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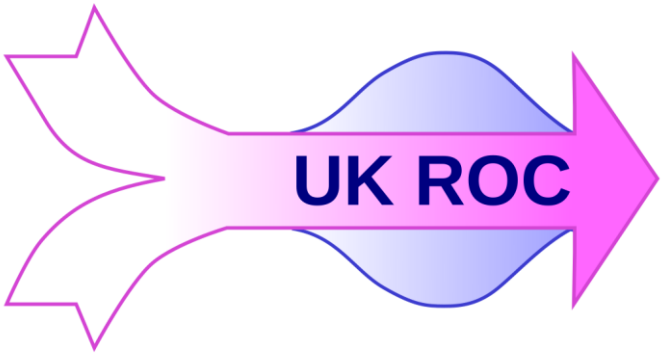

UK Rehabilitation Outcomes Collaborative (UK ROC)

Six-year report 2015-2021

Prepared by the UK ROC Team:

Professor Lynne Turner-Stokes
Mr Keith Sephton
Mr Alan Bill
Ms Heather Williams
Ms Lynette George
Ms Margaret Kaminska

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The UK Rehabilitation Outcomes Collaborative (UK ROC)

UK ROC was originally set up through a Department of Health NIHR Programme Grant (RP-PG 0407-10185) under its Programme Grants for Applied Research funding scheme from 2008-2015, and was registered as a Payment by Results Improvement Project for the Department of Health.

- The aim was to develop a national database for collating case episode for inpatient rehabilitation and to inform the development of costing and national tariffs for specialist rehabilitation.
- At the time of this report, UK ROC is commissioned by NHSE to provide the commissioning dataset all specialist neurorehabilitation services (levels 1 and 2) across the England.
- It is supported by active patient and public involvement.

UK ROC is directed by Professor Lynne Turner-Stokes, and based at Northwick Park Hospital in London.

Engagement of rehabilitation specialists across England is achieved through the **British Society of Rehabilitation Medicine (BSRM)** Trauma Rehabilitation Working Group and the **NHSE Clinical Reference Groups for Specialist Rehabilitation.**

All enquiries in regard to this document should be addressed to:

The UK Rehabilitation Outcomes Collaborative
Regional Hyper-acute Rehabilitation Unit
Northwick Park Hospital, Watford Road
Harrow, Middlesex
London
HA1 3UJ

Tel: +44-208-869-2427
Email: LNWH-tr.ukroc@nhs.net

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List of Abbreviations and glossary of terms

List of abbreviations

Abbreviation	Full Term
APIA	Aligned Payment and Incentive Approach
ADRT	Advance Decision to Refuse Treatment
Ax	Assessment
BASCIS	British Association of Spinal Cord Injury Specialists
BMA	British Medical Association
BSRM	British Society of Rehabilitation Medicine
CAG - HRA	Confidentiality Advisory Group (to the Health Research Authority)
CCG	Clinical Commissioning Group
COVID-19	Novel coronavirus
CRG	Clinical Reference Group
CRM	Consultant in Rehabilitation Medicine
CRS-R	Coma Recovery Scale - Revised
CSU	Commissioning Support Unit
DH	Department of Health
DOB	Date of Birth
DSCRO's	Data Services for Commissioning Regional Offices
FOI	Freedom of Information
FIM+FAM	Functional Independence Measure and Functional Assessment Measure
HES	Hospital Episode Statistics
HQIP	Health Quality Improvement Partnership
H & W	Health and Welfare
ICS	Integrated Care Systems
ICU	Intensive Care Unit
IG	Information Governance
LNWUH	London North West University Healthcare NHS Trust
LOS	Length of stay
LPOA	Lasting Power of Attorney
MCS	Minimally conscious state
MPAI	Mayo Portland Adaptability Inventory
MASCIP	Multidisciplinary Association of Spinal Cord Injury Professionals
NCASRI	National Clinical Audit for Specialist Rehabilitation following major Injury
NCDR	National Commissioning Data Repository
NHS	National Health Service
NHSI	NHS Improvement

Abbreviation	Full Term
NHSE	NHS England
NIS	Neurological Impairment Set
NPCNA	Northwick Park Care Needs Assessment
NPDS	Northwick Park nursing Dependency Score
NPTDA	Northwick Park Therapy Dependency Assessment
OBD	Occupied Bed Day
ONS	Office of National Statistics
ODS	Organisation Data Service
PbR	Payment by Results
PCAT	Patient Categorisation Tool
PCN	Primary Care Network
PDOC	Prolonged Disorder of Consciousness
PEG	Percutaneous Endoscopic Gastrostomy
PICUPS	Post Intensive Care Unit Presentation Screen
PLICS	Patient Level Information and Costing System
RCP	Royal College of Physicians
RCS-E	Rehabilitation Complexity Score - Extended
RM	Rehabilitation Medicine
RP	Rehabilitation Prescription
RR&R	Recovery, Rehabilitation and Re-enablement
SCI	Spinal Cord Injury
SCIC	Spinal Cord Injury Centre
SMART	Sensory Modality Assessment and Rehabilitation Technique
TARN	Trauma Audit and Research Network
UK ROC	United Kingdom Rehabilitation Outcomes Collaborative
VS	Vegetative State
WHIM	Wessex Head Injury Matrix
WHO	World Health Organisation
WBD	Weighted Bed Day
WTE	Whole Time Equivalent

Glossary of terms

Term	Description
Caldicott Guardian	A senior person responsible for protecting the confidentiality of people's health and care information and ensuring correct usage
Confidentiality Advisory Group (HRA)	The Confidentiality Advisory Group to the Health Research Authority that reviews applications for access to confidential patient information without consent under Section 251 of the Care Act 2014
Clinical Reference Group (CRG)	Groups appointed by NHS England to provide clinical advice for the strategic planning and commissioning of Specialised Services
Consultant in Rehabilitation Medicine (RM)	A consultant physician with higher specialist training and accreditation in the field of rehabilitation medicine
Data Access Request Service	A service offered by NHS Digital to provide NHS data for analysis and linkage with other datasets
Data Protection Act	UK Act of Parliament designed to protect stored personal data
Integrated Care Systems	Integrated Care Systems (ICS) are new partnerships between the organisations that meet health and care needs across an area, to coordinate services and to plan in a way that improves population health and reduces inequalities between different groups. ICS may be seen as a response to the fragmented delivery of health and social services being an acknowledged problem within England
Information Governance	Information Governance is the overall strategy for information within an organisation. Information governance balances the risk that information presents with the value that information provides
UK Functional Independence Measure and Functional Assessment Measure (UK FIM+FAM)	The UK FIM+FAM assessment tool is a global measure of disability for brain injured population. It is the mandatory outcome measure tool for level 1 and 2 specialist rehabilitation units
Mayo-Portland Adaptability Inventory (MPAI)	A clinical tool to assist in the clinical evaluation/rehabilitation programme following an acquired brain injury. Including physical, cognitive, emotional, behavioural and social issues
Monitor	Executive non-departmental body. Was responsible for promoting efficiency in health care provision. Subsequently replaced by NHS Improvement and NHSE/I
Neurological Impairment Set (NIS)	A clinical for tool for recording the severity and types of impairments
NHS Digital	Trading name of the Health and Social Care Information Centre which is the national provider of information, data and IT systems for commissioners, analysts and clinicians in health and social care in England, particularly those involved in the National Health Service
NHS England (NHSE)	An executive non-departmental public body of the Department of Health that oversees the budget, planning, delivery and day-to-day operation of the commissioning side of the NHS in England
NHSE/I	An executive non-departmental public body of the Department of Health formed through merger of NHS England and NHS Improvement
Northwick Park nursing Dependency Score / Northwick Park Care Needs Assessment	A clinical for tool for measuring a patient's level of dependency on care and nursing, which translates by a computerised algorithm to estimate the needs for, and costs of providing, care in the community
Patient Categorisation Tool (PCAT)	A clinical tool for identifying and describing a patient's complex needs for rehabilitation, and categorising these into four levels (A-D) in line with the NHSE criteria for requiring specialist rehabilitation services
Post Intensive Care Unit Presentation Screen (PICUPS)	A clinical tool developed to support triage of patients as they progress from Intensive care into acute wards and onwards to rehabilitation
Rehabilitation	A process of assessment, treatment and management with on-going evaluation by which the individual (and their family/carers) are supported to achieve their maximum potential for physical, cognitive, social and psychological function, participation in society and quality of living
Rehabilitation Complexity Score (RCS-E)	A clinical for tool for measuring a patient's resource requirements for rehabilitation in terms of nursing, therapy and medical care

Term	Description
Rehabilitation Prescription (RP)	A personalised rehabilitation plan for ongoing needs following discharge from the acute wards. Assists in identifying where needs are/are not being met and shortfalls in service provision
Specialist rehabilitation	The total active care of patients with complex disabilities by a multi-professional team who have undergone recognised specialist training in rehabilitation, led/ supported by a consultant trained and accredited in rehabilitation medicine
Sign-posting	UK ROC is responsible for collating service profile and complexity data for each provider, which is updated annually. The data are compared with the national standards as set out by the British Society of Rehabilitation Medicine to sign-post the appropriate service level for designation by NHSE
Survey Monkey	Survey Monkey is an online survey development cloud-based software service company. The company provides free, customisable surveys, as well as a suite of paid back-end programs
UK Rehabilitation Outcomes Collaborative (UK ROC)	An organisation commissioned by NHSE that provides the national clinical database for specialist rehabilitation services in England
UK ROC Oversight Group	A group formed of Commissioners, Providers and Patient Representatives for the principal purpose of delivering oversight of the UK ROC database and to provide a forum for shared decision-making (see Appendix 9 for further details)
Weighted bed-day	The specialist rehabilitation mandated currency that takes account of patients with different levels of complexity in a way that is fair to commissioners and providers

1. Background

1.1 What is specialist rehabilitation?

According to the NHSE 2014 Service Specification for Specialist Rehabilitation [1]:

- **Rehabilitation** is a process of assessment, treatment and management with ongoing evaluation, through which the individual (and their family/carers) is supported to achieve their maximum potential for physical, cognitive, social and psychological function, participation in society and quality of living. Patient goals for rehabilitation vary according to the recovery trajectory and stage of their condition [2].
- **Specialist rehabilitation** is the total active care of patients with complex disabilities by a multi-professional team who have undergone recognised specialist training in rehabilitation, led by a consultant trained and accredited in Rehabilitation Medicine.

Evidence: There is now a substantial body of trial-based evidence and other research to support both the effectiveness and cost-effectiveness of specialist rehabilitation [3]. Early transfer to specialist centres and more intense rehabilitation programmes are cost-effective [4, 5] particularly in the small group of people who have high care costs due to very severe brain injury [6-8].

Despite their longer length of stay, the cost of providing early specialist rehabilitation for patients with complex needs is rapidly offset by longer term savings in the cost of community care, making this a highly cost-efficient intervention [9].

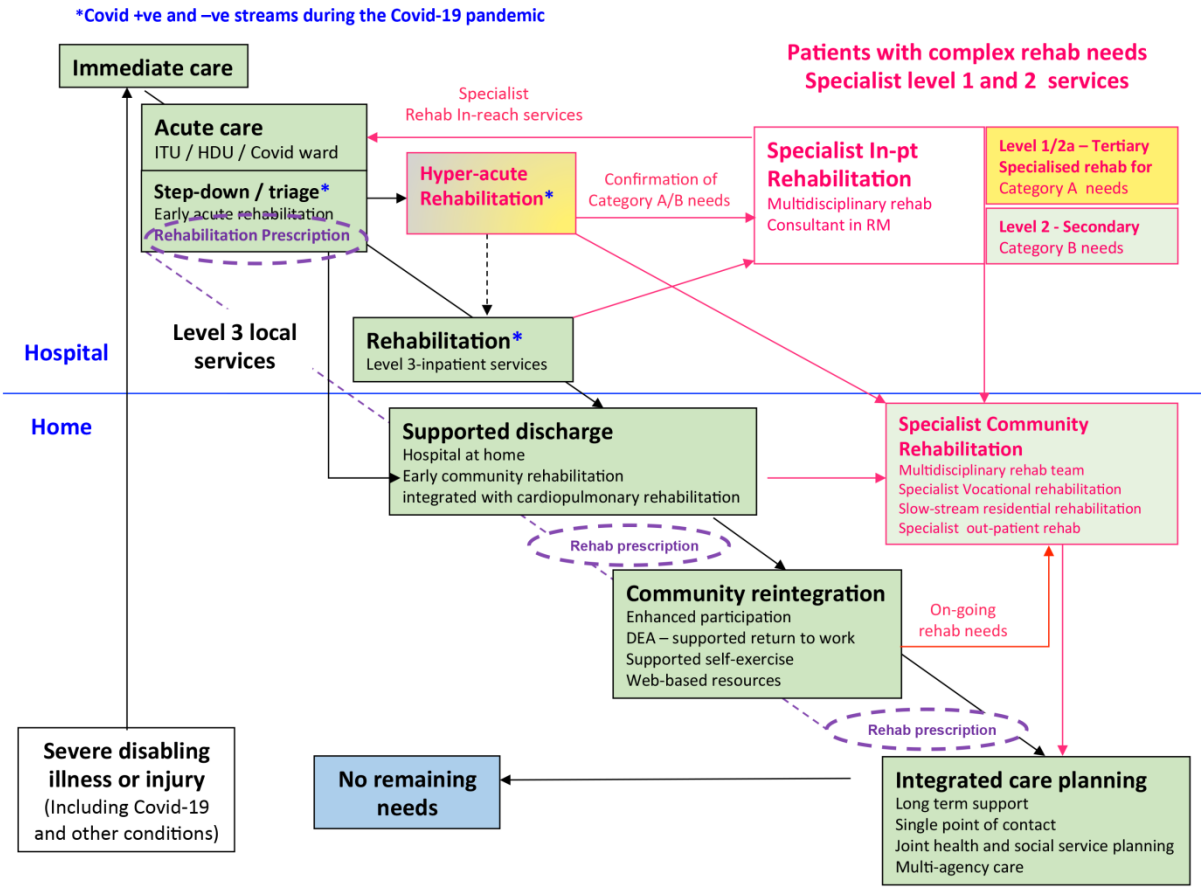
1.2 Which patients need specialist rehabilitation?

The NHSE Service Specification for Specialist Rehabilitation [1] defines three levels of service (1 to 3) and four categories of patient need (A to D).

- Following severe disabling illness or injury, the majority of patients will have an uncomplicated recovery and progress rapidly down the 'Recovery, Re-enablement and Rehabilitation' (RR&R) pathway. Their rehabilitation needs (Category C or D) can be met within their local general (Level 3) rehabilitation services (see Figure 1.1).
- Those with more complex (Category B) needs may require referral to their local specialist (Level 2) rehabilitation services for coordinated intensive rehabilitation programmes.
- A small number of patients with highly complex (Category A) needs require the specific staff expertise and facilities of tertiary specialised (Level 1) rehabilitation services.
- Level 1 rehabilitation units are expected to have a casemix with over 85% category A patients. Level 2 units may have a more varied casemix of patients with category A or B needs.
- Spinal injury units are currently not part of the NHSE service specification for specialist rehabilitation, but Level 1 and 2 units nevertheless take a proportion of patients with spinal cord injury (SCI) – especially where the SCI is an incomplete injury or with medical aetiology.

Further detail on the criteria for rehabilitation needs within each category can be found in the NHSE Service specification D02: Specialist rehabilitation services for patients with highly complex needs [1] http://www.england.nhs.uk/wp-content/uploads/2014/04/d02-rehab-pat-high-needs-0414.pdf.

Figure 1.1: Pathways for rehabilitation following illness or injury



1.2.1 Types of rehabilitation provided

Patient goals for rehabilitation vary according to the recovery trajectory and stage of their condition. According to the NHSE service specification, specialist rehabilitation services may be provided along three main (frequently overlapping) pathways:

- **Restoration of function** (eg for those recovering from a 'sudden onset' or 'intermittent' condition) where the patient goals are focused not only on improving independence in daily living activities, but also on participatory roles such as work, parenting, etc.
- **Disability management** (eg for those with stable or progressive conditions) where the patient / family goals are focused on maintaining existing levels of functioning and participation; compensating for lost function (eg through provision of equipment / adaptations); or supporting adjustment to change in the context of deteriorating physical, cognitive, and psychosocial function.
- **Neuro-palliative rehabilitation** where the goals are focused on symptom management and interventions to improve quality of life during the later stages of a progressive condition or very severe disability, at the interface between rehabilitation and palliative care.

The specification covers a range of different programmes of care including:

- Programmes for people with complex physical disability
- Cognitive/behavioural rehabilitation programmes for people who are independently mobile

- Programmes for patients with profound disability requiring very high level nursing/medical and/or therapy needs (eg those with tracheostomies or requiring assisted ventilation)
- Assessment/management of vegetative and minimally conscious states (dedicated units)
- Specialist community integration / vocational rehabilitation programmes
- Programmes for children or adolescents (including 16-18 year olds)

1.3 Rehabilitation Service provision in the UK

Since the re-organisation of the NHS following the Health and Social Care Act 2012, tertiary specialist rehabilitation for patients with highly complex (Category A) needs are commissioned directly by NHS England. Local specialist and general services are commissioned by the Clinical Commissioning Groups (CCGs). At the time of writing this report, commissioning arrangements were transitioning from NHSE to the more population centric Integrated Care Systems (ICSs).

Hyper-acute specialist rehabilitation services. Development of the major trauma networks has instigated a new category of 'Hyper-acute rehabilitation' [10]. These units are sited within acute care settings. They take patients at a very early stage in the rehabilitation pathway, when they still have unstable medical and surgical needs requiring continued active support from the trauma, neuroscience or acute medical services. These units are still undergoing development and a variety of service models for hyper-acute rehabilitation exist in different parts of the country [11].

Tertiary 'specialised' rehabilitation services* **(Level 1)** are high-cost/low-volume services, which provide for patients with highly complex rehabilitation needs that are beyond the scope of their local and district specialist services. These are normally provided in coordinated service networks planned over a regional population of between 1 and 5 million, through NHSE specialised commissioning arrangements. These services are sub-divided into:

- **Level 1a:** for patients with high physical dependency;
- **Level 1b:** mixed dependency;
- **Level 1c:** mainly mobile patients with cognitive/behavioural disabilities.

Local (district) specialist rehabilitation services (Level 2) are typically planned over a district-level population of 350,000 to 500,000, and are led or supported by a consultant trained and accredited in Rehabilitation Medicine (RM), working both in hospital and the community setting. The specialist multi-disciplinary rehabilitation team provides advice and support for local general rehabilitation teams. These are **Level 2b** services. As some parts of England have no access to tertiary specialised rehabilitation services, local specialist rehabilitation services have extended their reach in some areas to support a **supra-district** catchment of 750,000 to 1 million people, and take a higher proportion (at least 50%) of patients with very complex needs. These are **Level 2a** services.

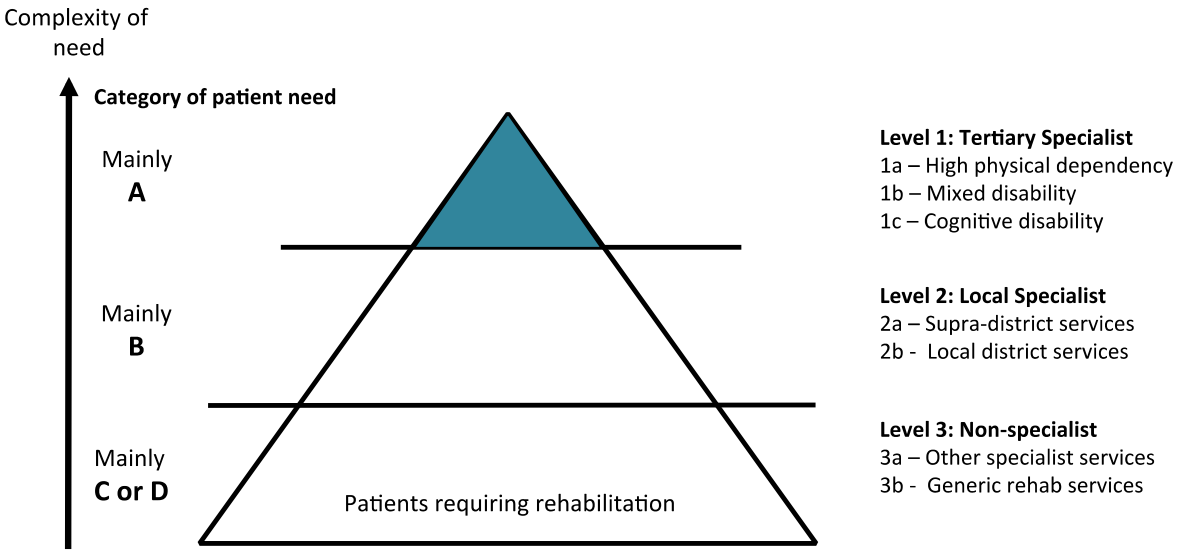
Within each locality, **local non-specialist (Level 3) rehabilitation** teams provide general multi-professional rehabilitation and therapy support for a range of conditions within the context of acute services, intermediate care or community services. These are **Level 3b** services. In addition, local services which 'specialise' in certain conditions and include a significant component of rehabilitation (for example stroke, or care of the elderly) may act as a local source of expertise, even though they do not meet the criteria for designation as a 'specialist rehabilitation service'. These are **Level 3a** services.

These developments have led to a 5-tier system, as shown in Figure 1.2.

* Previously known as 'Complex specialised rehabilitation services' in the National Definition Set, version 2.

As noted above, all specialist rehabilitation services will have a mixture of patients with category A and B needs, but Level 1 services are expected to have a higher proportion of category A patients (>85%). Approximately 50-80% of the caseload for level 2a service is expected to have Category A needs, whereas proportion for a Level 2b service may be about 30-50%.

Figure 1.2: Different levels of specialisation in rehabilitation service provision in England



1.4 The UK Rehabilitation Outcomes Collaborative (UK ROC)

UK ROC provides the national clinical database for specialist rehabilitation services in England. It was established in 2010 through an NIHR programme grant for applied research (2008–2015) [10]. It is based at Northwick Park Hospital in London and is overseen by the BSRM.

UK ROC systematically collates patient level data for all case episodes admitted for in-patient specialist rehabilitation in England; the database now contains over 61,000 recorded episodes. The dataset comprises socio-demographic and process data (eg waiting times, discharge destination) as well as clinical information on:

- the complexity of rehabilitation needs;
- the inputs provided to meet those needs;
- outcomes including functional gain and cost-efficiency.

The database endeavours to meet the challenge of capturing activity and outcomes for the highly diverse range of patients, programmes and pathways described above. It continues to develop over time in accordance with need.

Since July 2015, UK ROC has been directly commissioned by NHSE to provide the commissioining dataset for specialist rehabilitation services. Registration and submission of the full UK ROC dataset is a commissioining requirement for designation, and for eligibility for payment as a Level 1 or 2 specialist rehabilitation service.

From a commissioning perspective, UK ROC performs key functions:

- It collates information on service chraracteristics (staffing levels, caseload complexity and catchment population) to 'signpost' services for designation at the appropriate service level;
- It provides monthly activity reports for contracting and commissioining purposes;
- It also provides quarterly benchmarking reports on quality and outcomes, including response times for assessment and admission, functional gain and cost-efficiency. The figures for each specialist rehabilitation unit are compared to average figures for providers within the same service level.

Key measurement tools within the UK ROC dataset are summarised in Table 1.1 and further detailed in Appendix 1. An exemplar quarterly standard report is given in Appendix 2.

