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# Audit of Delayed Transfer of Care among Neuro- Rehabilitation Patients in Acute Irish Hospitals

2019

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Commissioned by the National Clinical Programme for  
Rehabilitation Medicine

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## Sponsor's Foreword

This piece of work, commissioned by the National Clinical Programme for Rehabilitation Medicine, is important. Although delayed in coming to publication owing to the pandemic, we consider it still holds contemporary relevance. While progress has been made regarding Delayed Transfers of Care within the HSE, they continue to occur at significant scale within hospitals across Ireland. Given the current issues with accommodation shortage, a growing population, increased survivorship from severe illness and an increasing longevity, improved patient flow will remain a priority for our hospital system into the near future.

We present data on the amount of days lost in acute hospitals owing to 'Delayed Transfer of Care' for patients who require access to neuro-rehabilitation. Delayed Transfers of Care (DTC) is the terminology used currently to describe the situation where people have finished their hospital treatment but it is not possible to discharge them from the hospital. This situation may arise for a number of reasons such as a delay in accessing specialist rehabilitation services, lack of appropriate accommodation and lack of necessary support in the community.

For the person that experiences a DTC, the loss of agency and uncertainty associated with this position will be challenging, leading to poorer health and social outcomes. From a health system perspective, such delays result in inefficient and inappropriate use of resources with resulting consequences, such as longer waiting times in the Emergency Department, work environments that are demoralising for staff and the dehumanisation of people into 'delayed discharges'.

Data is essential to begin to find solutions for problems. There is an urgent requirement for a national rehabilitation database to gather metrics, and thereby support quality improvement. Often 'problems' are talked about but it is less common that a step further is taken to gather data in order to characterise the problem objectively. This audit is a start. As Clinical Lead, I would like to thank Caitriona Begley who completed this important piece of work.

The study highlights the complex, specialist needs of the neuro-rehabilitation population. Many of the cohort within this study were young and of working age. Despite the relatively low volume of patients with neuro-rehabilitative need in our health system, this work reports a very high total number of beds days taken by DTC, while awaiting access to neuro-rehabilitation (n=110, 17,413 acute bed days lost). Of note, this audit was from a small sample of only 8 acute hospitals. The total national figure is undoubtedly far greater. The magnitude of bed days lost should cause us to ask – what would the health system be like if the factors leading to such delays were resolved and importantly where does money need to be invested in order to bring about the change that is needed.

Another significant finding is that two-thirds of the people found to be experiencing DTC in this study were not recorded as such by the HSE. Furthermore, 86.5% of those who were reported to the HSE as delayed, were not known to the HSE as requiring neuro-rehabilitation. This suggests there is substantial under-estimation by the HSE's National Delayed Discharge Database for the neuro-rehabilitation population.

The National Neuro-Rehabilitation Strategy and National Clinical Programme for Rehabilitation Medicine's Model of Care present a pathway to deliver improved access to specialist neuro-rehabilitation services. The development of Managed Clinical Rehabilitation Networks will enable a seamless continuum of care for patients with neuro-rehabilitative need. This audit clearly highlights the urgent need for such development, as a means to improving quality of care, patient experience and patient flow through the entire health system.



Dr Paul Carroll  
Clinical Lead, National Clinical Programme for Rehabilitation Medicine

## Executive Summary

It is estimated that in Ireland between 9,000 and 11,000 people sustain a traumatic brain injury annually (Headway Ireland) with a further 10,000 Irish people diagnosed with a stroke (Irish Heart Foundation 2015) and an average of 3 people per week sustain a spinal cord injury in Ireland (Spinal Injuries Ireland). There is strong evidence in support of the benefits & cost-effectiveness of specialist Neuro-Rehabilitation services. However, the demand for Neuro-Rehabilitation in Ireland has been historically difficult to define for many reasons and includes the following barriers.

- Poor baseline reference of Neuro-Rehabilitation services nationally i.e. there is no database on waiting lists for rehabilitation. Moreover, waiting lists cannot be generated for services that don't exist.
- No comprehensive database for neurological conditions/injuries.
- No standardised reporting of rehabilitation (clinical) needs. HIPE data captures information on diagnosis but does not include any additional information on level of complexity/dependency or need. It is further limited, as many of those with neurological conditions who require access to Neuro-Rehabilitation services are in the community and not in acute hospital setting.
- Inaccurate reporting on patients delayed in acute hospitals secondary to the lack of access to Neuro-Rehabilitation services and the impact of these delays.

This audit was commissioned by Clinical Innovation and Design following a request from the National Clinical Programme for Rehabilitation Medicine (NCPRM) in an attempt to address the last point above i.e. the impact on the acute hospital setting, particularly with respect to those who are no longer acutely unwell and do not require an acute hospital bed. It is noted at the outset that this is not wholly representative of the demand for Neuro-Rehabilitation services as many people are living with the long-term impact of neurological illnesses and injury. This audit did not include Neuro-Rehabilitation patients 'delayed' in non-acute settings.

This audit collected data over a seven-week period in 2019. In summary this audit found that; seventy eight percent of the Neuro-Rehabilitation audit population (n=110) are experiencing a delayed transfer of care. This population are mostly young people of working age (56% under 65 years) with an acquired brain injury (including stroke) (77%), who have complex needs (84%). There is substantial under-reporting of these delayed cases to the HSE (65%). Their ALOS is 51 days (median) and they had accrued a total of 17,413 beds days as a consequence of being a DTOC in acute hospitals (at the time of data collection).

This audit will hopefully contribute to increasing awareness of the impact of underinvestment not just on each individual but on a 'health system' level and conversely, how investment in Neuro-Rehabilitation could contribute to resolving some of the long-standing challenges such as Emergency Department trolleys and increasing levels of disability of those with neurological conditions.

## KEY FINDINGS

Among eight Level 1 Irish hospitals, 110 patients were identified as being a delayed transfer of care (DTOC) owing to lack of access to Neuro-Rehabilitation services.

56% of patients experiencing a DTOC in acute hospitals were between 17 and 65 years of age. A further 31% are aged between 65 and 79 years. The median age of DTOC cohort was 60 years.

77% of audit group had a diagnosis of Acquired Brain Injury (including Stroke) with 20% having a spinal cord injury. 17% of DTOC patients had sustained a traumatic injury.

84% of the DTOC group required specialist interdisciplinary Neuro-Rehabilitation as indicated by RCS-E scores (>11). The needs of these individuals could not be met in primary care settings.

The median length of stay for DTOC patients (at time of data collection) was 51 days.

The complete count of acute bed days lost to DTOC for Neuro-Rehabilitation patients during the audit period amounted to 17,413 bed days.

The proportion of occupied bed days was spread relatively evenly among stroke, ABI and SCI. However, the considerably smaller populations of ABI and SCI occupied almost as many bed days as Stroke.

65.5% of DTOC patients had not been reported to the national DTOC database and are therefore not known to the HSE as delays.

86.5% of DTOC patients reported to the HSE as delayed, were not known to the HSE as requiring Neuro-Rehabilitation.



## Chapter 1 Introduction

### Background

Delayed discharges are a major concern for the Irish healthcare system. Delayed discharges contribute to emergency department pressures (ED Task Force Report March 2015) and long waiting times which are two of the greatest challenges facing our health system over many years (Sláintecare, 2019). A Health Service Capacity Review 2018 reported that Ireland had the second highest acute bed occupancy rate among OECD countries. This indicates that the system is under pressure as acute bed stock typically acts as a buffer for pressure across the system. The consequences of delayed discharges are far reaching and impact on patient's physical and mental health, healthcare staff and the economy (Rojas Garcia et al 2017).

The current HSE Special Delivery Unit definition of a delayed discharge is “a patient who remains in hospital after a senior doctor (consultant or registrar) has documented in the medical chart that the patient can be discharged”. The Department of Health (2009) similarly define a delayed discharge as “a patient who is delayed in an acute hospital despite being medically fit to be discharged.. (a patient whose) acute care is complete / medically fit for discharge or the period of continued hospital stay after a patient is deemed medically fit to leave hospital but is unable to do so for non-medical reasons (Bates A. DTOC in NHS 2015).

The Department of Health published an independent expert review on delayed discharges in November 2018. This review, commissioned by Minister Jim Daly TD, highlighted a number of concerns in relation to the HSE definition of a delayed discharge and associated with this, the recording and reporting of delayed discharges. This report recommended a more rigorous process and guidance to support the interpretation and application of the definition and how it should be operationalised. The report also recommended a change in nomenclature from delayed discharge to delayed transfer of care (DTOC) which will be used throughout this report. The recommendation for clarity regarding the definition of a DTOC has previously been made by the Emergency Department Task Force Report in March 2015. This report called for one of the short-term actions to “agree what is meant by a delayed discharge so that it can be appropriately measured and targeted at hospital and community level”.

Sláintecare promotes the need to identify and profile population health status and healthcare needs of cohorts for priority attention, in order to inform service redesign to deliver healthcare in the most appropriate setting. The DTOC population includes a distinct cohort of patients with acquired neurological illness or injury, who have completed their acute medical and surgical care and yet remain in acute hospital beds throughout Ireland. This type of patient population is known through anecdotal information such as waiting lists for rehabilitation services. These patients present with a complex range of impairments and disabilities, which requires specialist input from a range of rehabilitation disciplines in order to achieve successful re-integration

back into the community (BSRM core standards for specialist rehabilitation 2014). There are noted discrepancies between these waiting lists and what is currently reported on the HSE Delayed Discharge report. The purpose of this audit report was to;

- a) quantify the extent of this discrepancy between demand for services and reporting to the HSE
- b) understand the profile of these patients
- c) describe the impact of this DTOC population on the acute hospital system

## Neuro-Rehabilitation in the Irish Context

The National Neuro-Rehabilitation Strategy (2011) and National Clinical Programme for Rehabilitation Medicine (NCPRM) outline the need for patients who experience impairments resulting from a neurological illness or injury to have access to Neuro-Rehabilitation services through coordinated networks. Patients with complex needs typically present with a combination of physical, sensory, communicative, cognitive, behavioural, psychological and social difficulties that require specialist input from a range of rehabilitation disciplines (Turner -Stokes 2014). The NCPRM's Model of Care for the Provision of Specialist Rehabilitation in Ireland (2018) is reflective of the Neuro-Rehabilitation Strategy.

The NCPRM's 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.
- Development of 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).
  - 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 organisations.

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

The demand for rehabilitation services is growing and is anticipated to continue to increase due to improvements in emergency and trauma health care and an aging and increasing population. Advances in acute Irish stroke care management has resulted in a 26% drop in mortality between 2008 and 2015 (National Stroke Audit 2015). The development of trauma systems of care internationally, has led to improved retrieval and intensive care management of people who have sustained severe traumatic brain injuries (Trauma Steering Group 2018). This has yielded a group of patients, mostly of working age, who demonstrate slow and incomplete recoveries.

The NCPRM has identified that there are 'significant resource and delivery gaps in rehabilitation services in Ireland' when compared to other OECD countries. The Model of Care document describes 'long delays in waiting (time) for a specialist Neuro-Rehabilitation bed' and a 'varied level of access across the acute hospital network' (NCPRM 2018).

To date assessing the level of need for specialist Neuro-Rehabilitation services in Ireland has been hindered due to the absence of epidemiological research and the lack of a single comprehensive data source for recording and monitoring this information within the health services (NCPRM 2018). The aim of this audit was to examine the demand for Neuro-Rehabilitation services in Ireland specifically among those experiencing a DTOC in acute hospitals in Ireland. It is acknowledged that this approach will lead to underestimate in terms of demand as it doesn't capture the need being generated at community level.

## National Reporting of Delayed Transfer of Care

Currently, information on those delayed in acute hospitals is gathered at a national level through the HSE acute hospital Business Information Unit (BIU) Delayed Discharge report. This is a live system in which data is collected at hospital level and a report is generated weekly. The report details the number of delayed discharges recorded by Hospital and Hospital Group each week. The BIU collate and validate the National Delayed Discharge Database to generate information that contributes to the National Performance Report which is available to the HSE and Department of Health. The report is used to examine where 'bottlenecks' occur with respect to discharging patients from acute hospital setting. As investment is linked to these bottlenecks, it is essential that the causes for delays are accurately reflected in the BIU report. This has not been the case with respect to those waiting for Neuro-Rehabilitation to date where typical weekly numbers reported as waiting for rehabilitation equal no more than 30-60 people at any one time. This figure does not reflect the waiting list for the National Rehabilitation Hospital which at any point in time has in excess of 200 people waiting, with 90% of referrals typically generated in

the acute hospital setting. This discrepancy warranted further investigation and as such, funding was sought to carry out this audit.

## Aims of Audit

The aims of this audit were as follows;

- Identify the number of patients experiencing a delayed transfer of care from acute hospital, who require Neuro-Rehabilitation. Identify population needs, in the case of this cohort, rehabilitation needs.
- Validate data gathered against the National Delayed Discharge Database. The standard against which the audit is being measured is that 'The National Delayed Discharge Database is 100% accurate'.

The rationale for this audit is aligned with the requirement for a population needs assessment as outlined by Sláintecare (2019) and supports the NCPRM's Model of Care for Specialist Rehabilitation published in 2018. It is also in line with step 2 of the Implementation Framework for the Neuro-Rehabilitation Strategy which identifies the need for service developments to be informed by current and future population needs.

## Chapter 2 Methodology

### Audit Design

A prospective audit was conducted in eight Level 4 acute Irish hospitals over a seven-week period (August 20th to October 10th 2019). The audit was carried out by a senior Health and Social Care Professional with clinical and academic experience in Neuro-Rehabilitation. Due to the time and resource restrictions of the audit, it was not possible to audit every acute hospital in Ireland. Originally ten hospitals were identified for the audit. One of these failed to provide data within the data collection period and a second hospital (group) declined to participate on the grounds of GDPR concerns. The remaining eight hospitals were all Level 4 hospitals with the largest inpatients populations and had the highest number of 'delayed discharges' reported to the (BIU) HSE.

### Scope

The scope of this audit included all adult inpatients, aged 16 and over, with an acquired neurological illness or injury. Specifically, this was defined as patients with a diagnosis of an acquired brain or spinal cord injury or condition (including traumatic, non-traumatic, hypoxia, infections, tumours, aneurysms etc.). The audit also included Stroke, Multiple Sclerosis and Parkinson's Disease. The scope of the audit included the most prevalent neurological illness / injuries that lead to life-changing disability. Details of diagnosis included in the audit are outlined in the results. These diagnoses are based on ICD-10 International Statistical Classification of Diseases and Related Health Problems (ICD), a medical classification list by the World Health Organization (WHO). Demographic information included the patient's age, admission date and date of onset if different and length of stay. Clinical information included their medical status, and details on their degree of impairment in the domains of sensorimotor, cognition and communication. Information was also sought on the patient's psychosocial status as this is an important factor in the patients' transfer of care. Information relating to the patient's impairments allowed for completion of the Rehabilitation Complexity Scale-Extended (RCS-E).

