



National Strategy & Policy for the Provision of Neuro-Rehabilitation Services in Ireland



From Theory
to Action

Implementation Framework
2019-2021

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Acronyms

ABI	Acquired Brain Injury
ANP	Advanced Nurse Practitioner
ALOS	Average Length of Stay
BSRM	British Society for Rehabilitation Medicine
CHO	Community Healthcare Organisation
CNRT	Community Neuro-Rehabilitation Teams
CSPD	Clinical Strategy and Programmes Division (HSE)
CUH	Cork University Hospital
DRS	Disability Rating Scale
DOH	Department of Health
ED	Emergency Department
ESD	Early Support Discharge
HSCPs	Health and Social Care Professionals
HIPE	Hospital Inpatient Enquiry
HIQA	Health Information and Quality Authority
HSE	Health Service Executive
ICPCD	Integrated Care Programme for Chronic Disease
ICPOP	Integrated Care Programme for Older People
ICF	International Classification of Function
ICP	Integrated Care Pathway
IF	Implementation Framework
KPI	Key Performance Indicator
LOS	Length of Stay
MCRN	Managed Clinical Rehabilitation Network
NAI	Neurological Alliance of Ireland
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
NSIU	National Spinal Injury Unit
NSG	National Steering Group
PCT	Primary Care Team
RCS	Rehabilitation Complexity Scale
RM	Rehabilitation Medicine
RTA	Road Traffic Accident
SBH	Safer Better Healthcare
SCI	Spinal Cord Injury
VFM	Value for Money
WHO	World Health Organisation
WTE	Whole Time Equivalent

Foreword

The National Strategy & Policy for Neuro Rehabilitation Services was launched in 2011. This strategy noted that neuro-rehabilitation services have been underdeveloped and where they exist, have been developed in an ad hoc manner, primarily by the voluntary sector. Where services have been developed by the statutory health system, the focus of provision has been on medical rehabilitation, which, while most important, is not comprehensive. It is also a feature of current provision that many of the services and service structures are condition-specific, with access to some also determined by reference to age within the adult cohort.

The focus of the neuro rehabilitation strategy is on achieving best outcomes for people, by providing safe, high quality, person-centred care at the lowest appropriate level of complexity. This must be integrated across the care pathway, and provided as close to home as possible or in specialist centres where necessary.

At an individual level, the impact of not receiving appropriate and timely services and supports can include deterioration in function and the associated physical and psychological sequelae. At a system level, it can lead to increased hospital admissions, with consequential delayed discharges and with many of the early advances negated by the absence of downstream services.

In 2017 a National Steering Group (NSG) was established to oversee the writing and execution of a National Implementation Framework (IF). This Group has representation from Disability Services Strategy and Planning, the National Clinical Programme for Rehabilitation Medicine, Acute Hospital Service, Primary Care Division, Mental Health Division, Neuro Psychiatry, Health & Social Care Professionals, National Rehabilitation Hospital (NRH), Health & Wellbeing Division, Public Health and the Neurological Alliance of Ireland (NAI).

Since the publication of the Strategy in 2011, more robust evidence is now available to support the benefits and cost effectiveness of rehabilitation, both in terms of personal outcomes for the individual and also the reduced costs to the system. The impact of appropriately resourced rehabilitation service on patient flow should not be underestimated.

Research undertaken by the NSG in Q3 2017 demonstrated the potential numbers of bed days which could be released back into the acute hospital system if neuro rehabilitation services were well established. For example when compared to Ireland as a whole the average length of stay (ALOS) of patients with diagnoses of acquired brain injury (ABI), spinal cord injury (SCI) or stroke in Community Healthcare Organisation (CHO) 6 & 7 are higher for all three categories. For instance, the national average length of stay (ALOS) for stroke is 13.28 days whereas the ALOS for feeder hospitals (St James, Tallaght and St Vincent's Hospitals) in CHO 6 +7 is 16.29 days. This equates to 9,600 extra bed days per year for this group in the hospitals serving CHO 6 & 7. With the average daily cost of an acute hospital bed at €850, this equates to a cost of providing care for these individuals of €8.2 million per year. There is an important incentive to ensure that people who would benefit from care in a less expensive setting are accommodated when this

aligns with their health needs.

Importantly, in these times, where there is significant overcrowding in emergency departments nationally, the implementation of the strategy as outlined in this document provides the health service with a significant opportunity to address this service issue.

Development of specialist rehabilitation services is everybody's business. While the implementation of the Strategy is being led jointly by the office of Disability Services Strategy and Planning and the Clinical Programme & Strategy Division, this strategy cannot be viewed in isolation. It needs to be considered in terms of the numerous services strategies currently being advanced within and across the HSE and Department of Health including but not limited to;

1. A Trauma System for Ireland 2018- Trauma Network Policy¹:

One of the major points highlighted in this document is that people who suffer a traumatic injury will have significant rehabilitation requirements. Trauma Networks will fail if not supported by a well-developed rehabilitation network.

2. Committee on the Future of Healthcare- Sláintecare Report May 2017²:

The principles outlined in this report are reflective of the aim of the Strategy specifically with respect to timely access to all health and social care according to medical need

3. Health Service Capacity Review 2018- Executive Report Review of Health³:

This document outlines the case for the development of a more integrated, proactive and community-based care model with greater provision of home care, short term respite and step-down care.

This Implementation Framework reflects the main recommendation from these and other policies as they relate to neuro -rehabilitation services.

The NSG agreed to advance the implementation of the National Neuro Rehabilitation Strategy through a National Implementation Framework, adopting the 10-step Framework described by the Integrated Care Programme for Older People.

¹ A Trauma System for Ireland 2018:Report of the Trauma Steering Group - Dept of Health/HSE

² Committee on the Future of Healthcare- Sláintecare Report May 2017

³ Health Service Capacity Review 2018- Executive Report Review of Health

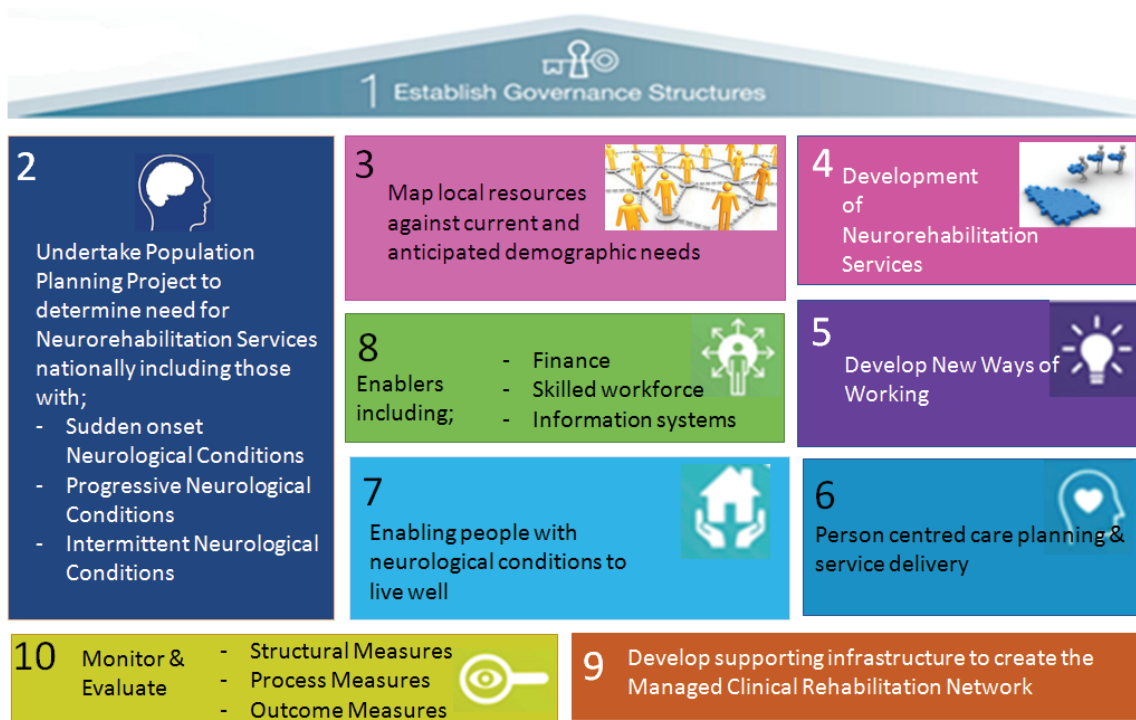


Fig1; 10 Step Approach to Implementation

This is a scientific approach based on data including population needs assessment, mapping of existing services, analysis of gaps in current services in line with benchmarked best practice. The ultimate goal of this approach is to put in place a national framework of acute, inpatient and specialist community services through;

- The development of local implementation teams,
- The development/enhancement of neuro-rehabilitation services at each level of the MCRN,
- The configuration of services into a Managed Clinical Rehabilitation Network Model,
- Governance structures including overall leadership and accountability,
- Involvement of all stakeholders on the local implementation teams and in the implementation process, including service users.

Further supporting evidence is presented in the recently published Model of Care of the National Clinical Programme for Rehabilitation Medicine 2018, where best practice with respect to specialist rehabilitation services across the continuum of care is clearly described. The Model of Care is one of the key reference documents informing this implementation framework.

The main premise underpinning all rehabilitation service delivery in the Model of Care is;

- Person centred 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).

The MCRN, while an effective model in a number of European Countries, is a new concept within the Irish healthcare system. To assess the feasibility of such a model, the NSG made the decision to pursue a demonstrator project so that the learning from introducing such a system could be applied nationally. The demonstrator project will see the development of inpatient and community based neuro rehabilitation services across CHO 6 & 7. The additional resources required to fund the MCRN demonstration pilot project on a phased basis will be highlighted in the Estimates process for 2019. The breakdown of posts and costs to have a dedicated Community Neuro Rehabilitation Team (CNRT) in each CHO will also be outlined through this process.

Evidence-based and informed by population needs, this National Implementation Framework addresses the rehabilitation continuum of care. It describes the requirement for a whole system approach and provides the blueprint for how we should deliver care and services for those who suffer from neurological conditions who require individualised, goal focused rehabilitation. It is recognised that continued investment in and development of neuro-rehabilitation services will need to be prioritised beyond the three year implementation period of this Implementation Framework in order to address the significant lack of capacity within existing services. Appendix 1 - Gantt chart outlines the proposed timelines for implementation.

Part 1 - Setting the Scene:

Introduction

The HSE's Office of Disability Strategy and Planning and Clinical Strategy and Programme Division are working in tandem to progress the implementation of the National Policy & Strategy for the provision of Neuro-Rehabilitation Services 2011-2015⁴ (referred to hereafter as 'the Strategy'). The Strategy outlines a proposed framework for neuro-rehabilitation service provision indicating the need for responsive services at various levels. It also calls for the establishment of managed clinical rehabilitation networks across the country to facilitate the development of integrated quality neuro-rehabilitation services.

This National Implementation Framework describes the fundamental principles of design and service delivery required to implement the Strategy. The Implementation Framework which is a 3 year plan, has been built on a 10-step programme which encompasses clear governance structures, population planning and a mapping approach to inform the service development requirements to improve the quality of life of people living with neurological conditions.

The recently published National Clinical Programme for Rehabilitation Medicine (NCPRM) Model of Care⁵ is reflective of the Strategy. The Model of Care main recommendations are:

- **Person centred approach to patient care**
- **Managed Clinical Rehabilitation Networks (MCRN)**; This model acknowledges the fact that different service users need different input and different levels of expertise and specialisation at different stages in their rehabilitation journey is fundamental to the development of specialist rehabilitation services. 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
- **The three-tier model of complexity-of-need**

There are three recognised levels of specialist rehabilitation described for the Irish context (from NCPRM, adapted from the British Society of Rehabilitation Medicine (BSRM)):

- **Complex Specialist service:** serves a national population and manages a high proportion of complex cases (60-70% have complex needs).
- **Local 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).

⁴ National Strategy and Policy for the Provision of Neuro-rehabilitation Services in Ireland, 2011-2015. Dept of Health & HSE

⁵ Model of Care, National Clinical Programme for Rehabilitation Medicine

- **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
- **Development of appropriately resourced interdisciplinary inpatient, outpatient and community based specialist rehabilitation teams across Ireland**
- **Case management of patients**

A **National Steering Group (NSG)** was established in 2017 as an overarching governance structure to advance the implementation of the Strategy. Please see below membership of the NSG.

Under the Governance of the NSG, 2 Working Groups were established (for membership of these 2 working groups please see appendices 2 & 3). The first working group was charged with developing a MCRN demonstrator project in CHO 6 & 7 and the 2nd was tasked with revising the National Implementation Framework based on feedback from public consultation process undertaken in 2016 and the learning from the Demonstrator Project.



Fig 2: Representation on the NSG

The Governance Structure for the NSG and Working Group is overseen by Ms Marion Meany, Assistant National Director (AND) Disability Services - Strategy and Planning and Dr Jacinta McElligott, Clinical Lead Rehab Medicine Programme, Clinical Strategy & Programmes Division.

Membership of NSG

- Ms M Meany AND Disability Services- Strategy and Planning (Co-Chair)
- Dr Jacinta McElligott Clinical Lead, Rehabilitation Medicine Programme (Co-Chair)
- Ms A M Ryan Project Manager, Neuro-rehabilitation Strategy
- Ms C Cuffe Head of Social Care CHO 7
- Ms E O Driscoll Programme Manager, National Clinical Programme for Epilepsy, Neurology & Rehabilitation Medicine
- Ms T Doran Acute Hospitals Representative
- Dr A Dee Health and Wellbeing Representatives
- Mr B Ebbitt Primary Care Representative
- Dr Amanda Carty National Rehabilitation Hospital Representative
- Ms F Duffy HSCP representative
- Dr D Cotter Neuropsychiatry Representative
- Mr O Claffey Mental Health Division Representative

- Ms M Rogers Neurological Alliance of Ireland representing all of the NAI organisations & people with neurological conditions. (NAI member organisations include; An Saol, Ataxia Ireland, Acquired Brain Injury Ireland, Alzheimer Society of Ireland, Aphasia Ireland, Bloomfield Health Services, Cheshire Ireland, Chronic Pain Ireland, Dystonia Ireland, Epilepsy Ireland, Enable Ireland, Headway, Irish Heart Foundation, Irish Hospice Foundation, Irish Motor Neurone Disease Association, Huntington's Disease Association of Ireland, Migraine Association of Ireland, Move4Parkinson's, Multiple Sclerosis North West Therapy Centre, MS Ireland, Muscular Dystrophy Ireland, Neurofibromatosis Association of Ireland, Parkinson's Association of Ireland, Polio Survivors Ireland, The Rehab Group, Spina Bifida Hydrocephalus Ireland, Spinal Injuries Ireland).
- A representative from the National Clinical Programme for Stroke has been identified

Why implement the National Strategy & Policy for Neuro-Rehabilitation Services in Ireland?

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. Implementation of the Strategy will see;

- 1. Improved Patient Outcomes**
- 2. Improved Access to specialist rehabilitation service**
- 3. Limited variation in patient pathway/experience**
- 4. Decreased Length of Stay (LOS) in acute hospital setting**

In addition to improving patient flow and patient experience, there is clear evidence that, shorter waiting times for access to specialist rehabilitation services correlates directly to improved patient outcomes and lessens the burden of disability.

This evidence demonstrates

- the cost effectiveness of high quality intensive interdisciplinary neuro rehabilitation with respect to functional outcomes (rehabilitation should begin within the first 48 hours of acute onset),
- the positive correlation between earlier access and better functional outcomes for patients, and
- reduced burden of care and lifelong costs following specialist rehabilitation (Turner Stokes, 2008⁶; Turner- Stokes et al 2004⁷; Rice-Oxley and Turner Stokes 1999⁸);

Further evidence demonstrates that rehabilitation provided within a specialist setting for traumatic brain injury (TBI), Stroke (CVA) and Spinal Cord Injury (SCI) is effective and provides value for money by reducing length of stay (LOS) and the cost of care in the long term (Turner Stokes, 2008⁹; Turner- Stokes et al 2006¹⁰).

⁶ Turner-Stokes L (2008). Evidence for the effectiveness of multidisciplinary rehabilitation following acquired brain injury: a synthesis of two systematic approaches. *J Rehabil Med* 2008; 40: 691-701

⁷ Turner-Stokes L (2004). The evidence for the cost-effectiveness of rehabilitation following acquired brain injury *Clinical Medicine* 2004; 4[1]: 10-12

⁸ Rice-Oxley and Turner Stokes 1999. Effectiveness of brain injury rehabilitation. *Clinical Rehabilitation* 1999;13:7-24
Turner-Stokes L (2008). Evidence for the effectiveness of multidisciplinary rehabilitation following acquired brain injury: a synthesis of two systematic approaches. *J Rehabil Med* 2008; 40: 691-701

⁹ Turner-Stokes L, Paul S, Williams H (2006). Efficiency of specialist rehabilitation in reducing dependency and costs of continuing care for adults with complex acquired brain injuries *JNNP*; 77(5):634-639

Interdisciplinary Services:

A framework of interdisciplinary services will need to provide the appropriate continuum of care across Community Health Organisations, acute hospitals and post-acute rehabilitation services. The service design framework will need to recognise the valuable contribution of the interdisciplinary teams at each level of service delivery. Services will be determined and needs will be informed by clear assessment, referral and service protocols. These policies and protocols will identify the assessment, treatment and care that can be provided to an individual and the clinicians/professionals who will deliver this care in the various settings outlined below. The provision of services is intended to ensure equity of access to high-quality, reliable, person-centred care, delivered as close to the home as possible.

- **Acute hospital**
- **Complex specialist rehabilitation services**
- **Post acute specialist inpatient rehabilitation services**
- **Community based specialist rehabilitation services**
- **Primary care**
- **Voluntary Organisations**

The multi-tier model of levels of complexity of need (figure 3.0) forms the basis for the provision of specialist rehabilitation services in the UK. It is a model that translates well into the Irish context.

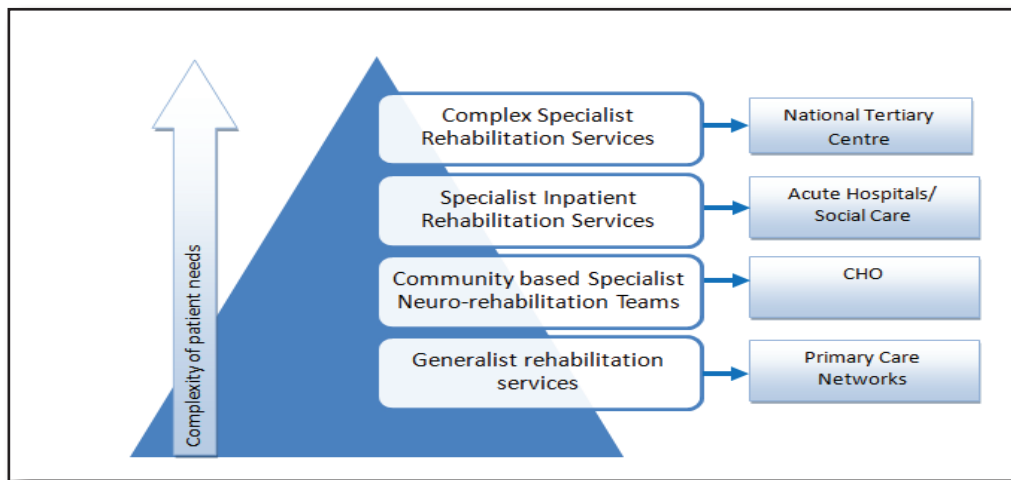


Fig.3.0; Levels of specialism as per Model of Care for Rehabilitation Medicine

* (Social Care title correct at time of publication of MOC- Social Care in its context references post acute inpatient facilities)

Benefits for people requiring neuro-rehabilitative services	Benefits for all Services
More efficient, joined up care	Cost effective services
Consistent care regardless of location	Improved access to rehabilitation beds / services
Service Designed with patients' needs at the centre	Partnership working to reduce handoffs and delays in the system
Understanding of how to re-access the services as the condition requires	Improved understanding of the type of care needed, appropriate activities, service complexity and dependency
Care delivered in the appropriate setting and as near to home as is practicable	Improved outcomes for the person and family from a holistic perspective

Table 1: Benefits of Implementation of the Strategy

Building on previous work

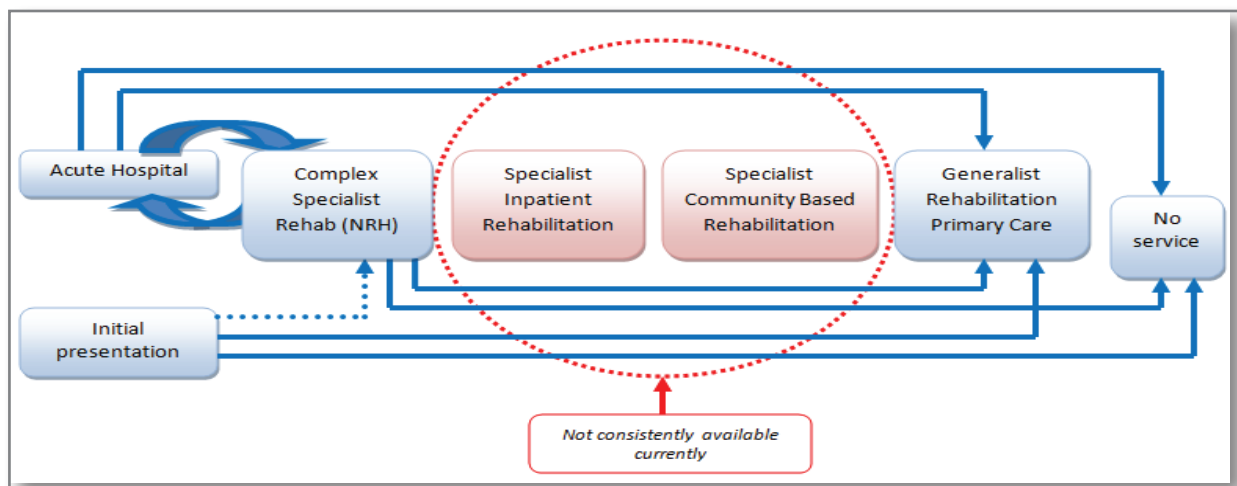


Fig 4; Gaps in current neuro-rehabilitation service provision

Neuro Rehabilitation Services Mapping:

A detailed mapping exercise was carried out by the NSG in Q3 2017 in an attempt to identify the dedicated neuro rehabilitation services and staffing across the country. There is a huge demand on the health and social care system to deliver dedicated neuro rehabilitation services across the patient's journey; however what has become evident from the mapping exercise is that the gap between demand and capacity for specialist rehabilitation services is ever widening. This is likely due to sustained improvements in retrieval and intensive care management of those who have sustained severe injuries or illnesses i.e. improvements in the area of stroke where recent advances in acute management of stroke have seen mortality rates drop significantly. Developments in neuro rehabilitation especially in the community have not kept pace with developments in the acute sector which has led to an ever increasing demand on neuro- rehabilitation services.