Table 1.1: Key measurement tools within the UK ROC dataset

Tool	Structure	Purpose
Needs for rehabilitation		
Patient Categorisation Tool (PCAT) [12, 13]	Checklist and ordinal measure Total score range 16–50	Records the types of need a patient may have that led to a requirement for treatment in a specialist rehabilitation unit (Category A or B needs).
Neurological Impairment Set [14]	Checklist and ordinal measure Total score range 0–50	Records the severity of neurological and other trauma-related impairments, against which to evaluate outcome.
Inputs		
Rehabilitation Complexity Scale (RCS-E) [15, 16]	Ordinal measure Total score range depends on version	Records the resource requirements to meet the patient's needs for medical support, basic care and nursing, therapy and equipment.
Northwick Park Dependency Score (NPDS) [17]	Ordinal measure Total score range 0–100	Records basic care and nursing dependency. Translates by a computerised algorithm within the UK ROC software to the Northwick Park Care Needs Assessment (NPCNA).
Northwick Park Care Needs Assessment (NPCNA) [18]	Interval scale of estimated care hours and costs	Provides a timetable of care needs and estimates the cost of care/week in the community.
Outcomes		
UK Functional Assessment Measure (UK FIM+FAM) [19]	Ordinal measure Total score range 30–210	A global measure of disability comprising 16 items addressing physical function (FIM+FAM motor) and 14 addressing cognitive, communicative and psychosocial function (FIM+FAM cognitive).
Cost-efficiency [9]	The time taken to offset the cost of rehabilitation by the resulting savings in the cost of ongoing care in the community. This is calculated from 'mean episode cost of rehabilitation' divided by 'mean reduction in weekly cost of care' between admission and discharge, as estimated by the NPCNA.	

Full details, including electronic versions of the tools, may be found on the UK ROC section of the Kings College Cicely Saunders website (as at the time of compiling this report the below link is valid. However, we are aware that Kings College is undertaking a major review of web content and therefore the link may change. We apologise for any inconvenience that this may cause. Please do not hesitate to email UK ROC (LNWH-tr.ukroc@nhs.net) should you need help in accessing the below)
https://www.kcl.ac.uk/cicelysaunders/research/outcome/rehabilitation/Rehab-outcome-measures

1.5 The roles of UK ROC

The primary purpose of the data collection is to support delivery of patient care under the NHS Service specification for specialist rehabilitation, but the UK ROC database also provides data for commissioning, service evaluation, audit and research. The database collates data on needs, inputs and outcome for all admissions to specialist Level 1 and 2 inpatient rehabilitation services in England. It also operates the mandated weighted bed day currency for these services. It also accepts data from other NHS funded specialist services (eg slow stream, specialist nursing homes, etc.).

Under the NHS England service specification for specialist rehabilitation, eligible services must be registered with UK ROC and provide the full UK ROC dataset for each admitted episode. Only activity counted through UK ROC is eligible for payment under the service specification.

UK ROC is responsible for collating service profile and complexity data for each provider, which is updated annually. The data are compared with the national standards as set out by the British Society of Rehabilitation Medicine to sign-post the appropriate service level for designation by NHSE. Appendix 3 shows an exemplar bench marking report.

It also provides the definitive source of service costing data to inform tariff development for NHSE and NHS Improvement, using the published costing methodology. Service costing information is collated alongside the complexity profiles to derive weighted bed day costs for each service.

It should be noted that UK ROC provides data to inform service development and commissioning, but serves only to analyse and present descriptive and comparative data. Commissioning decisions, including service designation, are made by the relevant commissioning bodies.

Since April 2013, UK ROC has provided the NHSE commissioning dataset for Level 1 and 2 Specialist Rehabilitation Services.

- Registered services provide monthly activity figures to UK ROC;
- These are collated by UK ROC and reported back to NHS England and the relevant CCGs, with monthly activity reports of eligible activity against contracted performance using the mandated weighted bed day currency;
- UK ROC also provides quarterly benchmarking reports of performance against the core standards within the service specification, relating to response times, complexity and outcomes – including cost-efficiency.

The data are analysed to identify expected outcomes, cost-effective service models and which types of rehabilitation works best for which patient groups.

Commissioning Support

UK ROC operates under the Data Protection Act under the registration of the IG toolkit held by the host organisation, LNWUH NHS Trust (ODS site code: R1K; registration number ZA083643) which acts as data controller for the UK ROC dataset.

UK ROC has a legal basis for the flow of identifiable verified data to Data Services for Commissioning Regional Offices (DSCRO's) under the Health and Social Care Act 2012 and the Directions issued to NHS Digital by NHS England. The appointed DSCRO will then anonymise the data before flowing it into the NHS England National Commissioning Data Repository for commissioning purposes.

NHS Commissioning Support Units (CSU) provide business intelligence services to NHS England for all directly commissioned services which includes Specialised Commissioning. One of the significant requirements of the CSU SLA is focused on financial reconciliation utilising patient level data flows which will flow from the National Commissioning Repository.

Key functions of UK ROC currently contracted by NHSE are detailed in Appendix 4 together with the dataflows. Other functions, such as research and clinical audit are provided through other funding arrangements.

2. Six-year report 2015-2021

A detailed report of UK ROC data and activity collected during the NIHR grant-funded period is available at https://www.kcl.ac.uk/cicelysaunders/research/studies/uk-roc (as at the time of compiling this report the above link is valid. However, we are aware that Kings College is undertaking a major review of web content and therefore the link may change. We apologise for any inconvenience that this may cause. Please do not hesitate to email UK ROC (LNWH-tr.ukroc@nhs.net) should you need help in accessing the above)

The purpose of this report is to provide a brief overview of the activities of UK ROC for the period 2015-2021, since the dataset was commissioned by NHS England.

Aims

The aims are to describe:

1. The registered services and their reporting activity
2. The total activity of inpatient specialist rehabilitation
3. Performance against key quality indicators
4. Summary of other activities
    a. Registry status
    b. Data linkage
    c. Further developments of UK ROC database
    d. Tariff development
    e. Planned NHS reforms and changes in commissioning
    f. Research and audit activity
    g. Data requests
    h. Analysis and report requests
    i. Training provided
    j. Support requests
    k. Monthly participation

2.1 The registered services and their capacity / activity

Tables 2.1.1-5 list the Level 1 and 2 services registered with UK ROC, together with their bed capacity and annual activity for 2020/21 and the most recent service profile data received. Services are listed under their designated level for 2020-21.

Table 2.1.1 – Level 1a Services

20/21 - Level 1a (8)		Capacity			Activity		Service profile (latest)
ID	Service	Total beds available*	Occupied bed years**	Completed episodes	OBD	WBD	
C029	Colman Centre for Specialist Rehabilitation, Norfolk Community Health and Care NHS Trust	20	17.5	51	6388	9066	18/19
C031	Regional Hyperacute Rehabilitation Unit, Northwick Park Hospital, London North West University Healthcare NHS Trust	24	17.7	90	6444	10061	18/19
C035	Neuro-Rehabilitation Unit, Walkergate Park Centre for Neurorehabilitation and Neuropsychiatry, Northumberland Tyne and Wear NHS Trust	35	30.5	103	11131	14477	18/19
C038	Oxford Centre for Enablement, Nuffield Orthopaedic Centre, Oxford University Hospital NHS Trust	18	17	85	6218	5051	18/19
C075	Brain Injury Unit, University Hospital of Leicester NHS Trust	9	7.8	64	2830	4438	18/19
C090	The Royal Hospital for Neurodisability, Putney	42	38.9	124	14188	20305	18/19
C130	Lipton Rehabilitation Unit, The Walton Centre NHS Foundation Trust	10	6.3	50	2298	3151	18/19
C181	Acute Neuro Rehabilitation, Ward C2, Salford Royal NHS Foundation Trust	20	15.8	75	5763	8228	17/18

*No. of beds reported in service profile **As calculated from the reported activity (OBD/365)

Table 2.1.2 – Level 1b Services

20/21 - Level 1b (6)		Capacity			Activity		Service profile (latest)
ID	Service	Total beds available*	Occupied bed years**	Completed episodes	OBD	WBD	
C054	Inpatient Neurological Rehabilitation Unit, Moseley Hall, Birmingham Community Healthcare NHS Trust	32	29.1	149	10630	16044	18/19
C085	The Royal Leamington Spa Rehabilitation Hospital, South Warwickshire NHS Foundation Trust	38	24.5	133	8940	12619	17/18
C088	Regional Neurological Rehabilitation Unit, Homerton University Hospital NHS Trust	27	17.7	64	6471	8876	18/19
C131	Complex Rehabilitation Unit, The Walton Centre NHS Foundation Trust	20	14.9	55	5424	7008	18/19
C201	Preston Barton Ward Neuro-Rehabilitation Unit, Lancashire Teaching Hospitals Trust	16	13.8	75	5047	4808	16/17
C226	Frenchay Brain Injury Rehabilitation Centre, Fourseasons/Huntercombe	29	28.8	82	10517	15568	17/18

*No. of beds reported in service profile
**As calculated from the reported activity (OBD/365)

Table 2.1.3 – Level 1c Services

20/21 - Level 1c (3)		Capacity			Activity		Service profile (latest)
ID	Service	Total beds available*	Occupied bed years**	Completed episodes	OBD	WBD	
C091	Lishman Brain Injury Unit, Maudsley Hospital, South London and Maudsley NHS Trust	15	4.8	14	1770	1442	18/19
C122	Blackheath Brain Injury Rehabilitation Centre - TBIRU unit, Fourseasons/Huntercombe	16	14.1	55	5143	6194	18/19
C137	Neurobehavioural Unit, Walkergate Park Centre for Neurorehabilitation and Neuropsychiatry, Northumberland Tyne and Wear NHS Trust	14	11.4	36	4148	5649	18/19

Table 2.1.4 – Level 1d Services

20/21 - Level 1d (2)		Capacity			Activity		Service profile (latest)
ID	Service	Total beds available*	Occupied bed years**	Completed episodes	OBD	WBD	
C086	The Children's Trust, Tadworth Court, Tadworth, Surrey	12	11.8	55	4299	5657	18/19
C208	Paediatric Neurology, University Hospital Southampton	4	2.1	8	761	938	18/19

*No. of beds reported in service profile
**As calculated from the reported activity (OBD/365)

Table 2.1.5 – Level 2a Services

20/21 - Level 2a (15)		Capacity			Activity		Service profile (latest)
ID	Service	Total beds available*	Occupied bed years**	Completed episodes	OBD	WBD	
C009	Intermediate Neuro-rehabilitation Unit, Manchester Royal Infirmary, Central Manchester Foundation Trust	40	25.7	147	9365	12152	18/19
C025	Leeds National Demonstration Centre in Rehabilitation, Leeds Teaching Hospital NHS Trust	30	27.2	149	9910	12579	18/19
C040	Dorset Brain Injury Unit, Poole Hospital	5	5	21	1814	2556	18/19
C041	Phoenix Rehab Centre, Portsmouth Hospitals NHS Trust	13	13.2	104	4800	6500	18/19
C053	Osborn Unit, Sheffield Teaching Hospitals NHS Trust	14	15.3	73	5573	4786	18/19
C059	Sussex Rehabilitation Centre, Princess Royal Hospital, Brighton and Sussex University Hospitals NHS Trust	39	33	197	12058	15046	16/17
C064	North Staffordshire Rehabilitation Centre, University Hospital of North Staffordshire NHS Trust	23	15.4	71	5632	8889	18/19
C069	Neuro-rehabilitation Unit, UCLH NHS Foundation	18	15.1	67	5527	7734	18/19

C071	Ashby Rehab Unit, United Lincolnshire Hospital NHS Trust	18	17.8	87	6498	8381	18/19
C076	Specialist Neuro-Rehab Unit, Ward 2, University Hospitals of Leicester	16	14	88	5097	7061	18/19
C121	Blackheath Brain Injury Rehabilitation Centre - HNDU unit, Fourseasons/Huntercombe	18	15.9	39	5811	7644	18/19
C183	Ward L1, Salford Royal NHS Foundation Trust	10	10.1	61	3675	5175	17/18
C228	Thomas Young Ward, St George's University Hospitals NHS Foundation Trust	16	12.4	52	4508	5704	18/19
C229	Wolfson Neuro-rehabilitation Unit, Queen Marys Hospital, St George's University Hospitals NHS Foundation Trust	16	14.8	63	5396	5908	18/19
C245	Neuro Rehabilitation Unit, Mount Gould Hospital, Plymouth Community Healthcare	15	13.6	74	4960	6724	18/19

*No. of beds reported in service profile
**As calculated from the reported activity (OBD/365)

Table 2.1.6 – Level 2b Services

20/21 - Level 2b (36)		Capacity			Activity		Service profile (latest)
ID	Service	Total beds available*	Occupied bed years**	Completed episodes	OBD	WBD	
C003	Robertson Rehabilitation Unit, Willesden Centre for Health and Care, London North West University Healthcare NHS Trust	20	14	107	5098	6587	18/19
C005	Buckinghamshire Neuro-rehabilitation Unit, Amersham General Hospital, Amersham, Buckinghamshire Hospitals NHS Trust	17	16.3	91	5959	7010	16/17
C010	Hume Neuro Rehabilitation Unit, South Tyneside and Sunderland NHS Foundation Trust	21	12.8	122	4664	5754	18/19
C012	Kings Lodge Neuro Rehab Unit, University Hospitals of Derby and Burton NHS Foundation Trust	19	16.6	118	6073	8583	18/19
C014	East Kent Neuro-Rehabilitation, East Kent University Hospital Trust	19	12.8	81	4665	3304	18/19
C015	Rakehead Rehabilitation Centre, East Lancashire Hospitals NHS Trust	17	8.7	62	3170	3753	18/19
C018	Alderbourne & Daniel's Rehabilitation Units, Hillingdon Hospitals NHS Trust	34	25.3	178	9224	12303	18/19

C022	Frank Cooksey Rehabilitation Unit, Kings College Hospital NHS Foundation Trust	15	14.3	62	5228	8050	18/19
C026	Neuro-Rehabilitation Unit, Dewsbury & District Hospital, Mid Yorks NHS Hospitals Trust	12	7.8	31	2848	2326	18/19
C028	Neuro Rehabilitation Centre, Goole, North Lincolnshire and Goole NHS Foundation Trust	14	11.8	32	4292	5103	18/19
C030	Pine Cottage Amputee Rehabilitation Unit, Colman Hospital, Norfolk Primary Care Trust	9	5.1	85	1877	1454	18/19
C036	Linden Lodge Neuro-rehabilitation, Nottingham University Hospitals Trust	25	16	100	5850	7054	18/19
C046	Marie Therese House Neurorehabilitation Unit, Royal Cornwall Hospital NHS Trust	12	10.8	24	3953	4669	18/19
C049	Donald Wilson House, St Richards Hospital, Chichester, Royal West Sussex	12	11.1	62	4036	4359	17/18
C057	Snowdon Neurological Rehabilitation Unit, Solent NHS Trust	14	17.4	72	6360	6361	18/19
C065	Bradley Unit, Ashford and St Peters NHS Foundation Trust	20	17.4	106	6348	8109	18/19
C067	Somerset Neurological Rehabilitation Centre, Musgrove Park Hospital, Taunton and Somerset NHS Foundation Trust	10	7.7	43	2805	3151	18/19

C068	The Floyd Unit, The Pennine Acute Hospitals	18	14.4	74	5261	7518	12/13
C080	Clatterbridge Rehabilitation Centre, Wirral University Teaching Hospital NHS Trust	10	2.1	24	769	895	16/17
C081	West Park Rehabilitation Medicine, West Park Hospital, Wolverhampton	10	8.2	76	2982	3915	17/18
C092	Department of Rehabilitation Medicine, Airedale NHS Trust	6	0.3	2	97	62	18/19
C095	Royal Free Neurological Rehabilitation Centre, Royal Free Hampstead NHS Trust	13	4.8	35	1736	1953	18/19
C098	James Cook Neurorehabilitation Unit, James Cook University Hospital, South Tees NHS Trust	16	14.2	128	5170	5122	18/19
C102	Barnsley Neuro Rehabilitation Unit, Kendray Hospital, South West Yorkshire Partnership NHS Foundation Trust	12	8.3	59	3045	3279	18/19
C132	Phoenix Centre, Specialist Rehabilitation Unit, Royal Liverpool and Broadgreen University Hospitals NHS Trust	15	10.1	63	3694	4874	18/19
C133	Specialist Rehabilitation Unit, Elyn Lodge, St Helens & Knowsley Teaching Hospitals NHS Trust	20	12.5	74	4565	5509	18/19
C135	Gwynne Holford Ward, Queen Mary's Hospital, Roehampton, St George's Hospital NHS Trust	10	8.6	45	3133	3465	18/19

C187	Frank Cooksey Rehabilitation Unit - Ontario Ward, Orpington Hospital, King's College Hospital NHS Foundation Trust	14	13.6	81	4952	6960	18/19
C202	Preston Bleasdale Neuro-Rehabilitation Unit, Lancashire Teaching Hospitals Trust	12	0.5	7	187	117	16/17
C209	Sid Watkins Spoke Unit, Walton Centre for Neurology and Neurosurgery, The Walton Centre NHS Foundation Trust	10	2.5	21	927	1234	18/19
C221	Charing Cross Neuro-Rehabilitation Unit, Imperial College Healthcare NHS Trust	15	12.3	96	4503	6631	18/19
C227	Frenchay Brain Injury Rehabilitation Centre, Fourseasons/Huntercombe, Bristol	23	17.4	40	6348	9194	17/18
C232	J2 Rehabilitation Service, Cambridge University Hospitals NHS Foundation Trust	4	2.7	20	986	1248	17/18
C233	J2 RAAR, Cambridge University Hospitals NHS Foundation Trust	10	14.4	149	5246	6224	17/18
C234	Lewin Unit, Cambridge University Hospitals NHS Foundation Trust	4	2.7	17	977	765	17/18
C243	Mardon Neuro-Rehabilitation Centre, Royal Devon and Exeter NHS Foundation Trust	10	9.4	43	3425	4069	18/19

*No. of beds reported in service profile

**As calculated from the reported activity (OBD/365)

2.2 The total activity of inpatient specialist rehabilitation

Compliance reporting for outcome measures ranges from 90-98% per year. However, the impact of COVID-19 required an approved relaxation of reporting requirements as listed in Table 2.2.1.

Table 2.2.1 Minimum dataset during COVID-19 crisis

Domain	Minimum Data reporting during COVID-19
Patient Identification & Demographics	Patient Name (for local use only)
	NHS Number
	Date of Birth
Commissioning & Referral	Patient Category
	CCG Name/Code
	Referral Date
Diagnosis	Diagnosis Category
	Diagnosis Sub-category
Admission Details	Date of Admission
	Admitted from…
	Programme Type
Discharge Details	Discharge Date
	Discharge Destination
Assessment/Outcome measures	RCS on admission & discharge

Level 1 and 2 services had the option of just collecting the minimum COVID dataset or maintaining a larger dataset to provide additional information to assist in describing the impact of the COVID crisis on rehabilitation services.

Table 2.2.2 summarises the total activity and costs within each service level year by year. Full compliance information by service type is available in electronic appendices. The year-by-year data in Table 2.2.2 gives some basic activity and service cost information by Service Level. It is quite noticeable within the Table 2.2.2 data the effect that the COVID-19 pandemic has had on Services. All show a decline during the latter part of 2019/20 and all of 2020/21 in activity and reporting compliance (see 2.2.1 below). Also of note is the reduced number of weighted bed days (WBDs) representing not only a decrease in total numbers but also in relative complexity as many services necessarily adjusted their patient profile to accommodate their Trusts' response to the pandemic.

Please note that the data in Table 2.2.2 is also represented graphically in Figures 2.2.1 – 4 below.

Table 2.2.2 Specialist rehabilitation activity year by year

2015/16	Level 1				Level 2		Total
	1a	1b	1c	1d	2a	2b	
Total no. beds (OBD/365)	165	144	26	21	258	495	1109
Activity / year							
OBDs	60,185	52,556	9,377	7,674	94,182	180,768	404,742
WBD	86,724	71,014	11,869	10,999	123,637	225,682	529,925
Costs							
Total service costs	£38.1m	£29.1m	£7.1m	£5.3m	£47.2m	£78.4m	£205.2m

2016/17	Level 1				Level 2		Total
	1a	1b	1c	1d	2a	2b	
Total no. beds (OBD/365)	167	140	28	20	278	520	1153
Activity / year							
OBDs	60,975	51,069	10,233	7,340	101,328	189,790	420,735
WBD	87,783	71,462	13,585	10,595	134,351	237,545	555,321
Costs							
Total service costs	£38.5m	£29.2m	£8.2m	£5.4m	£51.7m	£82.3m	£215.3m

2017/18	Level 1				Level 2		Total
	1a	1b	1c	1d	2a	2b	
Total no. beds (OBD/365)	161	143	34	21	281	536	1176
Activity / year							
OBDs	58,875	52,203	12,290	7,489	102,667	195,739	429,263
WBD	85,694	73,232	15,538	10,398	136,955	251,148	572,965
Costs							
Total service costs	£37.6m	£30.0m	£9.4m	£5.7m	£52.6m	£87.1m	£222.4m

2018/19	Level 1				Level 2		Total
	1a	1b	1c	1d	2a	2b	
Total no beds (OBD/365)	166	155	34	29	284	517	1185
Activity / year							
OBDs	60,543	56,469	12,315	10,747	103,620	188,740	432,434
WBDs	88,627	79,409	15,512	13,737	137,639	237,792	572,716
Costs							
Total service costs	£38.9m	£31.1m	£8.7m	£6.2m	£52.5m	£92.4m	£229.8m

2019/20	Level 1				Level 2		Total
	1a	1b	1c	1d	2a	2b	
Total no beds (OBD/365)	166	149	30	24	280	486	1135
Activity / year							
OBDs	60,613	54,384	11,084	8,752	102,117	177,552	414,502
WBDs	88,248	76,055	14,059	11,189	137,244	220,444	547,239
Costs							
Total service costs	£39.9m	£32.0m	£8.9m	£6.3m	£53.9m	£94.8m	£235.8m

2020/21	Level 1				Level 2		Total
	1a	1b	1c	1d	2a	2b	
Total no beds (OBD/365)	152	129	30	14	249	385	959
Activity / year							
OBDs	55,260	47,029	11,061	5,060	90,624	140,453	349,487
WBDs	74,777	64,923	13,285	6,595	116,839	170,964	447,383
Costs							
Total service costs	£40.6m	£32.5m	£9.1m	£6.5m	£54.7m	£96.4m	£239.8m

Figures 2.2.1 - 2.2.4 demonstrates the year on year trends in occupancy, activity and cost. All show a decline during the latter part of 2019/20 and all of 2020/21 reflecting the impact of the COVID-19 pandemic.

