Social Care Professionals (HSCPs) are core members of the rehabilitation team and are essential for the successful delivery of the rehabilitation model of care. The Health and Social Care Therapy Professions (HSCTPs) play a key role and are actively involved at all stages of the rehabilitation continuum from acute care, complex specialist rehabilitation, and regional rehabilitation through to community rehabilitation and supporting services.

Each profession has a particular specialty with distinct knowledge, skills and abilities to deliver safe, high quality services that enhance the service users' rehabilitation outcomes<sup>65</sup>. It is essential that the unique depth and breadth of skills, knowledge and expertise that these professions bring is understood, valued and appropriately utilised within service development and in the delivery of rehabilitation services. Table 5.4 above details a list of professions that the Department of Health identifies as HSCPs.

DOHC Health & Social Care Professions Professions regulated ¥ by CORU <sup>a</sup> Therapy Professions				
Ι.	Clinical Nutrition and	7. Clinical Biochemists	13.	Neurophysiologists
	Dietetics	8. Medical Scientists	14.	Orthotist
2.	Occupational Therapy	9. Medical Social Worker	15.	Prosthetist
3.	Orthoptist	10 Psychology		
4.	Physiotherapy			
5.	Podiatry			
6.	Speech and Language Therapy	12. Social Care Worker	35	additional professions on DoHC list.

<sup>\*</sup>Currently regulated or scheduled to be regulated

# Table 5.4 HSCP Professions in Ireland<sup>b</sup>

The HSCTPs use multidisciplinary and interdisciplinary teamwork approaches to promote, maintain and restore physical, psychological and social wellbeing of the person with rehabilitation needs. Intervention is person centred, goal orientated and delivered in one to one sessions or within a group setting. The service user is a core member of the rehabilitation team along with their family members/carers as appropriate.

The scope of practice is not limited to direct patient/client care but also includes: public health strategies, advocating for patients/clients and for health, supervising and delegating to others, leading, managing, teaching, research, clinical audit, developing and implementing health policy.

Core HSCTP team members include the dietitian, occupational therapist, physiotherapist and speech and language therapist along with trained therapy assistants. Access to non-core therapy services should be available as required e.g. podiatry and orthoptics. The roles of these professionals are outlined below.

Continuous Professional Development (CPD) is a statutory requirement under CORU and will support each professional in their ongoing development and should be tailored to each grade as appropriate. Postgraduate training and qualifications will further enhance rehabilitation specialisation.

There is clear evidence that multi-disciplinary intervention consistently benefits service users across the rehabilitation continuum. It is essential to maintain an appropriate skill mix of staff for specialised rehabilitation. This includes a mix of clinical specialist, senior, staff grade and assistant staff. The discipline specific HSCTP managers play a key role in leading and developing services, managing skill mix and workforce planning.

# HSCT professions' grading structure

# **Clinical specialist**

The clinical specialist provides expert clinical leadership and expertise for complex case management using evidence-based practice and advanced clinical judgement acquired through professional experience. The Clinical Specialist uses advanced and specialised knowledge to critically analyse, evaluate

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a CORU is Ireland's multi-profession health regulator set up under the Health and Social Care Professionals Act 2005 www.coru.ie

and synthesise new and complex ideas that are at the forefront of neurology and rehabilitation. They are involved directly or in collaboration with others in research that evaluate current practice and implement service initiatives leading to new knowledge -base and disseminating findings both locally and in wider health care arena. They have an important role in strategic planning and developing new pathways of care.

Following on from the recommendations of the Expert Group on Various Health Professions (2000) and the subsequent agreement between the HSEA and the IMPACT union the grade of clinical Specialist was introduced in 2001 with an initial allocation of 65 posts nationally<sup>a</sup>. The HSEA (2000) outlined 10 points regarding the introduction of this initial allocation including that a referral pathway should be established allowing for a regional remit to these posts in terms of their advisory, evaluation and research roles<sup>66</sup>.

A HSE review of the Clinical Specialist Therapist Grade (2007:27) concluded that 'the appointment of the clinical specialist grade has had a positive impact on the Irish Health Service' including the establishment of appropriate clinical protocols, development of evidenced based practice & an expert referral source, improved education and research within the professions. This review also, outlined 39 recommendations for the future development of this clinical grade to ensure optimal patient outcomes, patient centeredness and improved patient access in line with 'national priorities and care group needs'.

There is precedent for advancing roles within the HSCTP and wider HSCP professions<sup>67</sup>, <sup>68</sup>. 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 clinical thinking and the ability to apply in-depth knowledge to clinical decision making (HSCP advanced practice subgroup (2013) adapted from the ISCP scope of practice document, 2012), and is presented in figure 5.3<sup>69</sup>, <sup>70</sup>.

In the UK, following 'Agenda for Change' (1999) HSCP advanced practitioner and consultant grades have become integral to the development of appropriate, sustainable and affordable services, with tasks shifting between professions and non-medical leadership of care pathways emerging. Examples of advanced practitioner roles in the UK include:

- Physiotherapy-led musculoskeletal outpatient services and spasticity clinics (e.g. Carmarthenshire Physiotherapy led spasticity management service)<sup>71</sup>
- Occupational therapists working within stroke pathways at the interface between acute and community care. Here communication and clinical reasoning at an advanced level are significant in ensuring that the patient is guided appropriately in the right direction at the right time in the pathway.(NHS London & Skills for Health 2010)



Fig 5.3 Advanced Practice in Health & Social Care Professions

a Irish Society of Chartered Physiotherapists: ISCP scope of practice document 2012

In Ireland, the first 24 clinical specialist physiotherapists with advanced practitioner remit were appointed in 2010 as first contact practitioners to triage Orthopaedic and Rheumatology waiting lists. To date 48,279 patients have been removed from the combined waiting lists (figures from MSK programme from initiation until May, 2015).

In 2010, the Scottish government issued guidelines for the development of Consultant HSCPs (Scottish Government, 2010), anticipating that posts will be structured around four key themes<sup>72</sup>:

- Clinical/professional leadership;
- Expert practice;
- Policy and service development, research and evaluation; and
- Education and professional development

Examples of types of activity undertaken by therapy consultants in rehabilitation are:

- Consultant physiotherapist-led inpatient rehabilitation units e.g. post of Consultant Physiotherapist in Intermediate Care at a NHS community hospital in Derbyshire, England.
- Consultant speech and language therapists in highly specialist areas such an augmentative and alternative communication aids (AAC), dysphagia and speech & language therapy led voice clinics
- Consultant occupational therapists in stroke and vocational rehabilitation<sup>73</sup>
- Podiatric surgery being undertaken by consultant podiatrists as part of an integrated orthopaedic team

### **Senior therapist**

The senior therapist provides high level comprehensive assessments and interventions as part of a multidisciplinary team approach. Senior Therapists plan and implement individual and group interventions, discharge, follow up and onward referrals. They have and experience in working with clients with rehabilitation needs and provide training and support to staff and assistant therapy health contribute to the development of evidence-based practice; apply research outcomes to improve the delivery of service and ensure best use of resources.