The information was gathered through a number of specific questionnaires which sought information on the following;

- Longer term neuro rehabilitation facilities/services
- Post-acute inpatient neuro rehabilitation facilities/services
- Community based neuro rehabilitation facilities/services
- Day services including Rehabilitative Training etc
- Services provided by Voluntary Organisations outside of the above headings

The questionnaires were disseminated to Chief Officers, post-acute inpatient units and voluntary providers. Questions asked referenced not only capacity of the services but also operational issues such as admission criteria, waiting times, and assessment processes etc.

Through the advancement of the demonstrator project, the information gathered for CHO 6 & 7 was validated. This process brought to light a number of additional services in operation within the catchment area which weren't initially included in returns from respondents.

The initial responses from each CHO will be made available to each local Implementation Team and will require similar validation in line with parameters given by the National Steering Group.

Benchmarks for appropriate ratios of Consultants in rehabilitation and multidisciplinary teams were reviewed ([British Society for Rehabilitation Medicine](#)) and the recommended staffing levels per service delivery site can be found in appendices 4 & 5.

Our research found there is a lack of consistency of dedicated neuro rehabilitation services across the country and where a person lives can influence the services that one receives locally. These services are provided directly by the HSE and by voluntary organisations. Further details on the mapping exercise are outlined in Step 3.

How should the Implementation Framework be used?

The Implementation Framework is a framework which provides a structured approach and guidance to the nominated person by the respective Chief Officer who has responsibility for overseeing implementation at local level. The 10 step framework also provides a template for reporting on structural and process metrics to the NSG. This approach is in keeping with the international experience of systemic change (Dixon-Woods et al, 2013¹¹; Greenhalgh et al, 2012¹², Dixon-Woods et al, 2011¹³, West et al, 2014¹⁴; Ovretveit, 2011¹⁵). This builds incrementally through small scale local successes which collectively deliver improved health and social care outcomes for people within a local population.

¹¹ Dixon-Woods et al, 2013. Culture and behaviour in the English National Health Service: overview of lessons from a large multimethod study. <http://dx.doi.org/10.1136/bmjqs-2013-001947>

¹² Greenhalgh et al, 2012. "If We Build It, Will It Stay?" A Case Study of the Sustainability of Whole-System Change in London. 2012 Sep; 90(3): 516-547. Published online 2012 Sep 18. doi: [10.1111/j.1468-0009.2012.00673.x](https://doi.org/10.1111/j.1468-0009.2012.00673.x). PMID: [22985280](https://pubmed.ncbi.nlm.nih.gov/22985280/)

¹³ Dixon-Woods et al, 2011. Large scale organisational intervention to improve patient safety in four UK hospitals: mixed method evaluation. *Bmj*, 2011 - bmj.com

¹⁴ West M, Eckert R, Steward K, Pasmore B. Developing Collective Leadership for Health Care. London: The King's Fund. Available at: <http://www.ctrtraining.co.uk/documents/DevelopingCollectiveLeadership-KingsFundMay2014.pdf>

¹⁵ Ovretveit, 2011. Understanding the conditions for improvement: research to discover which context influences affect improvement success. *BMJ Qual Saf*: first published as 10.1136/bmjqs.2010.045955 on 30 March 2011

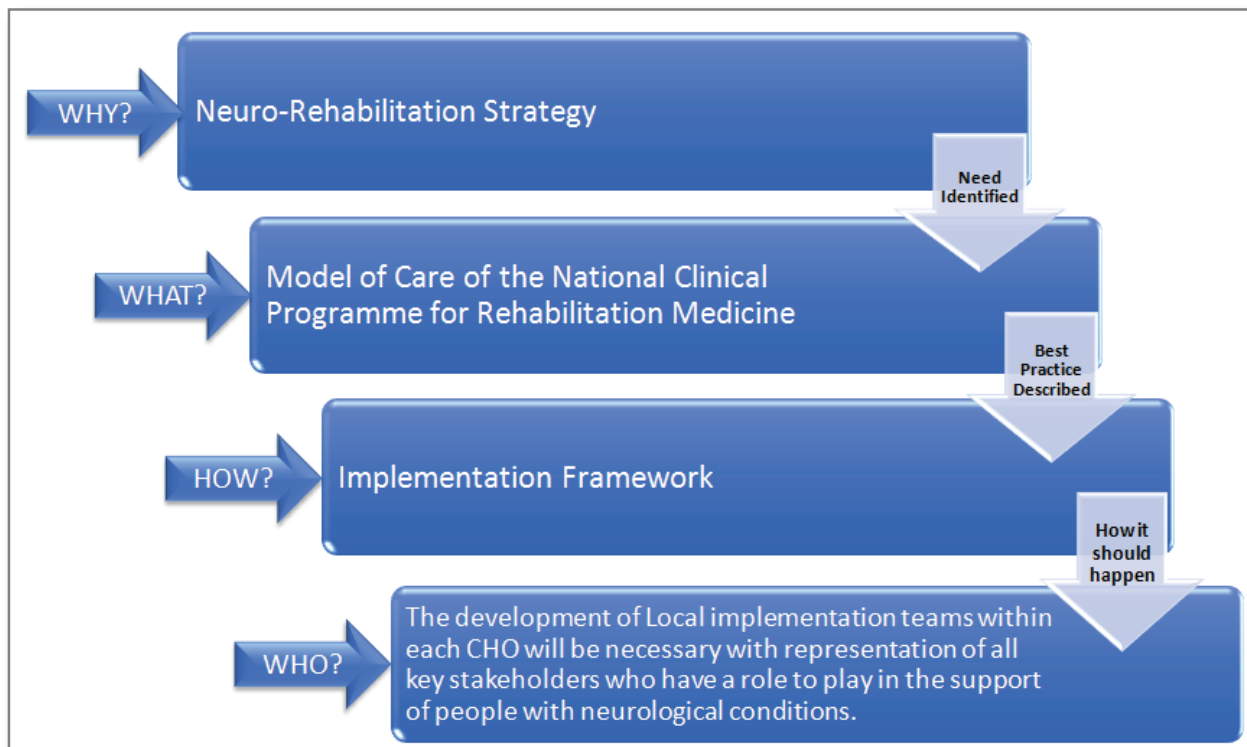


Fig 5; Steps to where we are now

Current Situation

Present Patient Journey

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. These services include specialist neuro-rehabilitation services at each level of the network, acute hospitals services, post acute facilities, community neuro-rehabilitation teams and voluntary organizations

Without development of these services, access to specialist neuro-rehabilitation services will remain as they are, with patients awaiting services, primarily of the national tertiary centre (in the absence of all other services), in acute hospitals and wholly avoidable discharge back to acute hospital in the absence of supports in the community. Limited access to specialist rehabilitation services, both inpatient and community based can be directly linked to inappropriate use of beds in acute hospitals. If specialist rehabilitation services are resourced adequately thousands of acute hospital bed days could be freed for treatment of other acutely ill patients presenting to emergency departments.

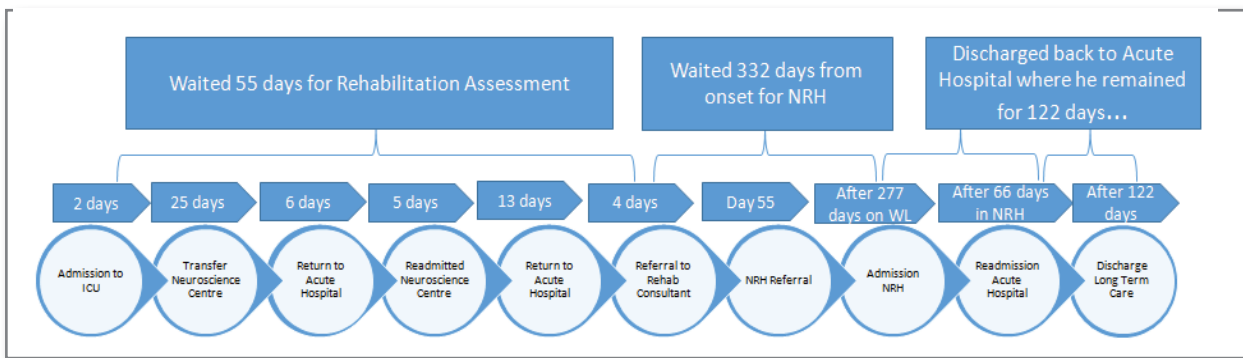


Fig 6; Example of one patient's journey



Fig 7; The ideal patient journey

The Vision

Generally, patients requiring specialist neuro-rehabilitation are those with complex disabilities. Such patients typically present with a diverse mixture of medical, physical, sensory, cognitive, communicative, behavioural and social problems, which require specialist input from a wide range of rehabilitation disciplines (e.g. rehabilitation-trained nurses, physiotherapy, occupational therapy, speech and language therapy, psychology, dietetics, orthotics, social work etc.) as well as specialist medical input from consultants trained in rehabilitation medicine, neuropsychiatry and other relevant specialities.

Current BSRM recommendations for specialist rehabilitation service provision are:

A minimum of 60 beds per million population for specialist in-patient rehabilitation medicine i.e. 288 for Irish population (This figure assumes other services are locally available for stroke rehabilitation and for rehabilitation of older people, nevertheless, a significant number of stroke patients, especially those of working age, require specialist rehabilitation to maximise their opportunities for return to independence and previous extended roles such as work, parenting etc). The minimum size of an inpatient specialist rehabilitation unit should normally be around 20 beds to achieve critical mass.

The beds must be co-located, together with therapy facilities, to provide a rehabilitative environment and to support co-ordinated inter-disciplinary team-working between nursing, therapy and medical teams.

In addition, complex specialised rehabilitation (tertiary) services should be provided for patients with complex rehabilitation needs e.g. severe brain or spinal cord injury, low awareness states, challenging behaviour or concurrent complex medical needs. These should:

- be provided in co-ordinated service networks over a population of >1-3 million
- be expected to have special facilities and to take a demonstrably more complex case-load, for which higher staffing levels will be required
- be subject to specialised commissioning arrangements¹⁶

It is acknowledged that each CHO area/hospital group will have specific challenges/issues in terms of implementation. The local team will need to have representation from all stakeholders in the specific localities who will need to work together to support implementation. As such, membership may vary across the country. The role of this local team will be largely operational and should include a mix of both clinical and service representatives.

The BSRM describes the requirements for community-based specialist rehabilitation services per million of population. Given the geographical spread of the country, the NCPRM would advocate for the adaptation of these recommendations to align with existing CHO structures i.e. fully dedicated Specialist Community Neuro-Rehabilitation Teams per CHO consisting of statutory and voluntary service providers. The configuration of the teams may also be open to local interpretation, particularly where the large geographic areas are expected to be covered.

The NCPRM is not prescriptive with respect to location of specialist rehabilitation services. What it does specify is the need for the development of population-based services as recommended by the BSRM.

Demonstrator Managed Clinical Rehabilitation Network Project

The overarching aim is the development of population based managed clinical rehabilitation networks around the country. As this is a fundamental change in the way rehabilitation services are delivered, it was felt to be appropriate to undertake a change management model to test ahead of the national implementation. As such, the decision was taken to advance a demonstrator pilot project across CHO 6 & 7 involving the NRH, Peamount Healthcare and the Royal Hospital Donnybrook and associated referring hospitals including St Vincent's University Hospital within CHO Area 6 and Tallaght & St James Hospitals within CHO Area 7 and their respective community rehabilitation services. Areas being explored include common waiting lists, direct referral protocols and delayed discharge information from the acute hospitals.

What has also become evident is that it is not possible to determine neuro-rehabilitation needs solely on the basis of the HSE National Delayed Discharge weekly report. An extensive review of population and population needs across the demonstrator sites has shown there is an ever increasing demand and complexity of referrals to NRH in recent years, in November 2016, there were 124 patients waiting for inpatient beds at the NRH compared with 195 in November 2017 as our census shows. This is an increase of 50% of patients needing specialist inpatient services. The NRH throughput has remained constant across the year at <60 patient per quarter, therefore the beds are being utilised to capacity, however the increase in demand is leading to excessive waiting

¹⁶ <https://www.bsrm.org.uk/downloads/standardsmapping-final.pdf> accessed April 2018

times for patients, some of whom could be managed in local and or community based services. While the In Patient Waiting lists (IPWL) contains almost 50% high dependency patients who require NRH Level 1 specialist services, there is a cohort of moderate-low dependency patients that could have their rehabilitation needs met elsewhere.

Even where post acute services provide neuro rehabilitation to patients there can be a gap between admission and discharge criteria and patient needs, resulting in patients receiving their rehabilitation in acute centres rather than in the more appropriate setting. This will require significant work to change across the system. The MCRN will be a good example of highlighting areas of difficulty. One must note that some of our acute hospital services have the capacity to deliver high quality neuro rehabilitation.

Without access to community neuro rehabilitation teams, patients may become delayed in NRH. In 2016, 2845 days were lost to delayed discharge, equating to 44 full admissions with a LOS each of 64 days. The development of services across the continuum of care would see improvements in patient flow, with patients accessing the service that most meets their needs at the right time.

While there is a requirement to develop services across all service delivery sites, this Demonstration Project is based on developing both post-acute rehabilitation services and community based neuro rehabilitation services in particular. Consideration needs to be given to both pathways into and out of services to support them to function within a network model and maximise efficiency and effectiveness. This is hugely important to the success of the Demonstration Project to show the full benefit of a MCRN.

The primary and secondary drivers and target areas for improvement are outlined below.

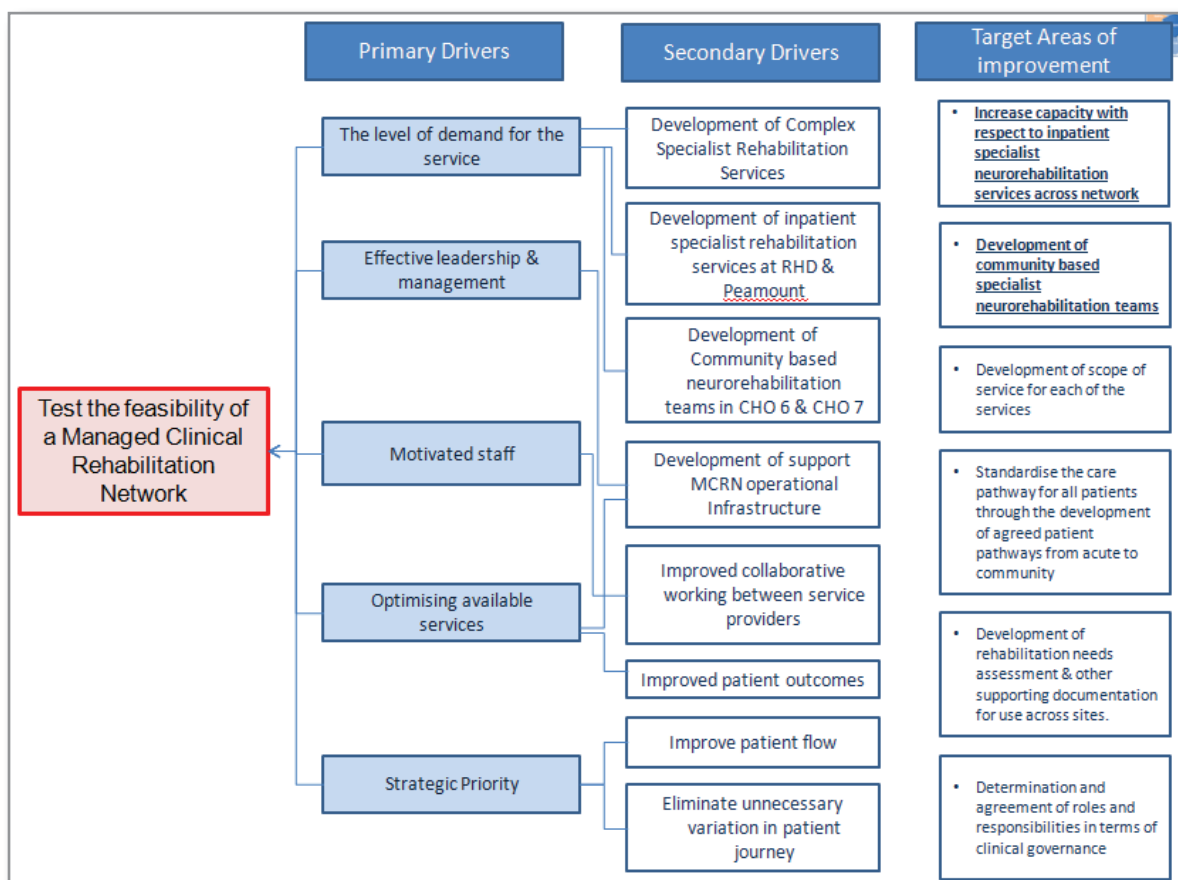


Fig 8; Driver Diagram for MCRN Demonstrator

What we want to achieve through this demonstration pilot site MCRN:

- Person centred coordinated approach to patient care,
- Development of appropriately resourced interdisciplinary inpatient, outpatient and home and community based specialist rehabilitation teams supported by education and training,
- Coordinated case management of patients,
- The three-tier model of complexity-of-need,
- Reduction in Waiting times for assessment and access to inpatient & community rehabilitation services,
- Improved patient outcomes and experience,
- Standardised pathway for people who require neuro rehabilitation,
- Standardised common assessment and referral system for the 3 sites involved in the demonstration project & community,
- Enhanced communication between inpatient and community services to support to delivery of the right care, in the right place, at the right time,
- Build up a supporting infrastructure for the demonstration project to deliver neuro rehabilitation to patients as required across the continuum of care,
- Develop a model of care that can be rolled out nationally.

While not fully operational as yet, the learning from the initial stages of development have helped inform the development of the Implementation Framework. As the demonstrator progresses, local implementation teams will be kept up to date with emerging information that may have national application. While it is acknowledged that the configuration of services into a network model is dependent on initial development of these services, the MCRN model provides the best possible opportunity to achieve the overarching goals of the Neuro rehabilitation Strategy which are;

- **Goal 1** is to provide a service that is LITI, meaning:
 - o Local; Rehabilitation where I need it.
 - o Individualised; Rehabilitation the way I need it.
 - o Timely; Rehabilitation when I need it.
 - o Integrated; Rehabilitation should I need it.
 - The underpinning principles of Goal 1 are:
 - person-centred;
 - dignity and respect;
 - service user participation;
 - responsive to need;
 - Access to information.
- **Goal 2** is the creation of a flexible, responsive and accountable system that will fully support the realisation of Goal 1, with the following underpinning principles:
 - equity;
 - person-centred;
 - effective;
 - efficient;
 - quality;
 - accountable and transparent;
 - Responsive.

Evaluation of the Demonstrator will be measured against the targeted areas of improvement as outlined above. The learning from the demonstrator will assist with informing NSG and subsequent Local Implementation Teams with respect to lessons learned.

Current Policy Drivers

1. A Trauma System for Ireland 2018:

The development of evidence-based and informed population needs is the basis for care pathways from prevention through to rehabilitation. This major report provides the blueprint for how we organise and deliver care for those who suffer traumatic injuries. With respect to Rehabilitation, the Trauma Report recommends the following:

- The HSE should ensure that all trauma patients in Major Trauma Centres, Trauma Units and Trauma Units with Specialist Services can access rehabilitation and have their rehabilitation needs assessed within 48 hours of admission, generating a flexible personal prescription for rehabilitation that should accompany all patients as they transition through the pathway.
- The HSE should ensure coordinated development of regional and community rehabilitation services and long-term support, to meet the needs of all trauma patients within a Trauma Network. This should include appropriately resourced and skilled Community Neuro Rehabilitation Teams (CNRTs), co-ordination with disability services and the appointment of case managers.

The NSG was pleased to see the inclusion of acute rehabilitation facilities/teams as recommended designation criteria for both Major Trauma Centres (MTC) and Trauma Units (TU). While actual hospital sites to be designated as either MTC or TU are as yet unspecified, their inclusion in MCRNs is essential. In terms of trauma networks, there will be 2 networks developed, a central network and a southern network. There are 16 hospitals identified that could potentially meet the criteria of TU. We also know that within these hospitals, 2 MTC will be identified.

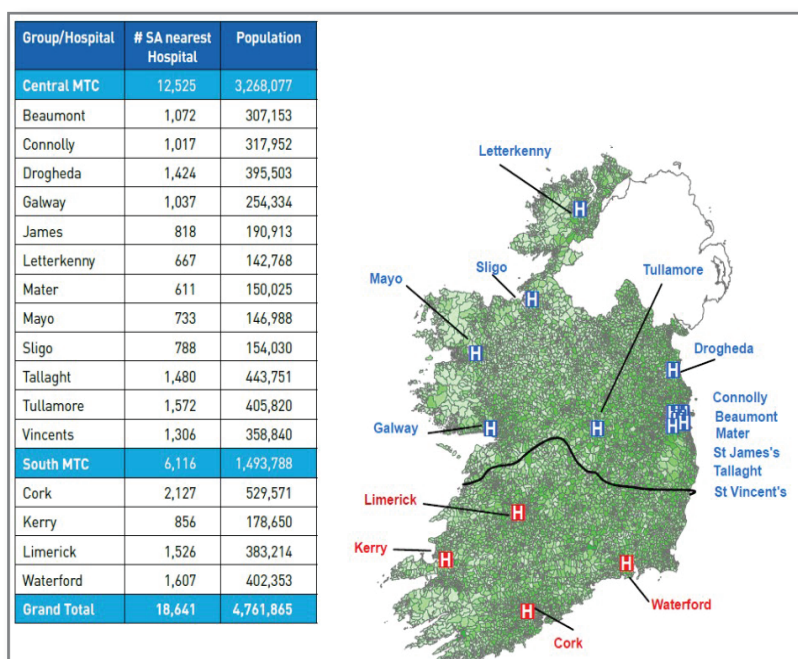


Fig 9: Potential sites for Major Trauma Centres and Units

The potential for post-acute inpatient rehabilitation facilities to be co-terminus with both MTC's and TU's will need to be explored as the plan for implementing trauma policy advances and sites are identified.