Figure 2.2.1: Yearly trends in occupied bed day activity

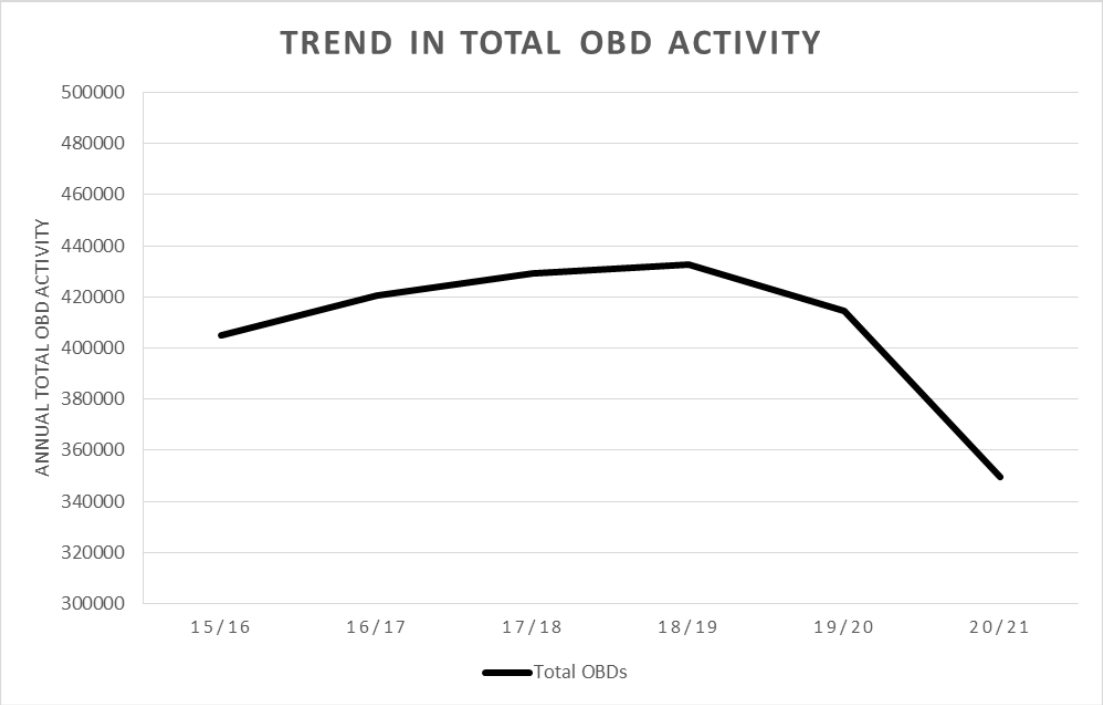
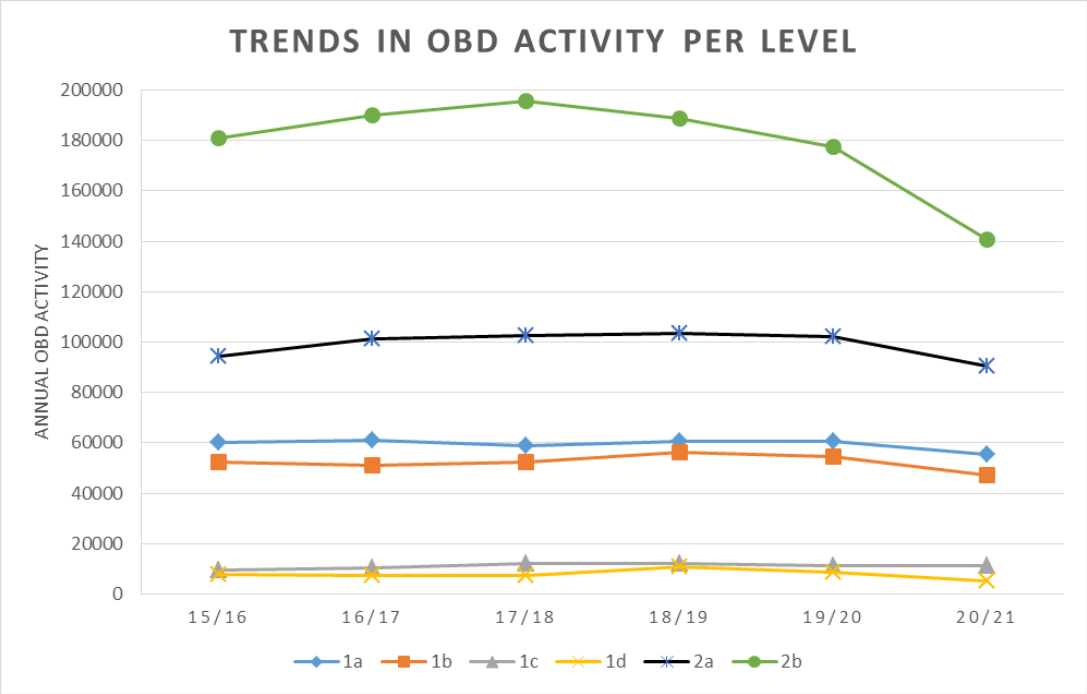


Figure 2.2.2: Yearly trends in OBD activity by service level



There was a reduction in capacity due to the onset of the Covid-19 pandemic in late 2019/20, with a more pronounced impact on 2020/21. Level 2b services were the most affected and staff were frequently deployed from these rehabilitation units to work in the front line acute services.

Figure 2.2.3: Yearly trends in total service costs

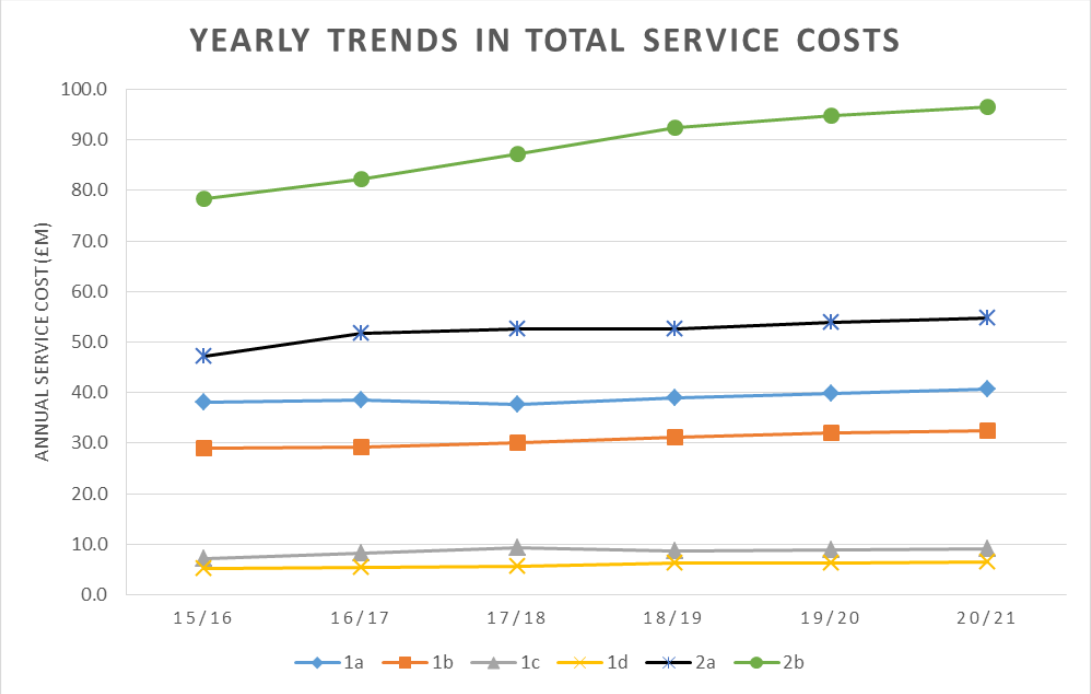
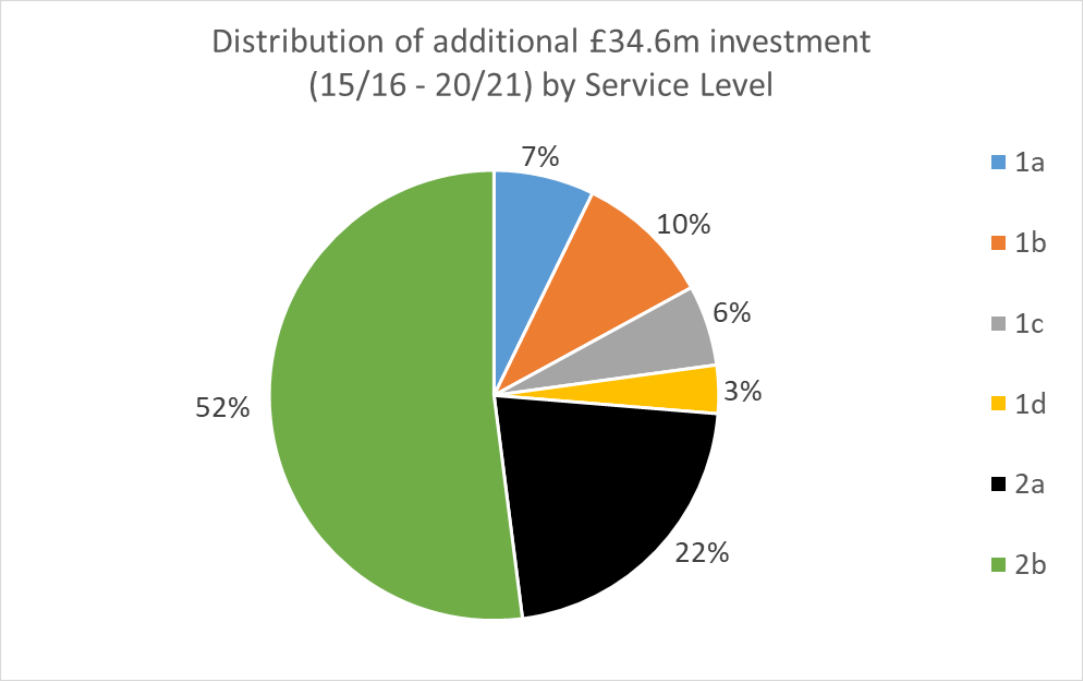
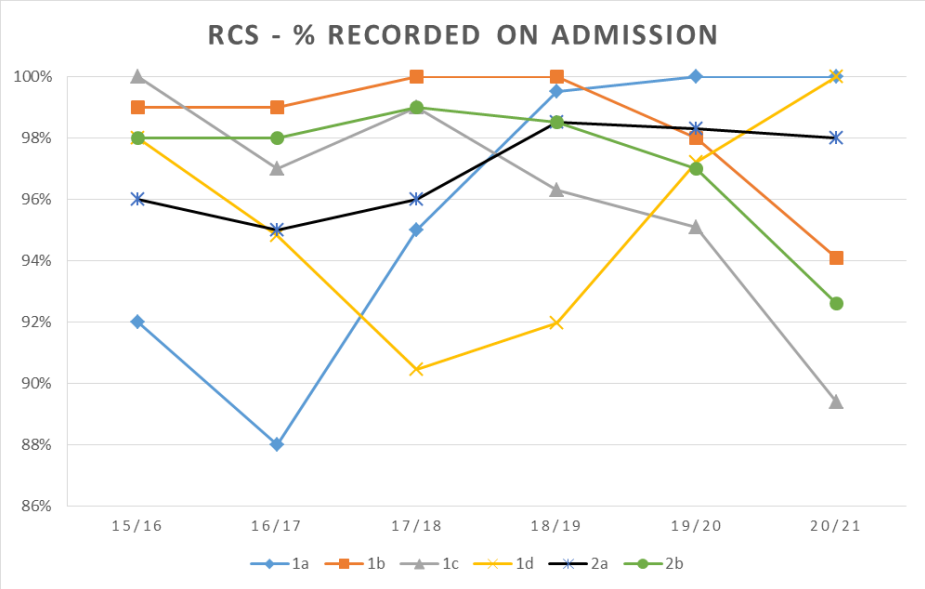


Figure 2.2.4: Distribution of additional investment by Service Level



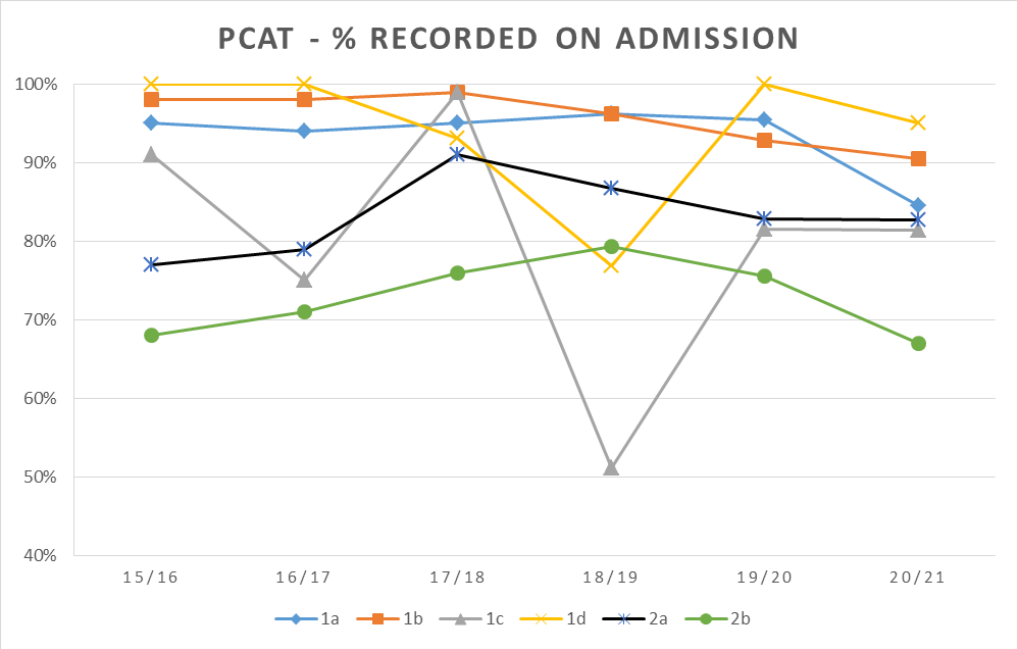
The above graph shows total annual service costs using the same cost indicative tariff rate over all years. This suggests that there has been some additional investment in specialist rehabilitation over the period, but this has mainly been by the CCGs to enhance local services, whilst the NHSE investment has been largely static.

2.2.1 Compliance Reporting

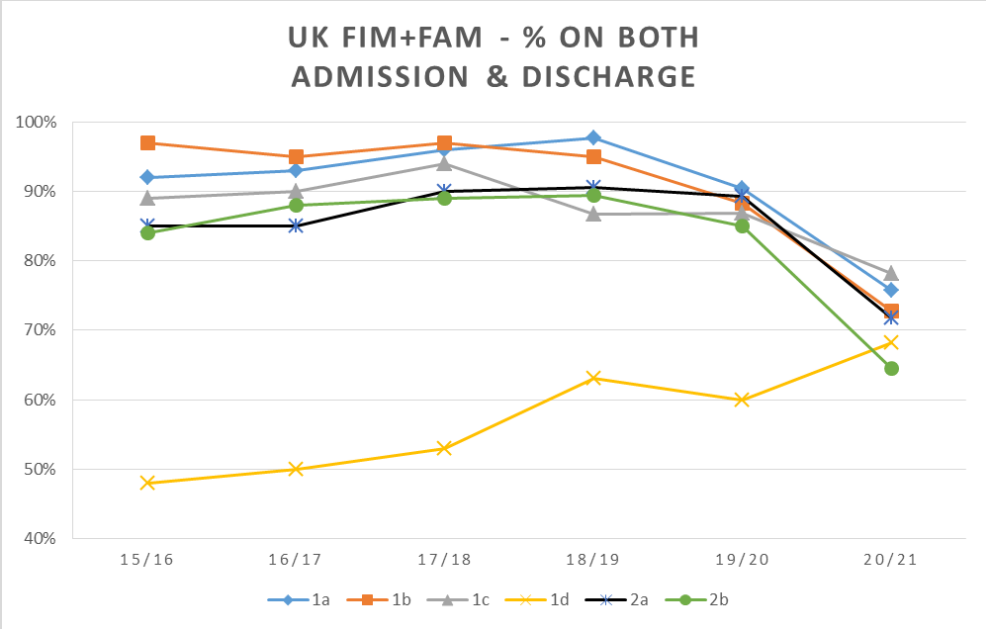


As part of the UK ROC commissioning dataset fortnightly RCS scores throughout the in-patient episode is a mandatory requirement, therefore all Level 1 and 2 units would be expected to have an RCS score on admission for all episodes.

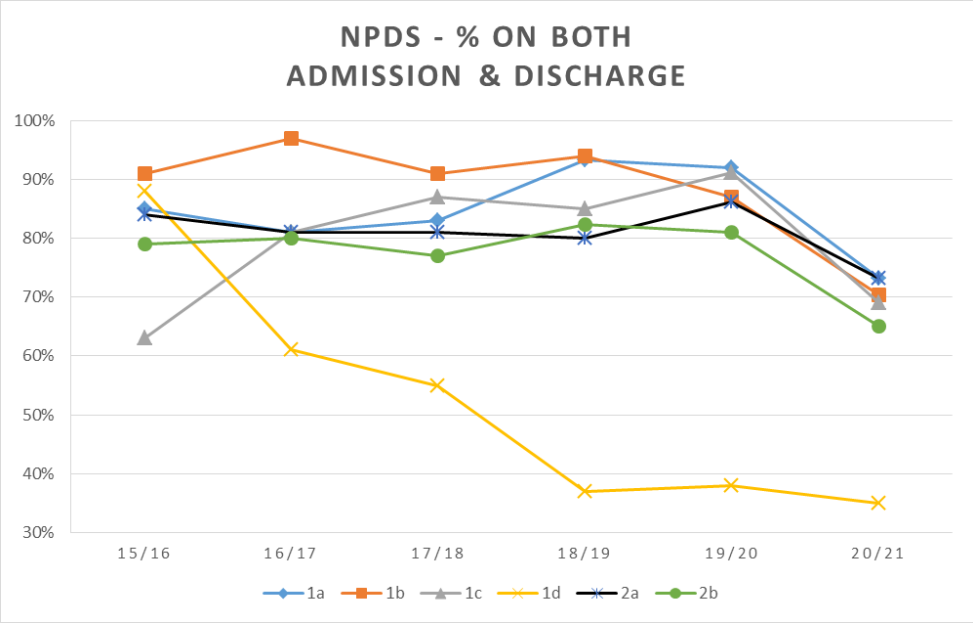
The reason for the drop in compliance in Level 1a units in 2016/17 is unclear. During the pressurised time of COVID-19, the Level 1 and 2 units continued to maintain admission RCS reporting levels at 88-100%. Although this represented a drop from pre-pandemic reporting standards, which were generally >95.



PCAT reporting remains constant for most service levels. Level 1c units were slightly more sporadic due to staffing issues.



The notable decline in FIM+FAM reporting during 2019/20 & 2020/21 is explained by NHS England having suspended the mandate for systematic data-reporting during the COVID pandemic crisis (minimum reporting requirements can be viewed on page 26 of this report).



As cost efficiency is calculated using the admission and discharge nursing dependency scores which were not a requirement during the COVID pandemic this is reflected in the cost efficiency compliance for all service levels.

2.3 Performance against key quality indicators

Tables 2.3.1 sets out the performance against the key quality indicators for the six years, broken down by service level.

There is a gradual yearly trend towards increased complexity and the proportion of category A patients, particularly in the level 1b and 2a services. This is also reflected in a similar trend towards greater dependency on admission.

Table 2.3.1 Key quality indicator performance by Service Level

Parameter		Level 1				Level 2	
2015/16		**1a**	**1b**	**1c**	**1d**	**2a**	**2b**
Mean length of stay (LOS)		100	106	146	115	74	67
% patients with **LOS >180 days**		12.9%	17.4%	29%	25%	6.9%	4.7%
Mean waiting time (days)							
Referral to assessment		10	10	25	15.5	6	6
Assessment to admission		31	31	54	51.1	19	14
Referral to admission		39	37	77	66.5	24	19
% category A patients							
(Clinical impression)		78.2%	71.5%	71.7%	54%	59%	34.2%
(PCAT score ≥30)		74.2%	68.4%	79%	72%	51.3%	38.1%
Mean RCS-s v 12 score admission		14.1	12.8	11.8	13.5	11.9	11.3
Mean outcome measure scores							
FIM+FAM	Motor Admission	40.1	47.7	74	47	51.8	56.9
	Motor Discharge	56.7	68.4	85.9	76.3	76	80
	Cognitive Admission	46.2	52	49.2	47.2	60.1	67.2
	Cognitive Discharge	56.4	65.2	61.2	62.2	73.7	77.9
NPDS	Admission	41.5	30.1	19.8	31.8	32.4	26.2
	Discharge	33.3	21.3	15.4	24.5	20.8	16.3
Care costs	Admission	£2056	£1593	£1263	£1502	£1635	£1371
	Discharge	£1688	£1190	£953	£1269	£1095	£865
	Saving in care costs/week	£368	£404	£310	£233	£540	£506

Parameter		Level 1				Level 2	
2016/17		**1a**	**1b**	**1c**	**1d**	**2a**	**2b**
Mean length of stay (LOS)		105	117	167	105	74	70
% patients with **LOS >180 days**		15.2%	18.5%	39.0%	17%	6.5%	5.3%
Mean waiting time (days)							
Referral to assessment		8	10	32	18.3	7	6
Assessment to admission		32	34	69	44.8	20	13
Referral to admission		39	40	84	63.1	23	18
% category A patients							
(clinical impression)		79.2%	78.0%	88.9%	52%	59.3%	29.7%
(PCAT score ≥30)		80.0%	73.9%	77.8%	73%	56.4%	36.4%
Mean RCS-s v 12 score admission		14.4	13.3	12.7	13.9	12.0	11.3
Mean outcome measure scores							
FIM+FAM	Motor Admission	36.4	43.7	61.6	50.3	52.5	57.2
	Motor Discharge	52.5	64.1	73.7	72.6	76.8	79.2
	Cognitive Admission	41.8	47.2	44.7	46.1	60.9	68.1
	Cognitive Discharge	54.6	60.3	55.7	57.9	73.5	78.3
NPDS	Admission	43.2	33.6	25.0	36.2	31.7	26.4
	Discharge	35.7	26.1	20.0	28.3	20.3	16.5
Care costs	Admission	£2210	£1785	£1402	£1747	£1589	£1438
	Discharge	£1852	£1383	£1158	£1413	£1040	£926
	Saving in care costs/week	£358	£401	£244	£334	£550	£512

Parameter		Level 1				Level 2	
2017/18		**1a**	**1b**	**1c**	**1d**	**2a**	**2b**
Mean length of stay (LOS)		100	129	167	83	74	70
% patients with **LOS >180 days**		10.9%	19.3%	27.8%	8%	6.6%	4.8%
Mean waiting time (days)							
Referral to assessment		8	9	20	15	7	6
Assessment to admission		22	34	28	34	18	12
Referral to admission		29	41	47	48	22	17
% category A patients							
(clinical impression)		92.2%	79.2%	96.6%	56%	54.6%	28.2%
(PCAT score ≥30)		86.4%	81.3%	81.4%	67%	49.1%	38.1%
Mean RCS-s v 12 score admission		14.5	13.4	12.0	13	12.0	11.6
Mean outcome measure scores							
FIM+FAM	Motor Admission	34.3	41.6	73.4	54.2	51.4	55.2
	Motor Discharge	53.5	62.4	88.3	77.7	77.0	79.1
	Cognitive Admission	40.1	46.4	48.4	49.8	58.4	67.1
	Cognitive Discharge	53.5	59.7	63.4	64.6	73.2	78.1
NPDS	Admission	46.3	35.7	17.9	36.7	32.3	26.1
	Discharge	36.3	25.9	11.3	30.6	20.4	16.4
Care costs	Admission	£2238	£1843	£1120	£1674	£1677	£1418
	Discharge	£1845	£1425	£791	£1381	£1087	£919
	Saving in care costs/week	£393	£418	£329	£293	£590	£499

Parameter	Level 1				Level 2	
2018/19	**1a**	**1b**	**1c**	**1d**	**2a**	**2b**
Mean length of stay (LOS)	98	127	129	110	79	67
% patients with **LOS >180 days**	10.5%	20.9%	22.9%	14%	6.4%	4.4%
Mean waiting time (days)						
Referral to assessment	7	7	15	15	7	10
Assessment to admission	25	33	24	44	20	14
Referral to admission	32	40	39	60	27	24
% category A patients						
(clinical impression)	84.5%	76.8%	57.8%	74%	50.5%	23.8%
(PCAT score ≥30)	80%	84.9%	78.3%	74%	49.2%	30.3%
Mean RCS-s v 12 score admission	14.2	13.9	12.8	14.2	12.8	12.0
Mean outcome measure scores						
FIM+FAM						
Motor Admission	36.2	38.5	78.6	44.3	52.8	55.7
Motor Discharge	54.3	62.3	95.0	64.1	77.7	80.0
Cognitive Admission	39.8	44.2	54.2	45.6	58.5	67.9
Cognitive Discharge	24.1	58.6	68.7	56.9	73.0	79.3
NPDS						
Admission	44.0	37.9	11.9	37.3	32.6	25.7
Discharge	33.7	27.9	6.6	33.3	19.5	16.0
Care costs						
Admission	£2193	£1958	£971	£1832	£1738	£1427
Discharge	£1774	£1479	£606	£1685	£1145	£932
Saving in care costs/week	£419	£479	£365	£147	£593	£495