#### **Graduate/entry level therapist**

The entry level therapist provides assessments and interventions in collaboration with the senior therapist and clinical specialists. Entry level therapists translate research evidence and use it to implement effective interventions; prepare and present appropriate information to the senior therapists to support operational and strategic planning. They have profession specific knowledge and skills which contribute to the rehabilitation process.

# **HSCT Profession Assistant**

The Expert Group on Various Health Professions (2000:15) report states that

"the introduction of Assistant health and social care professional/therapy assistant (to be decided) 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".

Assistant health and social care professionals, under the supervision of appropriate staff grade, senior and clinical specialist health and social care professionals can support implementation and monitoring of individual and group interventions.

# **Physiotherapist**

Physiotherapy, as defined by the world confederation of physical therapy (WCPT)<sup>a</sup> provides services to individuals and populations to develop maintain and restore maximum movement and functional ability throughout the lifespan. This includes providing services in circumstances where movement and function are threatened by ageing, injury, pain, diseases, disorders, conditions or environmental factors. Functional movement is central to what it means to be healthy. At the point of entry into the profession, physiotherapists have received education in rehabilitation, as it is a core component of the pre-registration programme curriculum.

Physiotherapy in rehabilitation is concerned with identifying and maximising quality of life and movement potential within the spheres of promotion, prevention, treatment/ intervention, habilitation and rehabilitation. This encompasses physical, psychological, emotional, and social wellbeing. Physiotherapy involves the interaction between the physiotherapist patients/clients, other health professionals, families, care givers and communities in a process where movement potential is assessed and goals are agreed upon, using knowledge and skills unique to physiotherapists. The physiotherapist's extensive knowledge of the body and its movement needs and potential is central to determining strategies for diagnosis and intervention.

### Physiotherapists are qualified and professionally required to:

- undertake a comprehensive examination/assessment of the patient/client or needs of a client group
- evaluate the findings from the examination/assessment to make clinical judgments regarding patients/ clients
- formulate a diagnosis, prognosis and plan
- provide consultation within their expertise and determine when patients/clients need to be referred to another healthcare professional
- implement an intervention/treatment programme
- determine the outcomes of any interventions/treatments
- make recommendations for self-management

# **Occupational Therapist**

Occupational Therapy is a client-centred health profession concerned with promoting health, well-being and quality of life through occupation. The primary goal of occupational therapy is to enable people to participate in the activities of everyday life. Occupational therapists achieve this outcome by working with people and communities to enhance their ability to engage in the occupations they want to, need to, or are expected to do, or by modifying the occupation or environment to better support their occupational engagement (WFOT, 2011)<sup>74</sup>.

At the point of entry into the profession, occupational therapists have received education in rehabilitation as it is a core component of the pre-registration programme curriculum. Occupational Therapists focus on developing and maintaining people's skills to carry out their everyday occupations such as work, self-care and leisure<sup>75</sup>. They assess the impact of changes in physical, psychosocial and cognitive functioning on a person's ability to manage daily life tasks. Intervention improves participation in meaningful roles, tasks and activities; minimizes secondary complications and provides education and support to the person and their caregivers (Rowland TJ et al 2008)

a World Confederation for Physical Therapy (WCPT) www.WCPT.org

Occupational Therapists' focus on independence, client- centred practice, and their specialist skills in activity analysis, activity adaptation and environmental modification underpin the professions contribution to the rehabilitation team.

### The role of the Occupational Therapist includes:

- m Assessment of physical, psychosocial and cognitive /perceptual skills through interview, observation, standardised assessment and liaison with family/carers and other members of the rehabilitation team
- m Assessment of the clients performance skills in relevant activities of daily living e.g. personal care activities , domestic activities , community living skills and work/vocational skills
- m Assessment of the client's home and/or work environment
- m Goal setting and intervention planning (including discharge planning) in collaboration with the client and team

m Provision of individualised evidence based occupational therapy interventions which can include:

- Practice of relevant daily living skills, incorporating compensatory assistive equipment and/or strategies when required
- Physical, Cognitive and Vocational rehabilitation programmes
- · Practical advice and recommendation on environmental modifications/ adaptations
- Trialling and recommendation of assistive technology devices e.g. alternative input devices for computer access/ environmental control systems
- Postural management/Seating
- Splinting
- Stress management / relaxation therapy

Education and support for the client, family/carers in relation to their goals, occupational therapy programme, self-management and ongoing needs

### Speech and Language Therapist

Speech and Language Therapists are responsible for the diagnosis, management and treatment of individuals who are unable to communicate effectively and/or who have difficulties with eating and drinking. Speech and Language Therapists are actively involved at all stages of the rehabilitation care pathway. At the point of entry into the profession, Speech and Language Therapists have received education in rehabilitation, as it is a core component of the pre-registration programme curriculum. The role of the Speech and Language Therapist is diverse and individualised to the patient, dependent upon their stage of rehabilitation. It includes:

- Assessment, differential diagnosis and management of acquired speech, language, voice, cognitivecommunication disorders (including low Awareness States); and feeding, eating, drinking and swallowing disorders (dysphagia) including the provision of appropriate therapy/intervention to minimise preventable respiratory and/or nutritional complications of swallowing difficulties
- Providing individualized evidence based patient focused therapy programmes which incorporate functional activities aimed to maximise independence and participation in the community. These may include skills required for returning to/ remaining in work, living independently, or enhancing social interactions.
- Group therapy and computer based rehabilitation may also be offered if appropriate
- Trialling and recommending augmentative/alternative communication aids when appropriate (e.g. alphabet boards, communication boards, voice amplifiers and speech generating devices, communication/speech apps (android, iPad)

- Providing support for patients and families through the provision of counselling and education about communication, feeding, eating, drinking and swallowing difficulties (dysphagia)
- Advocating on behalf of the patient in order that their communication and feeding, eating, drinking and swallowing needs are being met when they are not in a position to do this independently
- Liaising with medical, nursing and allied health & social care professionals, concerning overall treatment goals, prognosis and management to facilitate team discharge planning
- Management of dysphagia and communication in the palliative stage of illness.

### **Medical Social Work**

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. 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.

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
- Discharge planning
- 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
- Advocacy for patients and families

# **Clinical Neuropsychology**

As outlined by the American Psychological Association<sup>a</sup> clinical neuropsychology is a "specialty in professional psychology that applies principles of assessment and intervention based on the scientific study of human behaviour as it relates to normal and abnormal functioning of the central nervous

a American Psychological Association (2015) Public Description of Clinical Neuropsychology http://www.apa.org/ed/graduate/specialize/neuro.aspx

system". Clinical neuropsychologists use specialist knowledge in the applied science of brain-behaviour relationships to address neurobehavioural problems related to acquired or developmental disorders of the nervous system (e.g., acquired brain injury).

Clinical neuropsychologists are skilled in clinical and neuropsychological assessment, and in the treatment and rehabilitation of behavioural, emotional, psychological, and cognitive sequelae. Competence in neuropsychology requires the ability to integrate neuropsychological findings with neurological and other medical data, psychological and other behavioural data, and knowledge of the neurosciences, and the ability to interpret these findings within the social, cultural, and ethicolegal context in order to formulate tailored, person-centred recommendations for rehabilitation and psychotherapeutic intervention.