2. Committee on the Future of Healthcare- Sláintecare Report May 2017:

The principles outlined in this report are reflective of the aim of the strategy specifically with respect to the following;

- All care planned and provided so that the patient is paramount (ensuring appropriate care pathways and seamless transition backed-up by full patient record and information,
- Timely access to all health and social care according to medical need,
- Care provided free at point of delivery, based entirely on clinical need,
- Patients accessing care at most appropriate, cost effective service level with a strong emphasis on prevention and public health,
- Greater alignment of service provision for integrated care across care domains should be implemented at Community Healthcare Networks (CHN) level.
- Disability policy actively promotes living in the community and person-centered services for people with disabilities. People with disabilities should have priority access to a range of community care services, such as public health nurses, home helps, personal assistance, psychological services, speech and language therapy, occupational therapy, social work services, physiotherapy, day care and respite care.

3. Health Service Capacity Review 2018- Executive Report Review of Health:

This report is based on a desired future state for the health service. It seeks to demonstrate the potential impact on capacity across the health service of three interlinked reform areas, namely:

- Health and wellbeing initiatives,
- An improved model of care that repositions the health service towards a community-based care model.

The measures outlined in this document are not new and are very much in line with proposals in the Sláintecare report and various other national policy documents. These are clearly not the only changes that could or should occur over the next 15 years. The case for the development of a more integrated, proactive and community-based care model is broadly accepted. More proactive and planned care in the community, greater provision of home care, short term respite and step down care, better use of ambulatory care, and improved care pathways within and between healthcare sectors can all lead to a more effective model of care and improved health outcomes.

4. National Planning Framework Project Ireland 2040¹⁷:

Project Ireland 2040 represents an important shift from previous approaches to long-term planning and investment by Government. This document is a planning framework to guide development and investment over the coming years. It describes capital developments required to support the transformation of healthcare delivery and increasing capacity of healthcare services in the community. It also specifically references the redevelopment of the National Rehabilitation Hospital and establishment of Disability Rehabilitation Centres across the country. The provision of Day Hospitals, Day care centres as part of the Strategy, is also referenced.

¹⁷ Ireland 2040- Our Plan -National Planning Framework Project- A Government of Ireland Policy.

Part 2 - Plan of Action

Framework for Implementation

This plan is the implementation framework for the Strategy. The stages outlined in this plan follow the 10-step approach adopted by the National Integrated Care Programme for Older Persons. This approach is based on clear governance structures and development of services in response to a population planning and mapping approach at local level. The framework outlines the need for the development of local implementation teams in each CHO. The NSG is the governing body for the implementation framework and will provide guidance and support to the local implementation teams.

Local implementation teams will be required to oversee the development of a range of interdisciplinary services to provide the appropriate continuum of care across Community Health Organisations, acute hospitals and community rehabilitation services. It is envisaged these local service frameworks will be merged over time into a number of population based managed clinical rehabilitation networks as the long term vision for the development of rehabilitation services. Local implementation teams will need to ensure that clear links are developed with all potential referral sources including neurology, mental health and older age medicine services including shared care arrangements where necessary.

Ongoing linkages at national level with the National Stroke Programme will assist with informing the implementation of the IF in relation to the neuro-rehabilitation needs of stroke patients. In a similar fashion, there will be ongoing engagement with the National Clinical Programme for Neurology.

Step 1:

Establish Appropriate Governance Structures to Oversee the Development and Delivery of Specialist Neuro-Rehabilitation Services

Local Service Improvements driven by Local Implementation Team supported by the National Steering Group

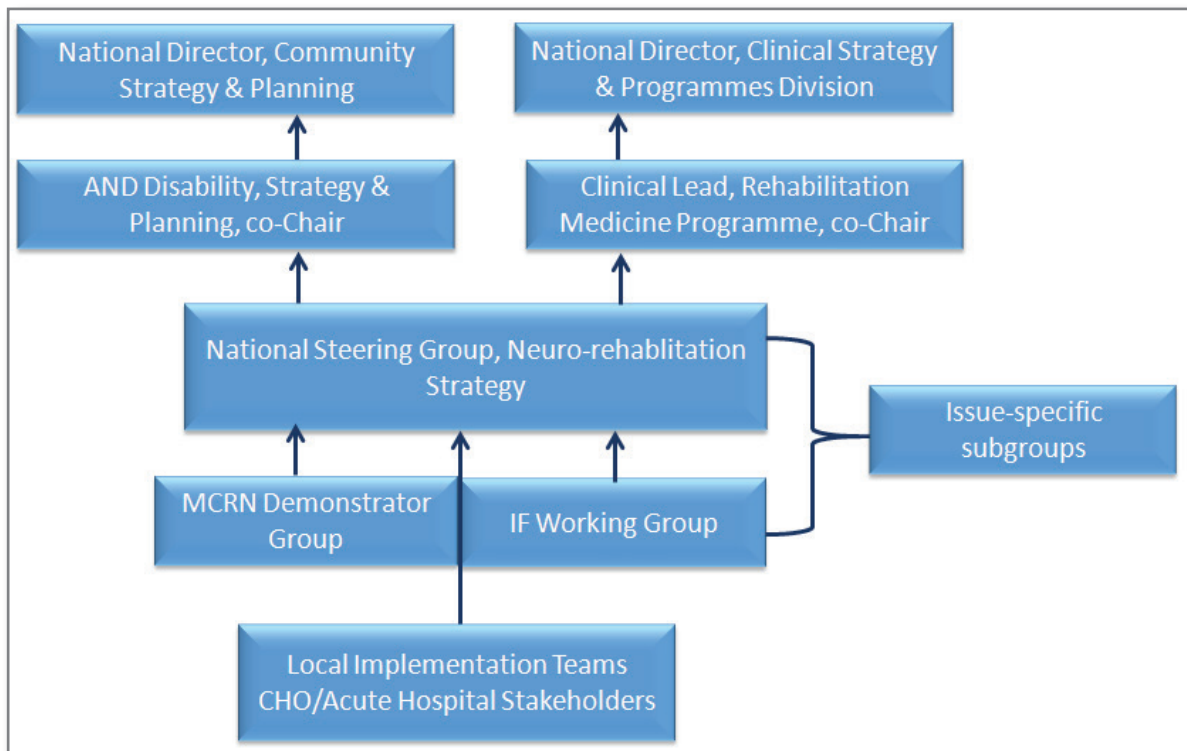


Fig 10; Current Governance Structure

The Governance Structure for the NSG and Working Group is overseen by Ms Marion Meany, Disability Services Strategy and Planning and the National Director, Clinical Strategy & Programmes Division.

Membership of NSG

- AND Disability Services - Strategy and Planning (Co-Chair)
- Clinical Lead, Rehabilitation Medicine Programme (Co-Chair)
- Project Manager, Neuro-rehabilitation Strategy
- Head of Social Care CHO 7
- Programme Manager, National Clinical Programme for Epilepsy, Neurology & Rehabilitation Medicine
- Acute Hospitals Representative
- Health and Wellbeing/Population Health Representatives
- Primary Care Representative

- National Rehabilitation Hospital Representative
- HSCP representative
- Neuropsychiatry Representative
- Mental Health Division Representative
- Neurological Alliance of Ireland representing all of the NAI organisations & people with neurological conditions. (NAI member organisations include; An Saol, Ataxia Ireland, Acquired Brain Injury Ireland, Alzheimer Society of Ireland, Aphasia Ireland, Bloomfield Health Services, Cheshire Ireland, Chronic Pain Ireland, Dystonia Ireland, Epilepsy Ireland, Enable Ireland, Headway, Irish Heart Foundation, Irish Hospice Foundation, Irish Motor Neurone Disease Association, Huntington's Disease Association of Ireland, Migraine Association of Ireland, Move4Parkinson's, Multiple Sclerosis North West Therapy Centre, MS Ireland, Muscular Dystrophy Ireland, Neurofibromatosis Association of Ireland, Parkinson's Association of Ireland, Polio Survivors Ireland, The Rehab Group, Spina Bifida Hydrocephalus Ireland, Spinal Injuries Ireland).

The Formation of Local Implementation Teams

The Implementation Framework describes the requirement for the development of local implementation teams. These teams will be made up of all the relevant stakeholders with similar representation to the NSG membership recommended. The local implementation teams will have responsibility for the enhancement/development of neuro-rehabilitation services in the community and appropriate pathways to and from acute and inpatient neuro-rehabilitation services. Development of acute and inpatient neuro-rehabilitation services will be in line with the recommendations of the Model of Care for Rehabilitation Medicine. The local lead, as identified by the Chief Officer, will need to ensure there is effective liaison with other services, including those whose operations are not co-terminus with existing CHO boundaries including hospital groups and voluntary and other providers. A challenge for the local implementation teams will be to mobilise all resources at local level in order to support the effective delivery of neuro-rehabilitation services.

Local implementation teams will be responsible for the implementation of the 10 step plan within the CHO for the delivery of neuro-rehabilitation services. This will address local service arrangements, service delivery, clinical governance and communication as well as a range of administrative aspects such as referral management, record management, quality improvement and reporting of identified KPI's.

As the nominated person by the Chief Officer to implement this framework, one will have responsibility for forming a local implementation team for neuro rehabilitation services if one does not already exist.

The outputs of the mapping exercise received from the CHO undertaken by the NSG in Q 3 2017 will be available through the NSG. The nominated lead will be required to validate this data and amend accordingly. The mapping exercise will inform the lead regarding the requirement of enhancing/developing the range of interdisciplinary services to provide the appropriate continuum of care across the Community Health Organisation, acute hospital and community rehabilitation services. It is envisaged these local service frameworks will be merged over time into a number of population based managed clinical networks as the long term vision for the development of rehabilitation services.

Information on population needs assessment per CHO is highlighted in the IF, a local population needs assessment should be carried out to ensure there is full visibility of the needs of the people within the CHO that have neuro rehabilitation requirements,

Each Local implementation team will need to ensure that clear links are developed with all potential referral sources including neurology, mental health and older age medicine services including shared care arrangements where necessary. These teams will also have to take note of the current service provision of neuro rehabilitations services within each CHO and where these services have age restrictions how equitable is this under equality legislation.

Monitoring and Evaluation

The monitoring and evaluation of progression at local level will be monitored through a suite of KPI's. In addition the local implementation teams will need to submit a yearly work plan to the NSG with proposed timeframes for implementation which will be overseen by the N SG. The Co Chairs of the NSG will have responsibility for overseeing the delivery of the IF.

Communication

The Working Group has developed a Communication Plan to assist the teams at local level. The Local Implementation Teams will be required to adapt this communication plan where relevant so stakeholders are kept informed of progress being made on implementation.

Comprehensive guidance will be given by the NSG to support implementation at local level. This will continue to be informed by the experience of the Neuro-rehabilitation Demonstrator Project (CHO 6 & 7).

The terms of reference for both working groups previously mentioned have been developed to support their work and give guidance of their roles and functions, providing all members will clear terms of accountability and responsibilities. These Terms of Reference will be made available to local implementation teams.

Deliverable	1.0	Establish Appropriate Governance Structures at local level	Responsibility	Timeframe
Steps	1.1	Establish a local implementation group with representation from list above	This will be supported through NSG	Q1 2019
Steps	1.2	Agree Terms of Reference	Draft TOR will be provided by NSG for consideration/ revision at local implementation team level	Q1 2019
Steps	1.3	Agree work plan for 2019	Agree work schedule for 2018/2019 based on the 10-step framework	Q1 2019

Table 2; Actions for Implementation of Step 1 of 10 step Framework

Step 2:

Population Planning Project

Service developments informed by current and future anticipated population needs

Needs Assessment

Needs vary depending on the severity of the deficit and the personal circumstances of each patient and can relate to scores of physical function but also cognitive, social and psychological function and ultimately quality of life. Diagnostic grouping does not necessarily give a reliable indication of the existing neuro-rehabilitation needs of a person however it is sometimes necessary to rely on research based on specific diagnoses to extract evidence for broader service planning.

In an ideal situation it would be possible to present data from all levels of service use for those with neuro-rehabilitation needs. This would include data from emergency departments, admissions to acute hospitals, community neuro-rehabilitation services and primary care. However, this needs assessment has only been able to source data from the acute hospital setting. This has meant that there is a focus on studying hospital admissions as a measure of normative need within the population but this does not take into account the health needs provided for in the community for which data was not available. This is an important consideration for future assessments.

Analysis on admission and discharge data was performed using the Hospital Inpatient Enquiry (HIPE) dataset for 2016. Data used in the comparative analysis of European Union countries was taken from Eurostat for the last year for which the necessary data was available, 2014. Regional breakdown within Ireland was based on Community Health Organisation (CHO). For the purposes of this analysis it was not possible to separate the populations of CHOs 6 and 7 accurately and therefore they were analysed together. EU comparator countries were chosen based on those in Ireland's peer group.

Every inpatient discharge from a public hospital in Ireland is entered into the HIPE database. HIPE data for each discharge includes demographic details, details relating to the hospital stay and the relevant diagnosis/diagnoses coded using the International Classification of Diseases (ICD) codes. Patients were identified as potentially requiring neuro-rehabilitation support based on their principle diagnosis for each inpatient stay. Diagnoses that may require neuro-rehabilitation were identified using the National Neurology Intelligence Network's (NIN) disease categories, published by Public Health England in 2015¹⁸.

Categories that were deemed to have a significant need for neuro-rehabilitation input included;

1. Central nervous system (CNS) infections,
2. Motor neurone disease (MND) and Spinal muscular atrophy (SMA),

¹⁸ National Neurology Intelligence Network's (NIN) disease categories, published by Public Health England in 2015

3. Multiple sclerosis (MS) and inflammatory disorders,
4. Neuromuscular diseases (NMD),
5. Parkinsonism and Other Extrapyrmidal disorders/Tic disorder,
6. Peripheral nerve disorders (PND),
7. Spondylotic myelopathy and Radiculopathy (SMR),
8. Traumatic brain and spine injury (TBSI),
9. Tumours of the nervous system(TNS) and,
10. Rare and other neurological diseases,
11. Cerebral Vascular Disease (CVD).

A sub-group analysis was not performed for “Rare and other neurological diseases”, however they were included in the combined “All neurological diagnoses” analysis.

In addition to these categories a further diagnostic grouping for cerebrovascular diseases was included in the analysis and sub-group analysis. This comprised of those with a principle diagnosis ICD code between I60 and I69. These are similar to the codes included in the analysis performed for the “Irish Heart Foundation/HSE National Stroke Audit 2015¹⁹”, but also includes codes under I69 (Sequelae of cerebrovascular disease) as these were considered relevant for the purposes of neuro-rehabilitation.

Data from Eurostat did not allow for the categories defined by the NIN to be used for analysis. Three disease categories were used;

- ICD-10 Classification G00-G99: Diseases of the nervous system (excluding G30, Alzheimer’s disease)
- ICD-10 Classification I60-I69: Cerebrovascular disease
- ICD-10 Classification S06: Intracranial injury

For the purposes of descriptive statistics retrieved from HIPE an age limit of 18 years or over was to be consistent with the current services provided by community neuro-rehabilitation teams. For comparative analysis populations were standardised to the European Standard Population 2013. Population data for Ireland and other European countries were taken from Health Atlas and Eurostat. For the age-standardised analysis only those between the ages of 20-85 years were included as the accurate population demographic breakdown necessary was not available for other ages.

By using the principle diagnosis as the means to identify those who potentially require neuro-rehabilitation input, there are patients who needed rehabilitation but were not included in the analysis because their neurological or neuro-psychiatric condition was listed as a secondary diagnosis (e.g. those admitted following a fall because of an underlying neurological diagnosis). The rationale for the use of principle diagnosis as the variable of interest is that it will not include patients who present to hospital with a condition not requiring neuro-rehabilitation but who have a chronic neurological condition recorded as a secondary diagnosis. Of patients transferred to the National Rehabilitation Hospital in 2016 showed that only 64 of the 134 discharges (47.8%) recorded a principle diagnosis that would be included within the analysis performed which suggests that there are many patients not considered in the HIPE analysis performed.

¹⁹ Irish Heart Foundation/HSE National Stroke Audit 2015

Total Bed Days, inpatients 2016, aged > 18 years									
	All	CHO 1	CHO 2	CHO 3	CHO 4	CHO 5	CHO6 +7	CHO 8	CHO 9
All ¹	234,347	24,378	21,233	17,218	26,632	24,786	60,062	25,397	32,949
CVD ¹	122,524	12,063	11,450	9,135	14,804	12,190	31,529	12,981	17,496
TBSI ¹	29,823	3,364	1,938	1,551	3,169	3,159	8,174	3,670	4,197
TNS ¹	18,694	2,637	1,744	845	1,916	2,528	4,054	2,613	2,305
MS ¹	7,565	838	687	696	924	801	1,716	997	899
Parkinson's ¹	13,557	1,764	1,107	1,127	1,220	1,048	3,211	1,630	2,444
NMD ¹	4,767	413	561	421	508	614	1,224	342	632
PND ¹	1,273	107	78	44	178	384	145	127	209
CNS infections ¹	10,570	856	988	1,116	1,395	1,454	2,735	912	1,062
SMR ¹	9,646	781	1,303	496	1,299	899	2,366	695	1,805
MND/ SMA ¹	2,016	144	344	59	388	152	534	205	190

1. All = All Neurological Diagnoses, CVD = Cerebrovascular diseases, TBSI = Traumatic brain and spine injury, TNS = Tumours of the Nervous System, MS = Multiple sclerosis and inflammatory disorders, Parkinson's = Parkinsonism and Other Extrapyrimal disorders/Tic disorder, NMD = Neuromuscular diseases, PND = Peripheral Nerve Diseases, CNS = Central nervous system, SMR = Spondylotic myelopathy and Radiculopathy, MND/SMA = Motor neurone disease and Spinal muscular atrophy

Table 3; Total Bed days per diagnosis and per CHO

Average length of stay in days, inpatients 2016, aged > 18 years									
	All	CHO 1	CHO 2	CHO 3	CHO 4	CHO 5	CHO6+7	CHO 8	CHO 9
All ¹	13.6	13.8	11.5	11.6	10.2	12.9	18.4	12.1	15.6
CVD ¹	16.5	16.6	15.8	13.7	14.0	15.5	20.2	14.6	18.5
TBSI ¹	12.9	13.4	9.1	9.8	13.0	10.5	20.7	10.5	12.5
TNS ¹	12.8	13.6	10.9	9.5	9.4	13.8	15.5	12.9	14.6
MS ¹	9.0	5.9	5.4	8.9	7.0	12.3	13.0	10.7	13.2
Parkinson's ¹	16.6	16.5	10.4	11.7	10.4	16.1	27.0	15.4	25.2
NMD ¹	9.8	8.8	8.5	8.4	7.5	12.5	10.6	8.1	14.4
PND ¹	4.5	4.7	1.7	2.3	2.7	8.5	4.8	4.9	8.4
CNS infections ¹	16.1	15.6	14.5	16.9	16.0	19.1	18.2	13.4	13.6
SMR ¹	6.7	7.6	8.4	4.8	3.0	4.9	13.6	5.2	11.8
MND/ SMA ¹	12.8	18.0	13.2	9.8	10.0	15.2	12.1	14.6	19.0

1. All = All Neurological Diagnoses, CVD = Cerebrovascular diseases, TBSI = Traumatic brain and spine injury, TNS = Tumours of the Nervous System, MS = Multiple sclerosis and inflammatory disorders, Parkinson's = Parkinsonism and Other Extrapyrimal disorders/Tic disorder, NMD = Neuromuscular diseases, PND = Peripheral Nerve Diseases, CNS = Central nervous system, SMR = Spondylotic myelopathy and Radiculopathy, MND/SMA = Motor neurone disease and Spinal muscular atrophy

Table 4; Average Length of Stay per diagnosis and per CHO

Age-adjusted bed days per 100,000 population¹, inpatients 2016, ages 20-85 years									
	All	CHO 1	CHO 2	CHO 3	CHO 4	CHO 5	CHO6+7	CHO 8	CHO 9
All ²	7121.2	8,353.2	6,040.9	6,180.7	5,805.9	6,515.3	8307.2	6,613.3	8,570.1
CVD ²	3,683.8	3,944.5	3,156.7	3,231.8	3,148.6	3,040.4	4,416.3	3,344.1	4,623.5
TBSI ²	849.8	1,093.3	518.0	573.2	663.9	815.6	1,019.2	934.3	1,028.8
TNS ²	614.4	1,011.7	538.4	306.9	435.3	717.7	603.6	718.5	661.3
MS ²	216.3	288.0	206.9	240.8	205.6	215.1	199.0	218.2	197.7
Parkinson's ²	471.0	682.7	304.5	467.4	297.6	327.5	542.4	456.3	680.0
NMD ²	140.3	148.0	115.4	166.3	116.5	156.0	162.3	89.4	136.5
PND ²	42.7	47.6	23.4	18.9	45.5	128.6	24.0	30.2	52.4
CNS infections ²	316.9	307.8	312.7	359.2	313.9	400.3	371.6	225.4	233.1
SMR ²	283.8	284.7	433.6	194.5	316.7	252.7	248.3	180.0	426.6
MND/ SMA ²	73.19	60.0	115.4	14.4	87.3	54.1	89.9	72.0	61.3

1. Adjusted to European Standard Population 2013
2. All = All Neurological Diagnoses, CVD = Cerebrovascular diseases, TBSI = Traumatic brain and spine injury, TNS = Tumours of the Nervous System, MS = Multiple sclerosis and inflammatory disorders, Parkinson's = Parkinsonism and Other Extraparamidal disorders/Tic disorder, NMD = Neuromuscular diseases, PND = Peripheral Nerve Diseases, CNS = Central nervous system, SMR = Spondylotic myelopathy and Radiculopathy, MND/SMA = Motor neurone disease and Spinal muscular atrophy

Table 5; Age adjusted bed days per 100,000 per diagnosis and per CHO

It must be noted that data from community and primary care services was not consistently available and could not be used to accurately inform the development of the framework.