Parameter		Level 1				Level 2	
2019/20		**1a**	**1b**	**1c**	**1d**	**2a**	**2b**
Mean length of stay (LOS)		99	120	112	78.3	86	65
% patients with **LOS >180 days**		13.5%	18.2%	14.9%	5%	7.1%	4.1%
Mean waiting time (days)							
Referral to assessment		7	8	11	13	10	8
Assessment to admission		21	28	17	43	21	12
Referral to admission		28	36	28	56	30.1	20
% category A patients							
(clinical impression)		85.7%	72.2%	69.3%	70%	58.4%	24.6%
(PCAT score ≥30)		85%	84.9%	70.2%	77%	55.7%	30.1%
Mean RCS-s v 12 score admission		14.2	14.1	12.6	13.6	13.3	12.0
Mean outcome measure scores							
FIM+FAM	Motor Admission	36.5	41.6	83.3	48.8	51.3	55.6
	Motor Discharge	55.6	65.5	95.4	80.4	76.5	81.2
	Cognitive Admission	41.0	48.7	58.0	45.9	56.2	67.0
	Cognitive Discharge	55.3	62.3	72.0	65.4	71.5	79.2
NPDS	Admission	44.2	35.4	11.1	33.4	34.3	26.3
	Discharge	31.4	26.0	8.9	29.3	20.1	15.3
Care costs							
	Admission	£2212	£1852	£879	£1626	£1865	£1501
	Discharge	£1625	£1479	£609	£1462	£1190	£940
	Saving in care costs/week	£587	£373	£270	£164	£675	£561

Parameter	Level 1				Level 2	
2020/21	**1a**	**1b**	**1c**	**1d**	**2a**	**2b**
Mean length of stay (LOS)	82	94	111	95	69	52
% patients with **LOS >180 days**	7.4%	3.6%	15.2%	11%	4.6%	1.7%
Mean waiting time (days)						
Referral to assessment	2	7	8	12	4	3
Assessment to admission	26	20	21	54	12	12
Referral to admission	28	27	29	66	14	14
% category A patients						
(clinical impression)	91.8%	85%	93.5%	86%	72.6%	32.5%
(PCAT score ≥30)	88.8%	83.2%	76%	89%	63.5%	42.4%
Mean RCS-s v 12 score admission	14.4	14.6	12.6	14	13.1	12.4
Mean outcome measure scores						
FIM+FAM						
Motor Admission	36.9	39.8	81.0	53.4	48.5	52.3
Motor Discharge	55.3	63.2	92.8	77.1	75.1	77.5
Cognitive Admission	41.7	46.2	57.1	49.8	58.0	67.8
Cognitive Discharge	55.5	61.7	68.1	65.9	72.4	78.0
NPDS Admission	45.5	38.0	14.1	36.2	36.3	28.4
Discharge	35.0	26.4	11.6	31.7	23.2	17.7
Care costs						
Admission	£2251	£1990	£1090	£1672	£1856	£1644
Discharge	£1854	£1463	£884	£1521	£1249	£1059
Saving in care costs/week	£397	£527	£206	£151	£607	£585

Individual unit response times and RAG rating are reported in Appendix 5.

Figure 2.3.1: Yearly trends in change scores

Figure 2.3.2: Yearly trends in the % Category A patients PCAT score ≥30 on admission

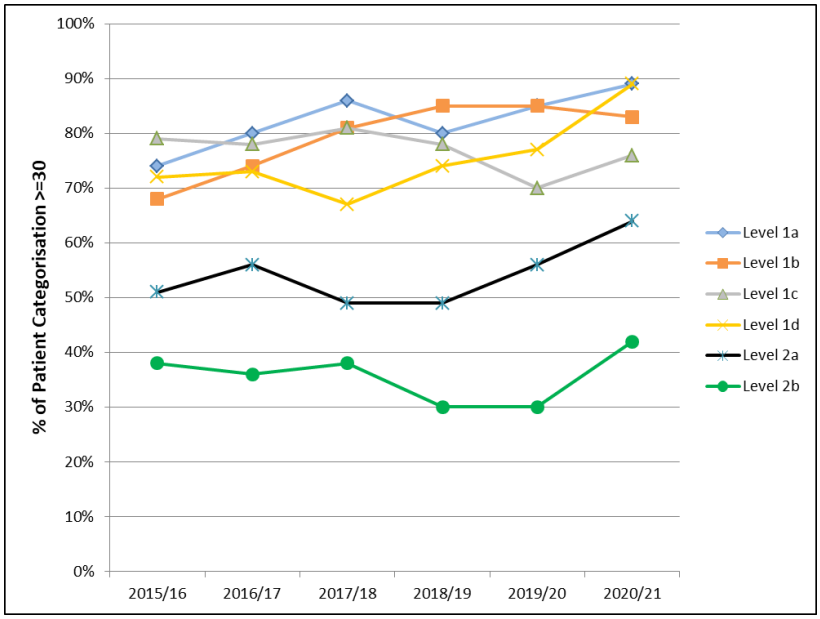


Figure 2.3.2. Illustrates an increased proportion of category A patients.

2.4 Summary of other activities

2.4.1 Registry status

During the NIHR-funded phase of its development, UK ROC collected only de-identified data.

In 2015, UK ROC was commissioned by the Healthcare Quality Improvement Partnership on behalf of NHSE to deliver the National Clinical Audit for Specialist Rehabilitation following major Injury (NCASRI). A key component of NCASRI was to link data from the UK ROC dataset to the national Trauma Audit and Research Network (TARN) database, using the NHS number, in order to track patients along their journey from the major trauma centres to the specialist rehabilitation services and to examine the outcomes and cost efficiency of rehabilitation for patients with major trauma.

Since it was commissioned by NHSE to provide the national commissioning dataset, UK ROC was mandated to provide identifiable patient level activity data to flow through to the Data Service for Commissioners Regional Offices (DSCROs) for contract and performance monitoring of the various service providers.

In addition, patients with complex disability following severe illness or injury form a vulnerable group of people for whom services are scarce. Clinical care can easily become fragmented as patients move between services (often over a wide geographical area) – and some patients literally get lost in the system.

UK ROC therefore required permission to collect and hold the NHS number for three different purposes - clinical, commissioning and audit. Working with NHS Digital, NHS England, the Health Research Authority and the Caldicott Guardians for all of the individual services who report data to UK ROC, we obtained the relevant permissions to collect the NHS number for these three purposes. Since April 2017, UK ROC collates identifiable patient data, including the NHS number, for all but four of the Level 1/2 services. This information can be used to track individual patients for clinical purposes.

2.4.2 Data linkage

Permission was obtained from the Health Research Authority Clinical Advisory Group (HRA-CAG) under Section 251 to collect and link identifiable data between TARN and UK ROC for the purpose of NCASRI. The s251 permission included linkage with datasets controlled by NHS digital, enabling linkage with the Hospital Episode Statistics (HES) and Office of National Statistics ONS) Mortality databases for the purpose of NCASRI.

Now that NCASRI has come to a close, further s251 permissions will be sought to take forward the work started by NCASRI through future data linkage with TARN and other acute datasets, eg Neurosciences.

2.4.3 Further development of the UK ROC database

The UK ROC software and database are updated periodically to take account of software upgrades within the platform (Microsoft Excel) and to add further fields as required.

Since 2015, updates have included the addition of the Mayo Portland Adaptability Inventory v4 (MPAI-4) as an optional outcome measure for those services that wish to use it.

The COVID-19 pandemic led to an increase in awareness of the need for rehabilitation for patients who are discharged from intensive care – especially those who have had prolonged stays. In 2020, the Intensive Care Society, the BSRM and UK ROC worked in partnership to form the National Post ICU Rehabilitation Collaborative which produced a framework for assessing rehabilitation needs -

https://www.ics.ac.uk/ICS/ICS/Guidelines/Framework_for_assessing_early_rehab_needs_following_ICU.aspx - that incorporated the Post ICU Presentation Screen (PICUPS) and the Rehabilitation Prescription (RP). In 2020 a variant of the UK ROC database was developed to facilitate the data collection of these tools, and a national pilot (see Section 2.4.6 below for more details). Appendix 6 provides an overview of the PICUPS dataset.

In 2020, the Royal College of Physicians published updated National Clinical Guidelines for Prolonged Disorders of Consciousness (PDOC). The guidelines recommended a national clinical registry for patients in PDOC to be held within UK ROC with associated dataset which is now being incorporated into the UK ROC software. Appendix 7 provides the proposed PDOC dataset.

2.4.4 Tariff and currency development

As part of the original Payment by Results Improvement Project, a multi-level weighted bed day currency model based on provider designation and complexity of patient need was developed to improve capacity, co-ordinate service provision and improve access to specialist rehabilitation services in England. The currency was designed to provide a fair and clearer payment approach for high cost specialised acute rehabilitation patients, but at the same time to be fair to commissioners as bed-days are paid at a lower daily rate once the patients' needs become less complex. This incentivises patient flow on to step-down and community services. The currency was mandated for use within the NHSE service specification for specialist rehabilitation since 2013/14 and published together with indicative tariff prices based on service costs in 2010/11.

In 2013/14, the NHSE Service specification D02 (*Specialised rehabilitation services for patients with highly complex needs*) set out stringent standards for delivery of tertiary services taking a selected caseload of patients with category A needs leading to a significant increase in service costs. However, 'steady-state' commissioning during the following 3 years, together with the absence of meaningful reference costs meant that roll-over of indicative prices from 2013/14 were subject to year-on-year efficiency savings without the corresponding adjustment from annually-reported service costs. As a result, in Autumn 2015 the indicative tariffs were withdrawn subject to re-evaluation of updated service cost data to re-base the prices at a level that would enable services to meet the national standards set out in the Service Specification.

Because the resulting tariffs were significantly higher, UK ROC also provided a summary of commissioning practice within the NHSE-commissioned specialised services and an impact analysis of introducing the new tariffs. This was fed back to Monitor and NHS England in December 2015. The findings showed that, despite the higher prices, there were significant savings to be made if NHSE services commissioned only the complex patients with category A patients in Level 1 and 2a services, in accordance with the specification (rather than a mixture of category A and B patients).

Further work was conducted with Monitor and NHSE between 2015-17 to update the tariffs but unfortunately was not included in the published tariffs. Following a further analysis based on the 2016/17 costs data, and working with NHS Improvement and NHSE, updated indicative tariffs were included in the 2019/20 National Tariff documentation.

Due to the suspension of usual commissioning annual updates due to the 2020 – 2021 Covid-19 pandemic outbreak, no further update on tariff prices has been submitted, but the prices have been rolled over in the 2021-2022 tariff prices.

2.4.5. Planned NHS reforms and changes in commissioning

Recent changes in commissioning and financial arrangements for NHS funded services will affect the future provision of specialist rehabilitation services.

In February 2021, legislative proposals were produced for a Health and Care Bill in the white paper named '**Integration and Innovation: working together to improve health and social care for all**'. https://www.gov.uk/government/publications/working-together-to-improve-health-and-social-care-for-all/integration-and-innovation-working-together-to-improve-health-and-social-care-for-all-html-version
The paper outlines the largest reform of the NHS in more than a decade. It builds on the NHS's 'Long Term Plan' (https://www.longtermplan.nhs.uk/) by promising closer integration health and social care, through the development of Integrated Care Systems (ICSs).

All specialised services, as prescribed in the NHSE regulations, will continue to be subject to consistent national service specifications and evidence-based policies determining treatment eligibility. NHSE will remain responsible for oversight to ensure consistency of access to specialised services across the country. However, it will devolve commissioning of the services to local ICSs. Over time, service specifications are likely to become more outcomes-focused to support innovative and flexible solutions to local circumstances.

Activity based payments through national tariffs are being replaced by block contracts using Aligned Payment Incentive Agreements https://www.england.nhs.uk/wp-content/uploads/2021/03/21-22NT_Guidance-on-aligned-payment-and-incentive-approach.pdf). Future contracts will be negotiated locally and based on local service costs obtained from patient level costing (PLICS), rather than national prices. To date, the PLICS systems do not include rehabilitation **but UK ROC provides the only source of patient level costing information and activity on which such contracts could be based.** Its role and data collection will become even more essential to support commissioning of services in the new local networks and integrated pathway systems.

Ways in which UK ROC is able to serve the developing ICS landscape

1. Each ICS Health and Care Partnership is required to develop plans to address the health needs of its population, including those in need of specialist rehabilitation. UK ROC holds a unique source of clinical and service data for all Level 1 & 2 units within England. This will be of vital importance to the correct placement of patients, measurement of outcomes, service development and commissioning
2. The Aligned Payment and Incentive Agreement (APIA) contains both a fixed and variable payment element. The fixed payment element is based on the costs of delivering a level of activity which conforms to their ICS system plan but is also expected to include funding for new ways of delivering services. UK ROC is uniquely placed to serve as it contains annual data on service costs and tariffs. The extensive UK ROC historical data would be helpful to strategise, incentivise and test new initiatives
3. The variable part of the APIA could represent many different things in future, including outcomes based commissioning, which UK ROC is uniquely placed to both advise on and capture
4. ICSs will now have the responsibility to plan for a person's entire recovery path, through both NHS and local government services. Analyses of the UK ROC dataset have demonstrated the substantial cost savings that accrue when specialist rehabilitation is given to a patient as early as possible and the flow-on savings in life-time care after discharge into the community
5. Specialised services will continue to be subject to consistent national service specifications and evidence-based policies determining treatment eligibility. UK ROC is a unique resource for the

continued evidence-based development of both national service specifications and ICS sub-specifications

6. By its nature, specialised rehabilitation is a highly specialised service portfolio, and therefore is likely to continue to be planned and commissioned on a national footprint. UK ROC data and extensive national service knowledge will be critical in the guidance of commissioning policy
7. As an established clinical and provider collaborative, UK ROC is uniquely placed to drive quality improvement, service change and transformation across specialised rehabilitation
8. Some current UK ROC data functions are:
    a. to determine eligibility for specialist rehabilitation and complex rehabilitation needs
    b. to manage waiting lists and monitor response times
    c. to measure demand and capacity
    d. for quality and benchmarking – performance against the service specification quality indicators and national comparisons
    e. for assuring data quality
9. The UK ROC team is in the process of developing a series of ICS-specific reports to help the ICS lead commissioners for rehabilitation services to understand the specialist Level 1 and 2 rehabilitation activity that they have been commissioning in the years running up to transition.

2.4.6 Research and audit activity

Key projects and publications

The UK ROC programme has always been based on high quality research published in peer-reviewed journals.

The proof of principle studies commenced back in the 1990s, with the agreement of the UK Rehabilitation Services to work towards collection of a common set of outcome measures - a principle that has been supported from the outset by the British Society of Rehabilitation Medicine (BSRM).

All the tools in the UK ROC dataset have been subjected to rigorous psychometric evaluation to establish their measurement properties. The under-pinning publications are summarised in Appendix 8.

Since the end of the NIHR-funded programme, we have continued to use the large UK ROC dataset for further validation of tools in different subsets of patients, using modern psychometric approaches, including Rasch analysis.

Many of the tools have been taken up in countries outside of the UK. In addition to the published papers, pages 76-80 also includes a list of national and international lectures and conferences abstracts since 2015.

Key recent publications since 2015 have used this large national multicentre cohort to demonstrate the cost-effectiveness of rehabilitation in different groups of patients (Acquired brain injury, spinal cord injury, peripheral neurological conditions (eg Guillain Barre syndrome) and progressive neurological conditions) [9, 11, 20, 21].

These findings consistently demonstrate that the cost of specialist inpatient rehabilitation is generally offset within about 18 months. Patients who are more dependent on admission are generally the most cost-efficient to treat, despite their longer lengths of stay. This is important as many of these individuals would not meet the criteria for admission to in-patient rehabilitation programmes in countries such as the US and Australia.

Despite their shorter life-expectancy, this most disabled group of patients still generated life-time savings of over 2/3 of a £million per patient. Our recent population-based analysis of patients with severe brain injury demonstrated total cost savings in excess of £4bn for population of patients with TBI requiring specialist rehabilitation, making this one of the most cost-effective treatments available within the NHS [24].

The Post ICU Presentation Screen (PICUPS) and Rehabilitation Prescription (RP) – a national pilot

As noted above, the PICUPS was developed by a multi-professional group brought together through the National Post ICU Rehabilitation Collaborative as a tool to assess rehabilitation needs for patients post discharge from Intensive Care Units (ICU). Due to lockdown and social distancing measures, webinars were conducted to provide awareness and training to wider professional community.

- The basic PICUPS is a simple 14-item clinical tool developed to support triage and handover of patients stepping down from ICU into the acute wards, and onwards into rehabilitation.
- The PICUPS Plus represents 10 additional items to identify potential higher-level items that may need to be addressed as the patient progresses during acute care.
- Together they inform the development of an individualised RP – a person-centred tool that travels with the patient, setting out their rehabilitation needs and the plans to provide for them. The associated data collection is designed to record how well these needs are met and to link with other datasets.

A national pilot across 26 ICUs and acute wards in July-August 2020 led to the two publications. The first showed the PICUPS to be a valid and psychometrically robust tool [22] that is clinically useful to assist with decision-making and triggering referral to the various disciplines, who should be involved. The second demonstrated its utility for identifying unmet needs in order to make the case for improved rehabilitation for patients discharged from ICU [23]. The piloting and ongoing development is led by the Intensive Care Society and British Society of Rehabilitation Medicine and UK ROC on behalf of the National Post ICU Rehabilitation Collaborative https://www.england.nhs.uk/wp-content/uploads/2021/03/21-22NT_Guidance-on-aligned-payment-and-incentive-approach.pdf. Data is being collected and collated by UK ROC.

An extended national pilot started in December 2020 and is still ongoing. The aim is to encourage all ICUs in the UK to be using the PICUPS and Rehabilitation Prescription (RP) routinely for all patients (COVID-19 and non-COVID) and to submit data to UK ROC.

The impact of the COVID-19 pandemic within Specialist Rehabilitation Services was unclear; therefore a survey was conducted by UK ROC on behalf of the British Society of Rehabilitation Medicine (BSRM) (report available as an electronic appendix).

List of collaborators

Whilst several countries (notably Denmark, Spain, Italy and Brazil) have requested access to the UK ROC tools to use in the context of their own health services, our principal research collaborators are with teams in the US, Australia and New Zealand. Key collaborators include those listed in Table 2.4.1 below.

Table 2.4.1: Key collaborators and projects 2015-2021

Country and organisation	Lead collaborator and organisation	Project
Australia University of Melbourne	Prof Fary Kan	Cochrane reviews of the effectiveness of rehabilitation in various conditions
Australia University of Wollongong	Prof Kathy Eagar Australasian Rehabilitation Outcomes Centre (AROC)	Comparative evaluation of outcomes between the Australasian and UK national databases [Appendix 8, pg 77]
Australia La Trobe University, Melbourne	Prof Natasha Lannin The Alfred Hospital, Caulfield,	Use of the UK ROC tools for the prospective evaluation of an acquired brain injury rehabilitation service in Melbourne [Appendix 8, pg 81]
Australia University of Western Australia	Prof Barby Singer	Use of the UK ROC tools (including GAS) for the prospective evaluation of acquired brain injury rehabilitation services in hospital and community [Appendix 8, pg 77]
Australia Brightwater Rehabilitation services	Janet Wagland Dr Angelita Martini	Use of the UK ROC tools for the prospective evaluation of a community acquired brain injury rehabilitation service in Perth [Appendix 8, pg 77]
New Zealand Auckland University of Technology	Prof Richard Siegert	Further psychometric evaluation of UK ROC tools and data in different subsets using modern techniques eg Rasch analysis [Appendix 8, pg 73]
New Zealand Auckland University of Technology	Prof Richard Siegert Prof Ajit Narayanan	Exploration of Machine Learning techniques to identify the best predictors of length of stay in tertiary specialist rehabilitation within the UK ROC database
United States The US Life expectancy Project, California.	Dr Robert Shavelle Dr Jordan Brooks Prof David Strauss	Analysis of functional outcome and mortality data to determine life expectancy in different groups of patients with acquired brain injury and to use the data to estimate life-time savings in the cost of care [Appendix 8, pg 77]

2.4.7 Data requests

Table 2.4.2 below summarises the requests for access to UK ROC data for specific analyses during the 6-year period.

Table 2.4.2 Requests for access to UK ROC data for specific analyses

Country and organisation	Lead collaborator and organisation	Project
UK – NHSE London	Mike Millen	Data from the London services for evaluation of waiting times and discharge delays for the purpose of capacity planning
New Zealand Auckland University of Technology	Prof Richard Siegert Dr Oleg Medvedev Lynne Turner-Stokes	Data for psychometric analysis of the FIM+FAM and PCAT tools
UK – Healthcare Quality Improvement Partnership (HQIP)	The Trauma Audit Research Network (TARN)	Data linkage between TARN and UK ROC for the National Clinical Audit of Specialist Rehabilitation following major Injury (NCASRI)
UK – University of Warwick	Prof Diane Playford Dr Bilal Mateen	Predictive modelling to anticipate outcome from in-patient rehabilitation outcome (Discharge Barthel/FIM+FAM Score) using the standard set of admission data collected by UK ROC centres

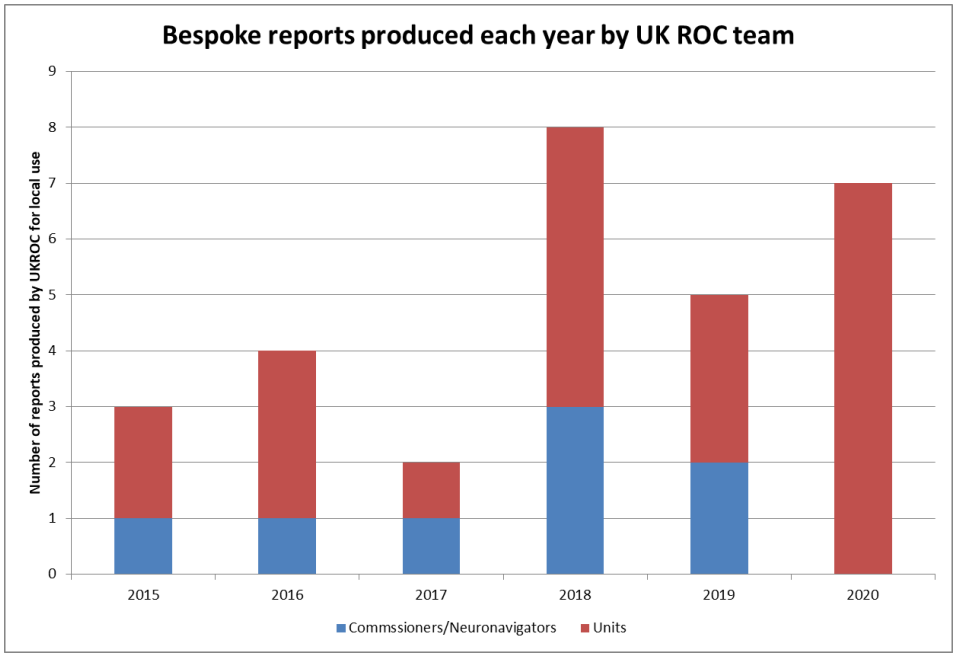
New Zealand Auckland University of Technology	Prof Richard Siegert Prof Ajit Narayanan Lynne Turner-Stokes	Exploration of Machine Learning techniques to identify the best predictors of length of stay in tertiary specialist rehabilitation within the UK ROC database
UK- University of Warwick – the Turing Study group NICE	Prof Diane Playford	Analysis of outcomes and cost efficiency from specialist rehabilitation in stroke patients
UK - British Society of Rehabilitation Medicine (BSRM)	Dr Ajoy Nair Lynne Turner-Stokes	Analysis of datasets to establish number and percentage of patient episodes with spinal cord injuries within Level 1 and Level 2 rehab units
London NHSE and ICS commissioners	Priscillar Batana Victoria Osbourne Smith	A series of bespoke reports for the 5 London ICS sectors to describe the Level 1 and 2 rehabilitation activity commissioned by, and provided within) each sector/ providers for the London Region to support transition of commissioning from NHSE to ICSs

2.4.8 Analysis and report requests from UK ROC participating sites

Figure 2.4.1 summarises the number of specific analyses and/or reports produced by the UK ROC team following requests from participating UK ROC sites during the 6-year period. There has been a steady increase in the number of requests year on year.