### The role of a clinical neuropsychologist includes:

- Use of specialised assessment techniques and measures to assess intellectual, cognitive, and psychological functioning
- Use of clinical and neuropsychological assessment skills to undertake assessment of decision-making capacity, with reference to the legislation
- On the basis of clinical and neuropsychological assessment, formulating person-centred plans for rehabilitation and/or behavioural or psychological interventions
- Using specialised, evidence-based intervention techniques (e.g., cognitive behaviour therapy, positive behavioural support), and applying an understanding of the implication of neurological conditions for behaviour and adjustment, as well as culturally apt approaches in neuropsychology, to optimise cognitive rehabilitation and psychological functioning, and to ameliorate behavioural difficulties
- Interventions that can be undertaken as an individual practitioner (i.e., facilitating individual, group, or family sessions) or within the context of interdisciplinary teamwork (e.g., sharing neuropsychological conceptualisations of neurobehavioural issues with the team in order to formulate rounded interdisciplinary rehabilitation goals, facilitating team reviews of goal attainment, or supervising the work of psychology or rehabilitation assistants)
- Selecting and using appropriate, evidence-based measures for measuring rehabilitation/ psychological/ behavioural outcomes
- Providing consultation to agencies and individuals (staff members, families and carers) involved in a client's care in relation to neuropsychological, emotional, and behavioural issues
- Facilitating education and awareness seminars for client groups, families, other care and State agencies, or the general public (e.g., in relation to cognitive, emotional, psychological, and behavioural issues that may arise when living with an acquired brain injury and ways of coping with/managing them)
- Using training and skills in research design and analysis for service audit, refining evidence-based practice, and contributing to the further development and revision of national policy and models of care.

# Dietitian

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. Therefore the role of the dietician is multifaceted:

- To optimise the patient's nutritional status to enable him / her derive maximum benefit from the rehabilitation programme
- Toprevent nutritional related complications which could interfere with the ability to engage in rehabilitation e.g. pressure sores, excess weight both during inpatient phase and in an ongoing capacity
- To prevent recurrence in at-risk groups.

The dietitian has a significant role to play in all conditions considered within scope for specialist rehabilitation including spinal cord injury, acquired brain injury, neurological conditions and patients with amputation. While the needs of the various patient groups will vary per condition, the role of the dietician can include:

- Weight management
- Treatment of patients who are nutritionally compromised
- Enteral tube feeding
- Dysphagia management in collaboration with Speech & Language Therapists
- Assessment/recommendations re: patients requiring PEG feeding.
- Risk factor modification

### **Pharmacy**

Pharmacists are responsible for the purchase, dispensing and supply of medicines. They are key members of the multidisciplinary team, ensuring safe, effective and economic use of medicines. Pharmacists aim to maximise the therapeutic effects of medications to individual patients while minimising associated risks and respecting patient choice. The role of the pharmacist is essential throughout all stages of patient care. They work closely with medical, nursing and therapy staff to ensure the patient receives the most appropriate treatment. The pharmacy team works with healthcare professionals to provide seamless pharmaceutical care for patients.

#### In-patient/secondary care

With respect to in-patient services, pharmacists are involved in the medicine reconciliation process at admission and discharge. Providing patients with the correct medications at all points of transfer within and between health and social care services. This involves contacting the patients GP or retail pharmacy to obtain an accurate, up to date list. Prescriptions are reviewed and discussed with medical staff to ensure:

- Medications are clinically appropriate
- Medications are being used safely, rationally and cost effectively.
- There are no contra-indications i.e. allergies or significant interactions.
- They are written unambiguously and comply with local and legal requirements.
- The correct formulation is prescribed and supplied e.g patients with swallowing difficulties/feeding tubes require different formulations or route.
- Appropriate dose and route of administration of medication.

### Supply of medications

- Pharmacists ensure that the medicines are dispensed accurately, available when needed and clinically appropriate.
- This supply can involve sourcing unlicensed medications from outside of Ireland.
- The pharmacy team takes steps to minimise omitted doses
- This supply can involve communication with the patient's retail pharmacy to ensure continuity of supply.
- This supply involves contracting and negotiations with Pharmaceutical companies to ensure economic purchasing.
- Ensuring medications are appropriately stored e.g. fridge

#### Medicines information

The pharmacy team provide expertise and advice to support the safe and effective use of medicines by patients.

Ideally, pharmacists should be accessible to provide advice for healthcare professionals on choice and use of medicines in both secondary and primary care settings.

#### Patient education

The pharmacist counsels patients on administration, storage, adverse effects and interactions thus empowering the patient to take responsibility for their own medications. This can be carried out in group or individual counselling. If staffing permits, individual counselling sessions should be provided.

The patient's right to be provided with accurate, objective information about their condition and the management of same has been proven to have a positive effect in their compliance with their prescribed medication. Edward Leigh has described in his book a set of guidelines which can assist in helping patients understand their medication<sup>76</sup>. These are:

- Confirm that the patient understands the reason for their medication. The patient should have a basic understanding of the nature of their disease and the rationale behind the medication being prescribed.
- Basic information about the medication. This should include;
  - Brand/generic name
  - Indication
  - How/why/when/length of time the medication is taken
  - Possible side effects
  - Foods/liquids/activities to be avoided
  - Medication storage
  - Obtaining medication
- Ask about use of herbal remedies, over the counter medication, vitamins and mineral supplements which could potentially interact with prescription medication.
- Financial issues; patients may not take medications because of financial hardship
- Dosage issues
- Provision of 'patient information leaflets' (PIL)
- Verifying patients' understanding of the information given
- Involvement of family/carers with respect to education around medications
- Identify patients at risk for non-compliance and discuss compliance aids

Education about key issues regarding medicines increases compliance and empowers patients thus reducing the potential for medication errors.

Pharmacy departments should be adequately staffed to allow for this essential educational component to be available to all patients. Ideally, in an in-patient setting, pharmacists should have the capacity to be ward based, making them and their services accessible to both patients and the other members of the team working with the patient

#### Medication safety

Medication safety does not look solely at the safety of individual medications, but rather the use of medications. '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.

The Irish healthcare system does not currently easily facilitate seamless transfer of information on patients. Multiple providers and systems are in place but systems currently operate in isolation with no immediate linkage to facilitate transfer of patient information. Information which references any change in a patients' medication or medication compliance issue should be readily available to all involved in the patients care. The pharmacist, in both primary and secondary care, plays a significant role in this information sharing. It is hoped that the planned unique patient identification system and eventual electronic patient record and electronic prescribing will help minimise medication safety related risks.

#### Orthoptist

The role of the orthoptist involves the diagnosis and non-medical management of strabismus (squint), eye movement disorders, performing and interpreting visual fields<sup>77</sup>. 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 guideline 2010<sup>a</sup>).

Patients with neurological conditions need to be assessed by an orthoptists when/if they develop ocular symptoms such as blurred vision or diplopia (double vision). Unless complaining of a specific ocular problem orthoptists are not routinely involved in the patient pathway.