### Defining Delayed Transfer of Care in Neuro-Rehabilitation

#### International Practice

This audit sought to identify patients who were experiencing a delay in transferring out of an acute hospital bed and were 'ready' for neuro-rehabilitation. Similar definitions to the HSE for DTOC are used in the UK and Australia. The (AROC)

Australian Rehabilitation Outcomes Centre inpatient database (revised June 2019) collects patient data on 'date clinically ready for rehabilitation'. AROC define a patient as being "clinically ready for rehabilitation" when the rehabilitation physician, or physician with an interest in rehabilitation, deems the patient ready to start their rehabilitation program and have documented this in the patient's medical record. The Australian definition is similarly broad to the HSE narrative however, they do offer some guidance by way of an example.

AROC further report on episodes where there is a delay between the patient being assessed as appropriate for rehabilitation and the rehabilitation program starting. The database provides categories for reporting the reason for delay, attributed to either medical issues or services issues. The example provided for guidance in relation to a delay due to medical issues is "The patient is not medically stable; he was assessed as appropriate for rehabilitation, but can only be admitted once he has been afebrile for 48 hours OR the patient requires further medical examination, investigation or tests, which cannot be provided on the rehabilitation unit". The example provided in relation to a delay due to service issues is that a rehabilitation bed is not available, or a single room or transport is not available. Three further reasons for a delay are provided, these include; issues with external supports, equipment or patient behavioural issues.

In the UK a National Clinical Audit of Specialist Rehabilitation Following Major Trauma (NCASRI) was published in April 2019. The NCASRI audit examined access to and provision of specialist rehabilitation for patients with traumatic injuries, including how patients that may require specialist rehabilitation are identified.

The 2019 NCASRI audit, as with the previous audit in 2016, revealed that there was confusion regarding the definition of the 'transfer ready (TR) point' – some Major Trauma Centres (MTC) were recording the point at which patients were ready to start engaging in rehabilitation, others at the point when they were ready for transfer, and others at the point of actual discharge from the MTC.

As a result, the NCASRI audit was unable to report against this standard as none of the MTC's were using the assessment tool correctly to identify 'transfer ready' as the optimum time point. The tool in question is the Rehabilitation Complexity Scale-Extended Medical Score (see below for further details). This national trauma audit demonstrates the ambiguity in interpreting and applying the definition for DTOC within a healthcare system (NHS) within a well-developed national rehabilitation network compared to current Irish systems. This illustrates the challenge with clearly defining patients who are 'fit' or 'ready' for transfer out of acute hospital to rehabilitation.

### Assessment Tool

The Rehabilitation Complexity Scale-Extended (RCS-E) Medical Score provides an objective assessment of a patient's medical fitness for transfer. The RCS-E is a simple measure of rehabilitation requirements in rehabilitation services. The RCS-E consists of five items: care (0–4), nursing (0–4), medical (0–4), therapy (0–8) and equipment (0–2) with a total score range of 0–22. The RCS-E-M subscale identifies

the level of medical support required. The scoring of patient's medical status to measure between M1-M3 is defined as the 'R point', that is 'ready' for transfer as outlined in the by British Society of Rehabilitation Medicine (BSRM) core standards for specialist rehabilitation (2014).

An RCS-E-M score of 3 can indicate a potentially unstable medical condition requiring the patient to be managed in a setting with on-site 24-hour emergency medical support immediately available. A score of 3 usually denotes that the unit's day-time medical team formally 'hand over' information to the out-of-hours medical service about the patient's current condition and likely needs for treatment, in case they are called to attend in the coming out-of-hours period. Typical medical conditions would be an unstable tracheostomy, ventilation, unstable dysautonomia, active/high risk of sepsis requiring intravenous antibiotics, unstable epilepsy likely to require intervention etc. An RCS-E-M score of 4 indicates that the emergency medical/surgical services actually attended the patient out-of-hours within the previous week.

In the UK the RCS-E score is used to indicate the level of speciality care that the patient can be transferred to. A classification system is applied to guide this decision i.e.

Level 1 complex specialist rehabilitation, Level 2 specialist rehabilitation and Level 3 non-specialist rehabilitation.

### Current Irish Neuro-Rehabilitation Services

In Ireland there is one complex specialist Neuro-Rehabilitation rehabilitation hospital, the National Rehabilitation Hospital (NRH). The NRH located in Dublin, admits a range of patients including those who require complex specialist Neuro-Rehabilitation, and can accept patients who meet the criteria for RCS-E M1-M3. However, the NRH is under-resourced to manage a caseload of 70% Category A patients, that is, those with highly complex needs, to meet the NCPRM's Model of Care for Specialist Rehabilitation's recommendation.

Other than the NRH, Neuro-Rehabilitation services where they do exist, have access criteria based on age (over or under 65) or diagnostic group (e.g. Stroke) and as such do not meet the aim of the Neuro-Rehabilitation Strategy. Similarly, they do not meet the recommendations of the NCPRM's Model of Care for Specialist Rehabilitation as they are not led by a rehabilitation medicine consultant or specialist interdisciplinary team. The majority of these services are predominantly for people over 65 years, as per the mapping undertaken by the National Neuro-Rehabilitation Strategy steering group. Some of these rehabilitation services may admit patients with an RCS-E score M1-M2, depending on the level of medical cover available.

Since the publication of the HSE independent expert review, a DTOC policy development group has been established to develop a national policy for the management of delayed transfers of care. The new policy was under development at the time the audit was being undertaken and therefore, could not be applied at that time. The proposal for a revision of the current definition of DTOC for the HSE is likely to be more aligned with the NHS England definition which defines a patient as being ready for transfer when:

- A clinical decision has been made that the patient is ready for transfer, and
- A multidisciplinary team has decided that the patient is ready for transfer, and the patient is safe to discharge/transfer.

For the purposes of this audit, defining a Neuro-Rehabilitation patient as 'ready' for rehabilitation and thereby a DTOC, drew on the principles, definitions and guidance NHS England - November 2018. These guidelines ask clinicians to consider if a patient is medically optimised by asking themselves the questions:

- Does the patients' care need to be continued in the current setting?
- Are the needs of the patient better met in a different setting?
- If the support and services required to meet the assessed need, were available at this moment, would the MDT in the hospital confirm that the patient could go now?

The guidelines provide further clarity regarding medically optimised for transfer:

- Does not mean whether all the assessments are completed and equipment has been delivered
- Is not dependent on whether the patient is returned to a baseline level of functioning

During the course of data collection, defining a patient as a DTOC was made in agreement with the stakeholders, based on the above criteria (definition and RCS-E M score) and did not rely on a clinical decision being documented in the healthcare record and reported to the national delayed discharge database.

## Data Protection

The data collected in this audit included pseudo-anonymised information on the patient's impairments as well as psychosocial considerations. Patients level of complexity and rehabilitation needs were determined using the Rehabilitation Scale-Extended (RCS-E) Version 13. Non clinical data collected included the patient's age and length of stay (LOS). A Data Protection Impact Assessment was completed, which identified and mitigated the risk to health data ensuring patient and hospital anonymity.

## Data Collection

In advance of data collection, the acute hospitals were contacted and provided with details of the purpose and scope of the audit, including the definition of 'delayed



transfer of care' as outlined in the introduction. A site visit was carried out to each hospital and data were collected in a single point in time i.e. on the day of site visit. Data was provided by senior clinicians and social care professionals (health and social care professionals) in acute care teams. Throughout the audit report these clinicians / HSCP are referred to as 'stakeholders. During the site visit, stakeholders were asked to determine if the patients selected within the scope of the audit, met the definition of 'delayed transfer of care'.

## Data Processing

Data was entered on Microsoft Excel and Excel and aggregated to describe trends in patient populations. Siciliani et al. (2014) compared health care waiting times in OECD countries and reported that the mean waiting times were systematically higher than the median. This demonstrates the skewed distribution of waiting times, and equally LOS and for this reason, average LOS in the audit was reported as both mean and median values. As the RCS-E is an ordinal scale (i.e. not assumed to be normally distributed) therefore, average scores, expressed as mean and median were calculated for RCS-E.

Descriptive statistics were used to describe the demographic and clinical characteristics of the audit population. General tendencies and variation in the data were identified for age, diagnosis, length of stay and DTOC status and to describe patient's rehabilitation needs. Through stakeholder feedback, information on reasons for delays in transferring patients out of acute care were gathered when available.

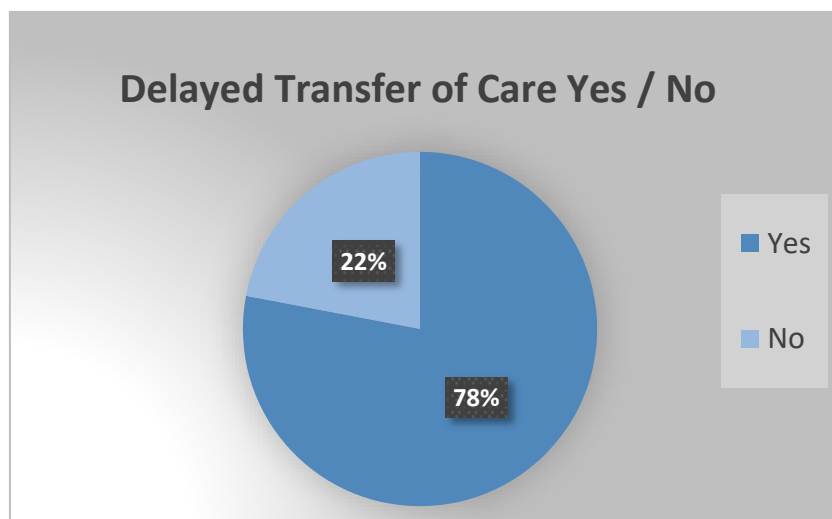
## Validation of Audit Data – Audit Standard

The data collected in the audit was validated against the HSE National Delayed Discharge Database managed by the Business Information Unit (BIU). The validation was conducted by the BIU.

## Chapter 3 RESULTS

### INCIDENCE OF DTOC CASES IN ACUTE HOSPITALS

Figure 1. Percentage of Neuro-Rehabilitation Patients Identified as Delayed Transfer of Care



One hundred and forty-one patients met the criteria of this audit. Seventy eight percent of these patients (n=110), were identified as delayed transfer of care (DTOC) as defined under methodology. The remaining 22% (n=34) did not meet the criteria for a DTOC as they were either too acute or too medically unwell at the time of data collection.

Table 1 Summary Table of Main Findings

	Total Audit Group (n=141)	DTOC Group (n=110)	Exceptions Group (n=12)
<b>Age (median)</b>	60	60	52
<b>Diagnosis</b>			
- Stroke	54%	50%	25%
- ABI	25%	27%	33%
- SCI	18%	20%	33%
- Other	3%	3%	8%
<b>RCS-E &gt;11 % (median)</b>	80%	84%	100%
<b>LOS (median)</b>	89 days	51 days	793 days
<b>Total Bed Days Lost to DTOC</b>	n/a	7,316 days	10,145 days
<b>% reported to HSE as DTOC</b>	n/a	34%	45%
<b>% on HSE DTOC database awaiting Rehab</b>	n/a	14%	

Table 1 provides a summary of the overall findings of the audit relating to age, diagnosis, severity (RCS-E), length of stay, bed days lost due to delayed status, and the gap in reporting of DTOC patients to the HSE. The three groups described in Table 1 include the total audit population (n=141), the DTOC population (n=110) and a sub-cohort of the DTOC population, exceptions, with distinct characteristics which warranted separate attention (n=12). The following results provide more detailed analysis of the audit findings and relate to the DTOC population only.

## AGE

Figure 2. Age Profile of DTOC Population

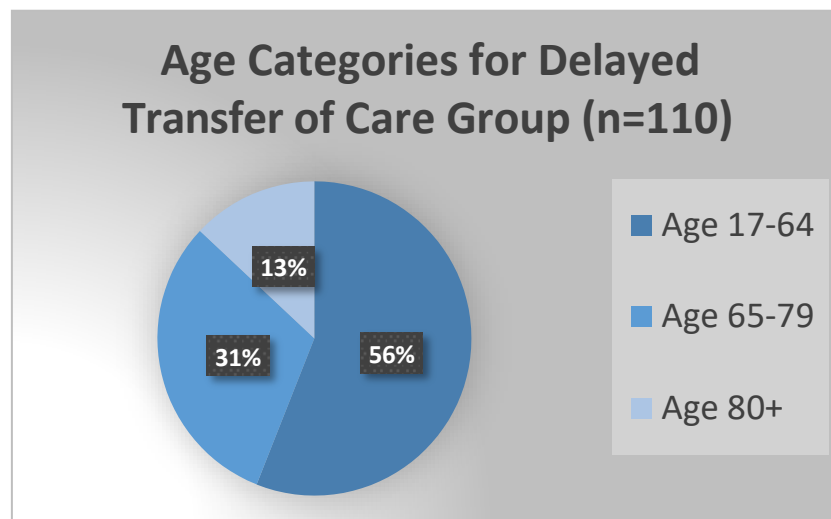
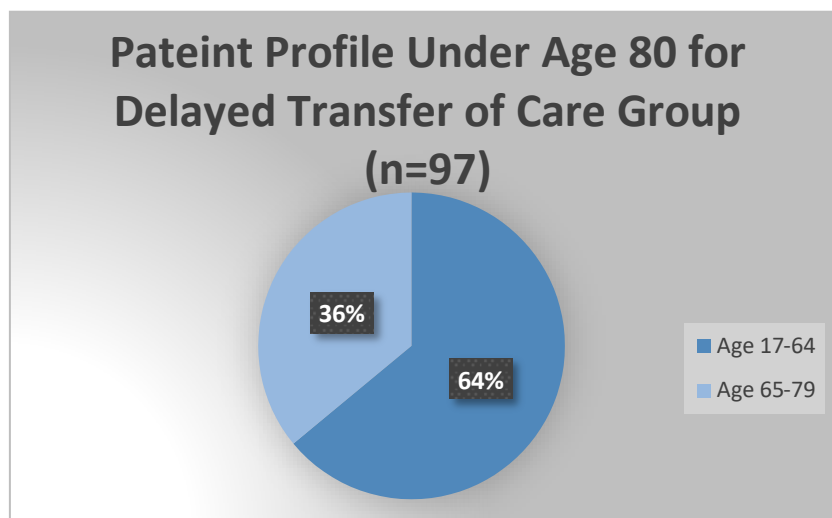


Figure 2 shows that the highest rate of DTOC (56% n=62) among neuro-disability patients in acute hospitals throughout Ireland, occurred in adults aged between 17 and 65 years that is, in the working age population. Almost a third of the patients (31% n=34) were aged between 65 and 79 years of age. Only 13% of the delayed population (n=14) were aged 80 or above. The average age of the total AUDIT group was 60 years old. It should be noted that one hospital limited their data to include those under 80 years due to their large patient population and limited resources to gather information on their entire Neuro-Rehabilitation population.