The unit reports generally reviewed assessments and identification of any trends. Commissioner reports were focussed on discharge destinations and/or delayed transfers of care in addition to patient categorisation and CCG information.

Figure 2.4.1 Reports produced by UK ROC for participating sites and commissioners



2.4.9 Training courses

Table 2.4.3 below summarises the training course provided in the last 6 years.

Table 2.4.3 Training courses provided by the UK ROC team 2015-2021

Month Year	Course	Topic	Number of attendees
February 2015	UK FIM+FAM Training day	How to score the FIM+FAM items/ interpret outputs	17
February 2015	UK ROC Data entry training	How to use UK ROC software/interpret monthly/quarterly reports	7
April 2015	Outcome Measure training	How to score RCS, NPDS & NPTDA	29
April 2015	UK ROC Data entry training	How to use UK ROC software/interpret monthly/quarterly reports	7
December 2015	UK ROC Data entry training	How to use UK ROC software/interpret monthly/quarterly reports	14
January 2016	Goal Attainment Scaling	Setting GAS goals and interpretation of T-Score	13
February 2016	UK FIM+FAM Training	How to score the FIM+FAM items/ interpret outputs	43
April 2016	Outcome Measure training	How to score RCS, NPDS & NPTDA	38
May 2016	UK ROC Data entry training	How to use UK ROC software/interpret monthly/quarterly reports	9
September 2016	Prolonged disorder of Consciousness training (PDOC)	Management of patients in PDOC and use of assessment tools (WHIM/CRS-R)	29
October 2016	UK ROC Data entry training	How to use UK ROC software/interpret monthly/quarterly reports	5
November 2016	UK ROC Data entry training	How to use UK ROC software/interpret monthly/quarterly reports	6
January 2017	Goal Attainment Scaling	Setting GAS goals and interpretation of T-Score	23
March 2017	Outcome Measure training	How to score RCS, NPDS & NPTDA	33
April 2017	UK ROC Data entry training	How to use UK ROC software/interpret monthly/quarterly reports	5
April 2017	UK FIM+FAM Training	How to score the FIM+FAM items/ interpret outputs	44
September 2017	Prolonged disorder of Consciousness training (PDOC)	Management of patients in PDOC and use of assessment tools (WHIM/CRS-R)	35
February 2018	Goal Attainment Scaling	Setting GAS goals and interpretation of T-Score	26
March 2018	Outcome Measure training	How to score RCS, NPDS & NPTDA	29
May 2018	UK ROC Data entry training	How to use UK ROC software/interpret monthly/quarterly reports	8
May 2018	UK FIM+FAM Training	How to score the FIM+FAM items/ interpret outputs	39

Month Year	Course	Topic	Number of attendees
September 2018	Prolonged disorder of Consciousness training (PDOC)	Management of patients in PDOC and use of assessment tools (WHIM/CRS-R)	45
October 2018	UK ROC Data entry training	How to use UK ROC software/interpret monthly/quarterly reports	8
November 2018	UK FIM+FAM Training (Aberdeen)	How to score the FIM+FAM items/ interpret outputs	24
December 2018	UK ROC Data entry training	How to use UK ROC software/interpret monthly/quarterly reports	8
January 2019	UK ROC Data entry training	How to use UK ROC software/interpret monthly/quarterly reports	8
February 2019	Goal Attainment Scaling	Setting GAS goals and interpretation of T-Score	16
April 2019	UK FIM+FAM Training	How to score the FIM+FAM items/ interpret outputs	37
May 2019	Outcome Measure training	How to score RCS, NPDS & NPTDA	33
February 2020	Goal Attainment Scaling	Setting GAS goals and interpretation of T-Score	15

From March 2020 onwards teaching was carried out virtually due to outbreak of the COVID-19.

October 2020	Prolonged disorder of Consciousness training (PDOC)	Management of patients in PDOC and use of assessment tools (WHIM/CRS-R)	115
May 2021	UK FIM+FAM Training	How to score the FIM+FAM items/ interpret outputs	46
June 2021	Prolonged disorder of Consciousness training (PDOC)	Management of patients in PDOC and use of assessment tools (WHIM/CRS-R)	38
June 2021	Outcome Measure training	How to score RCS, NPDS & NPTDA	60

Self-learning materials were provided on King's College London website:

(as at the time of compiling this report the below links are valid. However, we are aware that Kings College is undertaking a major review of web content and therefore the links may change. We apologise for any inconvenience that this may cause. Please do not hesitate to email UK ROC (LNWH-tr.ukroc@nhs.net) should you need help in accessing the below)

Patient Categorisation Tool:
https://www.kcl.ac.uk/cicelysaunders/resources/tools/pcat-patient-categorisation-tool

FIM + FAM:
https://www.kcl.ac.uk/cicelysaunders/resources/tools/fimfam

Goal Attainment Scaling:
https://www.kcl.ac.uk/cicelysaunders/resources/tools/gas

Nursing Dependency Scale:
https://www.kcl.ac.uk/cicelysaunders/resources/tools/npds

Therapy Dependency Assessment: Nursing Dependency Scale:
https://www.kcl.ac.uk/cicelysaunders/resources/tools/npds

2.4.10 Support requests

Requests for support to the UK ROC team include:

From Service providers:

- UK ROC Software
    - From Service Providers wanting to know how to extract and analyse their data
- Training requests
    - Bespoke local training to teams
    - Annual training provided at Northwick Park Hospital
    - Questions on how to score tools in specific circumstances "what if…." scenarios

From Commissioners and service planners

- Reference costs
    - Enquiries from both Providers and Commissioners. Providers often looking for guidance for business cases to their Trust's re expansion of services, and/or current funding for staffing and proposed changes. NHSE London looking at capacity planning.
- Provision of data
- Bespoke reports / analysis

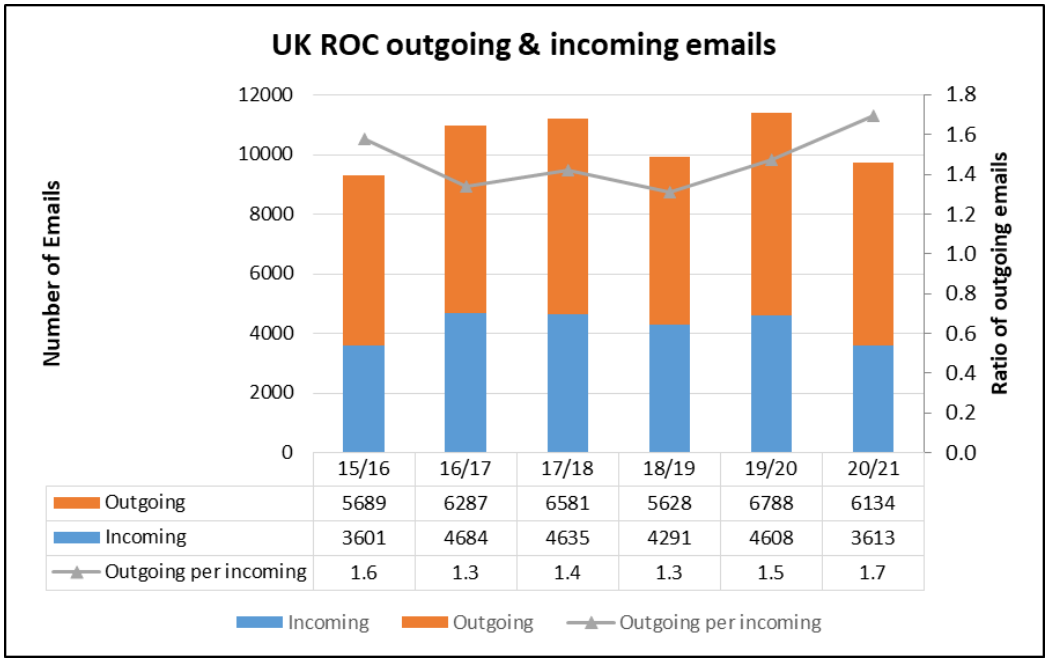
Data access

- Data access requests
- Shared data
- Approval of use of data for specific analysis
    - Enquiries from both Providers and Commissioners. Eg KPMG Stamford Hall Report; Frenchay marketing analysis for website and brochure
    - Local evaluation of service
    - Understanding of level 1 & 2 services within England

Email correspondence
Most information requests are via email although during the COVID-19 period MS Teams provided a face-to-face approach if required.

The number of emails received each year is between 3,600 - 4,600. Figure 2.4.2.

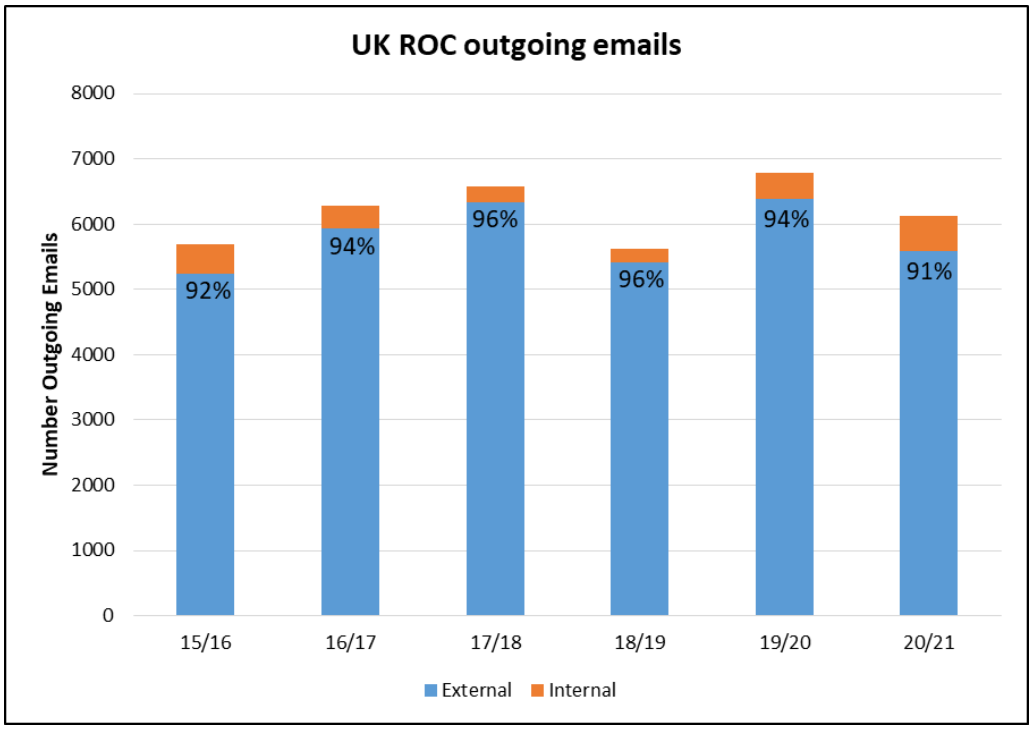
Figure 2.4.2 Outgoing and incoming emails to UK ROC



	15/16	16/17	17/18	18/19	19/20	20/21
Outgoing	5689	6287	6581	5628	6788	6134
Incoming	3601	4684	4635	4291	4608	3613
Outgoing per incoming	1.6	1.3	1.4	1.3	1.5	1.7

The largest proportion of sent emails (more than 90% each year) is to external services. Figure 2.4.3.

Figure 2.4.3 Proportion of external and internal emails sent by UK ROC



Other

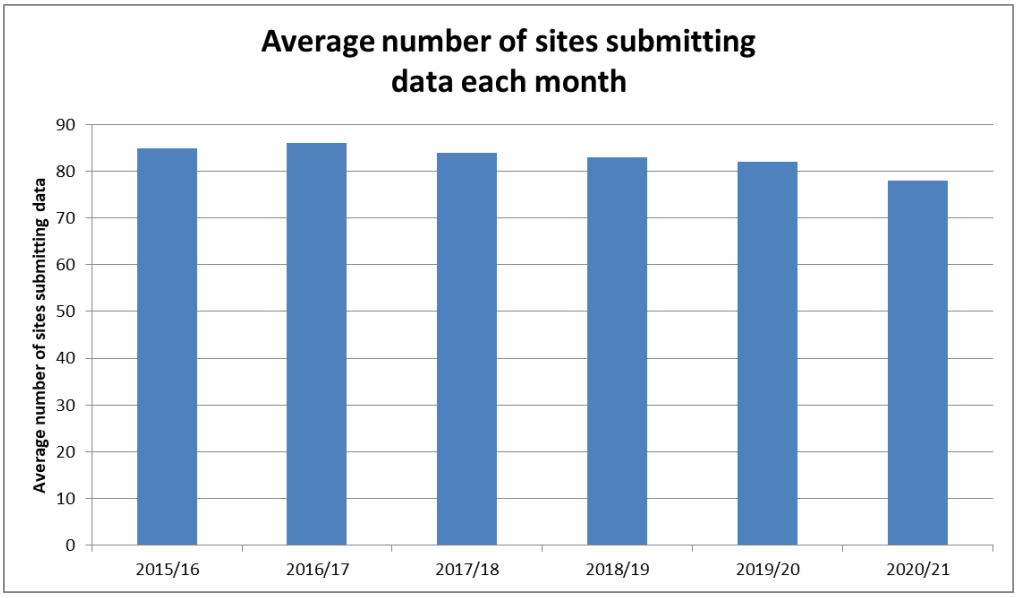
- Permission for translating tools
    - Initial contacts and requests to check back translation
    - NPDS - Chinese
    - RCS-E - Korean, Norwegian, Danish, Portuguese, & Swedish
    - GAS - Turkish

- Freedom of information requests
    - Consultancy companies researching possible areas to develop expertise in for clients

2.4.11 Participating site submissions

Sites registered with UK ROC are requested to submit data on a monthly basis. During this 6-year period there has been an average of 84 sites submitting data (this includes all service levels including specialist care homes).

Figure 2.4.4 Average number of sites submitting data per year



There has been a slight decrease in the number of sites submitting data in 2020/2021 due to the impact of COVID-19 leading to re-distribution of services.

During this 6-year period, 12 new sites have commenced data submissions. However, 20 services stopped data submission during this 6-year period, 6 of which were Level 2b services.

The COVID-19 pandemic in 2020/21 resulted in specialist rehabilitation units reviewing their services and admission policy and for some this resulted in a period of bed and/or unit closure. Whilst most units gradually increased their bed capacity following the first wave of the pandemic, 2 Level 2b services have not re-commenced data submissions.

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Appendix 1: UK ROC dataset – list of current data items

UK ROC is a hierarchical database, in which different service levels have different reporting requirements. Level 1 (tertiary) services are low volume high cost services which warrant a more exhaustive set of data requirements than the higher volume lower cost Level 2 (local) specialist services. The table below summarises the minimum data reporting requirements for each service level.

UK ROC Minimum Data Reporting Requirements Checklist – 2020/21						
Items	**Service Level** (actual or					**Notes**
	1*	**2a***	**2b***	**2b**	**Other**	* using weighted bed day tariff
Patient Identification & Demographics						
Patient Name	✓	✓	✓	✓	✓	local use only
Date of Birth	✓	✓	✓	✓	✓	age calculations & data linkage
Gender	✓	✓	✓	✓	✓	
Ethnicity						local use only (mandatory from April 2021)
Local Identifier						local use only
Hospital Number						local use only
NHS Number	✓	✓	✓	✓	✓	data linkage
Commissioning & Referral						
Funding Source (NHS England, CCG, private etc)	✓	✓	✓	✓	✓	
Service Level (1, 2a, 2b, 3)	✓	✓	○	○	○	if commissioned at several levels
Patient Category (a, b, c, d)	✓	✓	✓	✓	○	
CCG name or code	✓	✓	✓	✓	✓	
GP Practice name, code and/or postcode	?	?	?	?	?	may be required by commissioners
GP name and/or code	?	?	?	?	?	may be required by commissioners
Patient postcode	○	○	○	○	○	1st part is included in submission
Referral date	✓	✓	○	○	○	
Referral source	✓	✓	○	○	○	
Date of decision (added to active waiting list)	✓	✓	○	○	○	
Date fit for admission	✓	✓	○	○	○	
Initial Assessment						
Date of initial assessment	✓	✓	○	○	○	
Assessed by (uni/multi-disciplinary)	✓	✓	○	○	○	
Diagnosis						
Onset date (original and/or current)	✓	✓	○	○	○	
Diagnosis category/subcategory	✓	✓	✓	✓	✓	
ICD 10 codes						optional
Admission Details						
Date of admission	✓	✓	✓	✓	✓	
Proposed discharge date	✓	✓	○	○	○	
Proposed trimpoint date						
Admitted from	✓	✓	○	○	○	
Admission purpose	✓	✓	○	○	○	
Interruptions & Extensions						
Interruptions (start & end date, reason)	✓	✓	✓	✓	○	
Extension date	✓	✓	✓	✓	○	
Discharge Details						
Date fit for discharge	✓	✓	○	○	○	
Discharge date	✓	✓	✓	✓	✓	
Reason for delay	✓	✓	○	○	○	
Discharge mode	✓	✓	○	○	○	
Discharge destination	✓	✓	○	○	○	
Discharge postcode						1st part is included in submission
Admission & Discharge Assessments (all assessments should be submitted with fully itemised scores)						
Patient Categorisation Tool (on admission)	✓	✓	✓	✓	○	complexity measure
RCS-E version 13 – scored retrospectively	✓	✓	✓	✓	✓	complexity measure
FIM+FAM (including NIS)	✓	✓	✓	✓	○	outcome measure
NPDS-H (used to demonstrate cost efficiency)	✓	✓	✓	✓	○	outcome measure
Barthel or FIM+FAM or FIM or NPDS-H/NPCNA					✓	outcome measure
Mayo-Portland Adaptability Inventory (MPAI-4)						outcome measure
Fortnightly Assessments (scored retrospectively for all patients throughout the year based on what was provided)						
RCS-E version 13	✓	✓	✓	○	○	complexity/inputs measure
Cross-Sectional Data Tranches (all assessments should be scored retrospectively based on what was actually provided)						
Collected fortnightly for ALL patients until at least 100 sets of matching assessments have been completed						
Matching RCS-E, NPDS-H/NPCNA & NPTDA	✓	✓	✓	○	○	complexity/inputs measures
RCS-E version 13				✓	✓	complexity/inputs measure
Data Submission Frequency						
Monthly (including all current inpatients)	✓	✓	✓	✓		
Optional – no requirement to participate					✓	ideally submitted monthly
Other (submitted annually and following any significant changes to service)						
Service Profile	✓	✓	✓	✓	✓	including staffing levels and costs
○ level 2b & other services are strongly encouraged to submit these items even though they are not currently mandatory.						

Appendix 2 - Exemplar Quarterly Core Standard Report

Exemplar Quarterly Core Standards Report

UK ROC Summary - 2020/21 month 12

C000: XYZ Rehabilitation Service

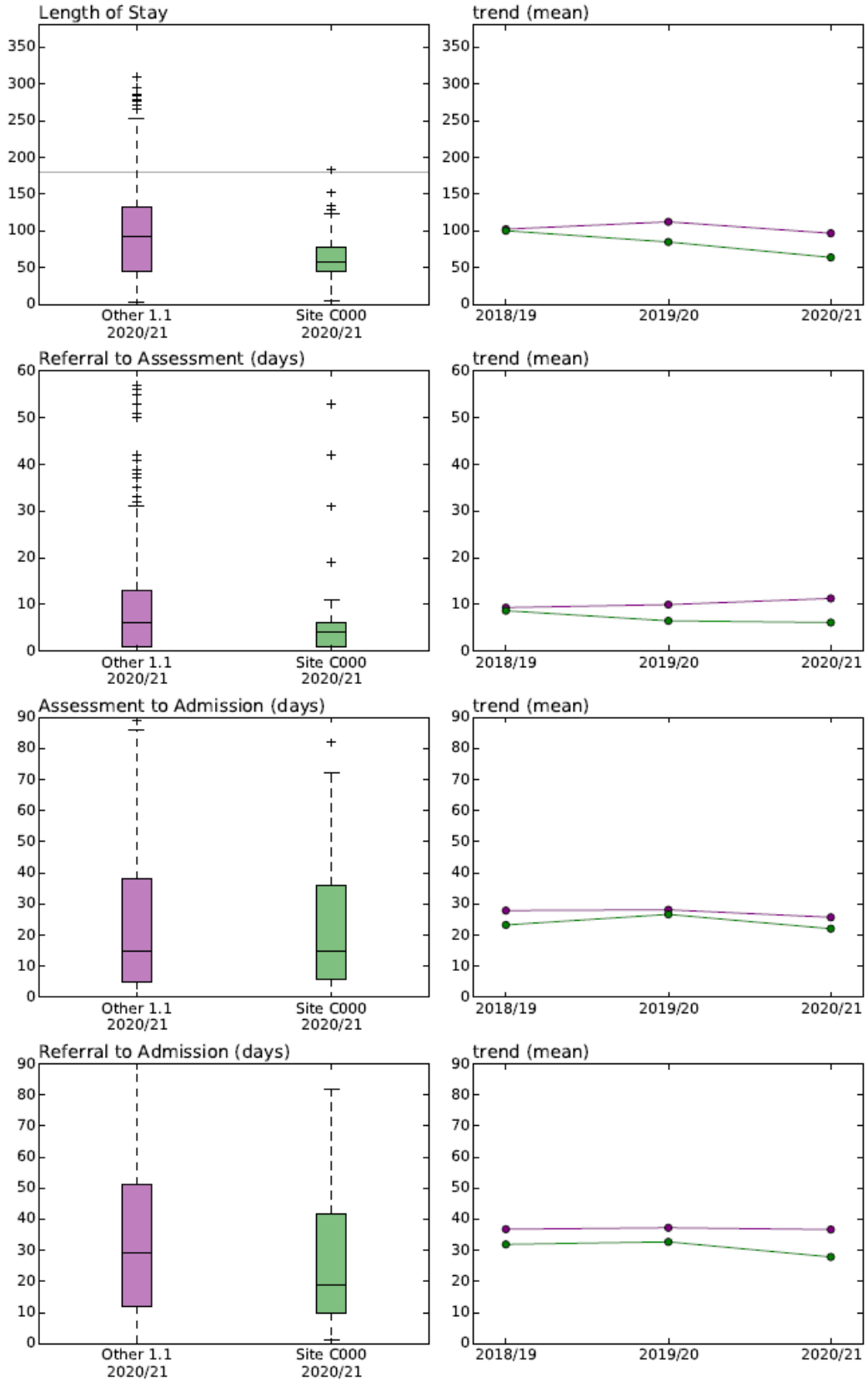
Service Class	1.1
Reference Group	other 1.1 services
Latest data submission	10/08/2021