Assessment and management of patients can be delivered in a variety of settings: from on the ward, in acute care to outpatient clinics for rehabilitation. 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. All qualified orthoptists have been trained to assess, diagnose and treat patients with a wide variety of neurological conditions.

Assessment of patients can occur at any stage of the disease based on individual presentation / need. Best practice states that assessment and management of a patient should be performed as soon as possible after an acute event. To investigate any possible ocular defects, for example in Stroke, patients should be assessed in the acute setting on the ward, while headache will only need to be assessed if symptomatic.

In scenarios where more junior members of the team are providing the service a supervisory process should be available. Access to orthoptic assessment is not consistent throughout the country, as several hospitals have no orthoptic department. Many departments only have part-time staff.

a Scottish Intercollegiate Guidelines Network (SIGN). Guidance 118, 2010

### **Podiatry**

Podiatry is a healthcare profession that specialises in the management of disease and disorder of the lower limb and foot. The foot is a highly complex structure, which can develop problems affecting a patient's overall health and quality of life. Podiatry can significantly improve peoples' quality of life by promoting and maintaining mobility<sup>a</sup>. The role of the Podiatrist in rehabilitation is associated with the patients' co-morbidities.

Neuropathy and Vascular insufficiencies: People with poor circulation and /or neuropathy of their feet are at an increased risk of developing foot ulceration and non-healing lesions that could lead to infection, gangrene and amputation.. Podiatrists offer health promotion and design, and implement, management plans to prevent problems occurring, such as the provision of offloading devices Podiatrists can provide regular screening to identify those with poor circulation or neuropathy at an early stage, undertake vascular and neurological assessments of the lower limb, manage skin and nail pathologies and provide wound care for those with foot ulceration.

Podiatric biomechanics can be understood as the study of the way the lower limb and foot moves, inclusive of the muscles and soft tissues as well as the anatomical structure and movement of the bones and joints. Podiatrist perform gait analysis on patients, this is a highly skilled clinical tool to aid the understanding of mechanism of why injuries occur and why tissues get stressed within the musculoskeletal system. Podiatrist will prescribe to patients when needed: stretching exercises, lifestyle changes, functional foot orthoses, and specialist footwear advice to enable the rehabilitation of patients' symptoms.

#### Orthotist

Orthotists are practitioners who provide gait analysis and engineering solutions to patients with problems of the neuro, muscular and skeletal systems. They are extensively trained at undergraduate level in mechanics, bio-mechanics, and material science along with anatomy, physiology and pathophysiology. Their qualifications make them competent to design and provide orthoses that modify the structural or functional characteristics of the patients' neuro-muscular and skeletal systems enabling patients to mobilise, eliminate gait deviations, reduce falls, reduce pain, prevent and facilitate healing of ulcers.

They are also qualified to modify CE marked Orthoses or componentry taking responsibility for the impact of any changes<sup>78</sup>. Orthoses are used to correct the shape and/or function of the body, to provide easier movement capability or reduce pain<sup>79</sup>.

Commonly treated conditions in patients presenting in a rehabilitation setting 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. Orthotists work as part of the multidisciplinary neuro-rehabilitation team therapist to determine how best to maximise functional independence

a National University of Ireland, Galway (2012) Available at: http://www.nuigalway.ie/faculties\_ departments/podiatry/what\_is\_podiatry.html

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### **Prosthetist**

Prosthetists are members of the multidisciplinary team. They provide gait analysis and engineering solutions to patients with limb loss. They work closely with the IDT to determine how best to maximise functional mobility.

They are extensively trained at undergraduate level in mechanics, bio-mechanics, and material science along with anatomy, physiology and pathophysiology. Their qualifications make them competent to design and provide prostheses that replicate the structural or functional characteristics of the patients absent limb. They are also qualified to modify CE marked prostheses or componentry taking responsibility for the impact of any changes. They treat patients with congenital loss as well as loss due to diabetes, reduced vascularity, infection and trauma<sup>80</sup>.

Limb prostheses are functional or cosmetic artificial replacement devices for any or all parts of a missing extremity. Prosthetics are typically used to replace body parts lost by injury (trauma), through diseases (most often vascular) or missing from birth (congenital).

# **Clinical Team Considerations**

### **Staffing ratios**

Staffing for specialist acute neurosurgical/neuroscience and spinal services need to be sufficient in terms of required intensity and range of therapeutic input and recommendations have been made by the CSPD Trauma and Orthopaedics, Neurology and Intensive Care Society of Ireland clinical care programmes.

### Minimum Staffing Provision for specialist in-patient rehabilitation services (BSRM).

	Specialised rehabilitation service WTE Per 20 Beds		Local specialist rehabilitation WTE Per 20 beds		
	Hyper-acute	Level Ia	Level I b	Level 2a	Level 2b
Medical Staff - Consultants Accredited in rehabilitation medicine	3.0-3.5	2.5-3.0	2.0	2.0	1.5
Medical Staff - Junior (Training grades above FY1 or Trust grades	3.0-3.5	2.0-2.5	1.5-2.0	1.5-2.0	1.5-2.0
Nurses	45-60	40-50	35-40	35-40	35-40
% Qualified nursing staff (Band 5 or above) (Depending on acuity of caseload)	65-75%	50-60%	45-50%	45-55%	45-55%
% Nurses with specific rehab training		At least 45%	At least 40%	At least 40%	At least 30%
Therapy Staff					
Physiotherapists (Depending on proportion of patients with tracheostomy)	6.0-7.0	6.0-7.0	5.5-6.5	5.5-6.0	4.5-5.5
Occupational Therapists	5.5-6.5	6.0-7.0	5.5-6.5	5.5-6.0	4.5-5.5
Speech and language therapists (Depending on proportion of patients with tracheostomy)	3.0-4.0	3.0-3.5	2.5-3.0	2.0-2.5	1.5-2.0
Clinical psychologist/counselling	2.5-3.0	2.5-3.0	2.5-3.5	1.5-2.5	1.5-2.0
(Depending on whether patients with severe behavioural problems are accepted)					
Social Worker/Discharge co-ordinator	1.0-1.5	1.5-2.0	1.5-2.0	1.5-2.0	1.0-1.5
Dietitian (Depending on the proportion of patients on enteral feeding/complex nutrition needs)	1.0	1.0	0.5-2.0	0.75-1.0	0.5-0.75
Clerical Staff	3.0 WTE, but dependant on caseload and throughput				

NOTE:

These staffing levels suport both the inpatients activity and associated out-reach work including assessments home-visits, follow-ups, case-conferences, etc.

Additional resources are required if the services also offer community rehabilitation services. Additional staff eg technicians, engineers, prosthetists, etc may also be required depending on the caseload.