Sudden Onset Conditions

Many factors have contributed to a substantial and enlarging number of disabled individuals in Ireland; certainly, diagnostic accuracy and disease registration systems have improved. Over the past 20 years sustained improvements in retrieval and intensive care management of those who have sustained severe injuries have yielded a group of patients who demonstrate slow and incomplete recoveries. Improved immunological therapies and other high-cost treatments have ensured the survival of many more patients. Another example of such improvements is in the area of stroke where recent advances in acute management of stroke have seen mortality rates dropped significantly. Many of these survivors however have ongoing rehabilitation needs post stroke.

Development of an effective trauma network has the potential to increase survival of those suffering major trauma by up to 30%. UK reports the odds of surviving major trauma were 63% better in 2014/15 than in 2008/2009. These people are likely to have significant rehabilitation requirements. Trauma Networks will fail if not supported by a well-developed rehabilitation network.

Progressive Conditions

The HIPE data used in this analysis cannot estimate number or the level of need for these patients with progressive neurological conditions in the community. Reliable disease registers for these conditions are not available in Ireland currently. This means that the estimation of incidence and prevalence of neurological disease relies on once off studies that may not be translatable to the entire population. For the purposes of this population needs assessment Multiple Sclerosis and Idiopathic Parkinson's Disease, two of the most important neurological conditions from the perspective of neuro-rehabilitation services within the pathway of care, were scoped to estimate their prevalence within the population.

A systematic review in 2013 identified 5 prevalence studies of MS in Ireland between 1989 and 2008²¹. These studies have estimated the prevalence of MS in Ireland at between 100.96-255.71 people per 100,000²¹²²²³²⁴. Translated onto the population from the 2016 census data (4,761,865 people), this would suggest that between 4,808 and 12,177 people in Ireland have a diagnosis of MS. However, this is a very crude estimate which does not account for demographic changes or a possible increase in the incidence of MS over the past 20 years²⁵.

Similarly when trying to estimate the prevalence of Idiopathic Parkinson's Disease there is no register and no prevalence studies from Ireland were identified for this needs assessment. Previous estimates in an Irish population have used data on prevalence from the UK. Methodologies of estimating IPD prevalence are heterogeneous and have resulted in wide variations in reported prevalence figures²⁶. A study by Schrag et al, in 2000, estimated prevalence in a community based cohort of patients in London using the criteria of the UK Parkinson's Disease Society Brain Bank, broken down by age and sex²⁷. Using these figures, translated into the population based on the 2016 census, it could be estimated that there are 6,917 people with a diagnosis of IPD in Ireland.

There are difficulties in estimating the numbers of patients with neuro-rehabilitation needs secondary to progressive neurological disorders in the community which are beyond the ability of this assessment to overcome. However, there is an unmet felt need which has been repeatedly expressed by both healthcare professionals and patients which is not easily quantifiable.

²⁰ Kingwell E, Marriott JJ, Jetté N, Pringsheim T, Makhani N, Morrow SA, et al. Incidence and prevalence of multiple sclerosis in Europe: a systematic review. *BMC neurology*. 2013;13(1):128

²¹ Gray O, McDonnell G, Hawkins S. Factors in the rising prevalence of multiple sclerosis in the north-east of Ireland. *Multiple Sclerosis Journal*. 2008;14(7):880-6.

²² Hawkins S, Kee K, editors. The changing prevalence of multiple sclerosis in Northern Ireland with reference to benign multiple sclerosis. Recent advances in multiple sclerosis therapy: proceedings of the Vth Congress of the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS), Brussels, 16-18 March 1989; 1989

²³ McDonnell G, Hawkins S. An epidemiologic study of multiple sclerosis in Northern Ireland. *Neurology*. 1998;50(2):423-8

²⁴ McGuigan C, McCarthy A, Quigley C, Bannan L, Hawkins S, Hutchinson M. Latitudinal variation in the prevalence of multiple sclerosis in Ireland, an effect of genetic diversity. *Journal of Neurology, Neurosurgery & Psychiatry*. 2004;75(4):572-6.

²⁵ O'Connell K, Tubridy N, Hutchinson M, McGuigan C. Incidence of multiple sclerosis in the Republic of Ireland: A prospective population-based study. *Multiple Sclerosis and Related Disorders*. 2017;13:75-80

²⁶ von Campenhausen S, Bornschein B, Wick R, Bötzel K, Sampaio C, Poewe W, et al. Prevalence and incidence of Parkinson's disease in Europe. *European Neuropsychopharmacology*. 2005;15(4):473-90

²⁷ Schrag A, Ben-Shlomo Y, Quinn N. Cross sectional prevalence survey of idiopathic Parkinson's disease and Parkinsonism in London. *Bmj*. 2000;321(7252):21-2.

Inpatient Discharges

There were 17,289 inpatient discharges identified in 2016 with a principle diagnosis of a neurological condition potentially requiring neuro-rehabilitation input. The median age of these patients was 66 years and the average length of stay was 13.6 days.

The most important diagnostic category in terms of number of bed days used is cerebrovascular diseases. It also accounts for the longest average length of stay. Patients were also older compared with those with other conditions with a median age of 70.5 years.

The next conditions with the next most bed days used were those with a traumatic brain or spinal injury followed by those with a tumour of the nervous system. These patients were younger with median ages of 58 and 62 respectively. There were 2,310 discharges of patients with a principle diagnosis of a traumatic brain or spinal injury. Their median length of stay was just 3 days compared to an average length of stay of 12.91 days reflected the prolonged admissions and need for rehabilitation of many.

By adjusting for age, it is possible to compare categories of neurological disease and CHOs in terms of the rate of bed day use per 100,000 population. The table above shows that people from the North-West (CHO 1) and Greater Dublin (CHOs 6, 7 and 9) regions had the most bed days used for many of the disease categories.

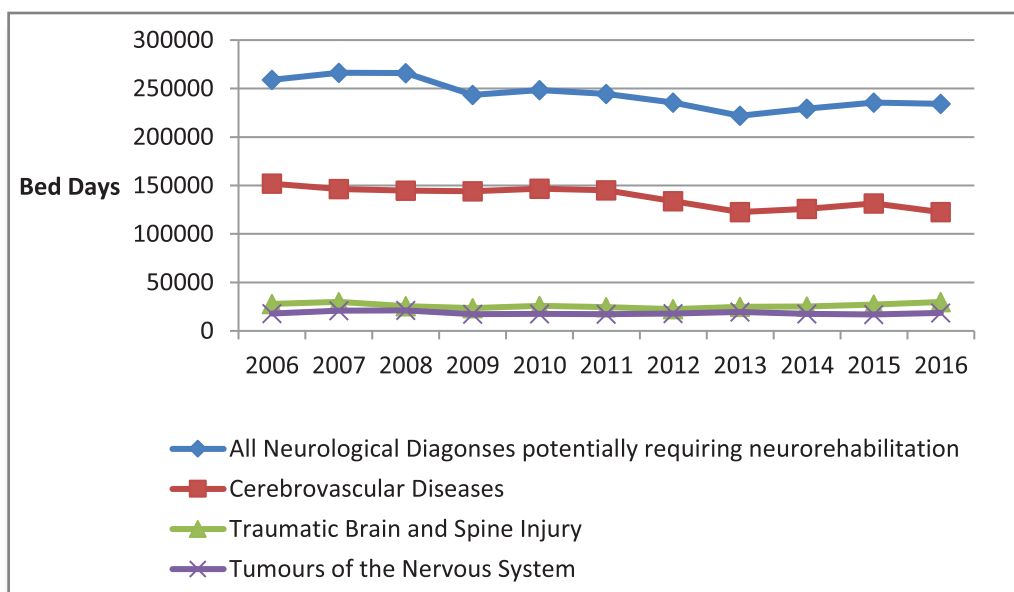


Fig 11: Total Bed Days, inpatients > 18 years, 2006-2016, by diagnosis

Figure 11 shows the trends in inpatient bed days over 10 years for all neurological diagnosis along the three most important neurological categories. It shows a small decline in overall bed day use mirrored by a decrease in bed use for cerebrovascular diseases.

Discharge Destination

There are limitations in interpreting discharge destination data from HIPE. However, Table 6 shows that those discharged from hospital with a neurological diagnosis potentially requiring neuro-rehabilitation are less likely to be discharged home. This is especially true from those with a principle diagnosis of cerebrovascular disease, of whom only 53.6% are discharged directly home. Neuro-rehabilitation can help to address the functional causes that may result in people with neurological deficits not being able to be discharged home.

Discharge destination, inpatients 2016, aged > 18 years				
	All diagnosis		All neurological diagnoses ¹	
	n	%	n	%
Home	482,353	87.9	11,550	66.8
Nursing Home/ Convalescence	27,661	5.0	1,662	9.6
Rehabilitation Facility	1,312	0.2	264	1.5
Emergency Transfer	6,937	1.3	737	4.3
Other Hospital	17,158	3.1	1,632	9.4
Died	11,018	2.0	1,299	7.5
Other	2,131	0.4	145	0.8

1. Includes all discharges with a principle diagnosis of a neurological diagnosis potentially requiring neuro-rehabilitation as defined in the methodology

Table 6; Discharge destination

Discharge destination, inpatients 2016, aged > 18 years, by CHO, all neurological diagnoses¹										
	Home		Nursing Home/ Convalescence		Rehabilitation Facility		Emergency Transfer		Other Hospital	
	n	%	n	%	n	%	n	%	N	%
All	11550	66.8	1662	9.6	264	1.5	737	4.3	1632	9.4
CHO 1	1141	64.4	172	9.7	39	2.2	163	9.2	119	6.7
CHO 2	1253	67.8	200	10.8	1	0.05	46	2.5	187	10.1
CHO 3	929	62.6	215	14.5	14	0.9	48	3.2	162	10.9
CHO 4	1926	74.0	125	4.8	50	1.9	42	1.6	225	8.6
CHO 5	1215	63.1	194	10.1	127	6.6	56	2.9	187	9.7
CHO 6+7	2091	64.1	431	13.2	1	0.03	157	4.8	308	9.4
CHO 8	1388	66.0	155	7.4	25	1.2	136	6.5	236	11.2
CHO 9	1504	71.1	167	7.9	5	0.2	72	3.4	187	8.8

1. Includes all discharges with a principle diagnosis of a neurological diagnosis potentially requiring neuro-rehabilitation as defined in the methodology

Table 7: Discharge Destination by CHO

Despite having the most bed days used, a similar proportion of patients from the Greater Dublin and North West regions are discharged home compared with the rest of the country.

International Comparison

In international comparison of Ireland with other peer EU countries of bed days used per 100,000 population using Eurostat data shows some general trends. Germany, Austria and Finland have much higher bed days used for all diagnoses. Ireland has a slightly higher rate of bed day use compared with the UK, France and Sweden. Denmark has less than half the numbers of bed days used for those with cerebrovascular disease compared with Ireland, the lowest of the countries compared.

Age-standardised bed days per 100,000 population¹, International comparison, Ages 20-85 years				
	All diagnoses ²	All neurological diagnoses ³	Cerebrovascular disease ⁴	Intracranial injury ⁵
Ireland	98,585.5	3,152.2	3,963.3	662.1
UK	90,178.7	2,669.6	3,953.7	601.8
Austria	236,864.3	10,349.3	11,060.4	1,377.8
Germany	237,692.5	8,450.5	9,276.0	1,474.1
Denmark	93,933.1	2,241.2	1,575.6	313.1
Belgium	108,964.6	4,676.4	3,228.5	789.3
France	92,466.9	2,769.9	2,445.6	549.3
Sweden	84,333.2	2,059.1	3,350.9	458.9
Finland	171,529.9	8,149.7	14,037.4	2,250.3

1. Adjusted to European Standard Population 2013
 2. ICD-10 Classification A00-Z99 excluding V00-Y98 (external causes of morbidity and mortality) and Z38 (live born infants)
 3. ICD-10 Classification G00-G99: Diseases of the nervous system (excluding G30, Alzheimer's disease)
 4. ICD-10 Classification I60-I69: Cerebrovascular disease
 5. ICD-10 Classification S06: Intracranial injury

Table 8; Age standardised bed days per 100,000 – international comparison

Delayed Discharges

As mentioned already, previous work by the NSG has shown that awaiting NRH or other form of rehabilitation make up 12% of all delayed discharges nationally²⁸. In 2017, this figure was 14% of all delayed discharges. However, it is not possible to determine Neuro-rehabilitation need solely on the basis of the HSE National Delayed Discharge data. Under the current definition, delayed discharges will only ever be a sub-group of the cohort of patients requiring neuro-rehabilitation. The Special Delivery Unit (SDU) definition of a delayed discharge is “A patient who remains in hospital after a senior doctor (consultant or registrar grade) has documented in the medical chart that the patient can be discharged.” This may not include patients who are clearly not ready for discharge home, but who may be ready for on-going care and rehabilitation in another setting.

For example- this is illustrated by the fact that in October 2017 the Mater Hospital was reporting 1 patient awaiting the NRH according to the HSE Delayed Discharge National Report, whereas the NRH waiting list has 14 patients on its waiting list currently in the Mater who have been assessed and accepted and who are well enough to transfer.

²⁸ Smyth B, Marsden P, Dee A, Donohue F, Collins L, Evans D. Health Information Paper 2015-2016. Dublin: Health Service Executive, 2015

Similarly, data returned from other hospitals (St Vincent's, Beaumont, Tallaght and St James') within the demonstrator area shows that not all patients referred/waiting for access to NRH and other rehabilitation facilities are recorded as delayed discharges.

The figure for patients assessed, accepted and well enough for transfer in these hospitals was 57 rather than the reported figure of 17 in the HSE National Delayed Discharge report. Therefore the need for rehabilitation services is not well captured by looking at delayed discharges alone, and is likely to be much higher than what is captured on the Delayed discharge data.

As currently structured, the National Delayed Discharge report has significant limitations as a basis for service planning. For example:

- It will not capture patient with significant injuries referred and accepted for rehabilitation, but who are still actively receiving treatment for acute injuries.
- It will not include patients who may be ready to transfer to a rehabilitation setting, but who continue to receive essential medical, nursing and therapy input pending a bed becoming available. The clinician may consider them ready for transfer but they cannot certify that they are ready for discharge, since they continue to receive essential care in the acute hospital.
- It could include a severely disabled patient classed by the acute hospital as 'delayed, requiring long term care', but who could subsequently be assessed as being appropriate for rehabilitation
- It will not capture patients who are in the community settings, including non-acute hospitals.

Deliverable	2.0	Population needs assessment per CHO	Responsibility	Timeframe
Steps	2.1	<p>Validate and further develop the population needs assessment completed by NSG for each CHO. This will need to include;</p> <ul style="list-style-type: none"> - Primary care & social care services - Activity data from relevant Voluntary Organisations providing services in CHO 	Local Implementation Team	Q2 2019
Steps	2.2	<p>The population needs assessment should also include a national census of;</p> <ul style="list-style-type: none"> - Patients in acute hospitals whose discharge is delayed secondary to lack of rehabilitation services. - Those currently in a rehabilitation setting who could be appropriate for a discharge home if community rehabilitation services were available. - Those waiting for access to community based services. - Those in inappropriate placements/nursing homes 	Local Implementation Team	Q2 2019

Table 9; Actions for step 2 of 10-step Implementation Framework

Step 3:

Map Local Care Resources against Current & Anticipated Demographic Needs

Benchmarking against best practice standards

The mapping exercise carried out in Q 3 2017 showed, there are less than five dedicated community neuro rehabilitation teams in the country. Some of the posts in these teams are funded through Disability Services with the majority of posts funded through Primary Care. These teams work from an inclusion/ exclusion criteria with some teams treating only a cohort of people under 65 years of age. The teams receive referrals from acute hospitals, NRH, GP, PHN, PCT, self referrals and Voluntary Organisations. A small number of posts are shared between the HSE and Voluntary organisations.

Regarding the number of posts allocated to these teams, there is no one team within the country which meets the requirement of a community neuro rehabilitation team. Specialist services i.e. neuro psychology and neuro psychiatry are extremely scarce and are in great demand. For example, a year after traumatic brain injury, approximately 30% of people will have at least one major psychiatric disorder and 40% will have neurobehavioral problems (Bryant et al 2010)²⁹. A further study suggested that after six years, 28% will have one or more psychiatric disorder and among these the disability is increased six-fold (O'Donnell et al, 2016)³⁰. Therefore, the long-term psychiatric consequences of severe injury are substantial, commonly psychiatric and psychiatric co-morbidity represents a significant contributor to long-term disability.

These figures estimate a neuropsychiatry need in traumatic brain injury of approximately 120 cases per 100,000 general population. Unexplained neurological symptoms are most commonly psychiatric in origin and include psychiatric diagnoses such as dissociative disorders/ non-epileptic seizures/conversion disorders and somatoform disorders (300 cases per 100,000 population). Approximately 22% of people who present with neuro psychiatry diagnoses pass through out juridical system.

Taken together, these estimates suggest that it is reasonable to expect 45-50 new referrals to specialist neuropsychiatry services per 100,000 population per year whose needs cannot be met by local mental health services

In one CHO there are no HSE directly funded neuro rehabilitation services; this CHO is totally reliant on the provision of neuro rehabilitation service through the Voluntary organisations. There is a centralised referral system within the local HSE services who forward referrals to the Voluntary Organisations. At the time of the mapping exercise

²⁹ Bryant RA, O'Donnell ML, Creamer M, McFarlane AC, Clark CR, Silove D. The psychiatric sequelae of traumatic injury. *Am J Psychiatry*. 2010 Mar; 167(3): 312-20

³⁰ O'Donnell ML, Alkemade N, Creamer MC, McFarlane AC, Silove D, Bryant RA, Forbes D. The long-term psychiatric sequelae of severe injury: a 6-year follow-up study. *J Clin Psychiatry*. 2016 Apr; 77(4): e473-9

the wait time for assessment from these services was 4-8 weeks, wait time to access the service 24 weeks with the ALOS in the service 28 weeks.

One dedicated CNRT based in CHO 3, made up of 4 posts including physiotherapy, OT, SLT and a rehab assistant. While this team is working well and providing excellent support to patients, their scope, catchment and breadth of services is limited as they do not have the resources as recommended by the BSRM. This CNRT operates more of a Social Model looking at clients overall needs – including physical, psychological, social and vocational. This team treats under 65 yrs and all conditions, sudden onset, including intermittent and stable conditions. The client must reside in the Mid West CHO. The team treats 70-80 people per year. Referral sources are UHL, UHE, Beaumont, MMH, Galway, CUH (46% from acute hospitals), NRH, other rehabilitation facilities, St Camillus' Hospital stroke rehab, PCT, nursing home, self referral, others referrals sources are Headway, Acquired Brain Injury Ireland, MS Society, Spinal Injuries Association and Mental health services. Referrals are screened weekly by two clinicians for appropriateness and prioritised and placed on waiting list -P1 urgent: 12 weeks; P1 22 weeks; P2 > 1year. The team is not medically lead. This team works very closely with their Primary Care colleagues Patients are referred onto Primary Care services if a review is needed.

The mapping exercise also demonstrated, of the neuro-rehabilitation service in place around the country, few are lead by a rehabilitation consultant. Some are lead by a GP or Geriatrician and others liaise with their local GP out of hour's service.

Through the advancement of the demonstrator project, the information gathered for CHO 6 & 7 was validated. This process brought to light a number of additional services in operation within the catchment area which weren't initially included in returns from respondents.

The initial responses from the CHO mapping exercise will be made available to each local Implementation Team and will require similar validation in line with parameters given by the NSG.

A comprehensive gap analysis is a challenge, given the low base rehabilitation medicine is starting from. Benchmarks for appropriate ratios of Consultants in rehabilitation and multidisciplinary teams were reviewed (British Society for Rehabilitation Medicine) and the recommended staffing levels per service delivery site can be found in appendices 4 & 5.



Fig 12; Mapping of services

Based on the population needs assessment and validation of the mapping process, it will be clear on a) the rehabilitation services currently available within the CHO, b) the demand for neuro-rehabilitation services within your CHO and the c) the gaps between demand and capacity (based on recommendations within Model of Care of the National Clinical Programme for Rehabilitation Medicine).

When planning any service development, one will need to be cognisant of the significant unmet need within each CHO. This is evidenced through mapping exercises i.e. that people are not being referred to services which do not currently exist – for instance, there will be no waiting lists for community neuropsychology. This does not infer that there is no need; it is purely reflective of the fact that this service is not available.

The mapping exercise also identified that there are 92 beds at the National Rehabilitation Hospital for Brain Injury & Spinal Cord Injury (this excludes the beds dedicated to the Paediatric Programme and the Prosthetic/Orthotic Programme). These beds have a national remit with no dedicated beds to any one particular CHO. While ideally the profile of patient population (i.e. population needs) should determine staffing levels within the service, this is not currently the case. At present for example, within the brain injury and spinal programme at the NRH, staffing levels allow for only 24% of beds to admit patients with the highest levels of dependency. The British Society of Rehabilitation Medicine would suggest that a Complex Specialist Rehabilitation Service such as the NRH should be resourced to manage a caseload whereby 60-70% of inpatients fall within the high dependency category.

At the time the mapping exercise was undertaken, there were 231 are waiting for the Brain Injury and Spinal Cord Injury Programmes. Of these, approx. 50% were estimated as having a high dependency score (>11 on Rehabilitation Complexity Scale). Accordingly, 50% of those waiting for access to Brain Injury and Spinal Programmes are waiting on 24% of the total beds within these 2 programmes. This leads to excessive waiting times for this cohort of patients in particular. Given the profile of these patients, the vast majority will await access to NRH in an acute hospital. At the time of mapping exercise, 54% were waiting longer than 3 months, and of these, 37% i.e. 85 people, were waiting more than 6 months.

To function effectively as a tertiary centre and have maximum benefit in terms of patient outcomes and flow through the continuum of care, the NRH will need to be developed and supported to enable it admit a higher proportion of patients with high dependency needs at any one time.

A similar mapping will need to be done to determine gaps between current staffing levels and those recommended for a tertiary service provider. This will be led by the NSG.