Figures from February 2020 onwards may be affected by changes to services and a temporary reduction to minimum data reporting requirements made in response to COVID-19

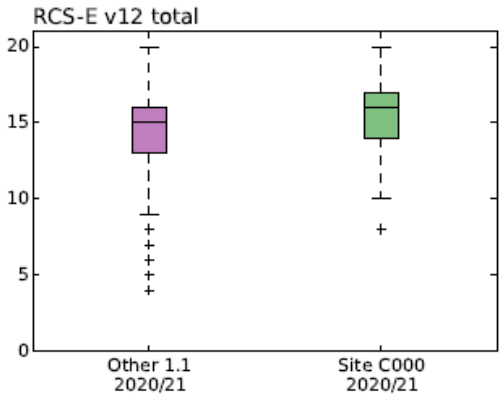
	Other 1.1				Site C000			
	2018/19	2019/20	2020/21	Total	2018/19	2019/20	2020/21	Total
Number of Admissions	408	394	433	1235	83	110	94	287
Number of Discharges	410	398	425	1233	83	114	90	287
Activity Figures								
Number of months	12	12	12		12	12	12	
% OBDs banded	98%	97%	82%		100%	100%	100%	
Unweighted OBDs					8732	8838	6444	
Weighted OBDs					13928	13954	10061	
Episode Length								
Mean length of stay (nights)	103	113	97	104	100	85	64	83
% episodes > 180 days	10.5%	16.3%	8.9%	11.8%	3.6%	0.9%	1.1%	1.7%
Response times (days)								
% referral date reported	99%	99%	100%	100%	100%	100%	100%	100%
Mean referral to assessment	9	10	11	10	9	6	6	7
Mean assessment to admission	28	28	26	27	23	27	22	24
Mean referral to admission	37	37	37	37	32	33	28	31
Patient Categorisation								
% reported	95%	94%	79%	89%	100%	100%	100%	100%
% admissions for cat. A (clinical impression)	87.3%	88.3%	92.6%	89.3%	100.0%	100.0%	92.6%	97.6%
% WOBDs for patients in category A	93.6%	91.7%	95.0%		100.0%	100.0%	94.5%	
% total ≥ 30	88.1%	86.2%	87.9%	87.4%	100.0%	99.1%	96.8%	98.6%
% WOBDs for patients with PCAT total ≥ 30	92.6%	92.4%	91.3%		100.0%	99.9%	99.1%	
Complexity (serial RCS-E scores)								
RCS-E v12 score (mean)	14.2	14.4	14.5	14.3	15.9	15.7	15.5	15.7
% High/Very High assessments	91.5%	94.8%	94.6%	93.6%	99.6%	99.9%	99.7%	99.7%
Functional gain (FIM+FAM scores)								
% reported	99%	89%	78%	88%	96%	91%	61%	83%
Motor score on admission (mean)	37.8	35.8	34.7	36.2	23.9	25.1	19.9	23.5
Motor score on discharge (mean)	54.5	52.6	50.3	52.6	38.1	40.4	32.4	37.8
Motor gain during episode (mean)	16.7	16.9	15.6	16.4	14.3	15.3	12.6	14.3
Cognitive score on admission (mean)	40.3	40.2	40.5	40.4	32.8	31.9	27.6	31.2
Cognitive score on discharge (mean)	53.4	52.5	51.0	52.4	42.6	40.2	39.1	40.8
Cognitive gain during episode (mean)	13.1	12.3	10.5	12.0	9.8	8.3	11.5	9.6
FIM+FAM efficiency (median)	**0.2**	**0.2**	**0.2**	**0.2**	**0.1**	**0.1**	**0.1**	**0.1**
FIM+FAM efficiency (pop. mean)	**0.3**	**0.3**	**0.3**	**0.3**	**0.2**	**0.3**	**0.4**	**0.3**
Reduction in cost of ongoing care								
% reported (optional)	94%	90%	67%	83%	100%	100%	100%	100%
Mean NPCNA cost/week on admission	£2153	£2267	£2235	£2215	£2383	£2378	£2557	£2436
Mean NPCNA cost/week on discharge	£1717	£1629	£1904	£1738	£1918	£1869	£2217	£1992
Mean saving in cost/week	£435	£637	£331	£477	£465	£509	£340	£443
NPCNA cost efficiency index (median)	**1.2**	**4.4**	**1.0**	**2.2**	**3.3**	**4.3**	**2.7**	**3.4**
NPCNA cost efficiency index (pop. mean)	**4.2**	**5.7**	**3.4**	**4.6**	**4.6**	**6.0**	**5.3**	**5.3**

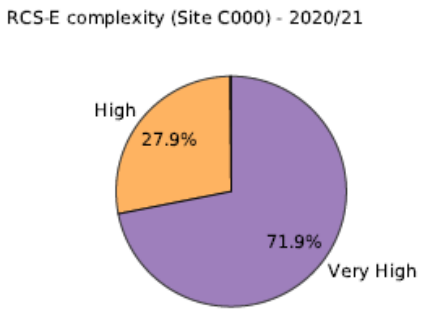
Please note... the raw data used to generate these reports is still in the process of being cleaned.

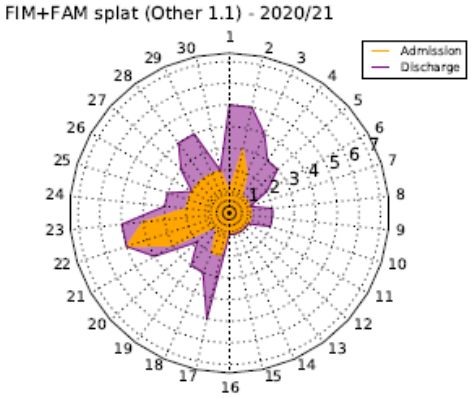
C000: XYZ Rehabilitation Service

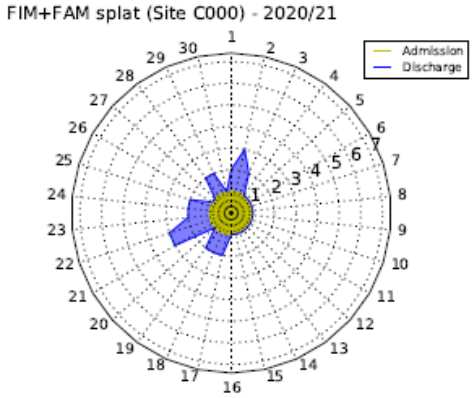


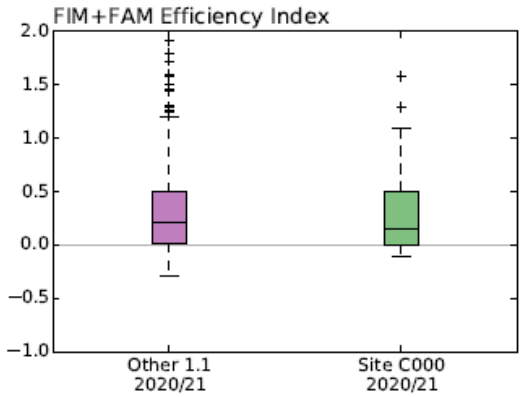
C000: XYZ Rehabilitation Service

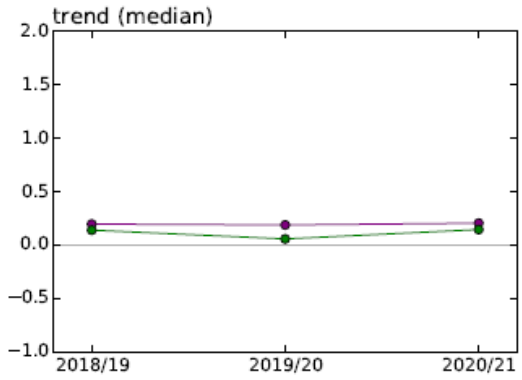


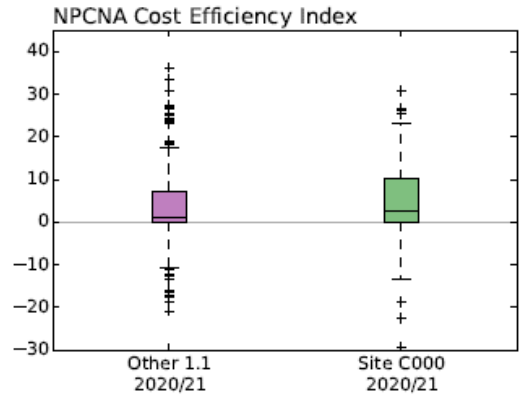


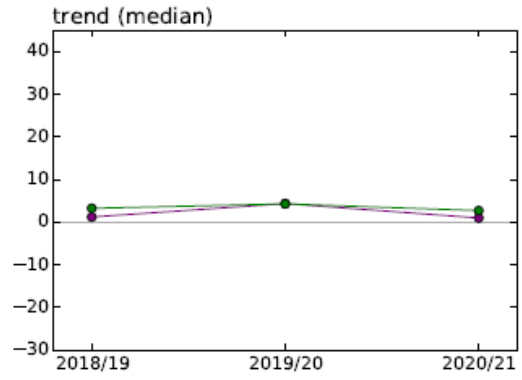












Appendix 3 - Exemplar bench-marking reports

Exemplar Sign-posting Comparison Table

Comparisons Table For:		C000	XYZ Rehabilitation Service								
Current Level:			1a								[Commissioning Region]
Level based on 18/19 data:			1a			Your Service Data					
Service aspiration:			1a								
							No. of Beds at start of year (information from Provider):				16.0
Mean	HA	1a	1b	2a	2b		No. of Beds at end of year (information from Provider):				16.0
[ver 1617]	Mean	Mean	Mean	Mean	Mean		Average Bed Base pa:				16.0
							18/19				
Staffing WTE/OB's pa							WTEs	Calculated OB's / pa	15.6		
Therapy	1.4	1.2	1.0	0.8	0.8	1.3	19.5	Reported OBDs	5,692	ie 97.5% occupancy	
Nursing/care	3.0	2.3	2.1	2.0	1.9	2.2	34.8	Weighted OBDs	8,821		
Medical	0.4	0.2	0.2	0.2	0.2	0.3	4.5	Cost excl MFF	£3,504,832		
Total	4.8	3.6	3.3	3.1	2.9	3.8	58.8	MFF%	18.29%		
Weighted Cost per OBD	£436	£344	£318	£345	£348	£361					
Cost per OBD	£774	£561	£479	£443	£426	£592	Mean Cost per OBD based on the number of OBD's as reported through UKROC (ie excluding >180 days)				
Dependency (hours) -E							No. records				
NPTDA	24.7	21.6	20.0	18.6	18.3	25.7	384				
NPDS	59.5	52.6	52.1	43.1	41.4	50.1	384				
Total	84.2	74.2	72.1	61.7	59.7	75.8					
Complexity											
RCS-Ev12	17.2	14.2	13.5	12.0	11.4	14.6	384				
%RCS: 11-20	99.6%	95.0%	87.8%	68.2%	59.9%	92.5%					
						92.5%	RCS 11-20% excluding the unbanded.		Average LOS (180 days or less)		93
						0.6%	% of Total OBDs that are > 180		Average LOS (all)		116

Therapy Hrs	
400.9	Per week total Therapy hrs (based on reported NPTDA hrs)
20.6	ie at this rate, each therapist is being recorded as putting in 20.6hrs / week actual therapy time with patients
54.8%	Therefore for this NPTDA Mean of 25.7 to be a true reflection of therapy hrs it would mean that 54.8% of each therapists time would be patient contact time

Nursing Hrs	
781.3	Per week total Nursing hrs (based on reported NPDS hrs)
22.5	ie at this rate, each Nurse is being recorded as putting in 22.5hrs / week actual therapy time with patients
59.9%	Therefore for this NPDS Mean of 50.1 to be a true reflection of nursing hrs it would mean that 59.9% of each Nurses' time would be patient contact time

Patient Categorisation:	By Itemised PCAT				By Clinical Impression		
	% of Admissions by PCAT total [Level 1 - 80%]		% of OBD's by PCAT total [Level 1 - 92%]		Admissions by category		
	% >= 30	% < 30	% >= 30	% < 30	% Cat A	% Cat B,C,D	Number Adms
	95.7%	4.3%	97.0%	3.0%	97.9%	2.1%	95

Sign-posting methodology

Because of the small number of highly diverse services within any given level, the usual approaches to statistical case-mix analysis are not appropriate. Instead sign-posting is done by:

- Individual service matching across multiple parameters including
  - Measures of needs, inputs and outcomes
  - Staffing and facilities
  - Catchment and commissioning base
- Feedback and discussion with the provider and commissioner for each service.

Data for service matching

UK ROC registered services are requested to provide a 'Service profile', which is updated annually. This includes information about facilities and equipment, the WTE of staff in each grade and the total pay budget, which is used for costing(10, 11).

Each unit is also asked to provide at least 100 sets of cross-sectional snapshot data per year to provide parallel data on

- Complexity (RCS-E)
- Nursing Dependency (NPDS/NPCNA) - to derive nursing and care hours
- Therapy Dependency (NPTDA) to derive therapy hours.

Means from these cross-sectional data on complexity and staff hours are collated alongside information from the service profiles on staffing in a comparison table for each service that includes:

a) Data for the given service;
- Staffing (therapy, nursing and medical) in WTE per bed
- Inputs - Mean estimated Nursing and therapy hours of direct patient contact time
  - (Expected to be 60-70% of total staff time from WTEs)
- Complexity – Mean RCS-E
- % category A patients (derived from Patient Categorisation data on admission)
- Total catchment population

b) The national means for each service level – (derived by excluding the outliers and using boot-strapping where data are skewed).

An exemplar comparison table is shown above. Sometimes a service will be finely balanced between two levels. This has particularly been the case for Level 1b and 2a services. In these cases, UK ROC provides more detailed comparison with both levels to help inform the discussions.

Sign-posting is conducted against a moving background as service profiles change to meet changes in caseload complexity and as services are reallocated to different levels.

At the start of NHSE commissioning from 2013/14, the original service designation was conducted in 2012 through an iterative sign-posting process as described above.
- After matching and re-allocation following discussion with providers and commissioners, the means were recalculated for each service level.
- The final designation of services to their respective service levels was signed off by the CRG for Specialist Rehabilitation.

These groupings were used to calculate mean service costs and to derive the weighting factors for complexity that form the basis for the weighted bed day tariffs.

The tariffs were rebased to update the non-mandatory prices for 2019/20. In 2017/18 UK ROC was asked to provide re-basing of service costs centred on the 2016/17 activity to support this process. The service levels used in this report are based on the sign-posted levels derived from that exercise.

Appendix 4 – Key function of UK ROC contract and Dataflow

Key functions included in the UK ROC contract with NHSE are:

Database maintenance and support to providers, including

- Programming, updating etc. as new tools are added or updated and providing updates of the software to all registered providers as required
- Providing support to providers regarding the tools and software – providing copies, assisting with queries
- Development and updating of training materials made freely available online to ensure accurate use of the tools by clinical teams.

Database management and information governance

- Obtaining and maintaining the relevant permissions for collation, storage and handling of identifiable patient-level data within the registry.
- Ensuring that data are stored safely and that the database complies with all data protection requirements.

Data collation checking and reporting:

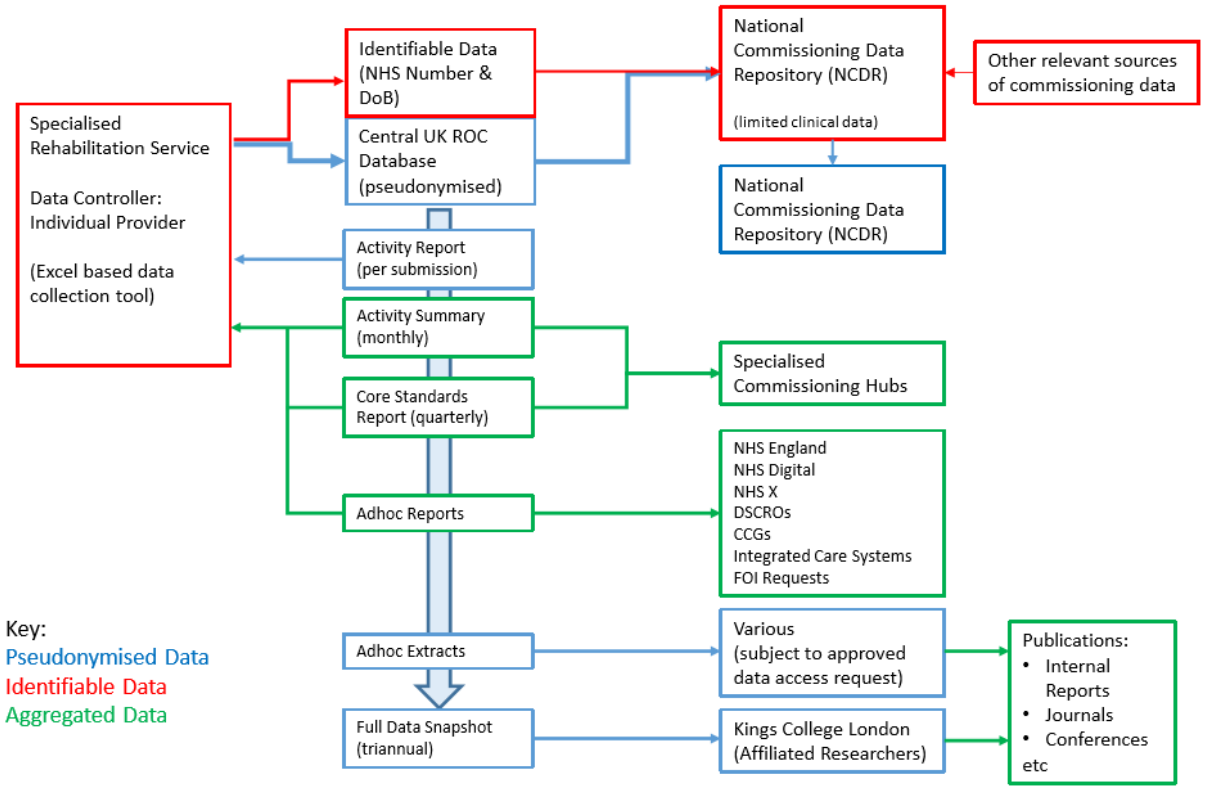
- Receiving and checking data – with feedback to providers on accuracy / completeness / compliance
- Running and checking the monthly activity data and reporting to providers / commissioners
- Providing patient level data flows to the National Commissioning Data Repository for financial reconciliation and service delivery monitoring by the DSCROs
- Providing quarterly reports for benchmarking with feedback to commissioners as per the current format, or as agreed with the CRG as the common report format
- Supplying Service costing data using the costing methodology developed with NHSE and NHSI to provide annually updated costs for development of the Weighted Bed Day (WBD) tariffs for Level 1 and 2 specialist Services
- Updating Service staff profiles based on annual returns from registered services and provide Service sign-posting for mandatory NHSE designation of service levels.

Dealing with queries and requests for information:

- Responding to enquiries regarding data accuracy / interpretation
- Supporting commissioners, providers and planners (NHSE and NHSI) with information on costing, activity, complexity profile to inform contract negotiation using the WBD payment currency and future pricing/ tariffs, subject to manageable levels of enquiry. Beyond this, additional staff and funding would be required
- Running a basic response service and dealing with specific requests for information within reason, depending on staff capacity to respond
- Dealing with Freedom of Information (FOI) requests as these arise from time to time.

Other activities, such as research and clinical audit are provided through separate funding arrangements.

UK ROC Dataset: Routine Data Flows (2020/21)



Appendix 5: Response time and reporting compliance with RAG rating

Colour-code	<65.0%	65.0 - 74.9%	75.0 - 79.9%	80.0 - 89.9%	90.0 - 100.0%

20/21			Response times within standard		On admission						On admission and discharge					
Level 1a (8)	Unit Name	Completed episodes	Assessed within 10 days of referral	Admittted within 6 weeks of assessment	PCAT Category	PCAT Total	PCAT Impression	NIS	Diagnosis Category	Diagnosis sub-category	RCS-E	UK FIM+FAM	NPDS	NPCNA	Discharge destination	Parallel data
C029	Colman Centre for Specialist Rehabilitation. Norfolk Connunity Health and Care Trust	51	47%	82%	90%	90%	86%	86%	100%	100%	100%	71%	92%	90%	100%	100%
C031	Regional Hyperacute Rehabilitation Unit, Northwick Park Hospital. London North West University Healthcare NHS Trust	90	94%	84%	100%	100%	100%	74%	100%	100%	100%	60%	100%	100%	100%	100%
C035	Neuro-Rehabilitation Unit, Walkergate Park Centre for Neurorehabilitation and Neuropsychiatry. Northumberland Tyne and Wear NHS Trust	103	81%	61%	100%	100%	100%	79%	100%	100%	100%	65%	97%	74%	100%	100%
C038	Oxford Centre for Enablement, Nuffield Orthopaedic Centre Oxford.	85	82%	95%	11%	11%	11%	11%	98%	98%	100%	59%	0%	0%	100%	0%
C075	Brain Injury Unit, Leicester General Hospital. University of Leicester NHS Trust	64	92%	98%	98%	98%	97%	0%	100%	100%	98%	98%	98%	98%	100%	100%
C090	The Royal Hospital for Neurodisability, Putney	124	48%	61%	98%	98%	98%	2%	97%	97%	98%	93%	95%	80%	100%	3%
C130	Lipton Rehabilitation Unit, The Walton Centre, Walton Centre for Neurology and Neurosurgery. The Walton Centre NHS Foundation NHS Trust	50	94%	92%	76%	76%	100%	72%	98%	98%	100%	58%	60%	60%	100%	100%
C181	Acute Neuro Rehabilitation, Ward C2, Salford Royal Hospital. Salford Royal NHS Foundation Trust	75	96%	92%	100%	100%	100%	0%	93%	91%	100%	96%	100%	88%	100%	0%

20/21			Response times within standard		On admission						On admission and discharge					
Level 1b (6)	Unit Name	Completed episodes	Assessed within 10 days of referral	Admittted within 6 weeks of assessment	PCAT Category	PCAT Total	PCAT Impression	NIS	Diagnosis Category	Diagnosis sub-category	RCS-E	UK FIM+FAM	NPDS	NPCNA	Discharge destination	Parallel data
C054	Inpatient Neurological Rehabilitation Unit, Moseley Hall Hospital, Birmingham. Birmingham Community Healthcare NHS Trust	149	91%	91%	100%	100%	100%	100%	99%	99%	100%	99%	68%	68%	100%	91%
C085	Central England Rehabilitation Unit (CERU) The Royal Leamington Spa Rehabilitation Hospital. Warwickshire Primary Care Trust	133	89%	97%	100%	100%	100%	99%	100%	100%	100%	98%	100%	100%	100%	100%
C088	Regional Neurological Rehabilitation Unit (RNRU), Homerton Hospital. Homerton University Hospital NHS Trust	64	42%	80%	88%	88%	86%	89%	100%	100%	95%	75%	92%	92%	100%	100%
C131	Complex Rehab Unit (CRU) Walton Centre. The Walton Centre NHS Foundation Trust	55	98%	93%	67%	67%	100%	58%	98%	98%	98%	53%	55%	55%	100%	100%
C201	Preston Barton Ward Neuro-Rehabilitation Unit, Lancashire Teaching Hospital. Lancashire Teaching Hospital Trust	75	97%	77%	51%	51%	51%	51%	100%	100%	44%	39%	39%	39%	100%	0%
C226	Frenchay Brain Injury Rehabiltiation Centre, Frenchay Hospital. Four Seasons Healthcare/Huntercombe Group	82	50%	67%	85%	85%	84%	71%	93%	93%	100%	39%	66%	65%	100%	0%