Tertiary specialised services taking patients with more complex needs the skill mix is adjusted to cater for the specific group of patients they serve - for example a cognitive behavioural rehabilitation services would require:

s A higher proportion of psychology/counselling staff
 s Consultant neuropsychiatrist support
 s A proportion of registered mental health nurses, and sufficient staffing levels to provide a safe environment for high risk patients, including 1:1 supervision when needed

### Table 5.5; Minimum staffing provision Specialist Rehabilitation Services (BSRM)<sup>a</sup>

The above ratios represent the core treating team. Access to other key services will be required including but not limited to;

- Neuropsychiatry
- Neuropsychology
- Counselling
  - Orthoptics

- Prosthetics

- Audiology - Neurology
- Podiatry
- Orthotics
- Rehabilitation Assistants

a http://www.bsrm.org.uk/downloads/specialised-neurorehabilitation-service-standards--7-30-4-2015pcatv2-forweb-4-5-16.pdf

Staffing of these services should be in line with international best practice staffing ratios for both inpatient and outpatient services.

Similar standards have been developed by the BSRM for community based specialist rehabilitation services and are adapted to the Irish context as outlined in table 5.6 below.

Staffing provision for community specialist rehabilitation service to support peo neurological conditions (population 1 million).Adapted from BSRM **	ple with
Team Leader/coordinator	2
Nurse Specialists	8
Physiotherapists	6
Occupational Therapists	10
Speech & Language Therapists	4
Clinical Psychologists	4
Social Work	8
Dietitian	2
Rehabilitation Assistants	8
Case Manager*	10
Consultant in Rehabilitation Medicine	2.4

\* Estimates for Case Manager are approximated from review of similar services nationally & internationally

\*\* Specific recommendations will need to be made per CHO based on review of population needs analysis and existing levels of service provision

 

 Table 5.6: Adapted staffing provisions for community based rehabilitation services for patients with long term neurological conditions

### **Co-ordinator roles**

#### Key worker role

The key worker should promote an environment where the patient feels able to discuss any 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 role of rehabilitation can be seen to be supporting and enabling a person to access life in the mainstream of society in a way that is in keeping with their goals and their abilities. There is a clear requirement for a co-ordinated approach to the provision of rehabilitation services to those with complex care needs.

The NCPRM model of care emphasises a seamless transition between different care settings and effective identification and management of the patient / service user's rehabilitative needs. It is unlikely that one agency will be in a position to offer all 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 the co-ordination and facilitation 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.

The International Classification of Functioning, Health and Disability (ICF) provides a useful tool which describes the role of rehabilitation and the case manager in reducing the impact of impairment and enhancing a person's participation in the community (see chapter 2)

The ICF underlines the critical importance of environmental factors in determining the functional outcome of a medical condition. Environmental factors include, but are not limited to, the built environment, social attitudes and the availability of therapeutic and care services.

A case manager is best described as the person who engages with and assists the person in coordinating appropriate environmental interventions and supports so that their activity and societal participation are optimised. The goals of case management are to support the provision of quality health care along a continuum, decreasing fragmentation of care across many settings and enhancing the client's quality of life.

It is proposed by the NCPRM that case management is the approach required to complete the network of services for the population of individuals with specialist rehabilitative needs.

The NCPRM sees a case manager as being a dedicated, distinct role within the Intra Disciplinary Team. The case manager for those with specialist rehabilitation needs will have an overarching role in facilitation and co-ordination but with specialist education and training with respect to neurorehabilitation and those with complex needs following neurological injury or illness.

There will be a need to work closely with the assigned key workers within the primary care networks who have a similar role with respect to supporting individuals with complex needs within the community.

The configuration of this role can vary depending on resources available across each of the CHOs. Models which are currently providing effective include;

- Direct provision of the Case Management function to HSE Physical & Sensory Disability Teams.
- Mixed Case Manager/Community Services Manager. Is this instance the individual is not part of the P&S Disability Team but manages the referrals for the CHO Area and has the remit as Case Manger within the CHO Area

Case Management as an Added Value Service. This service exists as an added value to the HSE funded Community Service Manager role.

The NCPRM is not prescriptive in terms of configuration of the case manager posts, other than to say that needs to be a dedicated role that is integrated with both hospital and community staff.

#### **Rehabilitation coordinator**

Rehabilitation Co-ordinators are required, who will work to co-ordinate the delivery of rehabilitation across the MCRN. The rehabilitation process should be provided in a co-ordinated manner with flexibility to allow for changes in rehabilitation needs.

Rehabilitation services need to have fluid referral and communication pathways in place. Referral between services should be based on patients' rehabilitation needs.

While there is an operational function to this role, there is also a clinical component required to look as issues such as dependency levels, specialist requirements and 'readiness' for rehabilitation ensure that all patients receive the appropriate level of treatment at the right time. Dedicated rehabilitation coordinators would be seen as central to this process. If these roles were ambulatory in nature, working across the MCRN the most current information on the status of all patients would be available and informed clinical decision making would be possible when planning admissions.

Rehabilitation Coordinator's should be appointed across each network to support the co-ordination of rehabilitation services, ensure adequate and timely documentation, support flow through the system and to improve communication and transition between rehabilitation providers.

# Technology

Assistive technologies provide solutions to many challenging aspects of neurological and POLAR rehabilitation care, the use of electronic assistive technologies (e.g. communication devices, environmental control systems and personal computers, tablets/smart phones) by service users can lead to increasing independence and greater involvement and re-integration into home, school/workplace and community.

What should be noted is that any decision to recommend a specific piece of assistive technology should be the result of a process which is considers many factors including the individual patients' abilities, disabilities, goals and anticipated outcomes. Literature addressing this issue advocates a model which matches 'person and technology that considers environments of device use, characteristics of the users preferences and expectations and device features and functions'<sup>81</sup>.

Factors such as cognitive impairments need to be considered and any recommendation for a specific piece of technology must accommodate the individuals' skills and deficits. This is further complicated by the individual nature of cognitive impairment, and as such, in general terms, a case of 'one size fits all' is not applicable. Memory difficulties, attentional deficits and impaired executive functioning can all impact on a persons' ability to learn to use and device and to use it prospectively, thus limiting its potential benefits.

A decision to recommend a particular device or piece of technology should be made by a multidisciplinary team working in collaboration with the patient. Previously, issues such as societal attitudes, social norms etc played a significant role in this decision making, however with the widespread use of technology across society, this is now less of a factor, but it would need to be considered when working with older patients who may be less familiar with such devices. The patients' motivation to use such a device also needs to be considered. Community services should also be considered in the context of these decisions as the primary funders.

Increasing demands for neurological and POLAR rehabilitation may require the provision of rehabilitation in the home or in local communities. This is possible through the use of Tele-medicine.

Telemedicine provides the opportunity to create virtual teams that can educate, train and support local clinicians. This type of service allows service users to carry out a programme of neurological and POLAR rehabilitation led by specialist experts, in their own homes, while being monitored and assessed virtually. Benefits of Telemedicine include: reduction of hands-on therapy time; improved monitoring of improvement; and the provision of sustainable and flexible services.

Interagency research collaborations also offer scope for improved service provision through development of new technologies (for example the TRIL Technology Research for Independent Living.

#### Research

High quality research performed by the inter-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 is felt that patients should be offered the opportunity to be involved in research projects that have aims of:

- I. Promotion of health research to build evidence based practice in the field of rehabilitation
- 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 fulfil their potential for health.