Deliverable	3.0	Map local care resources against current and anticipated demographic needs	Responsible	Timeframe
Steps	3.1	Mapping of existing neuro-rehabilitation services relevant to CHO/Hospital Group, both with respect to staffing but also operational policies and procedures	As referenced above, initial responses to national mapping exercise will be provided to each local team for review and validation.	Q2 2019
Steps	3.2	Compare existing services with internationally recognised best practice standards with respect to staffing ratios per population	Based on returns from each local team with respect to existing services, a gap analysis will be completed by the NSG. The output of this exercise should be a comprehensive document outlining full requirements for implementation including capital, staffing and equipment.	Q2 2019
Steps	3.3	Compare existing service levels at National Tertiary Centre to those recommended by BSRM for a tertiary service provider	NSG	Q1 2019
Steps	3.4	Address existing service delivery through submission to estimates process for essential staffing for inclusion in successive service plans.	Estimates proposal will be submitted through the NSG	Q2 2019

Table 10; Actions for step 3 of 10 step Implementation Framework

Step 4

Develop Rehabilitation Services

Development of evidenced based, equitable high quality rehabilitation services

The need to develop services across the continuum of care is wholly acknowledged, this includes;

Acute Rehabilitation

Early rehabilitation is important to utilise plasticity as effectively as possible and to reduce the potential for complications³¹. There is strong evidence that early access to rehabilitation leads to reduced LOS in hospital and improved outcomes³². Acute neuro-rehabilitation is provided by a consultant led inter disciplinary team within the acute hospital setting and should commence as early as possible.

Complex Specialist Rehabilitation Services (NRH)

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.

Post-acute Inpatient Specialist Rehabilitation Services

These services 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 Neuro-Rehabilitation Services

Community-based specialist rehabilitation teams should provide multi-professional rehabilitation, ideally with case managers, to patients with stable complex needs. In addition to the community specialist neuro-rehabilitation teams, there is a requirement for a range of specialist community based services to meet ongoing and longer term neuro-rehabilitation needs.

³¹ Gutenbrunner C et al. White Book on Physical and Rehabilitation Medicine in Europe. Journal of rehabilitation medicine. Supplement No. 45, Jan 2007

³² Turner-Stokes L. Evidence for the effectiveness of multidisciplinary rehabilitation following acquired brain injury: A Synthesis of Two Systematic Approaches. J Rehabil Med 2008; 40: 691-701

Voluntary Organisations

The role of voluntary providers is crucial in the rehabilitation and long term management of neurological conditions and is acknowledged in the 2011 Strategy thus:

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

A small number of voluntary organisations currently deliver clinically led specialist neuro-rehabilitation services in the areas of residential and transitional services, care, vocational services, day services, case management etc.

The majority of voluntary organisations in the community do not provide specialist neuro-rehabilitation services. They provide a range of services and supports to maintain the wellbeing and integration of people with neurological disability in the community including self management, family support, peer support, counselling, respite and home care. These ranges of services are a vital component to sustaining the person in the community in the long term. They are a core component of the overall framework required within the community in order to support the delivery of specialist rehabilitation services. Voluntary services play an important role in complementing specialist rehab services in ensuring clients have the best possible outcome and reach their maximum potential in terms of health and wellbeing, functional abilities and engaging with their communities.

Primary Care

Due to the lack of community neuro-rehabilitation teams nationally, there is an assumption that the neuro-rehabilitative needs of people are being met through primary care services. However, services provided through primary care are generally with a compensatory focus rather than rehabilitative focus i.e. provision of enabling equipment or environmental adaptations. Community therapy services are moving towards an enabling and outcome based focus when working with clients, i.e. effective referral conversation. The NSG will continue to engage with colleagues in Primary Care re; the evolving role of health & social care professionals in the community.

Primary Care does not currently have the capacity to provide specialist neuro rehabilitative interventions. Therefore, the needs of this cohort of patients are not being currently met in the community.

The effective functioning of any Rehabilitation Network will be predicated on the appropriate resourcing of services across all continuum of care as well as pathways within and across the continuum of care. This strengthens the requirement for the need to develop community neuro-rehabilitation teams as an essential component of the continuum of care.

Best Practice in Neuro-Rehabilitation

While resources are of course essential to the development of rehabilitation services, the supporting infrastructure is also essential. It is recognised that resourcing of services alone, does not infer high quality rehabilitation services.

The National Clinical Programme for Rehabilitation Medicine is working on the development of national standards for both post-acute inpatient specialist rehabilitation and community-based specialist rehabilitation. They will also make specific recommendations on requirements for data collection and information management and these are essential to the future development of rehabilitation services.

The adoption of these standards would be recommended for all services providing specialist rehabilitation, both developing and established services. These standards are to be considered in addition to the National Safer Better Healthcare Standards, not in lieu of them.

The standards will support the integration of best practice into rehabilitation services including issues such as;

- Role & function of service
- Service standards (i.e. scope of service available)
- Referral management
- Assessment
- Treatment
- Patient centeredness/patient engagement
- Links with other services
- Use individual goal-based approaches
- Interdisciplinary care
- Support education and self-management
- Focus on the ICF principles in acknowledgement of the fact that diagnosis alone does not predict service needs.

Scope of Service

A scope of service should be developed for each service. The scopes of service for community neuro-rehabilitation teams and post-acute inpatient rehabilitation units will be developed in collaboration between the National Clinical Programme for Rehabilitation Medicine, the National Steering Group for the Strategy and key stakeholders. The scopes of service should include:

- Population(s) served including parameters with respect to medical stability as appropriate etc
- Services/Therapies available
- Adjunctive services that can be accessed
- Hours of services
- Days of services
- Entry criteria
- Exit criteria

- Intensity of services
- Referral sources
- The specific services offered, including whether the services are provided directly or by referral.

Rehabilitation Process

Irrespective of the service setting, the rehabilitation process itself should not vary significantly. The process below illustrates the steps along the patients' rehabilitation journey.

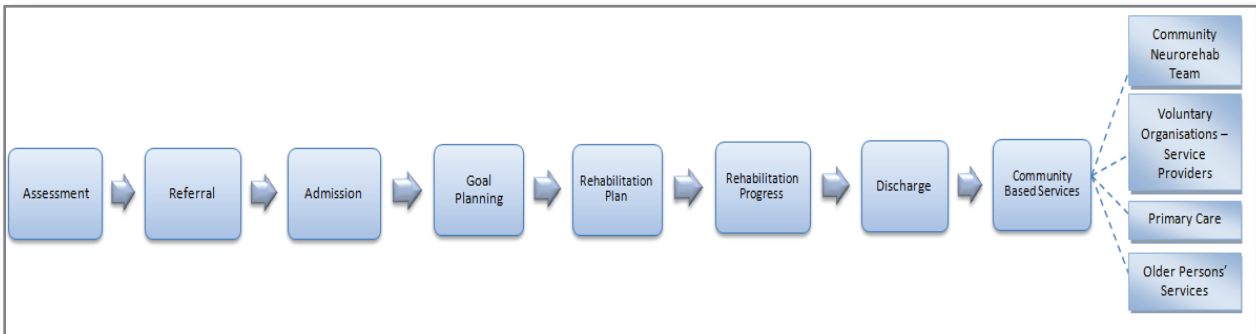


Fig 13; Rehabilitation Process

Inpatient Based Services

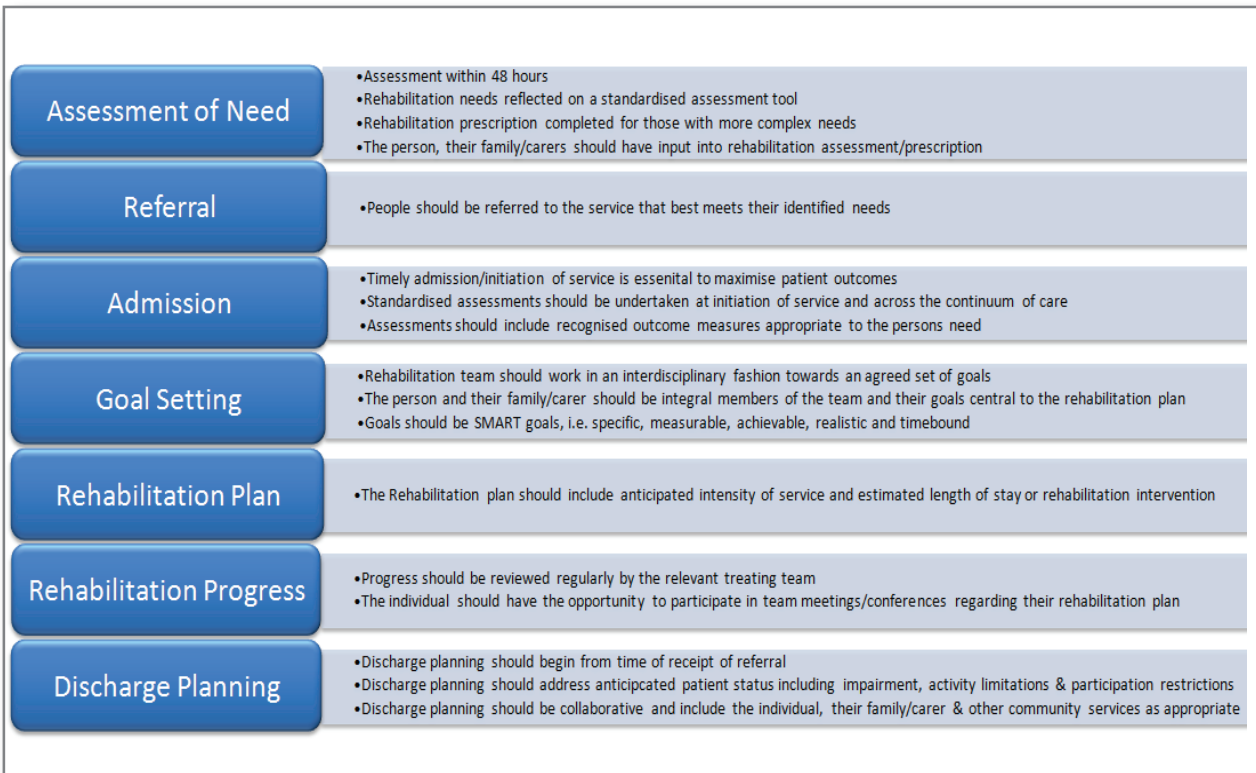


Fig 14: Steps in Rehabilitation Process in in-patient setting

Specialist In-patient Rehabilitation services should;

- Be located together in order to provide an appropriate environment for rehabilitation
- Be led or supported by a consultant trained and accredited in Rehabilitation Medicine and multi-professional team has undergone recognised specialist training in rehabilitation
- Work as a co-ordinated inter-disciplinary team - working towards an agreed set of goals
- Take patients with more complex rehabilitation needs than non-specialist services and have specialist equipment, facilities and staffing levels to meet those needs
- Have specialist facilities as appropriate to caseload including;
 - Exercise and specialist equipment
 - Facilities to assess activities of daily living including extended activities such as meal preparation, out-door mobility, driving assessment etc
 - assistive technology including communication aids,
 - Diagnostic equipment e.g. Scanning, Fees/dysphagia assessment,
 - Specialist orthotics
 - Specialist seating including postural support equipment which also links with the EAT service (e.g. including AT in head supports)
 - Spasticity management
 - facilities to support vocational training and use of leisure time
 - A wide range of information and educational services for patients, families and other HSCP's as well as teaching and research facilities

Community Based Services

When a patient is discharged from post-acute inpatient services, if needed, on-going rehabilitation services will be provided by Community based services. The rehabilitation standards and the rehabilitation process discussed above should also apply to Community Based Specialist Neuro-rehabilitation teams and community specialist providers.

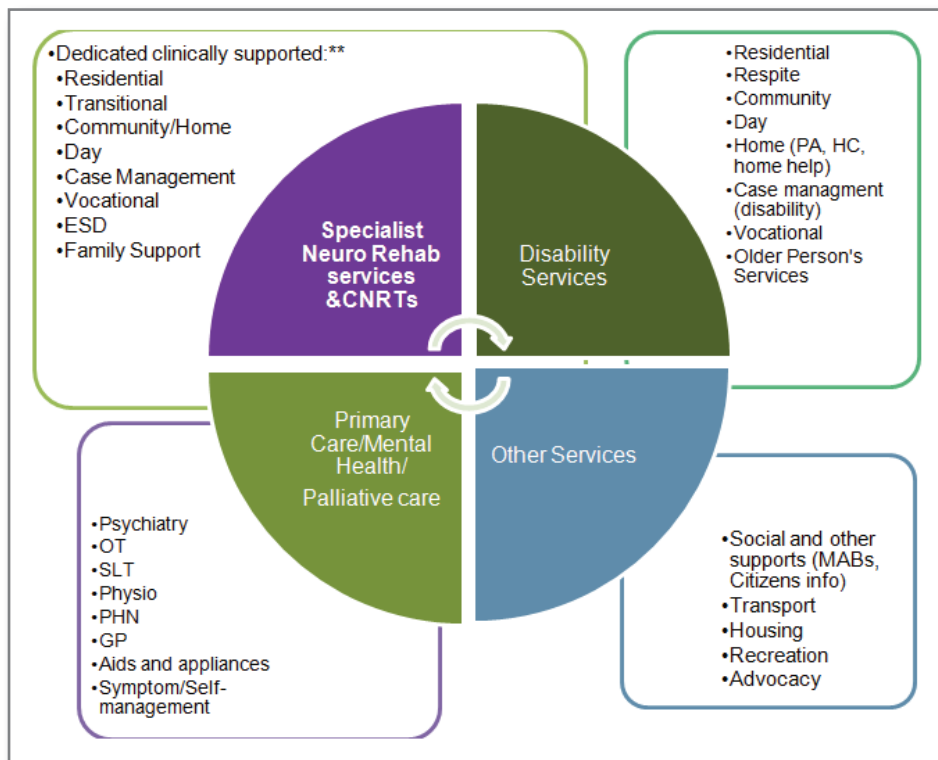


Fig 15; Continuum of Care

Community Neuro-rehabilitation Teams:

Community neuro rehabilitation teams (CNRTs) require a degree of specialisation and training that will enable them to provide services to people with complex presentations, such as:

- those who require a degree of specialised input beyond that available from a primary care team;
- those who require a level of intensity of therapeutic input that is not possible from a primary care team from a capacity perspective
- those who do not require in-patient facilities, but do require high-intensity neuro-rehabilitation interventions
- Those who need to transition from hospital to home (who have neuro-rehabilitative needs).

The proposed scope of service for community neuro-rehabilitation teams is under development by the NCPRM upon review of existing models & international best practice. This DRAFT scope of service is attached as appendix 6. The general principles include;

- Interdisciplinary team working
- Moderate to high intensity rehabilitation inputs
- Individualised rehabilitation programmes based on service users identified goals
- Measurement of outcomes
- Service based on assessed need and intervention based on clinical guidelines/ best practice

It is envisaged that as individuals with neuro-rehabilitation needs who move from acute to community, or require neuro-rehabilitation while in the community, should have access to services in the community with specialism in neuro-rehabilitation, as and when they need them. **Navigation through these services should be supported by case management.**

Depending on the nature of the disability and the level of complexity some people will need access to the specialist neuro-rehabilitation services in both the short and long term, while others will move from the specialist, to disability and other mainstream services.

These services include:

- Community Neuro-Rehabilitation Teams (CNRT) Community Neuro-Rehabilitation teams provide short term intensive rehabilitation input (up to 12 weeks) with access to the following specialist clinical supports;:
 - Neuro-psychology
 - Neuro-psychiatry
 - Occupational therapy
 - Speech and language therapy
 - Physiotherapy
 - Social work
 - Dietician
 - Rehabilitation Assistants
 - Case Manager
 - Medical and managerial supports.

AND

- Specialist community neuro-rehabilitation services (long term rehabilitation input beyond 12 weeks) to include:
 - Residential rehabilitation
 - Transitional rehabilitation (delivered in a transitional living unit, time-bound service)
 - Community/Home rehabilitation (to include intensive home care packages with a rehabilitation focus)
 - Day rehabilitation
 - Vocational rehabilitation
 - Family support services
 - Managerial Supports.

Community Specialist Neuro-rehabilitation Services are distinct from disability and other community residential/vocational, day services which do not have a rehabilitative focus. Community rehabilitation services already exist, but there is widespread variation

in accessibility across the country. The profile of clients who will need to access these services are those who require ongoing neuro-rehabilitation in the community beyond the timeframe and scope of that provided by the community neuro-rehabilitation team.

All specialist community neuro-rehabilitation services should meet the following criteria:

- Clinically-led and outcome focused (working on person-centred rehabilitation goals) by inter-disciplinary clinicians with specific expertise and experience in neuro-rehabilitation;
- Service provision based on evidenced best practice in rehabilitation;
- Neuro-rehabilitation specific case management a critical feature for complex cases;
- Service provision to individuals with neuro-rehabilitation needs where there is potential for rehabilitation to impact and willingness to engage;
- The need for both short term and long term focus, with recognition that for some, rehabilitation is a life-long process and for others it is a process of moving through the pathway and ultimately being discharged;
- Utilising internationally validated outcome measures to measure the impact and demonstrate effectiveness of the rehabilitation process
- Linkage to a consultant led neuro-rehabilitation service & wider system

The CNRT requires access to a shared referral forum/pathway attended by specialist community neuro-rehabilitation service providers and HSE Disability services, Primary Care, Mental Health, and Palliative Care as relevant. This allows for the services, which provide the necessary array of clinically-led services listed above, to assess and plan the service provision.

Community specialist rehabilitation services 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

Lack of availability of specialist community neuro-rehabilitation services for individuals with complex needs will directly impact a) the person's rehabilitation potential and b) the person's functional independence. This can result in further reliance on system wide services including health, social care, judicial and social protection services.

Other Services

In addition to specialist community neuro-rehabilitation services, there is a need for a range of disability services to provide care and supports for individuals and their families. These services focus on the delivery of care in residential and community settings. Their primary focus is delivering care services to people with disabilities and their families and, in the main, may not have a neuro-rehabilitation focus (but may have some of the components). These include:

- Residential services
- Respite services

- Day services
- Home care (PA, Home Care, Home Help)
- Disability case management (e.g. HSE Disability Case Manager)

The availability of these services is imperative to ensure that individuals can move through the pathway. For example, as an individual with neuro-rehabilitation needs gains independence / decreases dependence, they can be supported by disability services, if required, thereby allowing the specialist service providers to provide supports to other individuals with neuro-rehabilitation needs.

Individuals may also need access to the following supports within their community which may be provided through primary care, disability and local mental health services.

- Occupational therapy
- Physiotherapy
- Speech and language
- Psychology
- Psychiatry
- Symptoms management and self-management supports
- Medical supports via GP and PHN

Individuals and families also need access to a range of mainstream services and supports in the community, including:

- Housing
- Transport
- Information/money advice/social welfare
- Advocacy
- Vocational and educational supports

Deliverable	4.0	Develop Services and Care Pathways	Responsible	Timeframe
Steps	4.1	<p>Identify the role and function of each service across the patient journey</p> <p>Full scope of service for each service across the continuum of care to be developed. Each service should be asked to consider their programmes under the headings outlined above under 'scope of service'.</p> <p>For services with existing scopes of service, these should be reviewed with respect to compliance with Scopes of Service developed by NCPRM.</p>	Local Implementation Teams	Q2 2019

		<p>This exercise will show who does what, where, when and how under present circumstances. This is an essential building block for the development of a network model.</p> <p>When aligned, the scopes of service should cover the entire continuum of care for the patient with neuro-rehabilitative needs.</p> <p>The linkages between all services should be developed to ensure clear and transparent processes exist so support transition between services.</p>		
Steps	4.2	<p>Audit of current practice with respect to patient journey and current assessment of patients for rehabilitation services</p> <p>Baseline information should be gathered re; average waiting times for services/LOS etc from all services reportedly providing support to those with neurological conditions.</p> <p>This will give a clear picture of not only the services in the area but also the patient journey between services</p>	Local Implementation Teams	Q2 2019
Steps	4.3	<p>Identify specific ‘bottlenecks’ within the system which impact on the rehabilitation process currently i.e. flow between services.</p> <p>A review of these ‘bottlenecks’ should be undertaken which looks at the following;</p> <ul style="list-style-type: none"> - Root cause – i.e. lack of service, services with restrictive admission criteria etc <p>Barriers/issues relating to variation in patient pathway should be identified under the following headings;</p> <ul style="list-style-type: none"> - Internal Service specific limitations - External limitations/barriers - Organisational barriers <p>For internal barriers, potential solutions to issues should be explored by local implementation group. For external or organisational barriers, details on same should be submitted to the National Steering Group for consideration.</p>	Local Implementation Teams	Q2 2019

Steps	4.4	<p>Evaluation of current services against Standards</p> <p>Newly developed services should be established in line with the Standards which have recommendations around not only the rehabilitation process, but also in terms of governance, training of staff, staffing ratios and facility requirements.</p> <p>Existing Services; Where existing services are being developed/upgraded to provide the role of specialist in-patient, community neuro-rehabilitation teams and specialist community neuro-rehabilitation services, an evaluation of current processes should be undertaken against recommended standards, as per attainment process described above. In areas where there is no evidence of compliance, quality improvement plans will need to be developed describing actions to be taken to achieve compliance with standards.</p> <p>It is understood that barriers to achieving compliance may be outside the direct control of service managers. In these instances, the appropriate business cases – be they for capital funding or revenue should be generated and submitted through the estimates process</p>	Local Implementation Teams with support from NSG & Rehabilitation Medicine Programme	Standards are currently under development by with Rehabilitation Medicine Programme. Once approved, standards should be applied to both new and existing neuro-rehabilitation services at inpatient and community level
Steps	4.5	Develop services in each CHO annually with new investment if necessary	Local Implementation Teams with support from NSG & Rehabilitation Medicine Programme	2019-2021

Table 11; actions for step 4 of 10 step Implementation Plan

Step 5

Develop New Ways of Working

Services working together to support the person in an integrated way

Integrated Pathways

In terms of new ways of working, the development of integrated care pathways, which describe the continuum of care for patients across all service settings and across organisational boundaries are felt to be key. They describe what the patient journey should look like in its entirety working across care settings.