20/21			Response times within standard		On admission						On admission and discharge					
Level 1c (3)	Unit Name	Completed episodes	Assessed within 10 days of referral	Admittted within 6 weeks of assessment	PCAT Category	PCAT Total	PCAT Impression	NIS	Diagnosis Category	Diagnosis sub-category	RCS-E	UK FIM+FAM	NPDS	NPCNA	Discharge destination	Parallel data
C091	Lishman Brain Injury Unit, Maudsley Hospital. South London & Maudsley NHS Trust	14	0%	7%	57%	57%	0%	86%	0%	0%	36%	36%	0%	0%	100%	0%
C122	Blackheath Brain Injury Rehabilitation Centre - TBIRU unit, Blackheath Brain injury and Rehabilitation Centre & Neurodisability Service. Four Seasons Health Care/Huntercombe Group	55	84%	85%	96%	96%	95%	69%	100%	100%	89%	89%	89%	89%	100%	100%
C137	Neurobehavioural Unit, Walkergate Park Centre for Neurorehabilitation and Neuropsychiatry, Newcastle upon Tyne. Northumberland Tyne and Wear NHS Trust	36	69%	81%	100%	100%	100%	83%	97%	97%	100%	78%	75%	75%	100%	100%

20/21			Response times within standard		On admission						On admission and discharge					
Level 1d (2)	Unit Name	Completed episodes	Assessed within 10 days of referral	Admittted within 6 weeks of assessment	PCAT Category	PCAT Total	PCAT Impression	NIS	Diagnosis Category	Diagnosis sub-category	RCS-E	*UK FIM+FAM	NPDS	NPCNA	Discharge destination	Parallel data
C086	The Childrens' Trust, Tadworth Court	55	62%	56%	100%	100%	98%	98%	100%	100%	93%	55%	91%	89%	100%	100%
C208	Paediatric Neurology Southampton General Hospital. University Hospital Southampton	8	100%	100%	100%	100%	100%	0%	100%	100%	100%	75%	0%	0%	100%	0%

* UK FIM+FAM assessments are only completed for over 7 years olds

*One level 1d unit did not have in-patients 2020/2021 (C060 – Children's Head Injury service, Chailey Heritage Clinical Services. Southdowns NHS Trust)

20/21			Response times within standard		On admission						On admission and discharge					
Level 2a (15)	Unit Name	Completed episodes	Assessed within 10 days of referral	Admittted within 6 weeks of assessment	PCAT Category	PCAT Total	PCAT Impression	NIS	Diagnosis Category	Diagnosis sub-category	RCS-E	UK FIM+FAM	NPDS	NPCNA	Discharge destination	Parallel data
C009	Intermediate Neuro-rehabilitation Unit (INRU), Manchester Royal Infirmary. Central Manchester Foundation Trust	147	91%	95%	88%	88%	88%	71%	99%	99%	99%	90%	99%	97%	100%	74%
C025	Leeds National Demonstration Centre in Rehabilitation, Chapel Allerton Hospital. Leeds Teaching Hospital NHS Trust	149	91%	91%	88%	88%	85%	0%	96%	96%	97%	35%	36%	36%	99%	20%
C040	Dorset Brain Injury Unit, Poole Hospital. Pool Hospital NHS Foundation Trust	21	95%	95%	95%	95%	95%	86%	90%	90%	95%	86%	76%	76%	100%	100%
C041	Portsmouth Phoenix Rehab Centre, Portsmouth. Portsmouth Hospitals NHS Trust	104	89%	88%	92%	92%	92%	39%	100%	100%	88%	33%	88%	84%	99%	100%
C053	Osborn Unit,The Princess Royal Spinal Injuries and Neurorehabilitation Centre. Sheffield Teaching Hospitals NHS Trust	73	64%	100%	97%	97%	97%	70%	96%	96%	75%	85%	0%	0%	100%	0%
C059	Sussex Rehabilitation Centre, Princess Royal Hospital Hayward Heath. Brighton and Sussex University Hospitals NHS Trust	197	20%	20%	64%	64%	63%	89%	99%	99%	92%	85%	92%	91%	100%	0%
C064	North Staffordshire Rehabilitation Centre, Haywood Hospital. University Hospital of North Staffordshire NHS Trust	71	92%	77%	100%	100%	99%	100%	97%	97%	100%	100%	100%	100%	100%	100%
C069	Neuro-rehabilitation Unit, National Hospital for Neurology and Neuroscience, London. UCLH NHS Foundation	67	63%	81%	52%	52%	51%	52%	100%	100%	87%	45%	39%	39%	100%	100%
C071	Ashby Rehab Unit, Lincoln County Hospital. United Lincolnshire Hospital NHS Trust	87	94%	95%	79%	79%	79%	0%	100%	100%	99%	93%	94%	94%	100%	100%
C076	Specialist Neuro-Rehab Unit (SNRU), Leicester General Hospital. University Hospitals of Leicester NHS Trust	88	92%	99%	100%	100%	100%	88%	100%	100%	100%	86%	92%	92%	100%	100%
C121	Blackheath Brain Injury Rehabilitation Centre - HNDU unit. Blackheath Brain Injury Rehabilitation Centre and Neurodisability Service. Four Seasons Health Care/Huntercombe Group	39	72%	100%	90%	90%	87%	41%	100%	100%	100%	82%	100%	100%	100%	100%
C183	Salford Royal Hospital - Ward L1, Salford Royal Hospital. Salford Royal NHS Foundation Trust	61	90%	80%	97%	97%	97%	0%	93%	89%	0%	97%	95%	100%	97%	100%
C228	Thomas Young Ward, St George's Hospital, London. St George's University Hospital NHS Foundation Trust	52	83%	92%	65%	65%	65%	52%	100%	100%	94%	46%	40%	40%	100%	100%
C229	Wolfson Neuro-rehabilitation Unit, Queen Marys Hospital, London. St George's University Hospital NHS Foundation Trust	63	57%	68%	38%	38%	38%	35%	98%	98%	98%	27%	24%	22%	100%	100%
C245	Plymouth Neuro Rehabilitation Unit (Plym Rehab), Mount Gould Hospital. Plymouth Community Healthcare	74	91%	89%	100%	100%	100%	97%	100%	100%	100%	100%	100%	100%	100%	100%

20/21			Response times within standard		On admission						On admission and discharge					
Level 2b (36)	Unit Name	Completed episodes	Assessed within 10 days of referral	Admittted within 6 weeks of assessment	PCAT Category	PCAT Total	PCAT Impression	NIS	Diagnosis Category	Diagnosis sub-category	RCS-E	UK FIM+FAM	NPDS	NPCNA	Discharge destination	Parallel data
C003	Robertson Rehabilitation Unit, Willesden Centre for Health and Care, London. London North West University Healthcare NHS Trust	107	90%	100%	100%	100%	100%	100%	99%	99%	100%	99%	100%	100%	100%	100%
C005	Buckinghamshire Neuro-rehabilitation Unit, Amersham General Hospital. Buckinghamshire Hospitals NHS Trust	91	0%	0%	0%	0%	0%	4%	90%	90%	89%	62%	62%	62%	100%	0%
C010	Hume Neuro Rehabilitation Unit, City Hospital Sunderland. South Tyneside and Sunderland NHS Foundation Trust	122	2%	2%	3%	3%	3%	0%	13%	13%	92%	84%	90%	90%	95%	100%
C012	Kings Lodge Neuro Rehab Unit, Derby City Hosptial. University Hospitals of Derby and Burton NHS Foundation Trust	118	89%	92%	85%	85%	85%	72%	100%	100%	100%	92%	90%	89%	100%	100%
C014	East Kent Neuro-Rehabilitation (EKNRU), Kent and Canterbury Hospital. East Kent University Hospital Trust	81	93%	84%	59%	59%	58%	67%	100%	100%	10%	54%	64%	62%	100%	10%
C015	Rakehead Rehabilitation Centre, Burnley General Hospital. East Lancs Hospitals NHS Trust	62	71%	69%	82%	82%	82%	77%	92%	92%	87%	73%	71%	71%	100%	100%
C018	Alderbourne & Daniel's Rehabilitation Units, Hillingdon Hospital. Hillingdon Hospitals NHS Trust	178	86%	98%	98%	98%	98%	91%	100%	100%	100%	98%	93%	93%	100%	0%
C022	Frank Cooksey Rehabilitation Unit (FCRU), Kings College Hospital. Kings College Hospital NHS Foundation Trust	62	94%	89%	63%	63%	63%	0%	100%	100%	92%	39%	92%	92%	100%	100%
C026	Neuro-Rehabilitation Unit, Dewsbury & District Hospital. Mid Yorks Hospitals NHS Trust	31	48%	45%				0%	100%	100%	94%		68%	68%	100%	98%
C028	Neuro Rehabilitation Centre, Goole Hospital. North Lincolnshire and Goole NHS Foundation Trust	32	69%	100%	75%	75%	75%	94%	100%	100%	94%	91%	44%	44%	100%	100%
C030	Pine Cottage Amputee Rehabilitation Unit, Colman Hospital, Norwich. Norfolk Community Health and Care Trust	85	64%	92%	54%	54%	54%	0%	100%	100%	100%	61%	61%	61%	100%	0%
C036	Linden Lodge Neuro-rehabilitation, Nottingham City Hosptial. Nottingham University Hospitals NHS Trust	100	78%	82%	79%	79%	78%	55%	94%	94%	92%	43%	47%	47%	99%	100%
C046	Marie Therese House Neurorehabilitation Unit, St Michaels Hospital. Royal Cornwall Hospital NHS Trust	24	100%	96%	8%	8%	8%	0%	100%	100%	100%	13%	0%	0%	100%	0%
C049	Donald Wilson House, St Richards Hospital, Chichester. Western Sussex Hospitals NHS Foundation Trust	62	98%	95%	98%	98%	98%	98%	100%	100%	100%	98%	97%	97%	100%	0%
C057	Snowdon Neurological Rehabilitation Unit, Western Community Hospital. Solent NHS Trust	72	43%	49%	13%	13%	13%	0%	53%	53%	89%	32%	31%	31%	74%	0%
C065	Bradley Unit, Woking Community Hospital. Ashford and St Peters Hospitals NHS Foundation Trust	106	87%	93%	98%	98%	97%	69%	100%	100%	95%	64%	10%	10%	100%	0%
C067	Somerset Neurological Rehabilitation Centre, Musgrove Park Hospital. Taunton and Somerset NHS Foundation Trust	43	86%	98%	98%	98%	98%	0%	100%	100%	95%	74%	95%	95%	100%	63%
C068	The Floyd Unit, Birch Hill Hospital. The Pennine Acute Hospitals NHS Trust	74	1%	3%	86%	86%	86%	74%	97%	97%	100%	65%	97%	97%	99%	100%

20/21			Response times within standard		On admission						On admission and discharge					
Level 2b (36)	Unit Name	Completed episodes	Assessed within 10 days of referral	Admittted within 6 weeks of assessment	PCAT Category	PCAT Total	PCAT Impression	NIS	Diagnosis Category	Diagnosis sub-category	RCS-E	UK FIM+FAM	NPDS	NPCNA	Discharge destination	Parallel data
C080	Clatterbridge Rehabilitation Centre, Wirral Neuro Rehabilitation Unit, Clatterbridge Hospital. Wirral University Teaching Hospital NHS Foundation Trust	24	100%	100%	100%	100%	96%	58%	100%	100%	96%	63%	25%	25%	100%	0%
C081	West Park Rehabilitation Medicine, West Park Hospital, Wolverhampton. The Royal Wolverhampton NHS Trust	76	29%	32%	0%	0%	0%	0%	100%	100%	96%	0%	5%	5%	100%	19%
C092	Department of Rehabilitation Medicine, Airedale General Hospital. Airedale NHS FoundationTrust	2	100%	100%	0%	0%	0%	0%	100%	100%	50%	0%	0%	0%	100%	0%
C095	Royal Free Neurological Rehabilitation Centre (NRC), Royal Free Hospital. Royal Free London NHS Foundation Trust	35	83%	100%	94%	94%	94%	100%	100%	100%	100%	94%	66%	63%	100%	31%
C098	James Cook Neurorehabilitation Unit, James Cook University Hospital. South Tees Hospitals NHS Trust	128	94%	98%	89%	89%	89%	0%	97%	96%	99%	79%	80%	80%	100%	100%
C102	Barnsley Neuro Rehabilitation Unit, Kendray Hospital. South West Yorkshire Partnership NHS Foundation Trust	59	98%	98%				97%	93%	93%	95%	95%	88%	88%	100%	57%
C132	Phoenix Centre, Specialist Rehabilitation Unit, Broadgreen Hospital. Royal Liverpool and Broadgreen University Hospitals NHS Trust	63	97%	94%	98%	98%	98%	65%	95%	95%	8%	48%	97%	97%	100%	100%
C133	Specialist Rehabilitation Unit, Elyn Lodge, St Helen's Hospital. St Helens and Knowsley Teaching Hospitals NHS Trust	74	97%	100%	100%	100%	100%	55%	92%	92%	97%	42%	46%	46%	100%	100%
C135	Gwynne Holford Ward, Queen Mary's Hospital, Roehampton. St George's University Hospitals NHS Foundation Trust	45	78%	84%	51%	51%	51%	47%	100%	100%	91%	44%	42%	42%	100%	100%
C187	Frank Cooksey Rehabilitation Unit - Ontario Ward, Orpington Hospital. Kings College Hospital NHS Foundation Trust	81	95%	96%	59%	59%	59%	0%	100%	100%	89%	37%	84%	83%	100%	100%
C202	Preston Bleasdale Neuro-Rehabilitation Unit, Lancashire Hospital. Lancashire Teaching Hospitals NHS Foundation Trust	7	100%	100%	0%	0%	0%	0%	86%	86%	0%	0%	0%	0%	100%	0%
C209	Sid Watkins Spoke Unit, Walton Centre for Neurology and Neurosurgery, Liverpool. The Walton Centre NHS Foundation Trust	21	100%	90%	90%	90%	100%	86%	90%	90%	100%	76%	76%	76%	100%	0%
C221	Charing Cross Neuro-Rehabilitation Unit, Charing Cross Hospital. Imperial College Healthcare NHS Trust	96	98%	97%	99%	99%	99%	0%	100%	100%	100%	98%	100%	100%	99%	0%
C227	Frenchay Brain Injury Rehabilitation Centre, Four Seasons Health Care/Huntercombe Group	40	63%	65%	90%	90%	90%	85%	88%	88%	100%	48%	58%	55%	100%	0%
C232	J2 Rehabilitation Service, Cambridge University Hospitals. Cambridge University Hospitals NHS Foundation Trust	20	80%	95%	95%	95%	95%	0%	95%	95%	90%	75%	15%	15%	100%	0%
C233	J2 RAAR, Cambridge University Hospital. Cambridge University Hospitals NHS Foundation Trust	149	95%	95%	77%	77%	76%	0%	99%	66%	57%		22%	22%	100%	0%
C234	Lewin Unit, Cambridge University Hospital. Cambridge University Hospitals NHS Foundation Trust	17	24%	18%	59%	59%	59%	53%	82%	82%	41%	65%	6%	6%	100%	0%
C243	Mardon Neuro-Rehabilitation Centre, Royal Devon and Exeter NHS Foundation Trust	43	72%	91%	98%	98%	95%	91%	98%	98%	91%	77%	88%	88%	100%	100%

*One level 2b unit was unable to provide data during 2020/2021 (C073 – Neuro-rehabilitation unit, University Hospitals Coventry and Warwickshire NHS Trust)

Other services, regularly submitting to UK ROC but not formally designated

20/21			Response times within standard		On admission						On admission and discharge					
Level Other (17)	Unit Name	Completed episodes	Assessed within 10 days of referral	Admittted within 6 weeks of assessment	PCAT Category	PCAT Total	PCAT Impression	NIS	Diagnosis Category	Diagnosis sub-category	RCS-E	UK FIM+FAM	NPDS	NPCNA	Discharge destination	Parallel data
C013	Magnolia Lodge, Tickhill Hospital, Doncaster. Rotherham Doncaster and South Humber NHS Foundation Trust	50	78%	94%	56%	56%	56%	0%	94%	94%	26%	78%	0%	0%	100%	0%
C019	Ward 29, Queens Centre, Castle Hill Hospital. Hull and East Yorkshire Hospital NHS Trust	39	97%	95%	100%	100%	100%	0%	95%	95%	95%	95%	0%	0%	100%	0%
C108	Stroke Unit - Mount Gould Plymouth Hospital. Plymouth Community Healthcare NHS Trust	152	99%	100%	0%	0%	0%	0%	99%	99%	99%	69%	0%	0%	100%	0%
C110	Brain Injury Rehabilitation, Mossley Hill Hospital. Mersey Care NHS Trust	27	56%	70%	81%	81%	81%	0%	96%	96%	93%	11%	96%	96%	100%	100%
C116	Hothfield Manor Neurorehabilitation Unit. Hothfield Brain injury rehabilitation and Neurodisability Services. Huntercombe Group	64	91%	98%	31%	31%	31%	0%	100%	100%	91%	88%	45%	44%	100%	0%
C117	Woodlands Neurological Rehabilitation Centre - Yorkshire. Christchurch Group	43	67%	100%	72%	72%	67%	98%	100%	100%	100%	100%	100%	100%	100%	0%
C119	Hollanden Park Hospital Neuropsychiatry Unit. Raphael Medical Centre	2	100%	50%	50%	50%	50%	0%	100%	100%	100%	100%	100%	100%	100%	0%
C191	Hollanden Park Hospital Neurorehabilitation Unit. Raphael Medical Centre	42	93%	86%	100%	100%	79%	0%	100%	100%	98%	95%	98%	98%	100%	100%
C043	Oakwood Centre for Rehabilitation Medicine, Rotheram. Rotherham NHS Foundation Trust	49	98%	98%	4%	4%	2%	100%	98%	96%	100%	98%	100%	100%	100%	0%
C126	Mildmay Mission Hospital. Mildmay UK	34	0%	0%	0%	0%	0%	0%	0%	0%	82%	85%	0%	0%	3%	0%
C200	Kite Unit, Plymouth. Solent NHS Trust	22	86%	95%	77%	77%	73%	32%	100%	100%	95%	82%	91%	91%	100%	0%
C206	Helena Neurology Ward, Royal United Hospital Bath. Royal United Hospitals Bath NHS Foundation Trust	76	96%	100%	99%	99%	99%	4%	100%	100%	100%	0%	0%	0%	100%	0%
C207	Homerton Transitional Neurorehabilitation Unit (TRNU), Homerton Hospital. Homerton University Hospital NHS Foundation Trust	24	88%	100%	92%	92%	92%	100%	100%	100%	100%	100%	100%	100%	100%	95%
C220	The Royal Leamington Spa (RLS)- Level 2b, The Royal Leamington Spa Rehabilitaiton Hospital. South Warwickshire NHS Foundation Trust	44	95%	98%	100%	100%	100%	100%	100%	100%	100%	93%	100%	100%	100%	100%
C224	Neurorehabilitation beds at Pulross. Guys and St Thomas' NHS Trust	45	42%	44%	0%	0%	0%	91%	96%	96%	91%	82%	93%	93%	100%	80%
C230	ARTU Royal Stoke University Hospital. University Hospitals of North Midlands NHS Trust	53	92%	92%	100%	100%	100%	98%	94%	94%	96%	85%	94%	94%	96%	100%
C248	The Chantry Ipswich. Sue Ryder Home	30	77%	100%	90%	90%	87%	67%	100%	100%	97%	83%	97%	97%	100%	33%

*One additional unit did not have in-patients during 2020/2021 (C170 Stocksbridge Brain injury Rehabilitation Centre. Huntercombe Group)

Appendix 6: PICUPS data items

Post ICU Presentation Screen (PICUPS tool) (see PICUPS manual for scoring levels)

Domain	Item	Score at Stepdown	Score 2 (Rehab ready)
Medical / Care	Medical stability	(0-5)	(0-5) .....
	Basic care and safety	(0-5)	(0-5) .....
Breathing / Nutrition	Ventilatory assistance	(0-5)	(0-5) .....
	Tracheostomy care	(0-5)	(0-5) .....
	Tracheostomy weaning	(0-5)	(0-5) .....
	Cough / Secretions	(0-5)	(0-5) .....
	Nutrition / feeding	(0-5)	(0-5) .....
Physical Movement	Repositioning in bed	(0-5)	(0-5) .....
	Transfers (bed / chair)	(0-5)	(0-5) .....
Communication/ Cognition	Communication	(0-5)	(0-5) .....
	Cognition & delirium	(0-5)	(0-5) .....
	Behaviour	(0-5)	(0-5) .....
Psychosocial	Mental Health	(0-5)	(0-5) .....
	Family distress	(0-5)	(0-5) .....

PICUPS plus items

Domain	Item	Score at Stepdown	Score 2 (Rehab ready)
Upper Airway	Dyspnoea	(0-5)	(0-5) .....
	Voice	(0-5)	(0-5) .....
	Swallowing	(0-5)	(0-5) .....
Physical and Activities of daily living	Postural management / seating	(0-5)	(0-5) .....
	Maintaining hygiene	(0-5)	(0-5) .....
	Care needs	(0-5)	(0-5) .....
	Moving around (indoors)	(0-5)	(0-5) .....
	Arm and hand function	(0-5)	(0-5) .....
Symptoms that interfere with daily activities	Fatigue	(0-5)	(0-5) .....
	Pain	(0-5)	(0-5) .....