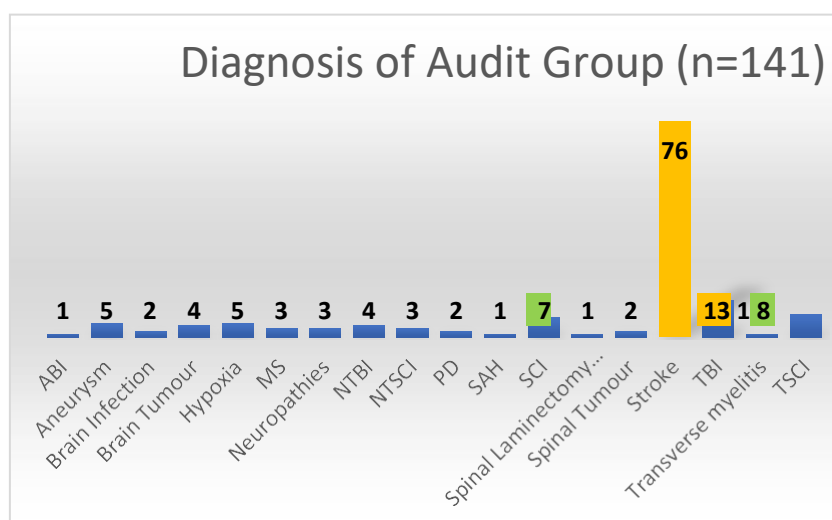
Figure 3. Age Profile of Patients under 80 years



In light of the disproportionately younger age profile of neuro-disability patients experiencing a DTOC in acute hospital hospitals, Figure 3 represents patients aged under 80 years only. This provides clear evidence of population needs for this patient cohort as 64% (n= 62) of patients experiencing a DTOC are under 65 years that is, of working age. The remaining 36% (n=35) are between 65 and 79 years old.

## DIAGNOSIS

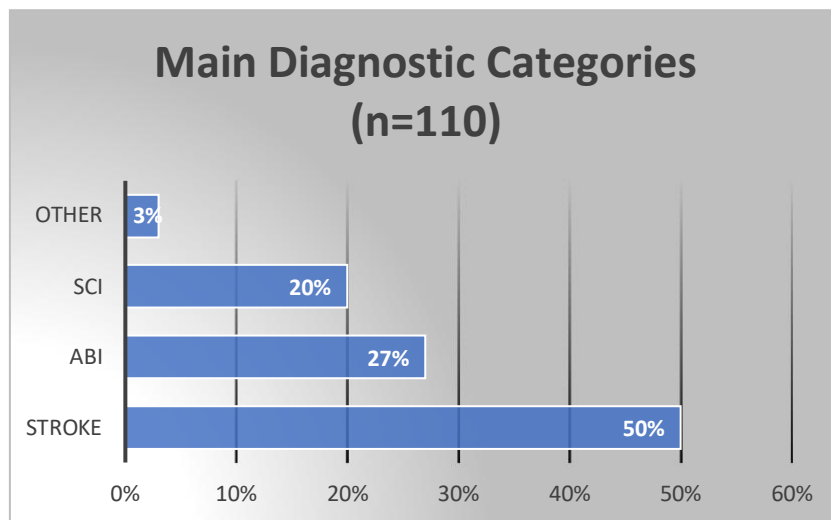
Figure 4. Diagnosis Included in Scope of Audit



**ABI:** Acquired brain injury. **MS:** Multiple Sclerosis. **NTBI:** Non-traumatic brain injury. **NTSCI:** Non-traumatic spinal cord injury. **PD:** Parkinson's Disease. **SAH:** Subarachnoid haemorrhage. **TBI:** Traumatic brain injury. **TSCI:** Traumatic spinal cord injury.

Figure 4 shows the range of 18 diagnoses for acquired neurological conditions included in the scope of the audit. This count represents the entire audit population n=141.

Figure 5. Main Diagnostic Categories for Delayed Transfer of Care Group (n=110)



**SCI:** Spinal cord injury. **ABI:** Acquired brain injury. **Other:** Parkinson's Disease and Multiple Sclerosis

Acquired brain injury, including stroke (77%, n=85) and acquired spinal cord injury (20%, n=22) formed the two main overall categories of neurological conditions for this audit population.

The acquired brain injury group includes the following diagnosis and terminology; traumatic brain injury, non-traumatic brain injury, acquired brain injury, stroke, subarachnoid haemorrhage, hypoxia, brain tumour, brain infection and aneurysm. The spinal cord injury group comprises; traumatic spinal cord injury, non-traumatic spinal cord injury, spinal cord injury, spinal tumour, spinal laminectomy with paralysis, transverse myelitis, and neuropathies (see discussion for analysis of neuropathies). Multiple Sclerosis (MS) and Parkinson's disease (PD) (progressive conditions) are presented in the results however their numbers are small and most likely under representative and therefore will not be used to draw conclusions.

More specifically, Figure 5 revealed that stroke formed the largest diagnostic group of patients in the audit (n=55, 50%). More than a quarter of the DTOC group had an ABI (n=30, 27%), followed by SCI (n=22, 20%).

## TRAUMA

This audit generated data on the occurrence of trauma patients among the audit population.

Table 2. Incidence of Trauma among DTOC Group (n=110)

Diagnosis	Percentage
TBI	10%
TSCI	7%
Non-Specified ABI	0%
Non-Specified SCI	4%
Other	78%

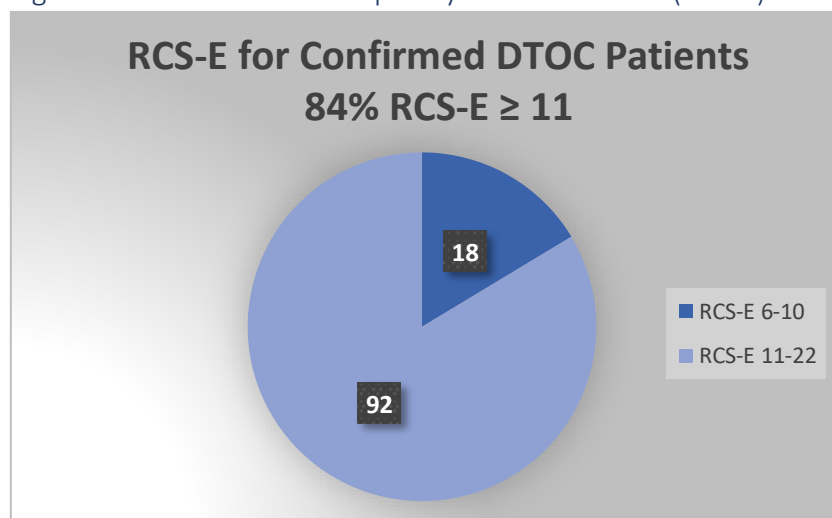
**TBI:** traumatic brain injury. **TSCI:** traumatic spinal cord injury. **ABI:** acquired brain injury. **SCI:** spinal cord injury.

Table 2 shows that 17% of the DTOC population acquired their neuro-disability as a result of trauma. Of these trauma patients, 10% suffered a traumatic brain injury (TBI) and 7% suffered a traumatic spinal cord injury (TSCI). There was a further possible 4% with a non-specified spinal cord injury who may have sustained a trauma.

Other investigations of Neuro-Rehabilitation trauma patients in Ireland were conducted in 2017 and 2018. Finding from these studies are detailed in the discussion section which adds to the data for this specific audit cohort.

## COMPLEXITY

Figure 6. Rehabilitation Complexity Score Extended (RCS-E) of DTOC Group (n=110)



The Rehabilitation Complexity Scale-Extended (RCS-E) has been described in detail in the introduction. This assessment tool was developed to detect the clinical need for higher-level services instead of local services; differentiating between ‘complex specialised’ and ‘district specialist’ rehabilitation services. The British Society of Rehabilitation Medicine (BSRM) state that patients with an RCS-E of 11 or greater have highly complex needs and will therefore require specialist interdisciplinary Neuro-Rehabilitation.

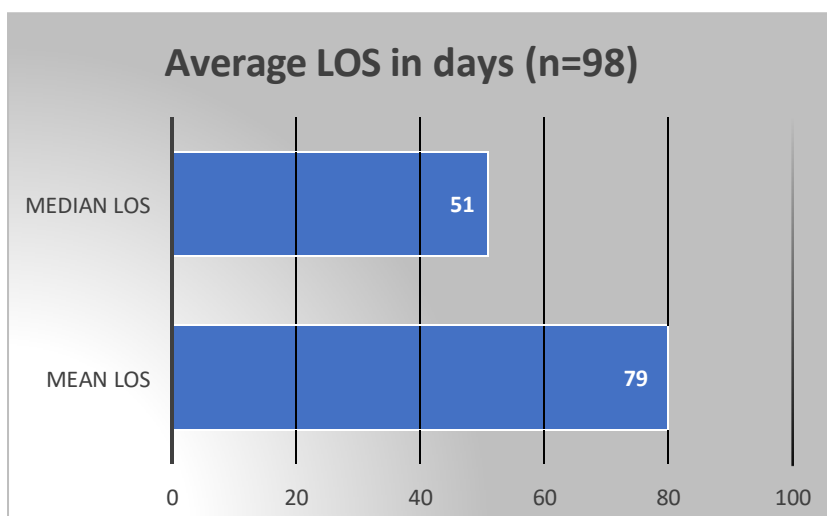
Figure 6 shows that 84% (n=92) of the DTOC group scored 11 or above and therefore require specialist interdisciplinary Neuro-Rehabilitation. This majority population who remain in acute hospitals could not have their needs met by a non-specialist service due to their level of complexity.

### PATIENT PROFILE – EXCEPTIONS GROUP

In the course of data analysis, it emerged that there were a number of cases recorded as having exceptionally protracted length of stays (LOS). These patients typically presented with more complex requirements in relation to their neuro-disability, clinical and social needs. As the data relating to these cases was well outside of what might be considered ‘normative’ or typical of the general patient population, their data was in some instances analysed separately (tables / figures are labelled accordingly). Twelve such ‘outliers’ were identified and are referred to in this audit as ‘Exceptions’.

### LENGTH OF STAY (LOS)

Figure 7. Average Length of Stay (LOS) of DTOC Group at Time of Data Collection (n=98, excluding exceptions)



The average length of stay (ALOS) for patients experiencing a delayed transfer of care in acute hospital was 51 days (median) or 79 days (mean). The national ALOS for acute hospital admission is 6 days HIPE 2019.

LOS for the audit was calculated from the date of onset to the date of data collection, minus 6 days. To allow for the acute medical episode, in line with the national ALOS, six days was subtracted from the overall total LOS for all group analysis. Figure 7 which (excludes exceptions group) is a count of the ALOS of the DTOC group at a single point in time, that is, on the day of data collection. It does not represent the actual patient LOS at the time of their onward transfer out of the acute hospital.

When examining the central tendency of the results of the audit, a marked variation is seen between the mean and the median LOS. This confirms the skewed distribution of LOS, which indicates outliers. Further analysis below provides a profile of the full patient cohort, including outliers (exceptions).

## BED DAYS – LENGTH OF DELAY

Table 3. Average Length of Stay of DTOC Group under Three Age Categories (n=98, excluding exceptions)

	No. of bed days lost at time of data collection	Mean LOS	Median LOS
Age 17-64	4548 days	84 days	55 days
Age 65-79	2983 days	90 days	56 days
Age 80+	373 days	29 days	23 days
<b>Total Bed Days Lost</b>	<b>7,904 – (98x6=588)* = 7316</b>		

\* National ALOS in acute Irish hospital is 6 days. Audit LOS less 6 days per patient (98) = Total.

LOS for Neuro-Rehabilitation patients, once they have completed their acute medical episode, equates to bed days lost due to the delay in transferring out of acute hospital. Removing outliers (exceptions) Table 3 provides a breakdown of mean and median LOS and the total bed occupancy of the DTOC group under three age categories, at the time of data collection.

**The total number of bed days lost for the DTOC group (with exceptions excluded) was 7,904 days, less national ALOS (98 x 6 = 588 days) which equals 7,316 days.**



Excluding exceptions, (n=110-12=98) 54% of patients experiencing a DTOC in acute hospitals are between 17 and 65 years of age. Table 3 demonstrates that this age group are occupying 57% of the total bed days lost to DTOC (4548 days). This indicates that not only are they the largest volume of patients but they are also occupying the majority of overall bed days. Similarly, DTOC patients aged 65-79 who account for 32% of the DTOC population, are occupying 38% of the overall bed days (2983 days). Specifically, within the DTOC Neuro-Rehabilitation population, patients aged 80 or above are occupying only 5% of total bed days (373 days). An important finding from this audit is that the average (median) LOS for patients over age 80 (23 days) is less than half the average (median) LOS for patients aged 17 to 79 (56 days).

## DIAGNOSIS / AGE / COMPLEXITY / LOS

Table 4. Diagnostic Groups: Age, Complexity and LOS (includes all ages and exception cohort n=110)

	<b>Group 1 Stroke (n=55)</b>	<b>Group 2 ABI (n=30)</b>	<b>Group 3 SCI (n=22)</b>	<b>Group 4 MS &amp; PD (n=3)</b>
<b>Age (mean)</b>	66	50	56	68
<b>RCS-E (mean)</b>	12	15	13	16
<b>RCS-E (median)</b>	12	13	13	15
<b>LOS (mean)</b>	97	193	224	354
<b>LOS (median)</b>	45	57	89	164
<b>Total Bed Days</b>	5326 (33%)	5779 (36%)	4937 (31%)	1062

Table 4 and Table 5 provide a comparison of age, complexity and LOS for the four main diagnostic groups. Table 4 summarises the entire DTOC population, including all ages and exceptions. Table 5 summarises the DTOC population excluding the (outliers) and those over 80 years.