The proposed model of care recognises the critical need for the design and delivery of specialist rehabilitation services to be 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 specialist rehabilitation and work collaboratively with our local health care providers in order to support research development and promote the development of relevant and forward thinking rehabilitation practices that will improve opportunities available to people with rehabilitation needs.

The NCPRM supports participation in research of all forms including phenomenological and qualitative research, health service delivery research using both formative and summative research methodologies, population based research and translational research. The programme supports the work of the Irish Brain Council in promoting enhanced networking and funding for all aspects of brain research, and developing career tracks including PhD & Post-doctoral training schemes for young Irish graduates.

### Programme metrics and evaluation

#### **Clinical Effectiveness**

All patients engaging in a rehabilitation programme should have at least one agreed, validated outcome measure assessed on admission and discharge from the programme. The outcome measure used will depend on the patient's condition and disability, their rehabilitation needs and the nature of their programme<sup>82</sup>.

A 'suite' of outcome measures should evaluate impairment, global activity, participation and emotional status. Outcome measures should be selected in relation to the individual goals for rehabilitation and success can be viewed in relation to pre-morbid function. Outcomes are better compared if all centres/ rehabilitation services use similar outcome measures.

The BSRM has developed a 'basket' of outcomes measures figure 5.7 below. It comprises a selection of scales that are scientifically evaluated, in routine use in clinical practice in the UK or recommended for routine use in BSRM guidelines. The basket is periodically reviewed by the BSRM Research and Clinical Standards Committee<sup>83</sup>.

Category	Recommended and widely used	Alternative options
Spinal cord Injury classification	(ASIA) (100)	SCIM
Motor function tests Generalised motor impairment	Motricity Index (2)	Motor Assessment Scale (3)
Mobility	10m walk (4)	Rivermead Mobility Index (6) Functional ambulation categories (7,8)
Mobility in Amputees	Haroldwood and Stanmore Mobility grades (5)	SIGAM mobility grades (9)
Upper limb function	Nine-hole peg test	Frenchay arm test
Global disability/Activities of Daily Living (ADL)	Barthel index UK FIM+FAM	Health Assessment Questionnaire
Dependency and care hours	Northwick Park Dependency Score Northwick Park Care Needs Assessment	
Extended ADL	Frenchay Activities Index	Nottingham eADL scale BICRO-39
General health		General Health Questionnaire
Pain	Numbered rating or visual analogue scale	Oswestry Low Back Pain Disability Questionnaire McGill Pain Score
Depression	Yale Question: 'do you often feel sad or depressed?' Graphic rating scale eg (DISCs) Signs of Depression Scale (SDSS) Geriatric Depression Scale	Hospital Anxiety and Depression Scale (HADS) Beck Depression Inventory (BDI-11)
Carer Burden	Caregiver Strain Index	

Table 5.7 Adapted from BSRM basket of recommended outcome measures

# Data collection and key performance indicators

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.

- This is a particular challenge for the NCPRM considering
- The number of conditions presenting that require intervention
- The variety of referral sources
- The number of sites across which rehabilitation is delivered
- The movement of patients among these sites
- The number of HSE Divisions within which services are delivered
- The long term nature of rehabilitation services

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

The major data collection system for in patient activity within HSE and Voluntary Hospitals is HIPE. While this system will allow us identify the number of patients admitted to acute hospitals, their diagnosis, their length of stay and discharge destination, the only measure of quality which can be inferred from this data is in relation to discharge destination i.e. whether the patient is discharged home, to a long term care facility or to rehabilitation. This is a crude measure of outcome.

Ensuring the data generated from HIPE is comprehensive and all-encompassing can also be a challenge given the wide range of conditions requiring specialist rehabilitation.

HIPE does not currently capture services provided outside of hospitals, nor does it reflect therapy services provided or referrals made. Progress made over the course of admission is also not recorded nor is service user satisfaction.

The result of this is that in relation to rehabilitation services, the focus is on only one specific aspect of the rehabilitation journey and does not look at the service as a whole across the continuum of care nor do they give the programme any real direction in relation to service or quality improvement.

While the National Tertiary centre of complex specialist rehabilitation services collects a comprehensive suite of data and outcome measures, given the capacity of this service, this data is only collected on a relatively small cohort of patients treated in this facility. It is also collected in isolation as such data is not collected by either referring agents or community service providers managing the patient in the long term.

With the establishment of additional units providing specialist rehabilitation services and the managed clinical rehabilitation networks proposed, the implementation of a comprehensive data collection system will be a central. It will be integral to measuring the successes and challenges of these services. A systematic approach to collecting overall data relating to rehabilitation services is required.

In terms of the continuum of care, it is necessary to know about process data (i.e. what is being done where, by whom and treatment outcome). At present, such data is not available. The task of determining the gap between Rehabilitation Services provided in Ireland and internationally recognised best practice is significant, particularly in relation to quality of service and outcomes. This will be an essential requirement of the programme the health care system moves towards a system of costing bundles of treatment in preparation for universal health insurance. The data requirements of the NCPRM include:

	Indicator	Current status of data measurement	Key areas for development
Quality	Reduce unnecessary discharge to nursing home from Complex specialist rehabilitation services	Currently information is gathered on patients discharge location	Anticipated discharge destination needs to be recorded against which actual discharge destination can be measured
	Rehabilitation provided in the most appropriate setting to meet' patients needs	Referral to rehabilitation is currently collected across acute hospitals	Dependency scores for admission to all specialist rehabilitation facilities need to be recorded which can then be measured against remit of that service
	Rehabilitation provided by multidisciplinary care teams in all specialist rehabilitation settings	Currently measured in tertiary centre only. This information is not currently gathered on HIPE interventions received.	Interventions required dependent on patients identified needs should be recorded and measured against This may require an 'add-on' screen to HIPE for inpatients & appropriate register for other centres.
	Decrease 'adverse events' i.e. interrupted services, falls etc during inpatient admissions	Measured locally. No current system for measuring/managing same. National baseline data not available currently.	National system is required for measuring same. Quality improvement plans will then be required in response to trends etc.
	Early transfer to specialist rehabilitation services from acute hospital.	Waiting lists managed locally by service providers	National register for recording waiting times for specialist rehabilitation services required
	Equitable access to specialist rehabilitation services for all those requiring specialist rehabilitation	Waiting lists managed locally be service providers	Transparent waiting list management systems required whereby patients with comparable level of need should be waiting comparable lengths of time for admission, irrespective of geographical area.
	Defined and tracked outcome measurement for specialist rehabilitation services in all service delivery sites	Inconsistently measured locally across service delivery sites	National system for measuring level of dependency at time of admission and discharge required to demonstrate effectiveness of services.