An integrated care pathway (ICP) is an interdisciplinary outline of anticipated care, placed in an appropriate timeframe, to help a patient with a specific condition or set of symptoms move progressively through a clinical experience to positive outcomes. ICPs can also be used as a tool to incorporate local and national guidelines into everyday practice, manage clinical risk and meet the requirements of clinical governance³³.

Integrated Care Pathways are being developed centrally through the National Clinical Programme for Rehabilitation Medicine in collaboration with all key stakeholders. They are reflective of the summary pathways included in the model of care of the NCPRM. There will be a formal consultation process for each ICP. ICPs will be disseminated through the NSG for local implementation. Summary ICP Spinal Cord Injury below gives an example of ideal pathway of care. Local implementation teams will be required to support the implementation of integrated care pathway for neuro-rehabilitation services within the CHO. This pathway should include rehabilitation co-ordinators, case managers and rehabilitation assistants across care settings: currently some of these roles are underdeveloped within neuro-rehabilitation services.

³³ <http://www.medicines.ac.uk/bandolier/booth/glossary/ICP.html> Accessed April 2018

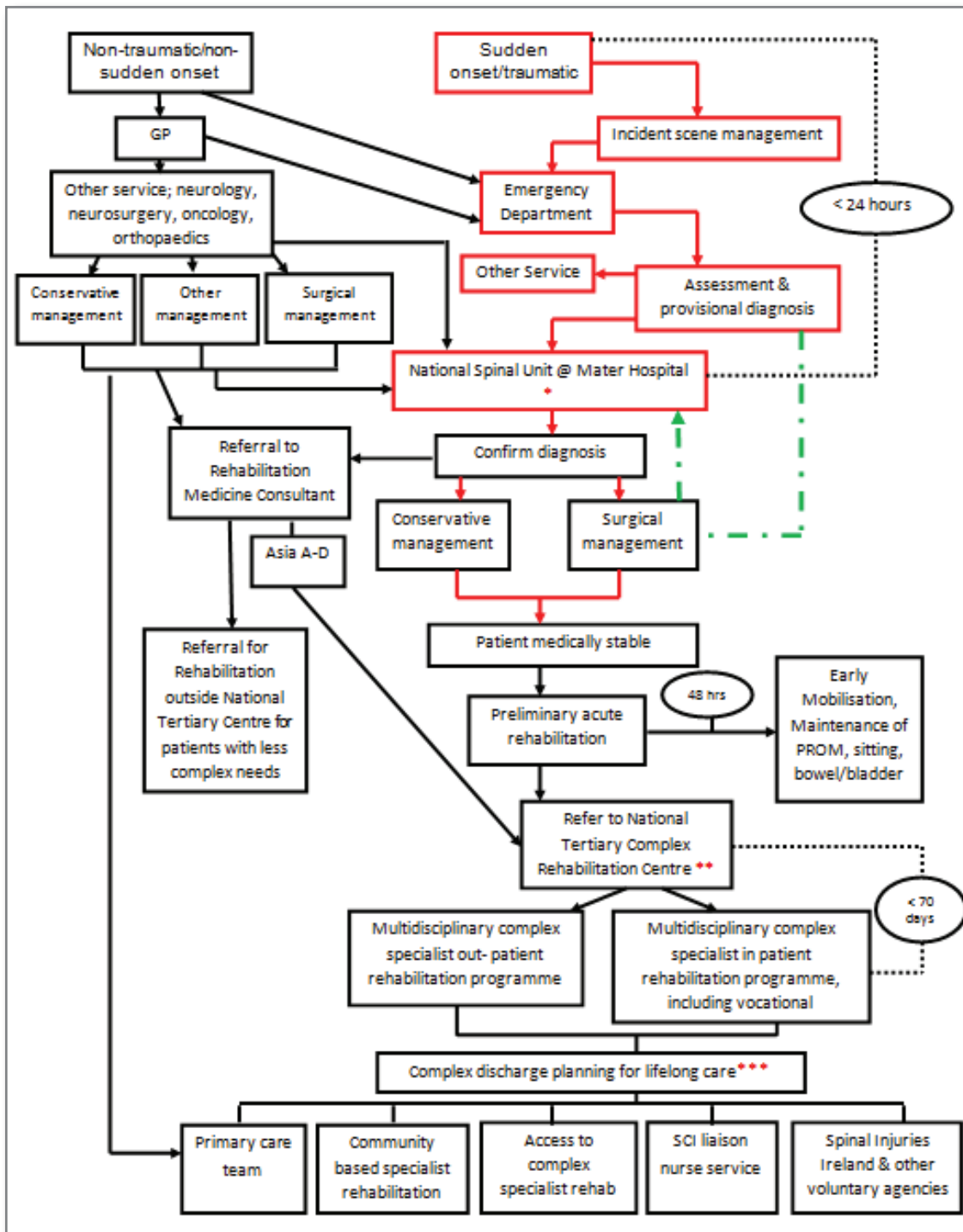


Fig 16; Example of Integrated Care Pathway (Spinal Cord Injury)

The pathways should also be considered in the context of improving quality for patients in line with the Framework for Improving Quality in our Health Service developed by the Quality Improvement Division. In this framework, quality improvement is considered to be ‘the combined and unceasing efforts of everyone – healthcare professionals, patients and their families, researchers, commissioners, providers and educators – to make the changes that will lead to

- Better patient outcomes

- Continued development and supported staff
- Better Experience of care

The current system does not support integrated care as it sees disjointed hospitals and services working in isolation and addressing individual components of the patient pathway without reference to the overall patient experience.

Not every diagnostic group will require a specific Integrated Care Pathway. Those with lower prevalence will be encompassed by the Pathway of Care outlined in 'Step 4' of the 10-step plan i.e. 'rehabilitation process'.

New Roles Across Care Settings

Implementation of the strategy should see the introduction of additional roles, supporting the continuum of care. While these roles are not 'new' per-se, they are relatively underdeveloped within the Irish neuro-rehabilitation context.

- Rehabilitation Coordinator

The rehabilitation coordinator will work to co-ordinate the delivery of rehabilitation across the services for each individual patient through appropriate placement along the continuum of care. Rehabilitation coordinators should be appointed across each network. The rehabilitation coordinator will provide for a centralised and standardised approach to the handling of each referral for neuro-rehabilitation network. They will ensure timely triage and assessment of each referral. This will ensure that all patients' needs and dependencies can be clearly established and the required placement identified in a consistent manner. This promotes equity of access for the patient based on their clinical needs. Ultimately this role will promote patient flow throughout the clinical network and improve communication and transition between the rehabilitation services within that network.

While there is the above operational function to this role, there is also a significant clinical component. The rehabilitation coordinator will be required to establish patient dependencies, specialist requirements and 'readiness' for rehabilitation to 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 and would coordinate all of the relevant patient referral details and sources to establish the above information.

The scope of these roles should be ambulatory in nature, working across the MCRN and ensuring the most current information on the status of all patients would be available and informed clinical decision making would be possible when planning admissions.

- Case Management

The second role is that of case manager. 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. This case manager post will differ from other case manager posts as this person will manage the cases of people with complex neuro rehabilitation needs as per the Model of Care of the NCPRM. The case manager has a remit across the patient's entire journey.

The British Society of Rehabilitation Medicine Standards for Rehabilitation Services (2009³⁴) states that people living in the community with long term neurological conditions should have timely and on-going access to a named individual with experience in the management of their condition.

For individuals with less complex neuro-rehabilitation needs, identification of a single point of contact or key worker role within each care setting is required to co-ordinate their journey from / to hospital (if relevant), to CNRT, to primary care or home with/ without supports. Once such individuals return to the community, a single point of contact should be identified as the first link for the individual and family if further issues arise.

However, a significant number of individuals with neuro-rehabilitation needs have complexity of presentation, to include physical, cognitive, emotional, behavioural, sensory, and social needs. For these individuals, the availability of dedicated neuro-rehabilitation case management is needed and it necessarily has to extend beyond the 12 week CNRT intervention. The neuro-rehabilitation case manager operates across a longer time span, to react to changing needs, to ensure the necessary supports are in place.

The scope of neuro-rehabilitation case management role includes being the first point of contact for the individual and provision of information as required. They also have a role liaising with the hospital, rehabilitation centre and/or other acute or post-acute services to ensure a seamless pathway. A neuro-rehabilitation case manager remains with the person on the pathway for a period of time until they are no longer needed in terms of their role, as outlined above. A case manager may work with a person over a short or longer term (6 months +).

- **Rehabilitation Assistant**

The third role is that of Rehabilitation Assistant (RA). The RA plays a unique and critical role in the specialist neuro-rehabilitation services in the community. While they are an element of the CNRT, the RA is essential to the execution of the neuro-rehabilitation services in the long term.

Working on a one-to-one basis, the RA implements the clinically-led individual rehabilitation plan. Person centred delivery is a cornerstone of the service. Their work is driven by a philosophy and practice of **enablement** and **empowerment**. This philosophy results in a level of risk being managed by RA staff, who receive additional training to ensure the appropriate identification of risk followed by risk assessment to minimise same and which is not impeding the rehabilitation efforts of the individual.

The RA works in all of the settings outlined in the specialist services (transitional, residential, home, community, day, and vocational services) and the CNRT. Therefore, they are a critical of the pathway in both the short and long term.

³⁴ The British Society of Rehabilitation Medicine Standards for Rehabilitation Services (2009)

Deliverable	5.0	Develop New Ways of Working	Responsible	Timeframe
Steps	5.1	Review of existing formal or informal care pathways within the CHO	Local Implementation Teams	Q2 2019
Steps	5.2	Identification of key stakeholders for ICP development group per ICP	NCPRM	Q 2 2019
Steps	5.3	Consultation on ICP	NCPRM & Local Implementation Teams	Q4 2019
Steps	5.4	Approval of ICP	NCPRM & project stakeholders & HSE Leadership Team	Q1 2020
Steps	5.5	Implementation of ICP	Local Implementation Teams	Q 4 2020 - resource dependent
Steps	5.6	Review of data post introduction of pathway	Gathered by local Implementation Teams.	ongoing

Table 12; Actions for Step 5 of 10 Step Implementation Framework

Step 6

Person Centred Care Planning and Service Delivery

Supporting person-centred care and involvement of the person and family in the design and delivery of services

The Rehabilitation Medicine Model of Care (2018) highlights the need to involve and empower patients. This document references the International Association Patient Organisations (IOAP) declaration on Patient Centred Healthcare³⁵ which includes 5 principles:

- Respect
- Choice & empowerment
- Patient involvement in health policy
- Access & support
- Information.

Person - centred care is at the core of many of the 10 steps in this implementation framework. The key components of such care being shared decision making, self-management support, health literacy and integration.

Person-centred care involves changes at every level from co-designing services at population level, to educating and supporting staff at an individual level. Following extensive research in collaboration with the Harvard Medical School the Picker Institute outlined 8 principles of person-centred care. These are reflective of the IAPO 5 principles and include;

1. Respect for patient's preferences	2. Coordination and integration of care
3. Information & education	4. Physical comfort
5. Emotional Support	6. Involvement of family & friends
6. Continuity and transition	8. Access to care

Fig 17; 8 Principles person-centred care

Disability Services have also developed a National Framework for Person- Centred Planning in Services for Persons with a Disability (March 2018³⁶). This framework contains two evaluation tools one for the person who owns the plan and one for the organisation/ CHO developing the plan. This framework informs and guides how person- centred planning is carried out across services for people with a disability. The components of

³⁵ The 35 www.patientsorganizations.org accessed 15th October 2014

³⁶ HSE Disability Services, Person - Centered Planning A National Framework (2018)

this framework should be considered by the local implementation teams when person centred plans are being developed for people with neuro rehabilitation requirements.

People who use neuro-rehabilitation services should have the opportunity to make informed decisions regarding their care & treatment, in collaboration with their health and social care practitioners. This requires healthcare services to work in partnership to deliver care responsive to people’s individual abilities, preferences, lifestyle and goals (The Health Foundation 2014). Internationally, person-centred care is seen as a key element of quality and safety within healthcare. It is also recognised that person-centred care results in greater patient satisfaction and improved outcomes.

In 2012 HIQA developed and published National Standards for Safer Better Healthcare³⁷. 8 themes were outlined with no 1 being Person-Centred Care and Support. Adoption of these standards is key to ensure patient centred care across each of the MCRNs.

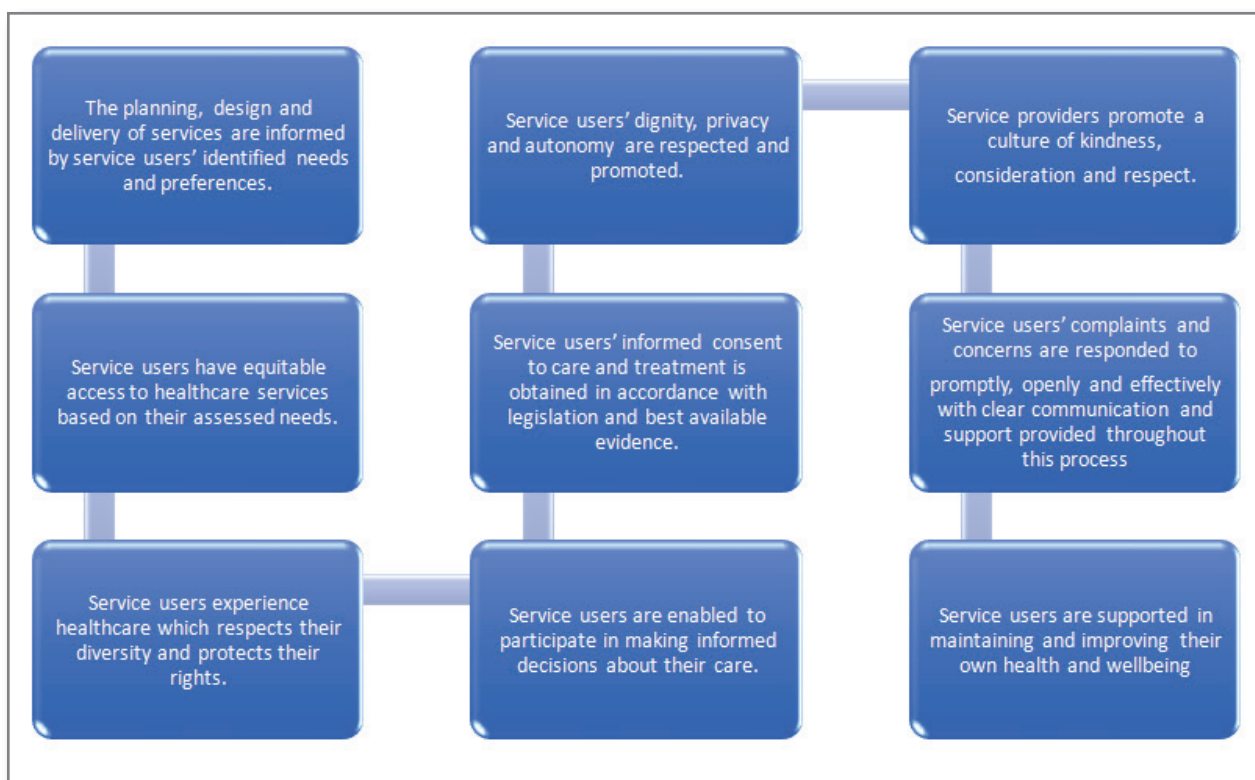


Fig 18; Standards from Theme 1, Safer Better Healthcare 2012

Each MCRN should have these standards as part of their mission statement, staff meetings, staff induction, CPD, KPIs and QIPs. HIQA (2013) have devised a workbook to support acute hospital services to develop these person centred care and support standards.

In 2015 Disability Services developed Interim Standards for New Directions³⁸ know as the EASI Tool, Guideline for **E**valuation, **A**ction and **S**ervice Improvement. This suite of standards requires service providers and key stakeholders to involve people in the design, delivery, monitoring and evaluation of the services and supports provided to them. EASI is a self evaluation process by each service provider and is a fundamental

³⁶ HSE Disability Services, Person – Centered Planning A National Framework (2018)

³⁷ National Standards, Safer Better Healthcare, HIQA 2012

part of the continuous quality improvement process. The purpose of the self evaluation is to explore and reflect with all stakeholders including people receiving services, staff and management delivering services, to report on the effectiveness and quality of the supports being provided to the individual. This evaluation will show good practice and areas requiring improvement. The monitoring will be tracked through a self evaluation record and a continuous quality improvement (CQI) action plan. This model could also be considered for adoption within MCRNs.

The HSE Integrated Care Programme for Older Persons (2017) in their ‘Practical Guide to Local Implementation³⁹’ have summarised the key principles and key elements of person-centred practice which they adapted from the Framework for Quality Improvement in Our Health Service (2016).

Person-centred practice principles		Key Elements
1.	Acknowledging patients as Partners in their own care	<ul style="list-style-type: none"> ● Patient and family engagement ● Treating patients as individuals ● Respect for patient autonomy ● Respect of patient privacy- value placed on patient/healthcare professional relationship rather than encounter (Kitson et al 2014) ● “What Matters to you” (2016) ● “Hello , my name is” ● Caring Behaviours Assurance System – Ireland (CBAS-I) (ONMSD 2016)
2.	Creating environments where managers and clinicians can engage with patients and deliver care that is focused on their individual needs and goals	<ul style="list-style-type: none"> ● Empowering patients to take an active role in their care plan/decision making ● Joint goal setting ● Multidisciplinary approach to manangement ● Patients and families as advisors ● Patients rights and responsibilities ● “Patients’ experiences should be the fundamental source of the definition of quality” (Donal M.Berwick)
3.	Supporting patients, families, and communities to participate in service design and delivery of care	<ul style="list-style-type: none"> ● Information/education for patients and families ● Be supported to stay well ● Language and different cultures ● Supports required and available to patients their families/carers ● Triage/referral so aptient seen by the most appraite healthcare professional

³⁸ Interim Standards New Directions- Guidelines for Evaluation, Action and Service Improvement EASI Tool (2018)

³⁹ The HSE Integrated Care Programme for Older Persons (2017) in their ‘Practical Guide to Local Implementation

4.	Providing care that is coordinated	<ul style="list-style-type: none"> ● Documentation ● Communication between clinicians & patients/ families ● Making sense of services required ● Connecting care-key healthcare professional co-ordinating single access point -case manager role ● Discharge planning and post discharge follow-up (Discharge Planning E-learning Programme HSELand)
5.	The Care Environment	<ul style="list-style-type: none"> ● Organisation leadership, mission statement and commitment to quality ● Context in wwhich care is delivered and including appropriate skill mix ● Systems that facilitate shared decision - making;effective staff relationships organisational system;the sharing of power;and the potential for innovation and risk -taking (McCormack & McCance 2006) ● Attitudes and organisational culture ● Attributes of staff ● The physical environment

Table 13; Adapted key principles and key elements of person-centred practice, ICPOP

Local implementation teams should ensure the incorporation of the key principles of person centred practice in the design and delivery of all neuro-rehabilitation services within the CHO through:

- Ensuring service user representation in the implementation process at local level and in relation to the ongoing development and delivery of services.
- Providing a dedicated point of contact within each service for the individual/ family, for those with more complex neuro-rehabilitation needs, this should be a dedicated case manager
- Assessment protocols for each service should ensure that all information gathered details the person’s preferences in relation to their support needs.
- Joint goal setting with the individual and family takes place at all stages of the rehabilitation journey. Specialist support for those individuals who have difficulties with insight due to their condition, in involving them in goal setting and decision making
- Information provision and specialist support and counselling are made available for the individual and family at all stages of the rehabilitation journey
- Delivery of neuro-rehabilitation services should include regular evidenced review of the involvement of the person and their family/others as per their preferences
- Structured opportunities for service users (including individuals and families) to feedback on what they want from their service but also what the service should look like in gene

Deliverable	6.0	Person centred care planning	Responsible	Timeframe
Steps	6.1	Patient representation on local implementation groups	Local Implementation Teams	Q1 2019
Steps	6.2	Review of compliance with Safer Better Healthcare standards under theme 1 across all sites and services within the network plus development of Quality Improvement Plan where areas are identified as needing improvement	Local Implementation Teams	Q4 2019
Steps	6.3	Each service provider across the continuum of care in your CHO should have these standards as part of their mission statement, staff meetings, staff induction, CPD, KPIs and QIPs.	Local Implementation Teams	Ongoing
Steps	6.4	Consultation with service users to inform development of standards for rehabilitation services	NCPRM & NSG	Q2 2019

Table 14; Actions for Step 6 of 10 step Implementation Framework

Step 7

Enabling People to Live Well

Empowering and enabling people to have an active role in the management of their condition

Step 7 aims to ensure that a locally co-produced health and wellbeing plan is in place. In order to achieve this, local service leaders will be required to work with voluntary agencies in developing a range of community supports that enable people living with neurological conditions to live well in their community including addressing areas such as;

- Social activities
- Home modifications
- Medication management
- Shopping
- Support carers
- Community transport



Fig 19; Self Management Support taken from National Framework and implementation plan for self-management support for Chronic Conditions, HSE 2017)

Self-Management Support is defined as the systematic provision of education and supportive interventions, to increase service users' skills and confidence in managing their health problems. The service user health professional relationship is a partnership approach and includes regular assessment of progress and problems, goal setting, and problem-solving support. (Adapted from Institute of Medicine, 2003⁴⁰). The HSE Self-Management Support Framework (2017⁴¹) sets out how the HSE wants to support people to engage with and manage their conditions, through collaborative relationships and supportive interventions. Voluntary organisations have developed a number of condition specific self management programmes and supports for people with neurological conditions, incorporating service user involvement in the design and delivery of these services.

The inclusion of the local self-management coordinator on local implementation teams is required to assist with the development of evidence based self- management programmes and promote the uptake of same.

The vision of Healthy Ireland (HI) A Framework for Improved Health and Wellbeing 2013 - 2025⁴² is a Healthy Ireland, where everyone can enjoy physical and mental health and wellbeing to their full potential, ⁴³where wellbeing is valued and supported at every level of society and is everyone's responsibility. The inclusion of the local health and wellbeing lead on local implementation teams is required in order to promote the health and wellbeing of people with neurological conditions to live well in their own communities for as long as possible

The Making Every Contact Count programme supports the implementation of Healthy Ireland through health professionals using their routine consultations to empower and support people to make healthier choices to achieve positive health outcomes to support chronic disease prevention and management.