This data shows that average age and complexity (RCS-E scores) are similar for both populations in Table 4 and 5. Table 5 summarises what could be viewed as a more typical or routine neuro-rehabilitation population. In Table 5, Stroke occupy the majority of bed days lost to DTOC (41%, 3094 days). However, among the complete audit DTOC population (Table 4), the proportion of bed days is more evenly spread between the three main diagnoses, with ABI accounting for a slightly higher proportion (36%, 5779 days) than Stroke (33%, 5326 days) or SCI (31%, 4937 days). Table 4 is more reflective of real-world population needs so these finding are important considering that Stroke comprise 50% of this population, ABI 27% and SCI 20%. This indicates that the smaller populations of ABI and SCI are accruing as many bed days as the majority Stroke Group. This finding suggests that Stroke patients transfer through the acute hospital system at a much faster rate than ABI and SCI. This supports the previous statement that rehabilitation services, where they do exist, often have admission criteria which exclude acquired neuro-disability other than stroke.

Table 5. Diagnostic Groups: Age Complexity and LOS. (Exceptions excluded, over age 80 excluded n=87)

	<b>Group 1 Stroke (n=42)</b>	<b>Group 2 ABI (n=25)</b>	<b>Group 3 SCI (n=19)</b>	<b>Group 4 MS &amp; PD (n=1)</b>
<b>Age (mean)</b>	62	49	57	71
<b>RCS-E (mean)</b>	13	15	12	15
<b>RCS-E (median)</b>	13	13	13	15
<b>LOS (mean)</b>	74	100	102	86
<b>LOS (median)</b>	48	56	83	86
<b>Total Bed Days</b>	3094 (41%)	2488 (33%)	1942 (26%)	86

## PROFILE OF EXCEPTIONS GROUP

Table 6. Exceptions Group (n=12)

Age U65/O65	LOS*	RCS- E	Notes	BIU Database
U65	1134 days	18	Requires very high levels of nursing and care with medical supervision. Complex social background.	No
U65	325 days	11	Re-admission following unsuccessful discharge.	Yes
U65	923 days	20	Psychosocial factors impacting on discharge.	No
O65	331 days	20	Medically stable but high nursing needs. Awaiting complex specialist rehabilitation.	Yes
O65	851 days	15	Complex discharge - barriers include high care needs plus poor compliance with treating team including discharge planning.	Yes
U65	724 days	12	Psychosocial factors impacting on discharge.	No
O65	351 days	15	Premorbid complex medical status.	No
U65	1765	15	High nursing needs. Has completed complex specialist rehabilitation programme	No
U65	881 days	13	Has completed complex specialist rehabilitation. High nursing needs.	Yes
U65	2628	20	Profound brain injury, high nursing needs. Complex social and care needs.	No
U65	128 *	22	Completed complex specialist rehabilitation. High care and nursing needs.	No
U65	54 *	12	Completed complex specialist rehabilitation. Requires ongoing continuous supervision.	Yes

\*LOS: length of stay at time of data collection

Table 6 summarises basic information on the 12 patients considered to be 'exceptions' including age category (over 65 or under 65), LOS and level of complexity (RCS-E). The main data point that identifies these cases as exceptions to the general DTOC population is their LOS. Eleven of these 12 patients were found by stakeholders to meet the criteria for DTOC, the 12th patient was considered to be too medically unstable at the time of data collection to be considered DTOC, despite an acute hospital LOS of over three years (1134 days). This particular patient's medical condition continued to fluctuate over this period, at times did meet DTOC criteria and at other times did not. This type of patient requires complex bespoke management.

As discussed in previous paragraphs, LOS in acute hospital was measured from date of onset (initial admission to acute hospital) to date of data collection minus 6 days (national average LOS) allowing for medical acuity. There are two cases in Table 6 (denoted by an asterisk \*) who appear to have relatively short LOS compared to the rest of the exceptions cohort. Both of these patients were readmitted to the acute hospital following completion of their specialist complex Neuro-Rehabilitation at the NRH. The LOS reported for these two patients, 128 days and 54 days, records their LOS since their second (re) admission to the acute hospital. To measure their true acute LOS, their initial acute admission LOS (date of onset) combined with the subsequent acute admission would represent their actual acute LOS. In order to ensure consistency in reporting data, this overall figure was not recorded for this audit. Findings on the exceptions group are summarised as follows:

- Four patients had completed a comprehensive inpatient Neuro-Rehabilitation programme at the NRH and were subsequently readmitted to acute hospital.
- The age profile of this patient group is that of working age adults, average age 52 years (see Table 7).
- LOS ranged from two months\* to seven years plus (2628 days).
- These 12 patients had a combined LOS of 10,023 days.

Of critical importance, considering their combined LOS of 10,023 days, only five of the 11 cases are known to the HSE (BIU). The other seven patients had not been reported to the National Delayed Discharge Database despite a combined LOS (for these seven) of 7,653 days.

The notes section in Table 6 provides a very brief outline of some of the factors contributing to their protracted LOS. Two patients had experienced an unsuccessful transfer out of acute care, one to a step-down hospital bed and one to their home. One readmission to acute care occurred due to the patients' medical needs and the other due to the patients care and social needs.

Table 7. Exceptions Group – Age, LOS and Complexity (n=12)

<b>Total number of bed days lost</b>	<b>10,097</b>
<b>Mean LOS</b>	<b>851 days</b>
<b>Median LOS</b>	<b>793 days</b>
<b>Average Age</b>	<b>52 years</b>
<b>RCS-E range</b>	<b>12-22 (average 16)</b>

National ALOS in acute Irish hospital is 6 days. Audit LOS less 6 days per patient (6x12) = Total.

When compared to the main patient cohort, the characteristics of the exceptions group differ with regard to age and level of complexity. The total audit cohort (not including exceptions) had an average age of 60 years and average RCS-E of 13. The exceptions group had an average age of 53 and average RCS-E of 16. This data confirms that the exceptions group are younger and have complex disability than the general audit population.

The most notable feature of the exceptions group is their disproportionately long LOS. As previously outlined, the average (mean and median) LOS for the DTOC group was 79 and 51 days respectively. The mean and median LOS for the exceptions group was 851 and 793 days respectively. This identifies a small number of patients who appear to be residing in the acute healthcare system.

**The complete count of acute bed days lost to DTOC for Neuro-Rehabilitation patients during the audit period (seven weeks), is the combined DTOC group: 7,316 days, plus the exceptions group: 10,097 days, which amounts to 17,413 bed days. This figure accounts for only eight hospitals which represents 16% of acute hospitals in Ireland.**

## VALIDATION WITH HSE (BIU) DATABASE

Table 8. Validation of Audit Database against HSE National Delayed Discharge Database BIU (exceptions included)

	<b>BIU DTOC Database (n=42)</b>	<b>Audit DTOC Database (n=110)</b>
<b>Number of DTOC</b>	42 (38*)	110
<b>Number awaiting Rehab (NRH or Other)</b>	18 (15*)	110
<b>Age (mean)</b>	62 years	60 years

\* Four patients found on the BIU delayed database were not identified by the audit as DTOC at the time of data collection.

The Acute Business Information Unit (BIU) is a central collection point for HSE data including the National Delayed Discharge Database. The audit database DTOC group (n=110) was validated against the BIU National Delayed Discharge Database (Table 8). The audit identified all 110 patients as DTOC requiring specialist interdisciplinary Neuro-Rehabilitation, as measured by RCS-E. The BIU found 42 matches, that is, 42 patients from the audit database had been reported as delayed on the national HSE database. \* At odds with the audit findings, the HSE data showed that there were four patients reported on the HSE database that were not identified as DTOC on the audit database. Three of these were reported as awaiting NRH. On further inspection of the data, these four patients had been reported to the HSE 1-2 months after the audit date of data collection. This finding indicates that these four patients became 'ready' for transfer to rehabilitation at a later time, post data collection, which supports the reliability of the audit assessment / data collection and mitigates the likelihood that the audit overestimated the occurrence of DTOC.

As the audit reflects a snapshot of the patient's status at a single time point, for the purposes of maintaining the validity of data at the time, the 4 (at odds) patients are discounted for the following analysis. The resulting 38 HSE DTOC patients can be reported against 110 audit DTOC patients. This reveals that only 34.5% of patients identified in the audit as DTOC had been reported to the HSE as delayed, meaning that 65.5% of DTOC patients had not been reported to the HSE as delayed.

The HSE database reported 15 patients as delayed 'awaiting NRH or other rehabilitation'. Based on the audit data, this accounts for only 13.5% percent of the actual demand for Neuro-Rehabilitation services among eight acute hospitals at the single time point of data collection. Every effort is made to support patients to transition home following an acquired neurological illness or injury. However, these patients require Neuro-Rehabilitation in order to determine the type of funding and support services necessary to transfer the patients back to the community. This highlights a major concern that current reporting practises are not capturing accurate health data based on actual need. This audit presents new evidence that up to a possible 86.5% of the population needs for Neuro-Rehabilitation (from acute care) are not known to the HSE.

Table 9. Profile of Patients in BIU and Audit DTOC Group

	<b>BIU DTOC (n=42)</b>	<b>Audit DTOC (n=110)</b>
<b>Age 17-64</b>	21 (50%)	62 (56%)
<b>Age 65-79</b>	14 (33%)	35 (32%)
<b>Age 80 +</b>	7 (16%)	13 (12%)
<b>Over 65</b>	34 (50%)	48 (42%)

Comparing age profiles of the audit and BIU databases provides a possible insight into reporting practices of DTOC patients. The BIU database shows that 50% of reported DTOC patients are over age 65 and 50% are under 65. Whereas the audit data shows that the greater proportion of patients are under 65, that is 56% and 42% are over 65. This may suggest that acute hospitals are more inclined to report older patients to the HSE database. Categorising patients as simply over or under age 65 is relatively crude in terms of determining population needs.

Table 10. Audit DTOC Group (n=110) – Reasons for DTOC viewed under eight time periods based on length of stay.

LOS	U65	RCS-E ≥11	Rehab main barrier	Social main barrier	Disability main barrier	BIU DD
<b>0-30 days</b> (n=31)	43%	63%	20%	0%	53%	23%
<b>31-60 Days</b> (n= 30)	66%	86%	7%	20%	65%	43%
<b>61-90 Days</b> <b>(2-3 months)</b> n=13	70%	84%	23%	0%	77%	23%
<b>91-120 Days</b> <b>(3-4 months)</b> n=8	50%	100%	0%	0%	100%	37%
<b>121-180 Days (4-6 months)</b> n=8	25%	100%	0%	0%	100%	37%
<b>181-360</b> <b>(6-12 months)</b> n=12	66%	91%	16%	16%	83%	41%
<b>361-720</b> <b>(1-2years)</b> (n=1)	50%	100%	0%	0%	100%	50%
<b>721-1080</b> <b>(2-3 years)</b> (n=4)	75%	100%	All have combined barriers including high care needs, unsuitable home environment / no alternative, poor compliance or psychiatric difficulties.			50%
<b>1081 days +</b> <b>(&gt;3 years)</b> (n=3)	100%	100%	All have high care needs and very high nursing needs. One is poorly compliant.			0%

Identifying the underlying causes for delays in transferring Neuro-Rehabilitation patients out of acute care are difficult to define as the reasons are often multi-factorial. Findings from the audit suggest that the reasons for delays usually reflect the patient's rehabilitation needs and social circumstances, in the context of service provision. It was beyond the capacity of the audit to collect detailed information on the possible factors that have led to DTOC and the quality of this data varied considerably among stakeholders. The author attempted to capture this data using broad categories which are outlined in Table 10 above. Key barriers that resulted in delayed transfers were related to the patient's rehabilitation needs, social needs or the overarching impact of their disability leading to a demand for ongoing rehabilitation and care. It should be noted that all of the above analysis in Table 10 must be considered in the context that these patients continue to be cared for in the acute setting because post-acute specialist interdisciplinary rehabilitation is not available, as per stakeholder feedback.

Table 10 categorised patients according to their LOS under the following nine timeframes; up to one month, one to two months, two to three months, three to four months, four to six months, six to 12 months, one to two years, two to three years, and greater than three years (up to seven years).

As expected, the occurrence of delays reduced as the LOS increased. Overall 93% of (DTOC) patients were transferred out of acute care within 12 months of admission. The remaining 7% waited in acute care more than 12 months. These high complexity, low volume care cohort had accrued 8,948 days at the time of data collection. The longest delay recorded during the audit was over 7 years (2634 days).

The main trend observed among DTOC patients with increasing LOS was that the degree of complexity increased, as per RCS-E scores. No trend was observed with regard to social circumstances identified as a barrier. However, this information was not available in a number of cases.

There were significant variations in the characteristics of the Neuro-Rehabilitation population identified as DTOC. The main categories / barriers resulting in delays, shown in Table 10 were 'Rehab', 'Social' or 'Disability'. Based on the clinical and non-clinical information collected during the audit, these headings denote which of these three factors had the greatest potential impact on delaying the patient's onward transfer out of acute care. As patients were grouped according to their LOS, the figures presented in Table 10 are aggregate so they may only apply to some patients within that group.

Those under the heading of Rehab typically had an RCS-E score less than 11, so from a disability point of view had less severe impairments and less complex needs. These patients had the potential to return to live in the community (with some support), and continue their rehabilitation in an ambulatory service, if such services existed. Stakeholders explained that these patients remained in an acute hospital bed due to the lack of rehabilitation services in the patient's home community.

Patients with a higher degree of complexity, usually with an RCS-E of 11 or more were categorised as 'disability' being the main barrier. This means that the severity of their disability was such that they required higher levels of care and ongoing inpatient rehabilitation. These patients could not feasibly be transferred out of acute care unless to an inpatient rehabilitation setting. This 'disability' category distinguishes those who require inpatient rehabilitation (level 1 - complex specialist or level 2, specialist inpatient) from those who are suitable for community-based Neuro-Rehabilitation (level 3 specialist community).

The figures under the heading of 'social' are most likely to be an under-representation of the impact of social barriers. This was the most incomplete information gathered from stakeholders.

In many cases the barriers to transfer out of acute care were the result of a combination of factors including the level of complexity (also referred to as the degree of disability), availability of inpatient or outpatient specialist interdisciplinary Neuro-Rehabilitation, suitability of the home environment, availability of support in the home, formal and informal, availability of funding for therapy and care services or procurement of long-term care placement.



## Chapter 4 Discussion

### Simple vs Complex Discharges

The HSE in 2014 recognised the distinction between simple and complex discharges. A 'simple' discharge relates "to 80% of service users discharged from hospital to their own home that have simple ongoing healthcare needs which can be met without complex planning and service delivery" (Integrated Care Guidance 2014).