Table 5.8: NCPRM Quality Indicators

	Indicator	Current status of data management	Key areas for development
Access	80% access to Specialist Rehabilitation assessment within 2 weeks of referral	Not currently measured	Clear indicators for referral and pathways to assessment required. Data system for measuring date of referral to date of assessment required.
	80% access to specialist inpatient rehabilitation beds within 60 days of referral	Measured locally at NRH	Appropriate targets for waiting times for inpatient specialist rehabilitation services to be agreed and collected/audited nationally.
	Reduction in the number of patients waiting to access complex specialist rehabilitation by 20%	Measured, audited and reviewed locally at NRH	Improvements in this area will not be achievable until other areas of service provision developed
	Reduction in delayed discharges from the tertiary centre to 8%	Currently being measured and reported nationally	Once specialist rehabilitation services are developed, a similar reporting requirement will be necessary

Table 5.9: NCPRM Access Indicators
	Indicator	Current status of data management	Key areas for development
Value	Reduced length of stay in acute hospital for patients requiring specialist rehabilitation	LOS measured by HIPE, however this is not measured against those referred for rehabilitation or waiting for rehabilitation services unless it is a delayed discharge.There is no measurement either of when the patient is 'ready' to engage in active rehabilitation.	To measure this effectively, patients identified as requiring specialist rehabilitation would need to be identified along with dependency scores (for identification of appropriate setting), date of referral to rehabilitation services as well as date of transfer.
	Reduce LOS in tertiary centre by 5 days	Data collection exists in national tertiary centre however this system is in isolation and does not interface with other hospital systems.	This data is routinely collected and reported on by NRH
	Reduction in days lost to delayed discharges in specialist rehabilitation services	As above	As above, this data is routinely collected and reported on by NRH. Similar collection systems will need to be adopted in all facilities offering specialist rehabilitation
	10% reduction in readmission and attendance at ED/AMAU	Currently there is no system for collecting this data. Patients self- report at review appointments is only source of information currently	Patients' full medical & rehabilitation history should be included when gathering data on admission. This will be supported by a unique patient identifier.
	Reduction in inappropriate discharge destinations from tertiary rehabilitation facilities	Discharge destination recorded	Anticipated discharge destination measured against actual discharge destination and reasons for variation between the 2 should be developed.

Table 5.10: NCPRM Value Indicators

# **APPENDICES**

### Appendix I Specialist rehabilitation Summary

#### Summary of clinical activities in specialist rehabilitation settings

	Tertiary Specialist	Regional Specialist	Specialist Community	Primary Care Teams
Service and Team Characteristics		Populations may not support sub-specialty, primary need in SPECIALIST REHABILITATION will be Neuro rehab (SCI will attend tertiary centre and POLAR primarily out- patient)		Single service or multidisciplinary team based rehabilitation. Low to moderate intensity Ongoing liaison with support of specialist community team. Provide service to mixed populations
Differentiating Criteria Key Activities /Nature of Service		20-25% of patient will have highly complex disabiliti Patients with complex neuro rehabilitation needs	es.	Non-SPECIALIST REHABILITATION service Home and clinic based service, health promotion & self-management groups

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**Appendix 3 Spinal patient pathway** 









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### Appendix 5 Transition checklist (Paediatric to Adult)

Area	Objectives	Achieved
Self-advocacy	I. Patient able to describe their condition	
	2. Patient asks appropriate questions in clinic	
	3. Patient is able to access information on their condition/disability	
	4. Patient can describe available adult care options	
	<ol> <li>Patient understands differences between paediatric and adult care.</li> </ol>	
Independent Health care	I. Patient understands what medication they are on and is able to discuss potential side effects	
Denaviour	2. Patient knows how to access help in an emergency situation	
	3. Patient understands principles of confidentiality	
	<ol> <li>Patient maintains a personal health care record book to keep track of appointments, health information, medication, treatments and health care providers</li> </ol>	
	5. Patient has met with adult consultant/specialist nurse	
Sexual health	<ol> <li>Patient understands changes associated with puberty and the implication of their condition on pubertal development</li> </ol>	
	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.	

Area	Objectives	Achieved
Psychosocial concerns	I. Parent's given an opportunity to discuss any support regarding transition or the future	
	2. Patient understands benefits of friends and supportive relationships	
	3. Patient able to set positive goals for their future	
	4. Any assistance for personal care identified	
Educational and vocational	I. Patient understands restrictions that may affect educational and recreational activities	
pianing	2. Discussion regarding employment and/or educational options	
	3. Information regarding health care benefits available	
Health & lifestyle	<ol> <li>Patient understands health implications of smoking, alcohol and recreational drug use</li> </ol>	
	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.	

# **GROUP MEMBERSHIPS**

#### \*Consultants in Rehabilitation Medicine

#### NRH – National Rehabilitation Hospital, Rochestown Avenue, Co. Dublin A96 E2H2

	Leadership team
Jacinta McElligott	Clinical Lead from June 2016
Dr. Jacinta Morgan	Clinical Lead from July 2013
Dr. Aine Carroll	Clinical Lead to Oct 2012, National Director, Clinical Strategy and Programmes Division October 2012 -
Edina O'Driscoll	Programme Manager from March 2014 Clinical Strategy & Programmes Division, HSE
Valerie Twomey	Programme Manager to March 2014 Clinical Strategy & Programmes Division, HSE
Multidisciplin	ary Working Group (includes leadership team)
Dr. Andrew Hanrahan	Mercy University Hospital Cork and NRH to March 2014
Noeleen Friel	Patient Advocacy Group to March 2014
Dervilla Danaher	Physiotherapy Manager Mater Misericordiae University Hospital Dublin
Fionnuala Duffy	Speech & Language Therapy Manager, St Vincent's University Hospital & St Michael's Hospital Dublin
Clare Conlon	Occupational Therapy Manager, Peamount Healthcare, Newcastle, Co. Dublin
Regina Kiernan	Consultant in Public Health Medicine, HSEWest
Anne O'Loughlin	Principal Medical Social Worker, NRH
Ciara Rowan	Clinical Nurse Specialist, Acquired Brain Injury Service Beaumont Hospital Dublin 9
Marion Meany	Head of Operations and Service Improvement, Disability Services, Social Care Division, Health Service Executive
Patricia McLarty	Disability Service, Social Care Division, Health Service Executive to May 2013
Mags Rogers	Development Manager, Neurological Alliance of Ireland
Niall Pender	Principal Clinical Neuropsychologist Head of Department of Psychology, Beaumont Hospital to July 2015
Elaine Whelan	Speech & Language Therapist, Community Rehabilitation Team, St Camillus' Hospital Limerick
Niamh Malone	Clinical Nurse Specialist, St Mary's Hospital, Dublin 7 until 2014
Spencer Turvey	Manager, POLAR service and Physiotherapy Department, Mercy University Hospital Cork
Dr. Brian Waldron	Senior Clinical Psychologist and Clinical Neuropsychologist, Acquired Brain Injury Ireland, from July 2015