Development of Peer Support Programmes to provide support to people living in their communities who are at high risk, such as people living alone, people recently discharged from hospital, and people living with progressive neurological conditions are advised.

Social prescribing is simply described as connecting people to non-medical sources of support in their own communities. It provides health professionals such as Hospital Consultants; GPs and other primary care professionals with non-medical referral options to improve health and wellbeing of their patients. Social Prescribing projects commonly refer to services provided by the voluntary and community sector. Local service leaders including the lead for health and wellbeing and the self-management support coordinators will work with statutory agencies including local authorities and voluntary agencies through collaboration with the NAI to develop a range of community supports that enable people with neurological conditions to live well in their communities.

⁴⁰ Institute of Medicine, 2003

⁴¹ Living Well with a Chronic Condition: Framework for Self-management Support National Framework and Implementation Plan for Self-management Support for Chronic Conditions: COPD, Asthma, Diabetes and Cardiovascular disease, HSE 2017

⁴² The vision of Healthy Ireland (HI) A Framework for Improved Health and Wellbeing 2013 - 2025

⁴³ Vision for Change Department of Health and Children 2006

Deliverable	7.0	Enabling People to live well	Responsible	Timeframe
Steps	7.1	Ensure there is a Health & wellbeing representative on each local implementation group, ideally the appointed self-management coordinator	Local Implementation Teams	Q1 2019
Steps	7.2	Mapping of supports to live well as part of Step 3 mapping exercise, including identifying gaps in services	Local Implementation Teams	Q2 2019
Steps	7.3	Outline of community supports as part of local service framework for rehabilitation services	Local Implementation Teams	Q4 2019
Steps	7.4	Development of peer support programmes across the CHO	Local Implementation Teams	Q4 2020

Table 15; Actions for Step 7 of 10 step Implementation Framework

Step 8

Enablers

Identification of essential supporting infrastructure

Enablers can be sub divided into a number of categories. With respect to the implementation of the National Neuro-rehabilitation Strategy, the enablers that will have the most significant impact would be;

- **Communication protocol:** In order for local teams to work effectively, good communication across the services will be essential. To this end, a communication tool has been developed by the NSG and will be made available to local teams. This may be adapted locally as required.
- **Information systems;** this refers not only to the development of registers for presenting conditions, it also includes the appropriate sharing of information across service providers to ensure the safe and efficient handover of clinical care, but also includes a system whereby patients outcomes can be recorded and shared and monitored. This will be facilitated by e-health and the Individual Patient Identifier (IHI). Performance monitoring is a continuous process that involves collecting data to determine if a service is meeting desired standards or targets
- **Finance;** Current funding and payment structures do not incentivise the delivery of rehabilitation in a timely or comprehensive manner. Current funding streams lead to delayed rehabilitation and delayed transfers within the system, which leads to suboptimal outcomes, inappropriate care in the wrong setting and increased stresses on patients and families. Similar to paediatric services, the completion of a specialist rehabilitation needs assessment/prescription should trigger the commencement of a planned release of funding to ensure timely care for those patients with severe and major injuries/illness most at need of multiagency input. It is recommended that patients with complex needs require a centralised ring-fenced funding stream for their ongoing care needs/homecare packages. Estimates submissions will need to be cognisant of this.
- **Additional Resources:** The additional resources required to fund the MCRN demonstration pilot project on a phased basis will be highlighted in the Estimates process annually. The breakdown of posts and costs to have a dedicated CNRT in each CHO will also be outlined through this process.
- **Resources.** Ultimately, each element of the continuum of care should be resourced according to international best practice recommendations.
- **Skilled competent workforce.** Competencies and standards for delivery of rehabilitation services are to be developed. Another aspect is the further

development of roles and professional practice as described within the model of care of the NCPRM; this includes development of case manager role, rehabilitation coordinator and advanced practice across nursing and health & social care professionals.

- **Interdisciplinary working**; 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. In addition to clinical competencies, staff may require additional training to support interdisciplinary approach to holistic rehabilitation across the continuum of care.

Deliverable	8.0	Enablers	Responsible	Timeframe
Steps	8.1	New roles; e.g. rehabilitation coordinator, case manager, complex discharge planner. Job descriptions to be developed for same and included in estimates proposals	NSG	Q2 2019
Steps	8.2	Local service frameworks to contain clear protocols for information sharing & communication between all services	Local Implementation Team	Q2 2019
Steps	8.3	Analysis of knowledge gaps with respect to staff training and experience	Local Implementation Team	Q2 2020
Steps	8.4	Supporting IT infrastructure including database for measurement of patient outcomes	Rehabilitation Medicine Programme	Q4 2020
Steps	8.5	Rehabilitation input into the development of a centralised funding of complex homecare packages for adults	Expert Advisory Group - Complex Discharges	ongoing

Table 16: actions for Step 8 of 10 step Implementation Framework

Step 9

Develop Supporting Infrastructure to Create the Managed Clinical Rehabilitation Network

Reconfiguration of services into a Managed Clinical Rehabilitation Network

It is envisaged with time the local neuro-rehabilitation services within each CHO will be merged into a number of population based managed clinical networks. The implementation of these population based networks will have to work in tandem with the 96 primary care networks being developed by the HSE across the CHO's.

Specialist rehabilitation, unlike many other speciality areas, sees the patient through services that span all HSE divisions. Supporting this, services will have to work across traditional organisational boundaries. The same will apply to funding of services. This will require a whole system approach supported by leadership at the highest levels. Within a network model the longer-term needs of people with neurological 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.

It is felt to be unlikely that the development of a Managed Clinical Rehabilitation Network will have to begin from scratch in any area in the country. Most clinicians will already work in fairly well established informal networks. This process is about formalising and developing these networks so that access to services is equitable across the country.

The local implementation teams will lead in the development of the local MCRNs under the guidance of the NSG and NCPRM. MCRNs must be managed and need clear structures and lines of responsibility. A clinician or a clinical manager should take a lead role but there should be clear responsibilities for all concerned. The Chief Officer will have the responsibility of nominating the person(s) who will lead on the implementation of this framework at local level. Depending on the groups/fora already established/under development in place in each CHO, additional resources may be required to support this person(s). This resource may vary in each CHO until the sub structure currently being examined, evolves into practice.

Supporting Operational Infrastructures

The effective functioning and transition of patients through the MCRN will be supported by the following;

Shared Assessment Protocols

- The initial completion of the specialist rehabilitation prescription/rehabilitation needs assessment should trigger a co-ordinated communication to relevant members of the team to ensure that appropriate services are notified. Although exact care needs may not be known at the very early stages, it is important that

the need for a home care package, housing adaptations and equipment be flagged at the earliest opportunity to allow time for funding requests to be processed, approved and released, which will in turn facilitate timely and safe discharge to home or an alternative residential facility (e.g. equipment, home care package requirements).

- The outcome of the assessment will signpost the patient to the most appropriate level of service to meet their needs

Shared Referral Protocols

Through the mapping exercise and subsequent follow up with services in various areas of the country, a shared central referral database is felt to be the most appropriate. This would be based on appropriate triage of referrals and assignment of the referral to the most appropriate agent within the network through a joint forum.

This process should;

- Avoid duplication of referral/triage
- Ensure services are aligned to meet the needs of the patient

The centralised referral management system will be trialled through the MCRN demonstrator pilot, with learning taken from areas around the country where such practice is established. Irrespective of whether referrals are managed centrally or by individual providers, the following key principle should apply;

- Criteria with respect to accepting a referral will predominantly be through clinically determined need for specialist neuro-rehabilitation services for those who require a degree of specialised input (either intensity or breadth of services) beyond that available from a primary care or generalist team. The person referred should have a primary diagnosis of a neurological condition and potential to benefit from specialist neuro-rehabilitative input

Shared Waiting List Management Protocols

A consistent approach to waiting list management is required to ensure that access to services is equitable irrespective of service type or geographical location. To this end, it would be recommended that the principles of the NTPF National Inpatient, day care, planned procedure waiting list management protocol are adopted in as far as feasible. It is acknowledged that planning admission/initiation of treatment for a person requiring neuro-rehabilitation is not as straightforward as an elective procedure and there are more variables to be considered. Having said that, the principles should apply to ensure 'safe, timely and effective access and treatment of patients in a fair and equitable manner' (NTPF, 2017);

Shared Discharge Planning Protocols

Effective flow within and across rehabilitation settings is essential, particularly given the demand on these services and the direct correlation between early rehabilitation and better outcomes.

The challenges to effective timely discharge or transfer of care are well known through the work of the Demonstrator MCRN pilot. They include;

- Gaps in onwards care
- Availability of funding for home care packages
- Availability of funding for equipment/aids and appliances

It is hoped that the following recommended steps will assist with streamlining processes and effecting more efficient discharges, however it is acknowledged that full implementation of the strategy, primarily appropriate resourcing and integrated care pathways will be essential for maximum effectiveness. It is also acknowledged that the optimum approach will require both an Individual Health Identifier and supporting Electronic Patient Record. In the interim, it is hoped that common data sets, particularly for referral and discharge will assist with streamlining of some systems.

1. The proposed standardised rehabilitation needs assessment and centralised management of referrals should also assist with discharge planning, as all those likely to be involved in onward care will be included in discussions/plans from the earliest possible time. This timely exchange of clinical data about patients will support transition through services. Again, through the MCRN demonstrator project, access to relevant patient information was reported as a barrier to assessment/provision of service, particularly for those providing services in the community.
2. Applications for relevant services/entitlements etc should also be made at the earliest possible time. Clear communication with patient, family and all relevant clinicians, current and future should be supported. Community conferences should be scheduled at regular intervals to ensure all involved in the management of the patient are aware of their current level of functioning and likely future needs. The discharge date should be determined by the individuals identified and agreed goals. This date, while potentially subject to change, should be communicated widely to allow for alignment of services in the community.
3. It must be noted, the learning's from the MCRN regarding model of care, patients pathways, discharge planning protocols, waiting lists management etc will be shared with the local teams across each CHO. This will assist the development of standardised neuro rehabilitation processes and protocols across the country. Depending on one's CHO population and demographic profile, these guidelines will be modified to meet the needs of the local population. Bearing in mind the difference between the population sizes within the CHO's from 364,464 in CHO area 6 to 674,071 in CHO area 7. The local implementation teams cannot examine population size in isolation and must consider all parameters including the numbers of people living in ones CHO with neuro rehabilitation needs and the demand this puts on service delivery.

The integration between the different levels of the MCRN is vital to its success. As further rehabilitation services develop within the community, outside of specialist neuro-rehabilitation services, it will be essential that services work together to ensure that each individuals rehabilitative needs are met. As care pathways develop there will be a need for all rehabilitation services in the community approach individual need in an integrated holistic way.

Complex Discharge Planning for High Dependency 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. Many will continue to require 24-hour care and/or significant ongoing care and supports. Options with respect to longer term care of this cohort of patients are currently limited. A return to home with an appropriately funded care package is the ideal for many patients with high dependency needs. Currently the funding of

such care packages is a challenge as they are funded out of local budgets and budget holders need to be cognisant of the many demands on a limited budget.

A policy framework and operational procedures to support the development of a centralised funding model for complex homecare packages is being developed. If operationalised, this would see funding of homecare supports taken out of local budgets and accessed based on clinically assessed need. The proposal is to replicate the similar model which is operational in children's services.

Beyond the highest level of complexity, there is a cohort of patients who will require substantial homecare packages. These home care packages will require funding through individual CHO's.

Some people will continue to require 24 nursing care and a discharge home may not be feasible. The individual and the family/carers preferences should be taken into account when long term care is being planned. Ongoing rehabilitative interventions within residential services is an area which requires further development, potentially through a sub-group of the NSG with representation from key stakeholders.

Clinical Governance

The basis of clinical governance is that service providers are accountable for the quality of care provided within their organisation. The issue of clinical governance within a network model is an issue that needs to be addressed as it looks at working across traditional organisational boundaries.

The recommendation, based on the learning from NHS Scotland is that the MCRN oversight group agrees the quality agenda. In the Irish context, it is proposed that the Standards developed by the NCPRM are adopted. The CEOs and clinical governance committees of participating organisations will need to be in agreement with same. Any issues pertaining to staff and their ability to deliver care in line with agreed standards will remain with the employing organisation.

Effective governance and accountability can be achieved by embedding leadership and operational management at a corporate and clinical level. This is underpinned by 6 key steps;

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

Staff Training

There has been considerable discussion as to what denotes the ‘specific training’ required of staff working in specialist neuro-rehabilitation services. Given the dearth of specific post-graduate training in Ireland in the area of neuro-rehabilitation, the consensus reached at a workshop facilitated by the NCPRM included the following;

- Case load with neuro-rehabilitation critical mass
- Access to clinical supervision
- Neuro-rehabilitation experience
- Evidence of continued professional development in the area of neuro-rehabilitation

The National Tertiary Centre, Regional Post-acute specialist inpatient services and community neuro-rehabilitation teams will have a role in education and training those in generalist services. Rotation of staff through the various service levels within the network would also be advocated to all staff working within the MCRN understand the demands of the roles across the continuum of care.

Deliverable	9.0	Develop Supporting operating procedures to support MCRN	Responsible	Timeframe
Steps	9.1	<p>Development of assessment policies & protocols</p> <p>Assessment of need will be through a nationally developed rehabilitation needs assessment. Recommended timeframes for assessment may need to be modified locally, particularly in community-based settings where acuity of patients may be less.</p> <p>Access to services should be based on assessed need.</p> <p>Waiting time to assessment is however proposed as a key performance indicator for each network, so every effort should be made to adhere to same.</p>	Local Implementation Teams with support from NSG and Rehabilitation Medicine Programme	Q4 2019
Steps	9.2	<p>Referral management policies & protocols</p> <p>Referral management policies should be developed per network, not per individual service. Ideally a centralised referral management system should be introduced. Examples of such centralised systems exist in a number of CHO's across the country, where referrals are triaged by a multi-agency forum and services are aligned based on the individual's need.</p> <p>Such a forum is proposed for the MCRN demonstrator pilot and learning from this initiation will be shared with local MCRN groups through the National Steering Group</p>	Local Implementation Teams with support from NSG and Rehabilitation Medicine Programme	Q4 2019

Steps	9.3	<p>Development of waiting list management policies & protocols</p> <p>A rehabilitation specific waiting list management policy needs to be developed based predominantly on the NTPF waiting list management policy but with some modifications specific to the delivery of specialist neuro-rehabilitation services. While neuro-rehabilitation services would not fall in to the category of unscheduled care, they are not purely elective either, and as such, the recommended priority criteria need modification for neuro-rehabilitation services.</p> <p>The management of an 'active' waiting list, the routine validation of waiting lists and equitable access are wholly supported.</p> <p>The revised waiting list policy will be made available to local implementation groups through the National Steering Group for adoption within each MCRN.</p>	Local Implementation Teams with support from NSG and Rehabilitation Medicine Programme	Q4 2019
Steps	9.4	<p>Discharge planning policies & protocols</p> <p>Discharge planning should begin at the point of entry to the MCRN, be it acute hospital, NRH, Post acute inpatient or community neuro-rehabilitation services. The discharge planning should however be for the eventual discharge location, not the next step in the continuum of care. Supporting documentation such as discharge checklist will be developed centrally and disseminated through the NSG.</p>	Local Implementation Teams with support from NSG and Rehabilitation Medicine Programme	Q4 2019

Steps	9.5	<p>Clinical Governance</p> <p>Establish Quality Agenda for each network which should include;</p> <ul style="list-style-type: none"> - the measurable safety, quality, access and cost objectives. - Ensure there is a documented standardised pathway in place. - Ensure that all parties involved in the pathway have total clarity of their accountability roles, responsibilities and governance arrangements. - Ensure there is a balanced set of metrics in place to track the performance of the pathway. - Ensure there is an effective clinical meeting held regularly, where those who are managing the pathway identify variance in its operational performance and log actions to be taken to improve the outcome for the patient. 	Local Implementation Teams with support from NSG and Rehabilitation Medicine Programme	Quality Agenda to be in place by Q4 2019 with annual reporting against same annually
Steps	9.6	<p>Education & training policies & protocols for both personnel & patients/carers;</p> <ul style="list-style-type: none"> - Identification of core competencies for staff working within and across the MCRN and monitoring system for same 	Local Implementation Teams with support from NSG and Rehabilitation Medicine Programme	Q4 2019

Table 17; Actions for Step 9 of 10 Step Implementation Framework

Step 10

Monitor and Evaluate

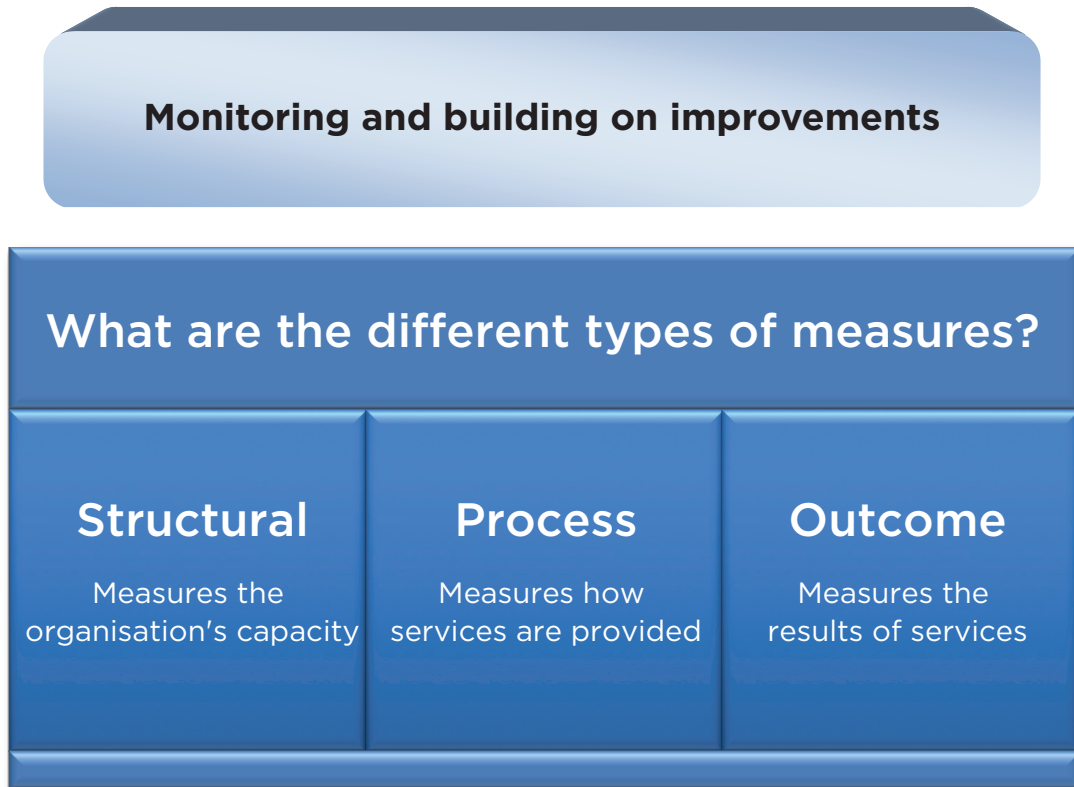


Fig 20; Different Types of Measures

The identification of key performance indicators (KPI's) within the delivery of rehabilitation services is not the challenge in itself. There are many targets across all 3 types of measures (i.e. structural, process and outcome) which the NSG 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. A standard set of performance indicators will be developed nationally.

The Key Performance Indicators proposed below include both process and outcome measures. They should support the implementation of the strategy and/or highlight areas that require attention. Regular review of how the MCRN is performing with respect to the KPI's should support the identification of;

- Trends
- Areas needing performance improvement
- Actions to be taken.

Structural measurement will be gathered through reporting on progress through the 10-step framework across NSG, Working Groups and Local Implementation Teams. The local lead will have responsibility for collating and reporting this information.

Below are some example KPI's for consideration for adoption at local level. Once agreed, KPI's will need to be further developed in line with National Service Plan KPI suite i.e. include exact title, description, rationale, target, target trajectory, data sources, data collection frequency, monitoring and report period. Baseline measurement of agreed indicators will need to be established against which services will be measured.

	ISSUE	IMPACT	SOLUTION	BENEFITS
ACCESS	Long waiting times for assessment	Pathway for patients & family unclear as appropriate service not identified for patients	Introduction of standardised rehabilitation needs assessment	Earlier identification of patients need and referral to appropriate level of service
	Waiting times for access to inpatient rehabilitation services	Patients remain in acute hospital environment for longer than necessary	Increase number of beds available for post acute specialist inpatient rehabilitation	Improve patient outcomes
		Patient outcomes negatively impacted		Release of tens of thousands of acute bed days into the acute hospital setting
	Waiting times for access to community specialist neuro-rehabilitation services & home care supports	Patients remain in acute hospital environment for longer than necessary	Introduction of population based community based neuro-rehabilitation teams	Facilitate earlier discharge of patients to their local environment
		Patients remain unduly delayed in post-acute specialist inpatient beds further limiting access		Improved patient outcomes
				Improved access to inpatient post acute specialist inpatient services
				Release of bed days into the acute hospital setting
	Equitable access to specialist rehabilitation services	Unclear or inconsistent planning is a source of distress to patients and families.	Standardised waiting list management systems across the MCRN	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.