'Complex discharges' were defined by the HSE (2014) as "service users who will be discharged home or to a carer's home, or to intermediate care, or to a nursing or residential care home, and who have complex ongoing health and social care needs which require detailed assessment, planning, and delivery by the multi-professional team and multi-agency working, and whose length of stay in hospital is more difficult to predict". Despite HSE reporting that 20% of the general population will transpire as complex discharges, this audit has identified that 78% of the DTOC patients (assessed as having an RCS-E equal to or greater than 11) met the criteria for 'complex discharge' as defined above. Unfortunately, there continues to be significant gaps in services to support complex discharges particularly for patients aged under 65 who require Neuro-Rehabilitation. The consequence of which are major delays in transferring patients from acute care. 'Failure to provide adequate capacity for specialist Neuro-Rehabilitation is counter-productive not only to patients but also to society: it makes economic and ethical sense to invest in such services' (Singh *et al.*, 2016).

### Evidence for Specialist Neuro-Rehabilitation

There is substantial evidence that intensive rehabilitation in specialised environments, delivered by trained staff, is both effective and cost-effective, in terms of reducing the burden and cost of onward care (Turner-Stokes *et al.*, 2016). Using the UKROC (UK Rehabilitation Outcomes Collaborative) Turner-Stokes *et al.*, (2016) conducted a large analysis of cost-efficiency in a mixed neuro-disability cohort (n=5739) (ABI 4182). Functional outcomes following specialist Neuro-Rehabilitation, measured by FIM+FAM efficiency (calculated as the total change / LOS) was highest in the medium dependency group.

There is level 2 and level 4 evidence for specialist inpatient rehabilitation for patients with moderate to severe ABI including shorter comas and LOS, increased cognitive function at discharge, higher FIM scores and increased likelihood of a discharge home (Evidence-Based Review of Moderate to Severe Acquired Brain Injury 2013).

The benefits of accessing early specialist Neuro-Rehabilitation are known to exploit neuroplasticity and minimise complications (Cheville and Basford 2014). Conversely, there is evidence that delayed access to rehabilitation for patients with TBI and Stroke results in slower rate of recovery, more severe disability, increased LOS and less likelihood of a discharge home or returning to employment (Andelic et al 2012; Salter et al 2006; Gagnon, Nadeau and Tam 2006; Lynch, Hillier and Cadilhac (2014).

In a joint report by the Royal College of Physicians and the British Society of Rehabilitation Medicine (Medical Rehabilitation in 2011 and Beyond, 2010), evidence is presented from intervention trials for sudden onset neurological conditions, progressive or intermittent neurological conditions, and limb absence. One such example is a 6- year cohort study of patients with ABI admitted to a tertiary referral centre.

All patients in each of the 3 graded categories of dependency, using RCS (early version of RCS-E) showed significant reduction in dependency and on-going care costs. The reduction in weekly cost of care was greatest in the high dependency group (at £639 per week); reduced mean costs for the medium-dependency group was about half this amount (£323 per week), and about £111 per week for the low dependency group. Despite their longer length of stay and higher treatment costs the time taken to offset the initial cost of rehabilitation was only 16.3 months in the higher dependency group (Turner-Stokes L, Paul S, Williams H 2006). Furthermore, there is strong evidence (Research grade A (RA)) from Cochrane and other systematic reviews that multidisciplinary rehabilitation can improve the experience of living with a long-term neurological condition, both at the level of functional activity and societal participation (Khan *et al.*, 2009).

## Ready for Rehabilitation

Delayed transfer to rehabilitation is a significant problem for the acute hospitals, extending length of stay for the patient, in a clinically inappropriate environment. The provision of acute rehabilitation is varied across hospitals in Ireland. While numerous patients do receive therapy input in acute hospitals, therapy is rarely delivered in an interdisciplinary way. Therapists are often assigned under named consultants/ named wards and patients with neurological conditions are not routinely cohorted which impacts on the development of specialist input, as well as patient's access to rehabilitation. Such patients are often 'repatriated' into non-specialist, non-rehabilitation beds, sometimes in a different acute hospital. This practice is not common in other specialties i.e. a patient requiring input of cardiology service is unlikely to be transferred to a hospital without a cardiology service. The same approach should apply to those who need specialist rehabilitation.

Turner-Stoke (2016) study of acute rehabilitation demonstrated that patients with complex neurological disability who are still medically unstable have the potential to gain from specialist rehabilitation across a wide range of conditions. Their study

provided evidence of the benefits for patients and their families in terms of gains in functional independence and reduction in on-going care needs. The BSRM recommends that hyper-acute rehabilitation can be delivered by a dedicated multi-disciplinary team in the acute care setting. This approach needs to be developed within the Irish context as a means of delivering specialist care for patient with complex needs in the hyper-acute/acute phase.

During the course of the audit, stakeholders, in most cases, did not provide time frames as to when patients could be considered 'ready' for transfer to rehabilitation, as this is not routinely recorded in the acute setting. A small number of stakeholders did provide approximate timelines but this information was not consistently available. The assessment of a patient's readiness to transfer from acute care to post-acute rehabilitation was discussed in the introduction. Using the Rehabilitation Complexity Scale Extended Medical Score, the 'R point' is the point in the pathway when the patient is ready to transfer from the acute care setting to a rehabilitation ward/to the care of the rehabilitation team. Daily recording of the RCS-E M-scores, may be used to inform definition of the R-Point and monitor continued fitness for transfer.

There are limitations to the measurement tool used in the audit, that is, the Rehabilitation Complexity Scale Extended V13. This assessment tool provides a measure of resource requirements (medical, nursing and therapy inputs) to meet the complex needs for rehabilitation. While it correlates with the Patient Categorisation Tool (PCAT) and Complex Needs Checklist (CNC), it describes the service elements, rather than individual patient characteristics. For example, it does not specifically measure the patient's communication or cognitive impairments. However, it is an easy tool that is relatively quick to score and was feasible for the purposes of the audit. It should not be used exclusively to describe category of need but it is used in the UK to identify the 'Transfer Ready' (TR) point – the point at which the patient's medical needs could be met in a post-acute rehabilitation setting as opposed to a neuroscience, neurosurgical or trauma unit. The RCS-E is also used for case-mix management in planning admissions to the National Rehabilitation Hospital. Considering these limitations, the NCPRM could, in consultation with the Clinical Advisory Group, agree a measure for assessment of 'ready for rehab' for consistent application across acute hospital settings, including those without input from a rehabilitation medicine consultant.

## Reporting Practices on Delayed Transfer of Care

In the UK the clinical evaluation of 'fitness to transfer' to rehabilitation is usually made by the acute care team on the daily ward round. In practical terms,

assessment for 'readiness' is only beneficial if there is an onward transfer destination, e.g. complex / specialist, inpatient / community rehabilitation or residential setting. Unfortunately, throughout Ireland there is very limited availability of rehabilitation beds to transfer patients to, without a prolonged wait of many months. In the absence of timely transfers, there is an understanding that the patient is likely to remain in the acute setting while awaiting access to rehabilitation and as a consequence, people are considered to be 'waiting' rather than 'delayed'. This experience of a protracted wait for access to rehabilitation, may influence formal reporting of patient as DTOC.

In the course of the audit, it emerged that many multidisciplinary teams base their decision to discharge patients on the availability, or lack thereof, of alternative Neuro-Rehabilitation services. In the absence of specialist interdisciplinary Neuro-Rehabilitation, many acute teams will elect to continue treating the patient in the acute hospital, even when they are ready for transfer, as they would otherwise not have access to any rehabilitation services. These teams however were clear in distinguishing the patients 'readiness' for transfer to rehabilitation. While this is understandable, and patients who remain in hospital will benefit from ongoing rehabilitative input, this fails to demonstrate the true demand for rehabilitation outside the acute hospital and as such impacts negatively on potential for investment, and so the cycle continues.

At the time of writing his report, the HSE were developing a new National Policy for Management of Delayed Transfers of Care. As part of this policy the definition of a DTOC has been revised as follows;

A 'Delayed Transfer of Care' occurs when a person is ready to leave inpatient hospital care but is still occupying a bed designated for such care. A person is ready for transfer or discharge after being in receipt of inpatient hospital care, when:

- a clinical decision has been made that the patient is medically fit for discharge (MFFD) to their home or for transfer to a non-acute setting AND
- a multidisciplinary team (MDT) have reviewed the patient and a decision has been made that they are ready for transfer or discharge home AND
- the patient is considered to be safe to discharge to their home /transfer to a non-acute setting or to community support as appropriate to their needs and yet they are still occupying an inpatient hospital bed.

A patient must meet all of the above conditions before they are identified as being a DTOC. As the data from this audit had been completed and analysed, the author had the opportunity to present the audit findings to the DTOC Working Group to support the new national policy

This audit has demonstrated that, at a single point in time in eight acute Irish hospitals, there were 110 such patients who are 'ready' for transfer to Neuro-Rehabilitation services, if such services existed. This presents an opportunity for the development of a dedicated interdisciplinary team to conduct assessments and provide direct input with bespoke recommendations including, education, training, signposting and support for the acute care team, the patient, family and the associated organisations. This recommendation is aligned with the BSRM recommendation for a dedicated multi-disciplinary team in the acute care setting as described above. The establishment of these teams will also be necessary to support the development of a Major Trauma Centre and Trauma and Rehabilitation Networks throughout Ireland.

## Methodology Critique

### Auditor

Both limitation and strengths of the audit methodology were observed throughout the process. Limitations included delays experienced while awaiting DPIA (Data Protection Impact Assessment) approval and individual hospital audit applications relating to GDPR. The majority of site visits were conducted from July to September 2019. Further time factors involved negotiating dates with stakeholders during the peak summer period which incurs high absence rates due to annual leave. A disadvantage of the audit being carried out by one individual was that it precluded the opportunity to complete a snapshot data collection on a single day / or single week. Conversely, a potential strength of having a single individual conducting the data collection was ensuring greater consistency and reliability in relation to data collection, interpretation, and analysis and reporting. Another benefit of having one individual handling data was the reduced risk of any potential breach of the pseudo-anonymised data. This audit provides the only real time accurate data available to date to demonstrate a service need and confirmed what we anecdotally known about under reporting of this cohort of patients in terms of DTOC.

### Data Quality

The methodology of this audit was defined and planned in advance of commencing data collection. However, the process of data collection was dependent on several factors including the cooperation, availability, and speciality of the stakeholders. Although this resulted in some variability in the richness of the data, it was reflective of real-world clinical practice and did not impact on the core data sets reported on. In some cases, the information was provided by a stakeholder with no direct

involvement in the patient's case. In other cases, the information was detailed and included first hand clinical and psychosocial data including knowledge of the barriers to transferring the patient out of acute care.

### Analysis of Findings

Sub-cohorts: During data collection, stakeholders advised that they were unable to provide data on many patients with a diagnosis of Multiple Sclerosis (MS) or Parkinson's Disease (PD). The reason for this is that many of these patients occupied non-specialist beds for medical or surgical management of issues relating to their condition and were often not under the care of a coordinated multidisciplinary team. Stakeholders advised that their data was likely to be a significant underestimate of the full patient cohort for these progressive disorders. As such, this audit yielded a very incomplete dataset for MS and PD, five such patients have been included in the results but due to the likelihood of missing data, cannot be compared with the other groups or used to draw definitive conclusions.

When analysing diagnosis, a particular group of sudden onset neurological conditions i.e. neuropathies (n=3), are not routinely categorised as either ABI or SCI (seen in Figures 4 and 5). In terms of informing service design, for this sub-cohort of three patients, it was not considered instructive to create a separate category for analysis. This cohort of patients can be treated under either specialty but in the national complex speciality hospital, are typically admitted under the care of the SCI programme. For this reason, these three (neuropathy) patients were included under SCI.

ALOS: LOS was calculated from the date of onset to the date of data collection. To allow for the acute medical episode, in line with the national ALOS, six days was subtracted from the overall total LOS for all group analysis. This count was conducted at a single point in time, that is, on the day of data collection. It does not represent the actual patient LOS at the time of their onward transfer out of the acute hospital.

The LOS results shown in Figure 7 provide a compelling contrast between the general acute patient population (national ALOS 6 days) and this Neuro-Rehabilitation population who had a snapshot ALOS of 51 days (mean) or 79 days (median).

### Scope – Missing Data

The methods used by stakeholders to gather data, varied among sites. In some of the larger hospitals, the auditor met stakeholders from various specialties, for example stroke, neurology, rehabilitation, neurosurgery, general medicine. In other hospitals stakeholders used patients lists based on referrals to therapy, or discharge planner etc. Many stakeholders advised that the data they provided may not have included the entire population within the scope of the audit. For example, they sometimes did not include 'outlying patients' or patients who were not under the care

of one of the following specialists; neurosurgeon, stroke physician, neurologist, geriatrician or rehabilitation consultant. In other words, it was not possible for stakeholders to 'find' these patients within the system. This issue was demonstrated by an informal survey conducted in the Mater Misericordiae University Hospital in 2014. This review involved 46 charts of patients admitted with an acquired brain injury. They found that these 46 patients were admitted under the care of 32 different specialties. The DTOC audit scope included patients with specified diagnosis, regardless of which speciality they were under the care of. However, stakeholders could not always provide data on the potential Neuro-Rehabilitation population because they were not aware of them. This almost certainly resulted in missing data.

Stakeholders participated in the audit out of good will and a shared aim to improve rehabilitation services nationally, however their time was limited and so it was necessary to accept the data provided with the assumption that it was in fact, likely to be an underestimation of the entire Neuro-Rehabilitation population, delayed in eight acute hospitals, requiring rehabilitation.

#### Interpretation of Scope – Diagnosis / Specialist Neuro-Rehabilitation

In preparation for data collection, stakeholders were provided with the scope for the audit detailing diagnosis of patients to be included. However, despite this, stakeholders often interpreted 'brain injury' or 'acquired brain injury' as being a traumatic brain injury rather than the broader definition to include those with brain infections, tumours, hypoxia etc. Figure 4 (Page 15) presents the 18 diagnoses included in the scope of this audit. Although not a comprehensive list of diagnoses, any illness/injury not specific, could be included under one of the more generic neurological categories, e.g. Guillain-Barre Syndrome under peripheral neuropathy diagnosis). This approach also allowed for stakeholders to report the patient's broad diagnosis when did not have information on the specific aetiology.

Another assumption relating to the audit scope occurred among stakeholders as many of them interpreted the audit as seeking information only on patients referred to rehabilitation, most often the NRH. As a result, some patients were omitted whom they considered not to require rehabilitation, typically patients with less overt impairments or those with more severe disabilities resulting from their acquired neurological illness or injury. An example of patients omitted from the audit were those who may have no significant physical deficits and yet remain in acute hospitals due to their impairments. However, this group of patients, presenting with cognitive and psychosocial factors which are often the principle limiting factors, are recognised (Turner-Stokes et al 2016), as having complex disability, due to their inability to resume independent living.