Dr. Eimear SmithNRH and Mater Misericordiae University Hospital Dublin (Chair 2013 - )Dr. Jacinta MorganNRH and Beaumont Hospital Dublin (Chair 2011 - 13)Dr. Jacinta McElligottNRH and Tallaght Hospital, DublinDr. Mark DelargyNRH, Beaumont and Mater Hospitals, Dublin
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Dr. Eugene Wallace Tallaght Hospital, St James' Hospital and NRH
Dr. Cara McDonagh NRH and Enable Ireland, Dublin Chair Disabled Drivers' Medical Board of Appeal
Dr. Paul Carroll NRH, St Vincent's University Hospital and Royal Hospital Donnybrook
Dr. Andrew Hanrahan Mercy University Hospital Cork and NRH to March 2014
Dr. Aine Cornell NIRL St. Vincent's Liniversity, Heapital and Revel Heapital
Donnybrook to October 2012
Model of Care Work Stream
Dervilla Danaher (Chair) NKR, St Vincent's Oniversity Hospital and Koyal Hospital Donnybrook to October 2012 Model of Care Work Stream Physiotherapy Manager, Mater Misericordiae University Hospit
Dr. Alle Carroli       NKH, St Vincent's Oniversity Hospital and Royal Hospital Donnybrook to October 2012         Model of Care Work Stream         Dervilla Danaher (Chair)       Physiotherapy Manager, Mater Misericordiae University Hospit         Mags Rogers       Development Manager, Neurological Alliance of Ireland
Dr. Alle Carroli       NKH, st Vincent's Oniversity Hospital and Koyal Hospital Donnybrook to October 2012         Model of Care Work Stream         Dervilla Danaher (Chair)       Physiotherapy Manager, Mater Misericordiae University Hospital Managers         Mags Rogers       Development Manager, Neurological Alliance of Ireland         Anne O'Loughlin       Principal Medical Social Worker, NRH
Dr. Alle Carroli       NKH, St Vincent's Oniversity Hospital and Royal Hospital Donnybrook to October 2012         Model of Care Work Stream         Dervilla Danaher (Chair)       Physiotherapy Manager, Mater Misericordiae University Hospital Mags Rogers         Development Manager, Neurological Alliance of Ireland         Anne O'Loughlin       Principal Medical Social Worker, NRH         Elaine Whelan       Speech & Language Therapist, Community Rehabilitation Team St Camillus' Hospital, Limerick
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Clare Conlon	Occupational Therapy Manager, Peamount Healthcare (Joint chair)
Michael Downey	Patient Representative
Joy O'Brien	Senior Speech & Language Therapist, Beaumont Hospital
Ciara Rowan	Clinical Nurse Specialist, Beaumont Hospital
Agnes Shiel	Professor of Occupational Therapy, School of Health Sciences, NUI, Galway
Anne Marie Morrissey	Lecturer, Discipline of Occupational Therapy, NUI Galway
Rachel Leonard	Lecturer, Discipline of Speech & Language Therapy, NUI Galway
Sinead Brosnan	Senior Speech & Language Therapist, Cork University Hospital
Liz Kelso	Physiotherapy Manager, St Luke's Hospital, Kilkenny
Catherine O'Keefe	Occupational Therapy Manager, St Luke's Hospital, Kilkenny
Christian Garcia	Senior Occupational Therapist, Tallaght Hospital
Jane Culligan	Brain Injury Liaison Co-ordinator, NRH
Fiadhnait O'Keeffe	Clinical Neuropsychologist, NRH
Kim Shiel	Dietitian Manager, NRH
Alison McCann	Senior Occupational Therapist, Brain Injury Programme (including Stroke), NRH
Mary Regan	Senior Medical Social Worker, Brain Injury Programme, (including Stroke), NRH
Dr. Jacinta Morgan	NRH and Beaumont Hospitals

# GLOSSARY

### Acronyms

ABI	Acquired Brain Injury
ANP	Advanced Nurse Practitioner
CBSRT	Community Based Specialist Rehabilitation Teams
CRT	Community Rehabilitation Team
CSPD	Clinical Strategy and Programmes Division (HSE)
CSRS	Complex Specialist Rehabilitation Service
CNM	Clinical Nurse Manager
CNS	Clinical Nurse Specialist
DRS	Disability Rating Scale
DML	Dublin Mid-Leinster
DNE	Dublin North-East
DoH	Department of Health
GCS	Glasgow Coma Scale
HSCPs	Health and Social Care Professionals
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
ICF	International Classification of Function
ISA	Integrated Service Area
LHO	Local Health Office
MCRN	Managed Clinical Rehabilitation Network
NCPOP	National Clinical Programme for Older People
NCPRM	National Clinical Programme for Rehabilitation Medicine
NDA	National Disability Authority
NHO	National Hospitals Office
NRH	National Rehabilitation Hospital
PCT	Primary Care Team
POLAR	Prosthetic, Orthotic & Limb Absence Rehabilitation
PTA	Post Traumatic Amnesia
RCS	Rehabilitation Complexity Scale
RTA	RoadTraffic Accident
SCI	Spinal Cord Injury
SRS	Specialist Rehabilitation Service
VFM	Value for Money
VFMPR	Value for Money and Policy Review
WHO	World Health Organisation
WTE	Whole Time Equivalent

### TERMS

ABI: An Acquired Brain Injury (ABI) is a term given to any injury to the brain sustained during a person's lifetime occurring as a result of traumatic brain injury, stroke, brain haemorrhage, brain tumour or infection. Crucially, each person who suffers an injury will have his or her own unique characteristics, difficulties or symptoms that can vary in severity from mild to severe.

Health & Social Care Professions (H&SCPs) The HSCP Act 2005 has given statutory basis to the regulation of 12 professions listed below. Any other health and social care profession deemed appropriate by the Minister for Health may be added in the future.

Managed Clinical Networks are linked groups of health professionals and organisations from primary, secondary and tertiary care, working in a coordinated manner, unconstrained by professional and health board boundaries, to ensure equitable provision of high-quality, clinically effective services.

National Policy: The National Policy and Strategy for the Provision of Neurorehabilitation Services in Ireland is an overarching Government policy for people with specialist neurorehabilitation needs.

Performance Indicators are data points used to measure inputs, activities, outputs or outcomes, and are used to monitor the progress of the programme being reviewed.

POLAR: Prosthetic, Orthotic and Limb Absence Rehabilitation (POLAR) Programme at NRH provides specialised, interdisciplinary limb absence rehabilitation for patients who have experienced amputation as a result of vascular disease, trauma, cancer, infection or any other cause, and patients with congenital limb absence. This comprehensive rehabilitation service is offered to patients whether or not prosthesis is appropriate.

Voluntary Agency is an autonomous non-profit and non-statutory organisation providing a social or community service. In the context of the Programme, a voluntary agency is a specialist non-profit provider of neurological or disability services or supports.

Voluntary Sector is the collective name for organisations with social, charitable or philanthropic function that are not established by statute and who do not generate profits or distribute dividends.

#### **Team-working**

- W Interdisciplinary: The interdisciplinary model uses a holistic, collaborative and patient focused approach. Effective joint goal-setting and review is the cornerstone of the IDT's process
- W Multidisciplinary:Traditional multidisciplinary team (MDT) approaches involve professionals working independently in order to achieve discipline specific goals. Individual team members may not communicate directly with all other team members in care planning

Whole-Time Equivalent is the equivalent number of combined part-time and full-time staff resources operating on a full-time basis, e.g. two staff members both working half-time are equivalent to one whole-time post.

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