QUALITY	Measurement of patient outcomes	There is currently no national requirement to measure patient outcomes including satisfaction. While it is often measured locally, it is not measured across the continuum of care. Without capturing this data we are unable to measure the effectiveness of rehabilitative interventions	Introduction of national, standardised reporting of patient outcomes including satisfaction and quality of life.	Accurate & patient centred service planning 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
	Measurement of discharge destination			
	Measurement of patient experience			
	Measure of patient quality of life and psychiatric outcome			
VALUE	LOS at acute hospital	Excessive waiting times in acute hospitals result in an inefficient and ineffective use of resources with poorer patient outcomes. There is Grade A evidence that rehabilitation services are cost effective. The population needs assessment undertaken for the demonstrator has also identified the significant amount of acute bed days lost annually for patients with neuro-rehabilitative needs. Considering the demand on acute bed days & ongoing issues with capacity of acute hospital, the impact of this is significant	Patients should be treated in the right setting at the right time - as determined by assessment of need. This would be supported by standardised assessment of need and earlier access to the most appropriate setting	This will result in improved patient outcomes and a reduction in disability levels on those with neurological conditions.
	LOS at inpatient rehabilitation facility			
	Reduce number of patients discharged inappropriately to long term care			

Table 18; Proposed KPI's

Deliverable	10	Monitor & Evaluate	Responsible	Timeframe
Steps	10.1	Development of KPIs for neuro-rehabilitation services, including specialist community neuro-rehabilitation services	NSG & NCPRM	Q 1 2019
Steps	10.2	Adopt Proposed KPIs Each Local Implementation Team will need to review proposed KPI's and consider their application to services. Additional KPI's can be proposed to the NSG which may further enhance collection of meaningful data on patient outcomes	Local Implementation Teams	Q2 2019
Steps	10.2	Establish reporting system In the absence of a national reporting system each Local Implementation Team will have to collect & collate data on process, clinical outcomes and patient outcomes locally until such a time as national data base is developed. Reporting on structural measures will be through submission of progress reports to NSG	Local Implementation Teams	Reporting on structural measures i.e. progress in relation to implementation will be quarterly from Q2 2019 to NSG. Process and outcome measurement will follow as rehabilitation services develop, The initial dataset from mapping exercise should be considered baseline against which developments/ improvements can be measured.
Steps	10.3	Establish supporting infrastructure/database to support regular review of KPI's As referenced, regular review of KPI's is essential to identify emerging trends and areas for improvement	Local Implementation Teams (This infrastructure will need to be established at national level and as local level.	Q4 2019
Steps	10.4	Monitoring & Evaluation structural measures Annual work plan with timeframes for implementation of IF	Local Implementation Teams	Ongoing

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Appendix 1:

Gantt Chart

		Q1 2018	Q2 2018	Q3 2018	Q4 2018	Q1 2019	Q2 2019	Q3 2019	Q4 2019	Q1 2020	Q2 2020	Q3 2020	Q4 2020	Q1 2021	Q2 2021	Q3 2021
1.0 Establish Appropriate Governance Structures at local level																
1.1	Establish a local implementation group with representation from list above					◆										
1.2	Agree Terms of Reference					◆										
1.3	Agree work plan for 2018/2019					◆										
2.0 Population needs assessment per CHO																
2.1	Validate and further develop the population needs assessment completed by NSG for each CHO.						◆									
2.2	The population needs assessment should also include a national census						◆									
3.0 Map local care resources against current and anticipated demographic needs																
3.1	Mapping of existing neuro-rehabilitation services relevant to CHO/Hospital Group, both with respect to staffing but also operational policies and procedures						◆									

3.2	Compare existing services with internationally recognised best practice standards with respect to staffing ratios per population																		
3.3	Compare existing service levels at National Tertiary Centre to those recommended by BSRM for a tertiary service provider																		
3.4	Address existing service delivery through submission to estimates process for essential staffing for inclusion in successive service plans																		
4.0 Develop Services and Care Pathways																			
4.1	Identify the role and function of each service across the patient journey Full scope of service for each service across the continuum of care to be developed																		
4.2	Audit of current practice with respect to patient journey and current assessment of patients for rehabilitation services																		
4.3	Identify specific 'bottlenecks' within the system which impact on the rehabilitation process currently i.e. flow between services.																		
4.4	Evaluation of current services against Standards																		
4.5	Develop services in each CHO annually with new investment if necessary																		

5.0 Develop New Ways of Working

5.1	Review of existing formal or informal care pathways within the CHO																			
5.2	Identification of key stakeholders for ICP development group per ICP																			
5.3	Consultation on ICP																			
5.4	Approval of ICP																			
5.5	Implementation of ICP																			
5.6	Review of data post introduction of pathway																			

6.0 Person centred care planning

6.1	Patient representation on local implementation groups																			
6.2	Review of compliance with Safer Better Healthcare standards under theme 1 across all sites and services within the network plus development of Quality Improvement Plan where areas are identified as needing improvement																			
6.3	Each service provider across the continuum of care in your CHO should have these standards as part of their mission statement, staff meetings, staff induction, CPD, KPIs and QIPs																			
6.4	Consultation with service users to inform development of standards for rehabilitation services																			

7.0 Enabling People to live well

7.1	Ensure there is a Health & wellbeing representative on each local implementation group, ideally the appointed self-management coordinator																	
7.2	Mapping of supports to live well as part of Step 3 mapping exercise, including identifying gaps in services																	
7.3	Outline of community supports as part of local service framework for rehabilitation services																	
7.4	Outline of community supports as part of local service framework for rehabilitation services																	

8.0 Enablers

8.1	New roles; e.g. rehabilitation coordinator, case manager, complex discharge planner. Job descriptions to be developed for same and included in estimates proposals																	
8.2	Local service frameworks to contain clear protocols for information sharing & communication between all services																	
8.3	Analysis of knowledge gaps with respect to staff training and experience																	
8.4	Supporting IT infrastructure including database for measurement of patient outcomes																	

8.5	Rehabilitation input into the development of a centralised funding of complex homecare packages for adults																			
9.0 Develop Supporting operating procedures to support MCRN																				
9.1	Development of assessment policies & protocols																			
9.2	Referral management policies & protocols																			
9.3	Development of waiting list management policies & protocols																			
9.4	Discharge planning policies & protocols																			
9.5	Establish Quality Agenda for each network which should																			
9.6	Education & training policies & protocols for both personnel & patients/carers																			
10.0 Monitor & Evaluate																				
10.1	Development of KPIs for neuro-rehabilitation services, including specialist community neuro-rehabilitation services																			
10.2	Adopt Proposed KPIs																			
10.3	Establish reporting system																			
10.4	Establish supporting infrastructure/database to support regular review of KPI's																			
10.5	Monitoring & Evaluation structural measures																			

Appendix 2:

Working Group - Development of Implementation Framework

Representative	Representing
Anne Marie Ryan	Office of the Head of Strategy & Planning, Disability Services
Edina O'Driscoll	National Clinical Programme, Rehabilitation Medicine, Neurology & Epilepsy
Dr Jacinta McElligott	National Clinical Programme, Rehabilitation Medicine
Mags Rogers	NAI members & people with Neurological Conditions
Karen Foley	NAI member organisations providing specialist community services
Dr Amanda Carty	National Rehabilitation Hospital
Dr Anne Dee	Health & Wellbeing and Population Health
Dr Christopher Carroll	Health & Wellbeing and Population Health
Trina Doran	Acute Hospital Services
Mary O'Kelly	Primary Care
Fionnuala Duffy	Health & Social Care Professionals
Carol Cuffe	Head of Social Care, CHO 7

Appendix 3:

Working Group Membership Demonstration Project

Representative	Representing
Anne Marie Ryan	Office of the Head of Strategy & Planning, Disability Services
Edina O'Driscoll	National Clinical Programme, Rehabilitation Medicine, Neurology & Epilepsy
Dr Jacinta McElligott	National Clinical Programme, Rehabilitation Medicine
Richard Stables	Headway Ireland
Karen Foley	Acquired Brain Injury Ireland
Sean Kinsella	MS Ireland
Dr Valerie Twomey	National Rehabilitation Hospital
Derek Greene	National Rehabilitation Hospital
Conor Leonard	Royal Hospital Donnybrook
Suzanne Corcoran	Peamount Healthcare
Catherine Slattery	Peamount Healthcare
Trina Doran	Acute Hospital Services
James Glover	Primary Care, CHO 6
John O'Donovan	Social Care, CHO 6

Appendix 4 & 5

Recommended staffing levels per service delivery site & BSRM recommendation

Profession	WTE Gap	Cost	Salary Mid	PRSI	Total	WTE Total
Consultant	2		€140,246.00	€15,076.45	€155,322.45	€310,644.89
Medical	1.5		76496	€8,223.32	€84,719.32	€127,078.98
Nursing	35		37137	€3,992.23	€41,129.23	€1,439,522.96
Physiotherapy			43191	€4,643.03	€47,834.03	€0.00
Manager	0		66121	€7,108.01	€73,229.01	€0.00
Senior	1		55578	€5,974.64	€61,552.64	€61,552.64
Basic Grade	4.5		43191	€4,643.03	€47,834.03	€215,253.15
Assistant	0	€107,977.00	31107	€3,344.00	€34,451.00	€0.00
Occupational Therapy						
Manager	0		66121	€7,108.01	€73,229.01	€0.00
Senior	1		55578	€5,974.64	€61,552.64	€61,552.64
Basic Grade	4.5		43191	€4,643.03	€47,834.03	€215,253.15
Assistant	0	€107,977.00	31107	€3,344.00	€34,451.00	€0.00
Social Work						
Manager	1		61648	€6,627.16	€68,275.16	€68,275.16
Senior	1		61648	€6,627.16	€68,275.16	€68,275.16
MSW	0	€29,010.00	48351	€5,197.73	€53,548.73	€0.00
Speech and Language						
Senior	1		55577	€5,974.53	€61,551.53	€61,551.53
Basic Grade	1.5		43,191	€4,643.03	€47,834.03	€71,751.05
Assistant	0	€38,871.00	31107	€3,344.00	€34,451.00	€0.00
Dietetics						
Senior			57987	€6,233.60	€64,220.60	€0.00
Basic Grade	1	€25,270.00	43,191	€4,643.03	€47,834.03	€47,834.03
Clinical Psychology						
Senior	1	€145,496.00	81420	€8,752.65	€90,172.65	€90,172.65
Basic Grade	1		64864	€6,972.88	€71,836.88	€71,836.88
						€2,910,554.85

Staffing & cost for a 20 bed post-acute specialist rehabilitation unit
The total figure of €2,910,554 does not include Pension, Overheads or equipment costs.

Posts	Cost	Salary mic	PRSI	Total	Total wte cost	
Team Leader/Coordinator	1.2 €80,982.00	61,648	6627.16	68,275	81930.19	
Consultant in Rehab	1.4 €233,122.00	140,246	15076.45	155,322	217451.4	
Clinical Nurse Specialists ANI	1 €249,443.00 (1 at ANP & 3.7 at CNS)	62,210	6687.575	68,898	68897.58	
CNS	3.7	51,874	5576.455	57,450	212566.7	
Physiotherapists senior	1 €162,810.00 (1 Sen- 2.5 Basic)	57,987	6233.603	64,221	64220.6	
Physiotherapist basic level	2.5	43,191	4643.033	47,834	119585.1	
Occupational Therapists seni	1 €271,043.00 (1 Sen & 5 Basic)	57,987	6233.603	64,221	64220.6	
OT basic	5	43,191	4643.033	47,834	239170.2	
Speech & Language Therapist	1 €155,188.00 (1 Sen & 1.4 Basic)	57,986	6233.495	64,219	64219.5	
S< basic	1.4	43,191	4643.033	47,834	66967.65	
Clinical Psychologists senior	1 €170,129.00 (1 Sen Clinical & 1.4 Clinical)	83,143	8937.873	92,081	92080.87	
Clin psychol	1.4	64,864	6972.88	71,837	100571.6	
Social Work PSW	1 €292,814.00 (1 PSW- 3.7 Team Leader)	67,663	7273.773	74,937	74936.77	
Social worker team leader	3.7	61,648	6627.16	68,275	252618.1	
Dietitian senior	1 €63,236.00 (1 Sen & .2 basic)	55,578	5974.635	61,553	61552.64	
Dietitian basic	0.2	42,945	4616.588	47,562	9512.318	
Case Managers	5	Senior HSCP g	55,578	5974.635	61,553	307763.2
Rehabilitation Assistants	4.7 €145,037.00 4.7 HCA	(Salary mid pt	31,107	3344.003	34,451	161919.7
Total	37.2				2260185	

Staffing & cost for CHO based Community Neurorehabilitation Team (based on population of approx 500,000- this figure of 500,000 is being used as a baseline)

When Pension (4%), Overheads (25%) and equipment costs (approx €80,000) are included, **the cost of introducing a 'new' CRT is €3,018,240 per CHO**

Profession	WTE	Cost	Salary Mid	PRSI	Total	WTE Total
Consultant	2.5		€140,246.00	€15,076.45	€155,322.45	€388,306.11
Medical	2.5		76496	€8,223.32	€84,719.32	€211,798.30
Nursing	45		37137	€3,992.23	€41,129.23	€1,850,815.24
Physiotherapy			43191	€4,643.03	€47,834.03	€0.00
Senior	2		55578	€5,974.64	€61,552.64	€123,105.27
Basic Grade	4.5		43191	€4,643.03	€47,834.03	€215,253.15
Occupational Therapy						
Senior	2		55578	€5,974.64	€61,552.64	€123,105.27
Basic Grade	4.5		43191	€4,643.03	€47,834.03	€215,253.15
Social Work						
Senior	1		61648	€6,627.16	€68,275.16	€68,275.16
MSW	1		48351	€5,197.73	€53,548.73	€53,548.73
Speech and Language						
Senior	1		55577	€5,974.53	€61,551.53	€61,551.53
Basic Grade	2.5	€38,871.00	43,191	€4,643.03	€47,834.03	€119,585.08
Dietetics				€0.00	€0.00	€0.00
Senior	1		57987	€6,233.60	€64,220.60	€64,220.60
Basic Grade	0	€25,270.00	43,191	€4,643.03	€47,834.03	€0.00
Clinical Psychology					€0.00	
Senior	1	€145,496.00	81420	€8,752.65	€90,172.65	€90,172.65
Basic Grade	2		64864	€6,972.88	€71,836.88	€143,673.76
Total						€3,728,664.00

BSRM recommended staffing ratios for a 20-bedded Tertiary Rehabilitation Service

DRAFT Scope of Service; Community Neuro Rehabilitation Team

Neuro-rehabilitation is a continuum of services and supports that will require appropriate responses at local and national level. 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. 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).

Generally, patients requiring specialist neuro-rehabilitation are those with complex disabilities. Such patients typically present with a diverse mixture of medical, physical, sensory, cognitive, communicative, behavioural and social problems, which require specialist input from a wide range of rehabilitation disciplines (e.g. rehabilitation-trained nurses, physiotherapy, occupational therapy, speech and language therapy, psychology, dietetics, orthotics, social work etc.) as well as specialist medical input from consultants trained in rehabilitation medicine, neuropsychiatry and other specialities.

Community based specialist rehabilitation teams (CNRTs) require a degree of specialisation and training that will enable them to provide services to people with complex presentations, such as:

- those who require a degree of specialised input beyond that available from a primary care team;
- those who require a level of intensity of therapeutic input that is not possible from a primary care team;
- those who do not require in-patient facilities, but do require high-intensity neuro-rehabilitation inputs;
- those who need to transition from hospital to home (who have neuro rehabilitative needs).

This model of practice for community neuro rehabilitation teams has been developed upon review of existing models currently operational across the country. While there may be variance across some CHO's with respect to how these models of practice are implemented, the general principles should not be subject to interpretation, these are;

- Interdisciplinary team working
- Moderate to high intensity rehabilitation inputs
- Individualised rehabilitation programmes based of service users identified goals
- Measurement of outcomes
- Service based on assessed need

It should be noted that recommendations made in this document are made with the following assumptions in mind;

- An appropriately resourced PCT with universal access i.e. not dependent on age/ medical card etc
- Access to essential supports including;
 - o Respite
 - o Residential services
 - o Vocational services
 - o Transitional living services
 - o Day services
 - o Neuro behavioural services
 - o Family/carer supports
 - o Self management supports
 - o Public Health Nursing
- The links to these services need to be explicitly described within each CNRT
- Links with mainstream services need to be developed for example, local gyms etc to support re-ablement and community integration
- Links to diagnostic services also need to be explicitly described

It is important to also recognise that the CNRT represent just one element of the pathway of care for those with neuro rehabilitation needs and their effective operation is contingent on the availability of other specialist community neuro rehabilitation services, as well as appropriately resourced primary care and disability services. In addition, the development of other specialist services with the managed clinical rehabilitation network (MCRN) including acute and post acute inpatient rehabilitation services is critical to enable CNRT s to operate effectively within a continuum of care.

Key Features of a Community Neuro Rehabilitation Team

- The multi-professional team has undergone recognised specialist training or with significant clinical experience in rehabilitation led or supported by a consultant trained and accredited in Rehabilitation Medicine.
- Smaller caseload allowing for more intensive input
- Clinically led with clinical and professional supervision
- A co-ordinated inter-disciplinary team-working towards an agreed set of goals
- Take patients who initially have more complex rehabilitation needs than non-specialist services
- Clinical data as defined by the UK National Dataset for Specialist Rehabilitation Services (including complexity and outcome data) are routinely collected and reported annually for all patients
- Meet the national standards for specialist rehabilitation services as developed by

the National Clinical Programme for Rehabilitation Medicine

- Support local rehabilitation teams in hospital and community
- Have a recognised role in education, training in the field of rehabilitation.

Therapeutic programmes are typically interdisciplinary and of moderate intensity for patients with an identified need for specialist rehabilitation. 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.

There is a wide breadth of services delivered in the community which play an essential role in maintaining the health & wellbeing of those with neurological conditions and ensuring that the gains made through engagement with clinical services are maintained and generalised into their everyday life. The role played by the Voluntary Organisations and Primary care is paramount in this regard.

Community Neurorehabilitation teams and those providing community neurorehabilitation supports should work in tandem with clear lines of communication and clear referral pathways to ensure each patient receives the supports they require across the continuum of care in a coordinated collaborative way.

Neuro Rehabilitation Continuum of Care

The multi-tier model of levels of complexity of need forms the basis for the provision of specialist rehabilitation services in the UK. It is a model that translates well into the Irish context.

Every service provided within this continuum of care play an essential role in the rehabilitation and ongoing support of the individual with a neurological illness/injury. The success of each intervention is in many ways dependent on the appropriate flow through the continuum of care and availability of services at each level.

The community neuro rehabilitation team play a critical role in this continuum of care, however it is acknowledged that the intervention of such teams is for a relatively short period of time in the life time of the individual with the neurological illness/injury. Without appropriate links to longer term services, for many, the full benefit of the intervention of the CNRT may not be sustained over time.

It is for this reason that the Rehabilitation Medicine Programme recommends to formation of forums within each CHO with representation from all those providing neurorehabilitative supports. This forum should play a key role in;

- Triaging of referrals
- Joint assessment of need
- Identification of appropriate services & prioritization in relation to need
- Coordination of services to support smooth transition between and across services

Rehabilitation Setting;

- Home
- Health centre
- Residential setting

Each CNRT should have access to appropriate facilities to discharge their services including;

- Co-location of team to support MDT approach
- Access to appropriate equipment/appliances/aids to assess patients
- Administrative support
- Appropriate IT infrastructure including telemedicine/telehealth opportunities

Hours of Service

The CNRT provides five days-a-week (Monday through Friday), 9am to 5pm treatment and care. Some services are available outside these times by pre-arranged appointment.

Referral pathway

Referrals are received from;

- Acute hospitals
- National Rehabilitation Hospital
- Other rehabilitation units
- Stroke rehabilitation services
- Primary Care
- GP
- Voluntary Service Providers
- Self-referral
- Neurologists

Admission Criteria

The person being referred must:

- Have a diagnosed primary neurological condition that is acquired or progressive
- Be determined as having the potential to benefit from specialist neurorehabilitation
- Have medical, cognitive, physical, communicative and/or behavioural needs related to their neurological illness or injury which can be met by the CNRT.
- Be able to benefit from and participate in an intensive period of rehabilitation
- Be medically stable
- Be able to access transport to attend the service (if being treated in a centre)
- Be in agreement with the referral to the team
- Be able to attend at least twice a week for up to a maximum of 12 weeks

Discharge Criteria:

Discharge from the CNRT will be progressed when;

1. The person is deemed to have received maximum benefit from the CNRT on completion of the rehabilitation programme
2. The person has improved to the projected functional level that will allow discharge to PCCC or other specified environment or service
3. The person experiences major intervening surgical, medical and/or psychological problems that precludes further benefit from a continuing with an intensive rehabilitation programme.
4. The person is no longer willing to be an active participant in their rehabilitation programme.

Re-referral to the service:

Re-referral is treated as a new referral and acted on accordingly. If the referral is appropriate for the CNRT it can be open to primary care until a position becomes available in the CNRT. A screening questionnaire is sent to the client to determine goals for second period of rehab if they have attended before. If this is not returned, the referral may not be accepted.

If the previous rehabilitation period was not completed (e.g. due to illness) a new period of rehabilitation will be offered. Referral criteria apply as above.

Services provided for the patient

- Case management
 - o 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.
 - o 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.
 - o The NCPRM sees a case manager as being a dedicated, distinct role within the Interdisciplinary 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.
- 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
- Dedicated case manager
- IDT intervention which provides individualized evidence based patient focused therapy programmes which incorporate functional activities aimed to maximise independence and participation in the community

- Activities of daily living (ADL) assessment and training
- Specific task focused interventions
- Cognitive rehabilitation
- Physical Rehabilitation
- Community reintegration
- Coping with and adjustment to disability support
- Dysphagia assessment and management
- Independent living skills assessment & training
- Nutritional counselling and management
- Patient education, training and counselling
- Psychosocial assessment and psychotherapeutic intervention
- Safety awareness and training
- Self management supports

Services not provided through CNRT include;

- Orthotics/prosthetics
- Specific muscle or joint injuries or mobility issues unassociated with neurological condition
- Applications/assessments for long term care packages
- Chronic back injury/pain unassociated with neurological condition
- Housing assessment or environmental adaptation or associated grant applications
- Wheelchair assessment and seating provision
- Driving assessment
- Adaptive equipment and technology
- Podiatry
- Specific assessment for educational supports
- Dental
- Specific nursing interventions/supports such as dressings/wound management/ bowel and or bladder management

Referrals to agencies (primarily Primary Care) providing these services can be facilitated.

Services provided for the family/carer

- Education/training about management of neurological condition/illness (formal education, printed resource material, instruction and practical skills training)
- Psychological support services
- Information about community support, advocacy, accommodation and assistive technology resources.

Discharge outcomes & environments/ essential supports

- Patients are discharged to the care of their General Practitioner and/or disability manager.
- The General Practitioner is invited to refer the patient back as outlined previously.

Ongoing management of their condition can be through community neuro rehabilitation supports such as those provided by;

- PCCC
- Voluntary Organisations

People may also be discharged on to specific services such as;

- Rehabilitative training
- Vocational Rehabilitation Services
- Educational and occupational activities
- Day services