Another cohort who were excluded by some stakeholders were patients with severe global impairments showing limited potential for a meaningful functional recovery.

Management of these patients was previously discussed under 'evidence for specialist Neuro-Rehabilitation'. Stakeholders are aware of the demands on specialist Neuro-Rehabilitation in Ireland and the limitations of this resource. With this in mind, many stakeholders do not refer the more profoundly impaired patients to complex specialist rehabilitation as they believe that referrals need to be prioritised according to potential for restoration of function (recovery). Based on this rationale, some hospitals did not consider this patient type as being eligible for the audit and so the data presented in this audit is in fact an underestimation of the full DTOC population. Furthermore, the audit revealed insights into stakeholders' perspectives and understanding of specialist Neuro-Rehabilitation, among acute care teams.

### Assessing Rehabilitation Needs

Not all patients following a neurological illness or injury will require specialist inpatient rehabilitation. This occurs in a small number of cases, typically in one of two scenarios. Patients with milder injuries / conditions who show a fast recovery trajectory may be suitable for discharge home following their acute admission and continue with community or ambulatory rehabilitation services. An example of this is Early Supported Discharge (ESD) teams for stroke. During data collection, patients who were referred to ESD teams were not identified as DTOC as they were within days of discharge to ESD services at the time of data collection. Similarly, not all patients with severe disability will require an admission to inpatients specialist rehabilitation. In order to determine this, patients require assessment by a specialist rehabilitation clinician / team. This team would determine:

- Which patients are suitable for Neuro-Rehabilitation
- When the patient is ready for transfer from acute care to rehabilitation (in consultation with the acute team)
- Which rehabilitation services are appropriate to meet that individual's rehabilitation needs

This audit gathered information on the severity of patient's disability resulting from their neurological illness / injury. The impairments described by stakeholders in addition to their medical condition formed the basis for identifying patients as DTOC. Patients described in the first scenario above were typically not identified as DTOC as they were scheduled for imminent discharge home to the care of ESD teams. The second scenario could only be determining following assessment by a rehabilitation specialist. With the exception of those patients assessed in person by either a rehabilitation consultant or brain injury liaison coordinator, the remainder were included in the DTOC category based on their diagnosis and disability.

A framework of interdisciplinary services will need to provide the appropriate continuum of care across Community Health Organisation, acute hospital and post-



acute rehabilitation services. Access to services should be determined by clear assessment, referral and service protocols which will identify the treatment required by the individual and the most appropriate services setting for this treatment across the continuum of care as described in the below model of care.

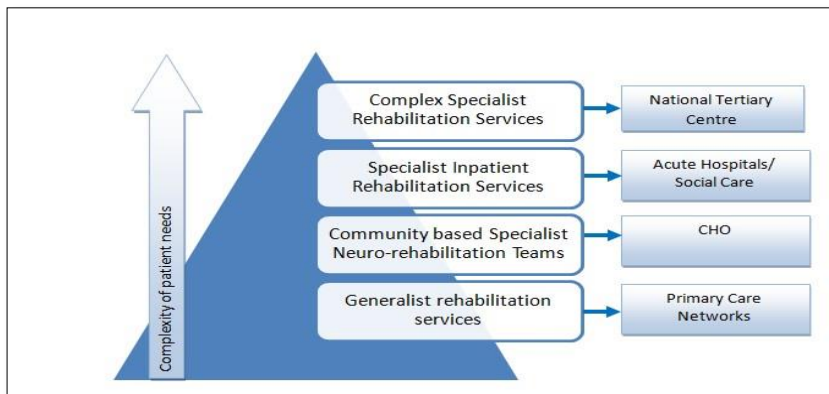


Figure 8. Levels of specialism as per NCPRM's Model of Care for Specialist Rehabilitation

## Population Health Approach

Many high-quality large population studies of neuro-disability patients, often use heterogeneous sampling. This audit population parallels these study designs which reflects real-world practice and offers broader application to this complex population who frequently receive rehabilitation in mixed cohorts. Research on neurological populations, as identified by aetiology (diagnosis) was addressed by Turner-Stokes et al., (2005) who stated that 'rehabilitation is increasingly defined based on the individual needs of the patient, rather than focusing on the underlying pathology'. This idea is further supported by the BSRM (2015) who state that "diagnosis is a poor indicator of need for rehabilitation or the cost of providing it". Similarly, the Trauma Steering Group recognise that rehabilitation requirements are not always correlated with the severity of injury (Department of Health 2018).

We need to ensure that when planning future needs for people with disabilities in Ireland that this cohort are included in this planning. The focus currently is largely on those with intellectual disability and autism. Those with acquired physical and sensory conditions are likely to need the same breadth of services including respite/participation support/community integration/transport/day services etc.

The NCPRM's Model of Care for Specialist Rehabilitation similarly recognises that diagnosis alone does not predict service needs, length of hospitalisation, care requirements or functional outcomes. The International Classification of Function (ICF) provides a more comprehensive model of disability than medical or social models in isolation. It recognises that disability is an interaction between the features of the person and the overall social context in which the person lives. More recently healthcare in Ireland recognises the need to move

beyond traditional systems and embrace concepts such as population health approach. This refers to the health of a population as measured by health status indicators and as influenced by social, economic and physical environments, personal health practices, individual capacity and coping skills, human biology, early childhood development, and health services (HSE 2018). This audit has captured the needs of population previously unknown, by identifying their demographic, clinical and psychosocial circumstances and what is required to support their onward transfer out of acute care.

This audit showed that patients experiencing the longest delays in acute hospitals were young (average age 52 years) and had complex ongoing needs (average RCS-E 16) see Table 7. An acquired brain injury outcomes audit conducted in the National Rehabilitation Hospital in 2018 found that 8% (35 patients) of all admissions to the NRH Brain Injury / Stroke programme, over a two-year period (2015 & 2016) were transferred back to the acute (referring) hospital on completion of their rehabilitation programme. This cohort of patients with complex needs, requires intervention from a specialist Neuro-Rehabilitation team from the acute stage to plan and organise an effective pathway of care, through a rehabilitation continuum in order to avoid DTOC in acute hospitals.

A study by Jaeger et al., (2014) on patients with severe traumatic brain injury (TBI) measured for impairment, function and quality of life. They demonstrated that long-term outcomes for patients following TBI, were varied and the authors concluded that the consequences of trauma are individual and related to biopsychosocial factors rather than clinical characteristics alone. An important factor impacting on extended LOS in acute hospitals is the lack of funding for high cost homecare packages or 'top-ups' for long term care placements. While the cost for many of these patients can be high, it has been shown to be more cost effective and is preferential to managing these patients on an open ward in an acute hospital, sometimes with 1:1 enhanced care for extended periods of time.

For example, the audit identified 1 individual with behaviours that challenge, who has been waiting >730 days for placement. At the time of data collection, the cost of caring for this patient in the acute hospital setting will have amounted to €620,000 based purely on FER of €850 per day. If 1:1 enhanced care is added to this, this could equate to an additional €324,000 to date (higher if agency nursing is required) i.e. €944,000 for the management of this one patient to date. The figure for specialist support per annum is €172,000 less than costs associated with care in an acute hospital with 1:1 enhanced care. The challenge however, is that funding for acute hospital care and community-based care originate from two different budgets so costs incurred in one budget will not be recouped by that budget.

The solution proposed is to establish a centralised fund for complex homecare packages / bespoke long-term placements. Access to this centralised fund should be based on criteria similar to the Complex Discharge policy & protocols utilised for

paediatric patients. “Solutions to DTOC need to be bespoke and creative” Anne O’Loughlin Principle Social Worker NRH 2019.

## Age

This audit revealed that Neuro-Rehabilitation patients of working age (17-65 years) account for over half (57%) of the total bed days lost to DTOC (4548 days). Patients aged 65-79 (32% of DTOC population) occupied 38% of the overall bed days (2983 days). Patients aged 80 or above are occupying only 5% of total bed days (373 days). Moreover, the average (median) LOS for patients over age 80 (23 days) is less than half the average (median) LOS for patients aged 17 to 79 (56 days). Patients aged 80 and above account for the smallest proportion of DTOC patients in both the audit (12%) and BIU (16%) DTOC datasets (see table 9).

Historically, allocation of protected funding in Ireland is based on the premise that older age cohorts are the highest users of most health and social care services. For the majority of the audit DTOC population (110 patients in eight acute hospitals) this has created unintended discrimination against those aged under 65, who do not have equal access to services and funding.

Due to pseudo-anonymising data, it was possible for the auditor to compare age categories between the HSE and audit database. Otherwise, the HSE (BIU) database simply reports patients as being either over or under 65 years. This gap in data collection is a missed opportunity to capture accurate patient demographics which would allow services to develop in keeping with population needs. Reflecting service provision, the BIU database is based on the traditional categorisation of over and under age 65. This oversimplified practice does not reflect the aging population who are experiencing better health later into life and indeed remain in the workplace for longer than ever.

## Relevant Irish Studies of Neuro-Rehabilitation Services

### Acquired Brain Injury Audit - National Rehabilitation Hospital

An audit conducted in the NRH in 2018 examined the impact of waiting times for admission to inpatient’s Neuro-Rehabilitation on functional outcomes following acquired brain injury. This audit reviewed 421 patients included on an outcomes database in 2015 and 2016.

The NRH audit revealed an overall trend with regard to waiting times for specialist rehabilitation and outcomes. That is, the group of patients with the shortest waiting time for admission to the NRH (41 days) had the least severe disability (admission FIM+FAM 185), the shortest length of stay (60 days) and were most likely to be discharged home (90%). The group with the longest waiting time for admission (158 days), who are ‘waiting’ in acute hospitals, had the most severe disability (admission FIM+FAM 125) the longest LOS (85 days), were least likely to be discharged home

(51%). This audit also revealed that from 2015 to 2016, there was a 1.2% increase (from 7.2% to 8.4%) in DTOC from the NRH. This equates to approximately 18-21 admissions to the NRH per year lost to DTOC. Admission to the National Rehabilitation Hospital does not represent the national demand for Neuro-Rehabilitation. However, this NRH audit does reflect the DTOC audit data with regard to complexity and LOS / waiting time (for admission to specialist Neuro-Rehabilitation).

### Traumatic Spinal Cord Injury Audit

Smyth and Synnott (2017) conducted an audit on patients who acquired a traumatic spinal cord injury (SCI) in Ireland during 2017, all of whom progressed from an acute hospital to the NRH. This trauma audit recorded 44 patients who they identified as DTOC which they referred to as “inappropriately” occupying a hospital bed, that is, patients who are medically ready for transfer to another setting but transfer has been delayed. The trauma audit recorded 3126 bed days lost due to DTOC from acute hospitals. The audit also recorded 771 days lost due to DTOC from the NRH.

This DTOC audit found that among the DTOC group (n=110) 17% of patients had sustained a traumatic injury causing their disability. Of these 19 trauma patients, 10% had an acquired brain injury (ABI) and 7% had a spinal cord injury (SCI). There was a further possible 4% with a non-specified spinal cord injury who may have sustained a trauma. Together this group occupied 1,821 bed days in acute hospitals, at the time of data collection. This issue has the potential to impact significantly on any new trauma network as access to these services will be dependent on egress from acute and rehabilitation services.

The NRH ABI audit 2018, revealed that just almost a quarter of admissions (23%) to the Brain Injury programme were patients who had sustained a traumatic brain injury. This service evaluation analysed waiting time for admission to specialist Neuro-Rehabilitation by complexity rather than diagnosis. However, the study showed that, compared to Stroke and ABI, patients with a TBI had a tendency towards the longest waiting time for admission to the NRH and were typically waiting in acute hospitals.

The major trauma audit completed in Ireland in 2017 found that those with head and spinal injuries represent 35% of all major trauma. However, only 9% were able to access rehabilitation units directly from acute hospital. This further illustrates the gap in rehabilitation services. Of note, TARN does not provide data on rehabilitation needs following trauma. So, although 9% transferred to rehabilitation, we do not know how many patients actually needed rehabilitation and did not get to access it.

The NRH ABI and SCI trauma audits show that the challenge of DTOC is not only an issue for acute hospitals but is a major concern for the NRH who admit the most complex cases across Ireland and inevitably have to manage their complex onward transfer. As a consequence, DTOC from the NRH is directly linked to acute hospital DTOC. Likewise egress from the NRH is a main determinant to access to the NRH and so delayed transfer of care are a measure not just of hospital performance, but of how well the wider health and care system is working.

The loss of bed days at the NRH is particularly concerning considering the demand on this service. In 2018, 2826 bed days were lost to delayed transfer of care out of the NRH. In effect, this is a loss of 2826 bed days\* to acute hospitals as the majority of those waiting to access the NRH are 'delayed' in acute hospitals (90%).

\* This national DTOC audit demonstrates that the NRH waiting list is not representative of the national demand for rehabilitation services.

## Implications of the DTOC Audit at a National Level

This audit presents new evidence that, up to a possible 84% of the population needs for Neuro-Rehabilitation (from acute care) are not known to the HSE. While the sample size was small, the potential implications are significant if applied to national population. For example, the eight hospitals included in the audit represent 16% of acute hospitals i.e. 49 hospitals. Consider that it may be inferred that the 110 patients identified in 16% percent of hospital represent only 16% of the national figure. In that case, it could mean that there are close to 700 Neuro-Rehabilitation patients delayed in acute hospitals nationally. Similarly, consider that the 17,461 bed days lost may equate to only 16% of the actual figure on a national scale. On that basis, the real number of DTOC for Neuro-Rehabilitation patients could be as high as 109,131 bed days lost. That equates to nearly 300 'beds', or put another way, with an average LOS of 6 days, an additional 18,188 patients could have been treated and discharged. This audit examined the demand for Neuro-Rehabilitation services generated from (eight) acute hospitals only. It did not identify the needs generated in the community; for example an estimated 30,000 people are living in the community with disabilities as a result of a stroke (Irish Heart Foundation 2015). Therefore, this audit is a partial representation of the real demand for Neuro-Rehabilitation services nationally.

One of the most concerning issues emerging from this audit was that 65% of the DTOC patients identified in the audit were not recorded with BIU. Of those that were recorded as delayed, only 13% were identified accurately as being delayed owing to lack of access to Neuro-Rehabilitation. This means that the number of reported delayed discharges for last year i.e. >260,000 may be significantly short of the real number if reporting practices were more reliable.

The impact of this is significant for the development of Neuro-Rehabilitation services. At times of crisis, such as winter planning, investments are made based on the perceived bottlenecks within the system. The weekly average number of people requiring Neuro-Rehabilitation, reported to the HSE is generally 40-60 people (out of approximately 450 i.e. representing only 10% - 15% of delays) and as such, Neuro-Rehabilitation is not been seen as a priority area for investment.

The audit confirmed what was already suspected in terms of the reported demand and impact of underdeveloped Neuro-Rehabilitation services on the acute hospital system in Ireland.

## Health Service Reform Agenda

The National Neuro-Rehabilitation Strategy was launched in 2011 and the supporting Implementation Framework was launched in February 2019. While the importance of implementing the strategy is described in three key national reports:

- The NCPRM's Model of Care for the Provision of Specialist Rehabilitation in Ireland (2018)
- A Trauma System for Ireland (2018)
- Sláintecare Implementation Strategy (2019)

To date, there has been no investment in implementation and the gaps between capacity and need continue to widen.

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. This vision is echoed in many of the key policy frameworks currently guiding the redesign of our health system where the focus is on;

- Planned pathways of care
- Patient centred care
- Seamless transitions between services
- Timely access to services based on clinically assessed need
- Greater alignment of hospital and community-based services
- Promotion of living in the community

For this vision to be achieved, there needs to be significant investment in community services including Neuro-Rehabilitation. The message is also consistent with the Health Service Capacity Review (2018) which describes the need for an improved model of care that repositions the health service towards a community-based care model.

## Summary & Recommendations

Rehabilitation is a dynamic and critical component of any modern health care system. 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 Neuro-Rehabilitation Strategy will see;

1. Improved Patient Outcomes
2. Improved Patient Experience
3. Improved Access to specialist rehabilitation service
4. Limited variation in patient pathway/experience
5. 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 comes from high quality clinical trials to support specialist rehabilitation for complex needs following central nervous system illness or injury.

While the benefits of Neuro-Rehabilitation are well known and accepted, what isn't known is the true demand for these services across the continuum of care and the true impact on the hospital system of the historical lack of investment in Neuro-Rehabilitation services. The purpose of this audit was to;

- a) Quantify the extent of the discrepancy regarding patients reported as being delayed waiting for Neuro-Rehabilitation and the real demand.
- b) To try and understand the profile of these patients and that their needs are and
- c) Describe the impact of this DTOC population on the acute hospital system.

The audit confirms that, to date, there has been a substantial underestimation of the true demand for Neuro-Rehabilitation services in Ireland. Recommendations from this audit include the need for an agreement on the use of an assessment tool to determine the patients 'readiness for rehab'. There is also a clear need to develop a specialist role, such as a 'Rehabilitation Coordinator', as described in the NCPRM's Model of Care (2018) and Neuro-Rehabilitation Strategy (2019). This role could support the specialist assessment of patients in acute hospitals, identify their rehabilitation needs and provide guidance and support to the acute care team, the patient and their families. This would ensure early specialist input to enable patients to transition between acute, rehabilitation and community services and progress through a seamless continuum of care.

There is an ever pressing need to support the implementation of the Neuro-Rehabilitation Strategy which would see;

- Additional 300 inpatient specialist Neuro-Rehabilitation beds

- Fully resourced Community Neuro-Rehabilitation Teams in each CHO
- Development of the national tertiary centre to allow it admit a higher proportion of highest complexity patients
- Development of specialist services within the community including vocational rehabilitation, respite, transitional living & case management of patients.

Continued investment in acute services without the equivalent investment in rehabilitation services will see the health service fail to achieve its aims in terms of;

- A Trauma System for Ireland (2018)
- Sláintecare Implementation Strategy (2019)

While this audit is focused on the acute hospital setting, resolving the issues will require cross divisional / cross departmental collaboration. Rehabilitation and disability owing to neurological conditions should be everyone's concern and not limited to HSE Disabilities as it is currently. As shown in this audit, the implications of under investment are widespread and contribute to some of our greatest challenges in health, including the overcrowding of our Emergency Departments.

We know from HIPE data that discharge to a rehabilitation facility is an outcome for only a small proportion of those with neurological conditions (in 2016 it was 1.5%). The question of 'where do the rest go' is in some way addressed by this audit with the reality being that many don't go anywhere, they remain in acute hospital beds, sometimes for years. The planned ombudsman review into the number of people under 65 years of age discharged to nursing homes will likely shed more light onto the appropriateness of outcomes for another cohort of these individuals. Recent publications from the Disability Federation of Ireland (DFI) suggest that a significant proportion of this cohort of >3,000 people have disabilities owing to neurological illness or injury.

Work still needs to be done with respect to describing the impact on the individual for those discharged home from acute hospital without the required supports. While a discharge home is often lauded as a good outcome for a person, if the discharge isn't supported with resources as required, the discharge will most likely fail resulting in the individual being readmitted to hospital through the emergency department. A number of such individuals were identified in the audit.

Progress needs to be made across the continuum of care if we are to address the issues highlighted in this audit. The Implementation Framework for the Neuro-Rehabilitation Strategy (2019) provides us with the blueprint for developing specialist rehabilitation services for those with disability following neurological illness & injury



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## Appendix 1

### Data Protection Impact Assessment

Section A: Background Information	
<b>Project Name</b>	Audit of Delayed Transfer of Care to Neuro-Rehabilitation
<b>Organisation/Department</b>	National Clinical Programme in Rehabilitation Medicine
<b>Assessment Completed By</b>	November 2019
<b>Job Title</b>	Project Manager
<b>Date completed</b>	
<b>Phone/Mobile</b>	
<b>E-mail</b>	caitriobegley@nrh.ie
<p><b>A(1) Project/Change Outline:</b> What is it that is being planned? If you have already produced this as part of the project's Project Initiation Document or Business Case or Research Application etc. you may make reference to this, however a brief description of the project/process being assessed is still required (in plain English).</p> <ul style="list-style-type: none"> <li>• The aim of this audit is to examine the demand for Neuro-Rehabilitation services in Ireland. Specifically, this project is focused on assessing patients in acute hospitals who often wait long periods for discharge to a rehabilitation or community setting with the appropriate care and rehabilitation services.</li> <li>• This survey will complete a real time review of the number of patients awaiting transfer of care from acute hospitals and the factors that influence prolonged admissions in acute hospitals.</li> <li>• Data will be aggregated to create a profile of patients in acute hospital who are considered delayed discharges, awaiting Neuro-Rehabilitation services, particularly those waiting longest for rehabilitation services. Identify trends among patient cohorts / geographical areas etc.</li> <li>• Compare this information against weekly delayed discharge database.</li> </ul>	
<p><b>A(2) Purpose / Objectives:</b> Why is DPIA it being undertaken? This could be the objective of the process or the purpose of the system being implemented as part of the project.</p> <p>On completion of a threshold assessment, it was determined that a DPIA was indicated.</p>	
<p><b>A(3) What is the purpose of collecting the information within the system?</b> For example patient treatment, patient administration, research, audit, reporting, staff administration etc.</p> <p>The purpose of collecting information is to audit patients experiencing a delayed transfer of care from acute hospital, who require Neuro-Rehabilitation.</p>	
<p><b>A(4) What are the potential privacy impacts of this proposal?:</b> How will this change impact upon the patients, visitors and staff? Provide a brief summary of what you feel these could be, it could be that specific information is being held that hasn't previously or that the level of information about an individual is increasing.</p>	

Data will be collected in person, by the service user, during site visits to each organisation. The service provider will use a code to pseudo-anonymise personal health information on commencement of data collection. This will remain on the (service provider) person during the site visit. Following the site visit, the information linking the code to the patient will remain in a secure, locked location in the service provider's hospital site (National Rehabilitation Hospital). Sensitive health information will be kept separate to patient identity information by means of pseudo-anonymisation so that personal data cannot be attributed to a special data subset.

**A(5)** Provide details of any previous Privacy Impact Assessment or other form of personal data compliance assessment done on this initiative. If this is a change to an existing system, a PIA may have been undertaken during the project implementation.

There is no existing Privacy Impact Assessment for this initiative.

**A(6) Stakeholders:** Who is involved in this project/change? Please list stakeholders, including internal, external, organisations (public/private/third) and groups that may be affected by this system/change.

The audit involves internal and external stakeholders. Internal stakeholders include leaders within National Clinical Programme in Rehabilitation Medicine, in particular Clinical Lead, Dr Jacinta McElligott, Programme Manager (Demonstrator Project) Edina O'Driscoll, Programme Manager Dervla Kenny, Project Manager Amanda Carty.

The audit involves site visits to selected acute hospitals throughout Ireland, in order to identify patients with a diagnosis of spinal cord injury, acquired brain injury, stroke, Parkinson's disease and multiple sclerosis. External stakeholders identified for this project are:

1. University Hospital Galway
2. Connolly Hospital Blanchardstown
3. Beaumont Hospital Dublin
4. Tallaght University Hospital Dublin
5. St James Hospital Dublin
6. St Vincent's University Hospital Dublin
7. Mater Misericordiae Hospital Dublin
8. University Hospital Waterford
9. Cork University Hospital
10. University Hospital Limerick

<b>B(1)</b>	Name	<input checked="" type="checkbox"/>	<p>Service user requires patient name and date of birth for two purposes, both of which are one-off episodes i) to audit if patients are recorded on national database and ii) to conduct a follow up assessment of patients discharge date from hospital. These two assessments will be conducted at a single point in time, after which, all identifying patient information will be destroyed. Coding system used for pseudo-anonymisation will be kept for a maximum of four months.</p> <p>Patients age is relevant as rehabilitation services differ significantly for certain conditions once the individual is over 65 years of age. This is an important consideration for profiling the patient population and developing future services.</p>
	Address	<input type="checkbox"/>	
	Postcode	<input type="checkbox"/>	
	DOB	<input checked="" type="checkbox"/>	
	Age	<input checked="" type="checkbox"/>	
	Gender	<input type="checkbox"/>	
	Sexual Orientation	<input type="checkbox"/>	
	Racial/ethnic origin	<input type="checkbox"/>	
	Tel no.	<input type="checkbox"/>	
	Physical description	<input type="checkbox"/>	
	IHI no. (or similar)	<input type="checkbox"/>	
	Mobile/home phone no.	<input type="checkbox"/>	
	Email address	<input type="checkbox"/>	
<b>B(2)</b>	Information relating to the individual's physical or mental health or condition. Information relating to genetic information(biological samples such as chromosomal or DNA samples) and biometric information( such as fingerprints or facial recognition)	<input checked="" type="checkbox"/>	<p>A physical description, that is a clinical description, is required in order to identify patients rehabilitation needs. This sensitive health information will be kept separate to patient identity information by means of pseudo-anonymisation so that personal data cannot be attributed to a special data subset.</p>
<b>B(3)</b>	Information relating to the individual's sex life.	<input type="checkbox"/>	
<b>B(4)</b>	Information relating to the individual's sexual orientation	<input type="checkbox"/>	
<b>B(5)</b>	Information relating to the family of the individual and the individuals lifestyle and social circumstances	<input checked="" type="checkbox"/>	<p>Deidentified information is required to enable the service user to trends, specifically these factors may have specific impact on the success or otherwise of (delayed) transfer of care. The data gathered will be used collectively to describe trends in patient populations.</p>
<b>B(6)</b>	Information relating to any offences committed or alleged to be committed by the individual	<input type="checkbox"/>	
<b>B(7)</b>	Information relating to criminal proceedings, outcomes and sentences regarding the individual	<input type="checkbox"/>	

<b>B(8)</b>	Information which relates to the education and any professional training of the individual	<input type="checkbox"/>	
<b>B(9)</b>	Employment and career history	<input checked="" type="checkbox"/>	Broad category deidentified information i.e. employment status is relevant for planning rehabilitation services i.e. vocational rehabilitation.
<b>B(10)</b>	Information relating to the financial affairs of the individual	<input type="checkbox"/>	
<b>B(11)</b>	Information relating to the individual's religion or other beliefs	<input type="checkbox"/>	
<b>B(12)</b>	Information relating to the individual's membership of a trade union.	<input type="checkbox"/>	
<b>B(13)</b>	<b>Will the information be</b> Anonymised	<input type="checkbox"/>	Data will be collected in person, by the service user, during site visits to each organisation. The service provider will use a code to pseudo-anonymise personal health information on commencement of data collection. This will remain on the (service provider) person during the site visit. Following the site visit, the information linking the code to the patient will remain in a secure, locked location in the service provider's hospital site (National Rehabilitation Hospital). Sensitive health information will be kept separate to patient identity information by means of pseudo-anonymisation so that personal data cannot be attributed to a special data subset.
	Pseudonymised	<input checked="" type="checkbox"/>	
	Identifiable	<input type="checkbox"/>	

Legal Compliance - is it fair and lawful?

**C(1)** **What is the legal basis for processing the information?** This is your valid legal reason for processing. These reasons are laid out in Article 6 & 9 of GDPR. Any processing of special categories of data such as health, genetic and biometric information will require TWO legal basis for processing- one from Article 6 and one from Article 9.

Answer

Safe and effective health and social care services require those involved to collect, use and disclose personal health information. It is therefore essential that a balance can be struck between respecting an individual’s privacy and using or sharing information about them to provide the care required. The processing of data as proposed represents a lawful purpose as outlined in GDPR;

Article 6 section 1.e. “for a task carried out in the public interest or in the exercise of official authority vested in the data controller”.



	<p>Article 9 section 1. (i) Processing of special categories of personal data “processing is necessary for reasons of public interest in the area of public health, such as protecting against serious cross-border threats to health or ensuring high standards of quality and safety of health care and of medicinal products or medical devices, on the basis of Union or Member State law which provides for suitable and specific measures to safeguard the rights and freedoms of the data subject, in particular professional secrecy”.</p>	
<b>C(2)</b>	<p>i) - Is the processing of individual’s information likely to interfere with the ‘right to privacy’ under Article 8 of the Human Rights Act?  ii) - Have you identified the social need and aims of the initiative and are the planned response actions proportionate in response to social need?</p>	
Answer	<p><b>(i)</b> No individual personal health information, or individual organisation will be identifiable at national report level. The data gathered will be used collectively to describe trends in the patient population.</p>	<p><b>ii)</b> The National Clinical Programme for Rehabilitation Medicine highlights that there is substantial evidence that intensive rehabilitation in specialised environments, delivered by trained and committed staff, is both effective and cost-effective, in terms of reducing the burden and cost of onward care. The challenge in the Irish context is the lack of accurate information detailing specific patient need. Accurate 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. While we have significant international evidence describing the demand for rehabilitation, we have limited Irish data, with the exception of waiting lists. Against this backdrop, it is difficult to fully describe the impact on a) the individuals but also b) the impact on the acute hospital setting and make fully developed proposals for development of rehabilitation services. This is an area that needs to be addressed in a standardised way to truly measure the impact of delayed discharges on the acute hospital setting.</p>
<b>C(3)</b>	<p>It is important that patients affected by the initiative are informed as to what is happening with their information. Is this covered by fair processing information already provided to individuals or is a new or revised communication needed?</p>	
Answer	<p>This audit is aimed at completing a one-off census of a cohort of patients. It may inform recommendations in terms of reporting practices into a national database; however, the project will not influence existing practices nor will it impact on the existing database. This audit will not have any direct effect on individual patients, organisations or services. Data processing will ensure that patient health information remains deidentified, is only accessible to the (single) service user and is reported in summary format only.</p>	

<b>C(4)</b>	If you are relying on consent to process personal data, how will consent be obtained and recorded, what information will be provided to support the consent process and what will you do if permission is withheld or given but later withdrawn?
<b>Answer</b>	Consent is not being sought for this audit.

### Purpose

<b>C(5)</b>	Does the project involve the use of existing personal data for new purposes?
<b>Answer</b>	Yes. Use of existing data to complete audit of delayed transfer of care from acute Irish hospitals.
<b>C(6)</b>	Are potential new purposes likely to be identified as the scope of the project expands?
<b>Answer</b>	Qualitative data will be gathered from organisations. The specificity of this data will depend on the individual stakeholder and their perspectives.

### Adequacy

<b>C(7)</b>	Is the information you are using likely to be of good enough quality for the purposes it is used for?
<b>Answer</b>	Yes. It is expected that there will be some variation in interpretation of the definition of patients identified as delayed transfer of care. Information will be collected via two streams, i.e. through the patient census identified by the organisation and through the qualitative information provided by the relevant stakeholder which will support the data provided.

### Accurate and up to date

<b>C(8)</b>	Are you able to amend information when necessary to ensure currency and accuracy?
<b>Answer</b>	Data is recorded on initial collection and time sensitive data will be updated at a single time point prior to data aggregation.
<b>C(9)</b>	How are you ensuring that personal data obtained from individuals or other organisations is accurate?
<b>Answer</b>	Personal data is provided by health and social care professionals within acute hospital organisations, who are required to have a data protection officer in place as per GDPR requirement.

### Retention

<b>C(10)</b>	What are the retention periods for the personal data and how will this be implemented?
<b>Answer</b>	Data will be retained for the duration of the audit collection and reporting period, that is three months.
<b>C(11)</b>	Are there any exceptional circumstances for retaining certain personal data for longer than is necessary?

Answer	If the audit period were to be extended then the data may be retained for this extended period. At this time, the audit is not expected to be extended.
<b>C(12)</b>	How will personal data be fully anonymised or destroyed after it is no longer necessary or fit for purpose?
Answer	The coding key and all personal health information will be securely destroyed on completion of the audit.

### Rights of the individual

<b>C(13)</b>	How will you action requests from individuals (or someone acting on their behalf) for access to their personal information once held? Will the information be provided to the data subject on their right to rectification, erasure, portability etc?
Answer	N/A – individuals cannot be identified at national reporting level.

### Appropriate technical and organisational measures

<b>C(14)</b>	What procedures are in place to ensure that all staff with access to the patient data have received adequate information governance training?
Answer	The audit is being carried out by a single individual (service user) who is compliant with the local organisation data protection and confidentiality policy.
<b>C(15)</b>	If using an electronic system to process subject access requests, what security measures are in place?
Answer	NA
<b>C(16)</b>	How will the information be provided, collated and used?
Answer	<p>Data will be collected in person, by the service user, during site visits to each organisation. The service provider will use a code to pseudo-anonymise personal health information on commencement of data collection. This will remain on the (service provider) person during the site visit. Following the site visit, the information linking the code to the patient will remain in a secure, locked location in the service provider's hospital site (National Rehabilitation Hospital). Sensitive health information will be kept separate to patient identity information by means of pseudo-anonymisation so that personal data cannot be attributed to a special data subset.</p> <p>Data will be processed using Excel spreadsheet on a secure NRH device. This will be password protected and accessible to the service used only. The data will be used to identify trends in patient populations, in practices among organisations, and the number of patients identified by organisations, fitting the scope of the audit, will be compared with the national database on delayed discharges.</p>
<b>C(17)</b>	<p>What security measures will be used to transfer the identifiable information?</p> <p>Have you identified any potential risk?</p> <p>The potential impact of any such risk on the data subject.</p> <p>The likelihood and severity of any risk.</p> <p>How you intend to deal with it.</p>

Answer	<p>The below security measures are in place to mitigate the risk of loss, unauthorised access, use, modification, disclosure or other misuse of data and to ensure the privacy rights of individuals involved?</p> <ul style="list-style-type: none"> <li>• Data is collected in person, by the service user, during site visits, rather than electronically or via post.</li> <li>• Coding will be used to pseudo-anonymise personal health information.</li> <li>• Sensitive health information will be kept separate to patient identity information (by means of pseudo-anonymisation) so that personal data cannot be attributed to a special data subset.</li> <li>• Data remains in personal position of one individual (service user) during site visit and in transit to / from site. On completion of data retrieval, data is kept in a secure locked location. Only service user and programme manager have knowledge of and access to the secure location.</li> <li>• Stakeholders providing data are health and social care professionals who are compliant with local data privacy and confidentiality policies.</li> <li>• Service user is the only stakeholder, external to organisations who provided data, who is collecting, collating and using data. Stakeholder is compliant with local data privacy and confidentiality policies.</li> <li>• All stakeholders (internal and external) have oversight of local corporate DPO.</li> <li>• Services user has agreement with NCPRM leaders regarding audit methodology.</li> <li>• De-identified data will be held for a limited period (maximum of four months) after which it will be destroyed.</li> <li>• Reporting of data will be presented in de-identified summarised descriptive format, no individual patient or organisation will be identified.</li> <li>• Audit does not involve direct contact with patients so does not pose any direct risk or burden to the patient.</li> <li>• The outcome of the audit will not impact on the patients care, rights or access to services.</li> </ul> <p><u>Benefits</u></p> <p>The benefits of the project will be the ability to comprehensively inform the National Rehabilitation Programme as to the real demand for Neuro-Rehabilitation in Ireland. This will include information on the specific needs of this patient population and the reasons for delays in patients accessing services close to or in their homes. This will help to ensure the development of high quality rehabilitation services to ensure optimal patient/ service user outcomes and contribute information that may reduce the consequences of delayed transfer of care from acute hospitals.</p> <p>Safe and effective health and social care services require those involved to collect, use and disclose personal health information. It is therefore essential that a balance can be struck between respecting an individual’s privacy and using or sharing information about them to provide the care required.</p>
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Transfers both internal and external including outside of the EEA	
<b>C(18)</b>	Will individual’s personal information be disclosed internally/externally in identifiable form and if so to whom, how and why?

Answer	<ul style="list-style-type: none"> <li>• Coding will be used to pseudo-anonymise personal health information.</li> <li>• Sensitive health information will be kept separate to patient identity information (by means of pseudo-anonymisation) so that personal data cannot be attributed to a special data subset.</li> <li>• Reporting of data will be presented in de-identified summarised descriptive format, no individual patient or organisation will be identified.</li> </ul>
<b>C(19)</b>	<p>Will personal data be transferred to a country outside of the European Economic Area? If yes, what arrangements will be in place to safeguard the personal data?</p> <p><b>No</b></p>

#### Consultation – link back to the stakeholders (A6)

<b>C(20)</b>	<p>Who should be consulted to identify privacy related risks and how will this be achieved? Identify both internal and external stakeholders.</p>
Answer	<p>Service user as consulted DPO office in own organisation (National Rehabilitation Hospital). DPO in relevant organisation (A6). Also refer to C(17).</p>
<b>C(21)</b>	<p>Following the consultation – what privacy risks have been raised? E.g. Legal basis for collecting and using the information, security of the information in transit etc. You should also include consultation with the data subject – have their views been sought?</p>
Answer	<p>Refer to section C(1) for legal compliance. Refer to section C(17) risks identified and security measures used to mitigate the risk of loss of data or risk to privacy rights of individuals involved. Data used in audit is existing data that is routinely collected by organisation or pre-existing data available on a national database. Deidentified data will be used to identify national trends. This audit, which is aimed at capturing a snapshot of a patient population in a limited time period did not seek consultation from individuals (see C(17) and C(3)).</p>

#### Guidance used

<b>C(22)</b>	<p>List any national guidance applicable to the initiative that is referred to.</p>
Answer	<p>Clinical Strategy and Programmes Division - National Clinical Programme for Rehabilitation Medicine (NCPRM) Model of Care for the Provision of Specialist Rehabilitation Services in Ireland. <a href="https://www.hse.ie/eng/about/who/cspd/ncps/rehabilitation-medicine/moc/final-ncprm-moc-web.pdf">https://www.hse.ie/eng/about/who/cspd/ncps/rehabilitation-medicine/moc/final-ncprm-moc-web.pdf</a></p>

## Section D: Privacy issues identified and risk analysis

Table 1 – Identify the privacy and related risks. (See Appendix 1 for further information)

Ref No.	Privacy issue – element of the initiative that gives rise to the risk	a) Risk to individuals (complete if appropriate to issue or put not applicable)	b) Compliance risk (complete if appropriate to issue or put not applicable)	c) Associated organisation /corporate risk (complete if appropriate to issue or put not applicable)
PR1	Audit involves gathering personal health information on a patient population.	Individuals personal health information is being processed.	Non-compliance with Article 6 1(e) and Article 9 1 (i).	May lead to public mistrust. May lead to sanction by the ODPC.
PR2	Individuals are not aware of the initiative as no communication materials have been planned	Individuals not aware that their data is being processed	Non-compliance with Article 5(1) principle /Concept 1 – fairness, lawfulness and transparency	1. May lead to public mistrust  May lead to sanction by the (ODPC)

Table 2 – Identify the privacy solutions

Ref No.	Risk – taken from column (a), (b) and/or (c) in table 1.	Risk score – see tables at Appendix 2			Proposed solution(s) /mitigating action(s)	Result: is the risk accepted, eliminated, or reduced?	Risk to individuals is now OK? Signed off by?
		Likelihood	Impact	RAG status			
PR1	Audit involves gathering personal health information on a patient population. Individuals personal health information is being processed.	5	5	25	Conforms with GDPR Articles 6 and 9. Service user will uphold the principles of minimisation and anonymisation. Minimum data necessary will be gathered for specific purpose outlined (see B1). Strict access and security controls are in place (C17). Service used will ensure secure disposal of data (C17). All reporting will be anonymised.	Reduced to an acceptable level.	Yes  Sign-off tbc
PR2	<i>Individuals not aware that their data is being processed</i> <i>Non-compliance with DPA</i>	5	5	25	Audits are conducted for the purpose of continued quality improvement in service delivery. For such audit purposes, the patient is not asked for explicit consent as data is de-identified. Given the purpose and scale of the population involved, it may be	Reduced to an acceptable level.	Yes  Sign-off tbc

	<p><i>principle 1 – fair and lawful processing</i></p> <p>1. <i>May lead to public mistrust</i></p> <p>2. <i>May lead to sanction by the ODPC</i></p>				<p>considered an exception “in cases where provision of information would be impossible or involve disproportionate effort..” Data Protection Commission.</p> <p>Transparency is ensured by all participating organisations having the full identity and contact details of the service user.</p> <p>Participating organisations have full control of the source and accuracy of the data. All participating research, innovation departments receive details of the project and can approve the DPIA. All reporting will be anonymised.</p>		
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Integrate the PIA outcomes back into the project plan

NB. This must include any actions identified in Table 1 and Table 2.

Who is responsible for integrating the PIA outcomes back in to the project plan and updating any project management paperwork? Who is responsible for implementing the solutions that have been approved? Who is the contact for any privacy concerns which may arise in the future?							
Ref No.	Action to be taken	Date for completion of actions	Anticipated risk score following mitigation			Responsibility for action – <i>job title not names</i>	Current status/progress
			Likelihood	Impact	RAG status		
PR1	Maintenance of privacy, quality and security of data will be upheld by service user in collaboration with internal stakeholders.		2	2	4	Project manager will maintain ongoing communication with internal stakeholders identified in 6(A).	Scheduled monthly meetings with all stakeholders and informal communication as required with stakeholders.

## Appendix 1: Types of privacy risk

### Risks to individuals

- i. Inadequate disclosure controls increase the likelihood of information being shared inappropriately.
- ii. The context in which information is used or disclosed can change over time, leading to it being used for different purposes without people's knowledge.
- iii. New surveillance methods may be an unjustified intrusion on their privacy.



- iv. Measures taken against individuals as a result of collecting information about them might be seen as intrusive.
- v. The sharing and merging of datasets can allow organisations to collect a much wider set of information than individuals might expect.
- vi. Identifiers might be collected and linked which prevent people from using a service anonymously.
- vii. Vulnerable people may be particularly concerned about the risks of identification or the disclosure of information.
- viii. Collecting information and linking identifiers might mean that an organisation is no longer using information which is safely anonymised.
- ix. Information which is collected and stored unnecessarily, or is not properly managed so that duplicate records are created, presents a greater security risk.
- x. If a retention period is not established information might be used for longer than necessary.

#### Examples of Compliance Risk

- i. Non-compliance with the common law duty of confidentiality
- ii. Non-compliance with the Data Protection Acts 1988 & 2003/ General Data Protection Regulation (GDPR).
- iii. Non-compliance with the Privacy and Electronic Communications Regulations (PECR)/e-Privacy Regulation.
- iv. Non-compliance with sector specific legislation or standards e.g. Health Information and Quality Authority (HIQA), Health and Safety Authority (HSA).
- v. Non-compliance with human rights legislation United Nations Declaration on human Rights (UNDHR).

#### Associated organisation/corporate risk

- i. Non-compliance with the IDPA or other legislation can lead to sanctions, fines and reputational damage.
- ii. Problems which are only identified after the project has launched are more likely to require expensive fixes.
- iii. The use of biometric information or potentially intrusive tracking technologies may cause increased concern and cause people to avoid engaging with the organisation.
- iv. Information which is collected and stored unnecessarily, or is not properly managed so that duplicate records are created, is less useful to the business.
- v. Public distrust about how information is used can damage an organisation's reputation and lead to loss of business.
- vi. Data losses which damage individuals could lead to claims for compensation.