Disciplines required in acute care stage		**Disciplines involved in acute care stage**	
❒ Physio	❒ Psychology	❒ Physio	❒ Psychology
❒ O/T	❒ Social work	❒ O/T	❒ Social work
❒ SLT	❒ Other	❒ SLT	❒ Other
❒ Dietitian		❒ Dietitian	

If thought to require ongoing specialist rehabilitation on discharge
Have they been reviewed by a Consultant in Rehabilitation Medicine? ❒ Yes ❒ No ❒ Don't know

The Rehabilitation Prescription (at discharge from acute care)

Does the patient have any on-going clinical needs for rehabilitation after discharge? ❒ Yes ❒ No

(If yes please tick all that apply)

Complex Physical eg	**Complex Cognitive / Mood** eg	**Complex Psychosocial** eg
❒ Tracheostomy weaning ❒ Ventilatory support ❒ Nutrition / swallowing issues ❒ Post ICU syndrome ❒ MSK management ❒ Re-conditioning / cardiopulm'y rehab ❒ Pain rehabilitation ❒ Neuro-rehabilitation ❒ Prolonged Disorder of consciousness ❒ Complex disability management ❒ Neuro-palliative / End of life support ❒ Amputee rehabilitation ❒ Specialist equipment needs ❒ Other	❒ Communication support ❒ Cognitive assessment/management ❒ Challenging Behaviour management ❒ Mental Health difficulties ○ Pre-injury ○ Post injury ❒ Neuro-psychiatric rehab ❒ Mood evaluation / support ○ Anxiety depression ○ Stress disorder ❒ Major family distress / support ❒ Emotional load on staff ❒ Other	❒ Complex discharge planning eg ○ Housing / placement issues ○ Major financial issues ○ Uncertain immigration status ❒ Drugs/alcohol misuse ❒ Complex medicolegal issues (Best interests decisions, safeguarding, DOLS, litigation) ❒ Educational ❒ Vocational /job role requiring specialist vocational rehab ❒ Other

What is their rehabilitation need	**What is their destination on discharge?**	
In-patient rehabilitation ❒ Specialist inpatient rehabilitation ○ Category A needs (Level 1)* ○ Category B needs (Level 2)* ❒ Non-specialist inpatient ○ Category C/D needs (Level 3)* **Community-based rehabilitation** ❒ Specialist out-patient rehab ○ Multidisciplinary ○ Single discipline ❒ Community-based rehab ○ Specialist MDT ○ Neuro Rehab ○ Cardiopulmonary Rehab ○ Vocational rehab ○ Generic MDT ***** *See Appendix 1 for definitions of the various categories of need*	❒ Transferred for ongoing acute medical/surgical needs ❒ Local hospital ○ Without specialist rehab ○ Awaiting specialist rehab ❒ Other in-pt rehabilitation than that recommended in the RP Specify…… ❒ Own home ○ Without rehabilitation ○ With rehabilitation ❒ Nursing home ○ Specialist NH / Slow-stream ○ Other residential ❒ Mental health unit without physical rehabilitation ❒ Other	**Are they being transferred to the appropriate facility?** ❒ Yes ❒ No **If NO – what would be the appropriate facility?** (Indicate from same list): **Reasons for variance:** ❒ Service exists but access is delayed ❒ Service does not exist ❒ Service exists but funding is refused ❒ Patient / carer declined ❒ Ongoing medical / surgical needs requiring rehabilitation at a later date Other
Is the patient likely to have capacity to consent to include these data in a central registry? ❒ Yes ❒ No		

Appendix 7: PDOC proposed minimum dataset

Proposed PDOC Minimum Reporting Requirements		
Patient Identificaion & Demographics	**Inpatient episode**	**Outreach Review**
Patient Name	✓	✓
NHS Number	✓	✓
Date of Birth	✓	✓
Gender	✓	✓
Commissioning & Referral		
Primary Funding	✓	✓
CCG Name and/or code	✓	✓
GP Practice Name and/or code	✓	✓
GP practice code	✓	✓
GP Name	✓	✓
GP Code	✓	✓
Patient postcode	✓	✓
Referral date	✓	o
Referral source	✓	o
Date of decision	✓	x
Date fit for admission	✓	x
Initial assessment following referral		
Type of assessment	✓	x
Date of assessment	✓	x
Diagnosis		
Diagnosis Category	✓	✓
Diagnosis Sub-Category	✓	✓
Predominant Localisation	✓	o
Date of Onset	✓	✓
Co-Morbidities	✓	o
Admission Details		
Admission Source	✓	x
Main Purpose of Admission	✓	x
Admission Date	✓	x
Proposed discharge date	✓	x
Interruption/Extensions	✓	x
Discharge Details		
Date fit for discharge	✓	x
Discharge date	✓	x
Reason for delay	✓	x
Discharge mode	✓	x
Discharge destination	✓	x
Assessment tools		
Patient Categorisation	✓	x
RCS-E (serial)	✓	x
NPDS/NPCNA (serial)	✓	x
FIM+FAM/NIS (Admission/Discharge/Emergence)	✓	x
GAS (Emergence/Discharge)	✓	x

Proposed PDOC Minimum Reporting Requirements				
PDOC Assessment	**Inpatient episode**	**Emergence**	**Discharge**	**Outreach Review**
Date of assessment	✓	✓	✓	✓
Reason for assessment	✓	✓	✓	✓
PDOC Diagnosis				
PDOC diagnosis (this Ax)	✓	✓	✓	✓
Continuing/Permanent VS/MCS	o	x	✓	✓
PDOC diagnosis (previous Ax)	x	x	x	✓
Date of previous PDOC diagnosis	x	x	x	o
Primary Visual Pathways	✓	x	✓	✓
Primary Auditory Pathways	✓	x	✓	✓
Tracheostomy in situ	✓	x	✓	✓
PEG in situ	✓	x	✓	✓
Assessment Tools (in addition to UK ROC assessment tools)				
WHIM (serial)	✓	x	✓	✓
CRS-R (serial)	✓	x	✓	✓
SMART (serial & final overview)	o	x	o	o
Decision Making				
ADRT in place	✓	x	o	✓
LPOA or Deputy for H&W	✓	x	o	✓
Relationship of LPOA	✓	x	o	✓
Best interest decision meeting/s	✓	x	o	✓
Ceiling of care plan in place	✓	x	o	✓
RCP form 2F	✓	x	o	✓
RCP form 2F date (if completed)	✓	x	o	o
Care Package				
Details of placement	x	x	✓	✓
Nursing Home code/postcode	x	x	✓	✓
Funding for placement	x	x	✓	✓
CCG funding code	x	x	✓	✓
Local authority funding code	x	x	✓	✓
Review				
Planned review	x	x	✓	✓
Planned review assessment team	x	x	✓	✓
Planned review date	x	x	✓	✓
End of Life				
Month/year of death	✓	x	✓	✓
Place of death	✓	x	✓	✓
Probably PDOC diagnosis at death	✓	x	✓	✓
Treatment Escalation plan (TEP)	x	x	✓	✓
Family aware of TEP	x	x	✓	✓
CANH withdrawal	x	x	✓	✓
CANH process	x	x	✓	✓
Second opinon as per PDOC guidelines	x	x	✓	✓
Palliative Care	x	x	✓	✓
Symptom control	x	x	✓	✓

✓ Mandatory item x Not required at this time point o May be required

Appendix 8: Key Publications from UK ROC

Proof of principle studies

Evidence for the effectiveness and cost-efficiency of rehabilitation

Systematic reviews

Turner-Stokes L, Disler P, Nair A, Wade D.
Multi-disciplinary rehabilitation for acquired brain injury in adults of working age. [Full review]
Cochrane Database of Systematic Reviews. 2005 Jul 20;(3):CD004170.

Turner-Stokes L.
Evidence for the effectiveness of multi-disciplinary rehabilitation following acquired brain injury: a synthesis of two systematic approaches
Journal of Rehabilitation Medicine 2008;40(9):691-701

Developing the cost-efficiency model

Turner-Stokes L, Paul, S, Williams H.
Efficiency of specialist rehabilitation in reducing dependency and costs of continuing care for adults with complex acquired brain injuries
Journal of Neurology, Neurosurgery and Psychiatry 2006; 77: 634-639

Turner-Stokes L.
Cost-efficiency of longer-stay rehabilitation programmes: Can they provide value for money?
Brain Injury 2007 21(10):1015-21

Costing and tariff development

Turner-Stokes L, Sutch S, Dredge R.
Healthcare tariffs for specialist inpatient neurorehabilitation services: Rationale and development of a UK casemix and costing methodology.
Clinical Rehabilitation. 2012: 26(3): 264-279

Turner-Stokes L, Bill A Dredge R.
A cost analysis of specialist inpatient neurorehabilitation services in the UK
Clinical Rehabilitation. 2012: 26(3):256-263

Engagement in standardised outcome measurement

Turner-Stokes L, Turner-Stokes T.
The use of standardised outcome measures in rehabilitation centres in the UK
Clinical Rehabilitation 1997; 11: 306-3

Skinner A, Turner-Stokes L.
The use of standardized outcome measures in Rehabilitation centres in the UK
Clinical Rehabilitation 2006**:** 20(7):609-15.

Turner-Stokes L, Williams H, Sephton K, Rose H, Harris S, Thu A.
Engaging the hearts and minds of clinicians in outcome measurement – the UK Rehabilitation Outcomes Collaborative approach
Disability and Rehabilitation. 2012: 34(22); 1871-9

Validation of UK ROC tools

UK Functional Assessment Measure (FIM+FAM)

Turner-Stokes L, Nyein K, Turner-Stokes T, Gatehouse C.
The UK FIM+FAM: Development and evaluation
Clinical Rehabilitation 1999; 13: 277-287

Law J, Fielding B, Jackson D, Turner-Stokes L.
The UK FIM+FAM Extended Activities of Daily Living (EADL) module: evaluation of scoring accuracy and reliability.
Disability and Rehabilitation. 2009;31(10):825-30.

Turner-Stokes L, Siegert RJ.
A comprehensive psychometric evaluation of the UK FIM+FAM.
Disability and Rehabilitation. 2013; 35(22): 1885-95

Medvedev O, Turner-Stokes L, Ashford S, Siegert R.
Rasch analysis of the UK Functional Assessment Measure in patients with complex disability after stroke
Journal Rehabilitation Medicine. 2018 Feb 28. doi: 10.2340/16501977-2324.

Turner-Stokes L, Medvedev O, Ashford S, Siegert R.
Rasch analysis of the UK Functional Assessment Measure (UK FIM+FAM) in a sample of patients with traumatic brain injury from the UK national clinical database.
Journal Rehabilitation Medicine. 2019 Sept.3 51 (8): 566-574, doi: 10.2340/16501977-2580.

Nayar M, Alexandrescu R, Siegert RJ, Turner-Stokes L.
The UK FIM+FAM: A first formal psychometric evaluation in patients undergoing rehabilitation following stroke.
PLOS One 2016; 29;11(1)

Northwick Park Dependency and Care needs Assessment (NPDS/NPCNA)

Turner-Stokes L, Tonge P, Hunter M, Nielson S, Robinson I.
The Northwick Park Dependency Score - a measure of nursing dependency in rehabilitation
Clinical Rehabilitation 1998; 12: 304-16

Turner-Stokes L, Nyein K, Halliwell D.
Care Needs Assessment - a directly costable outcome measure for rehabilitation
Clinical Rehabilitation 1999; 13: 253-268

Nyein K, Turner-Stokes L, Robinson I.
Sensitivity and predictive value of the Northwick Park Care Needs Assessment (NPCNA) as a measure of care needs in the community
Clinical Rehabilitation 1999; 13: 482-491

Williams H, Harris R, Turner-Stokes L.
Can the Northwick Park Care Needs Assessment be used to estimate nursing staff requirements in an in-patient rehabilitation setting?
Clinical Rehabilitation 2007**;** 21(6):535-44.

Williams H, Harris R, Turner-Stokes L.
Northwick Park Care Needs Assessment: adaptation for inpatient neurological rehabilitation settings
Journal of Advanced Nursing 2007; 59(6):612-22.

Siegert RJ, Jackson D, Tennant A, Turner-Stokes L.
A psychometric evaluation of the Northwick Park Dependency Scale (NPDS)
Journal of Rehabilitation Medicine 2010: 42: 936-943

Derivation of the Barthel index

Nyein K, McMichael L, Turner-Stokes L.
Can a Barthel Index be derived from the FIM?
Clinical Rehabilitation 1999; 13: 56-63

Turner-Stokes L. Williams H, Howley D, Jackson D.
Can the Northwick Park Dependency Scale be translated to a Barthel Index?
Clinical Rehabilitation 2010; 24 (12):1112-1120

Turner-Stokes L. Williams H, Rose H, Harris S, Jackson D.
Deriving a Barthel Index from the Northwick Park Dependency Scale and the Functional Independence measure – are they equivalent?
Clinical Rehabilitation 2010; 24 (12):1121-1126

The Rehabilitation Complexity Scale (RCS-E)

Turner-Stokes L, Disler R, Williams H.
The Rehabilitation Complexity Scale: a simple, practical tool to identify 'complex specialised' services in neurological rehabilitation.
Clinical Medicine 2007;7(6): 593-9.

Turner-Stokes L, Williams H, Siegert RJ
The Rehabilitation Complexity Scale: A clinimetric evaluation in patients with severe complex Neurodisability.
Journal of Neurology, Neurosurgery and Psychiatry. 2010; 81(2):146-53.

Turner-Stokes L. Scott H, Williams H, Siegert RJ.
The Rehabilitation Complexity Scale – extended version: detection of patients with highly complex needs
Disability and Rehabilitation 2012; 34(9):15-20

Northwick Park Therapy Dependency Assessment

Turner-Stokes L, Shaw A, Law J, Rose H.
Development and initial validation of the Northwick Park Therapy Dependency Assessment
Clinical Rehabilitation 2009; 23(10): 922-37

The Neurological Impairment Set (NIS)

Turner-Stokes L. Thu A, Williams H, Casey R, Rose H, Siegert RJ,
The Neurological Impairment Scale: reliability and validity as a predictor of functional outcome in neurorehabilitation.
Disability and Rehabilitation 2014;36(1):23-31 doi: 10.3109/09638288.2013.775360. PMID: 23721497

Alexandrescu R, Siegert R, Turner-Stokes L
The Northwick Park Therapy Dependency Assessment scale: a psychometric analysis from a large multicentre neurorehabilitation dataset
Disability & Rehabilitation 2015 Oct;37(21):1976-83. doi: 10.3109/09638288.2014.998779. Epub 2015 Jun 5. PMID: 25598001

Goal attainment scaling (GAS)

Turner-Stokes L, Williams H, Johnson J.
Goal Attainment Scaling: does it provide added value as a person-centred measure for evaluation outcome in neurorehabilitation following acquired brain injury?
Journal of Rehabilitation Medicine 2009: 41(7): 528-35.

Turner- Stokes L, Williams H.
Goal Attainment Scaling: a direct comparison of alternative rating methods
Clinical Rehabilitation 2010; 24(1): 66-73.

Turner-Stokes L.
Goal Attainment Scaling (GAS) in Rehabilitation: A practical guide
Clinical Rehabilitation 2009; 23(4): 362-70.

Turner-Stokes L.
Goal Attainment Scaling and its relationship with standardised outcome measures - a commentary
Journal of Rehabilitation Medicine 2011;43(1):70-72

Turner-Stokes L, Rose H, Ashford S, Singer BJ
Patient engagement and satisfaction with goal planning: Impact on outcome from rehabilitation
International Journal of Therapy and Rehabilitation 2015; 22(5):210-216

Turner-Stokes L, Rose H, Lakra C, Williams H, Ashford SA, Siegert RJ.
Goal-setting and attainment in Prolonged Disorders of Consciousness – development of a structured approach
Brain Injury. 2019 Oct 30:1-11. doi: 10.1080/02699052.2019.1682190. [Epub ahead of print]. PMID: 31661982

Patient categorisation tool (PCAT)

Turner-Stokes L, Krageloh CU, Siegert R.
The patient categorisation tool: psychometric evaluation of a tool to measure complexity of needs for rehabilitation in a large multicentre dataset from the United Kingdom.
Disability and Rehabilitation. 2018 Jan 18:1-9. doi: 10.1080/09638288.2017.1422033.

Siegert R. Medvedev O, Turner-Stokes L,
Dimensionality and scaling properties of the Patient Categorisation Tool (PCAT) in patients with complex rehabilitation needs following acquired brain injury
Journal Rehabilitation Medicine. 2018 May 8;50(5):435-443. doi: 10.2340/16501977-2327.

The post ICU Presentation Screen and Rehabilitation Prescription (PICUPS & RP)

Turner-Stokes L, Corner EJ, Siegert RJ, Brown C, Wallace S, Highfield J, Bear D, Aitken LM, Montgomery H and Puthucheary Z
The Post-ICU Presentation Screen (PICUPS) and Rehabilitation Prescription (RP) for Intensive Care survivors Part I: Development and preliminary clinimetric evaluation.
Journal of the Intensive Care Society 2021. First online 5 Feb 2021
doi: 10.1177/1751143720988715

Puthucheary Z, Brown C, Corner EJ, Wallace S, Highfield J, Bear D, Rehill N, Montgomery H, Aitken LM, and Turner-Stokes L,
The Post-ICU Presentation Screen (PICUPS) and Rehabilitation Prescription (RP) for Intensive Care survivors part II: Clinical engagement and future directions for the National Post-Intensive Care Rehabilitation Collaborative.
Journal of the Intensive Care Society 2021: First online 1 Feb 2021
doi: 10.1177/1751143720988708

Using the UK ROC dataset to make the case for rehabilitation

Using the tools in clinical practice

Turner-Stokes L, Poppleton R, Williams H, Schoewenaars K, Badwan, D.
Using the UK ROC dataset to make the case for resources to improve cost-efficiency in neurological rehabilitation
Disability and Rehabilitation 2012: 34(22); 1900-6

Poppleton, R; Turner-Stokes L, Schoewenaars K
The journey in trying to achieve eligibility for level 1 status in a specialised rehabilitation service
Social care and neurodisability 2012; 3(3) 131-9

Singh R, Sinha S, Bill A, Turner-Stokes L
Unmet need for specialised rehabilitation following neurosurgery: can we maximise the potential cost–benefits?
Brit J Neurosurg 2017; 31(2):249-253. doi: 10.1080/02688697.2016.1233318

Cost efficiency and life time savings

Turner-Stokes L, Williams H, Bill A, Bassett P, Sephton K.
Cost-efficiency of specialist inpatient rehabilitation for working-aged adults with complex neurological disabilities: A multicentre cohort analysis of a national clinical dataset
BMJ Open 2016 Feb 24;6(2):e010238. doi: 10.1136/bmjopen-2015-010238

Turner-Stokes L, Bavikatte G, Williams H, Bill A, Sephton K.
Cost-efficiency of specialist hyperacute in-patient rehabilitation services for medically unstable patients with complex rehabilitation needs: a prospective cohort analysis.
BMJ Open. 2016 Sep 8;6(9):e012112. doi: 10.1136/bmjopen-2016-012112.

Turner-Stokes L, Dzingina M, Shavelle R, Bill A, Williams H, Sephton K
Estimated life-time savings in the cost of on-going care following specialist rehabilitation for severe traumatic brain injury in the UK.
Journal of Head Trauma Rehabilitation. Accepted and in press 2018 (Subsequently published: doi:10.1097/HTR.0000000000000473. PMID: 30801440)

Turner-Stokes L, Harding R, Peihan Y, Dzingina M, Wei G
Cost-efficiency of specialist inpatient rehabilitation for adults with multiple sclerosis: A multicentre prospective cohort analysis of a national clinical dataset
Multiple Sclerosis Journal – Experimental, Translational and Clinical. 2020 Mar 16;6(1):2055217320912789. doi: 10.1177/2055217320912789. eCollection 2020 Jan-Mar.

Turner-Stokes L, LeFeuillee G, Francis R, Nayar M, Nair N.
Functional outcomes and cost-efficiency of specialist in-patient rehabilitation following spinal cord injury: A multi-centre national cohort analysis from the UK Rehabilitation Outcomes Collaborative (UK ROC)
Disability and Rehabilitation. 2021 Jul 20;1-9. doi: 10.1080/09638288.2021.1946603.

International collaborations

Turner-Stokes L, Khan F, Stevermuer T, Simmonds F, Eagar K
Comparison of rehabilitation outcomes for long term neurological conditions: A cohort analysis of the Australian Rehabilitation Outcomes Centre Dataset.
PLOS One 2015 Jul 13;10(7):e0132275. doi: 10.1371/journal.pone.0132275. PMID: 26167877

Jackson DM, Seaman K, Sharpe K, Singer R, Turner-Stokes L
Staged residential post-acute rehabilitation for adults following acquired brain injury: A comparison of functional gains rated on the UK Functional Assessment Measure (UK FIM+FAM) and the Mayo-Portland Adaptability Inventory (MPAI-4)
Brain Injury 2017;31(11):1405-1413. doi: 10.1080/02699052.2017.1350998. Epub 2017 Sep 12.

Turner-Stokes L, Rose H, Ashford S, Singer BJ
Patient engagement and satisfaction with goal planning: Impact on outcome from rehabilitation
International Journal of Therapy and Rehabilitation 2015; 22(5):210-216

Shavelle RM, Brooks JC, Strauss DJ, Turner-Stokes L.
Life Expectancy after Stroke Based On Age, Sex, and Rankin Grade of Disability: A Synthesis.
Journal of Stokes and Cerbrovascular Diseases. 2019 Oct 29:104450. doi: 10.1016/j.jstrokecerebrovasdis.2019.104450. [Epub ahead of print] P PMID: 31676160.

Williams E, Martini A, Wagland J, Turner-Stokes L
Impact of time between acquired brain injury and admission to community-based rehabilitation on cognitive and functional gains
Brain Injury. 2020 May 11;34(6):713-722. doi: 10.1080/02699052.2020.1740943. Epub 2020 Apr 7.

Turner-Stokes L, Rose H, Knight A, Williams H, Siegert RJ, Ashford SA.
Prolonged disorders of consciousness: identification using the UK FIM + FAM and cohort analysis of outcomes from a UK national clinical database.
Disabil Rehabil. 2022 Feb 15:1-10. doi: 10.1080/09638288.2022.2037754. Epub ahead of print. PMID: 35166637.

Other dissemination 2015 – 2021

National / International Lectures

Keynote lecture: National conference to mark the opening of the Walton Centre Rehabilitation Network in Liverpool March 2015

Rehabilitation complexity in acute and hyper-acute rehabilitation settings
Invited lecture: Fiona Stanley Hospital, Perth, Australia. May 2015

Using the UK ROC dataset to improve patient care
Invited lecture: The Alfred Hospital, Perth, Australia. May 2015

The cost-efficiency of specialist rehabilitation – Lessons learned from the UK ROC Dataset
Invited lecture: Centre for Health Service Research, Wollongong University. May 2015

The outcomes and cost-effectiveness of acute acquired brain injury rehabilitation
Keynote Lecture: The Brain Injury Rehabilitation Trust Conference. September 2015

Demonstrating the cost-efficiency of specialist rehabilitation
Keynote Lecture: The Italian Society of Physical and Rehabilitative Medicine. October 2015

Key learning points from implementing levels of specialist rehabilitation
Keynote Lecture: The Danish Society of Physical and Rehabilitative Medicine. November 2015

Current and future commissioning – an update with special reference to acquired brain injury
Keynote Lecture: the UK Acquired Brain Injury Forum (UKABIF). November 2015

Update on UK ROC and commissioning
Invited lecture: British Society of Rehabilitation Medicine, Annual Meeting. Royal College of Physicians, London. December 2015

Goal-setting in rehabilitation – how, what and why?
Invited lecture: Australian Physiotherapy Association, Perth. May 2016

Integrated rehabilitation services – parallels with the UK
Invited lecture: Training Centre in Sub-acute Care – Western Australia, Perth. May 2016

Goal-setting in rehabilitation
Invited Masterclass: The Alfred Hospital, Melbourne, Australia. May 2016

The UK Rehabilitation Outcomes Collaborative and outcomes following neurotrauma
Keynote lecture: Neuro-trauma Rehabilitation International Conference, The Walton Centre, Liverpool. September 2016

Impact of the RCP Prolonged Disorders of Consciousness national clinical Guidelines: 2 years on
Keynote lecture: Holy Cross 2nd National Conference. September 2016

Goal setting to drive decision-making and rehabilitation
Grand Round. The Alfred Hospital Melbourne. May 2017

National Clinical Audit of Specialist Rehabilitation following major Injury (NCASRI) – an update

Invited lecture: British Society of Rehabilitation Medicine Annual Meeting. September 2017

Current models of rehabilitation: How it works and how it should work
Keynote lecture: University College London Partners Centre for Neurorehabilitation Conference. December 2017

Identifying patients with Complex needs – the challenges of the specialist rehabilitation prescription
Keynote lecture: UK Acquired Brain Injury Forum (UKABIF), Leeds. December 2017

The cost-effectiveness of rehabilitation
Invited lecture: All Party Parliamentary Group for Acquired Brain Injury. Houses of Parliament. Jan 2018

The National Clinical Audit for Specialist Rehabilitation following major Injury – an update
British Society of Rehabilitation Medicine, Brighton. October 2018

A road less travelled by
Inaugural Lecture. Cicely Saunders Institute for Palliative Care and Rehabilitation, King's College, London. December 2018

Deciding best interests
Invited lecture: **Patients in a Prolonged Disorder of Consciousness: Diagnosis and Management. A one-day seminar. Oxford Brookes University. April 2019**

Best interests decision-making and end of life care in Prolonged disorders of Consciousness
Invited lecture: Cambridge Postgraduate Neuroscience Group. Cambridge University. June 2019

Rehabilitation for the long term effects of COVID-19
Invited lecture: BMJ Live – international webinar conference. October 2020

Rehabilitation for the long term effects of COVID-19
Invited lecture: International Foundation for Integrated Care (IFIC) webinar series, Making Integrated Care Happen. December 2020

Conference presentations – national and international meetings only

Vanderstay R, Ashford S, Siegert RJ, Turner-Stokes, L
Rasch analysis of the UK Functional Assessment Measure in patients with complex disability after stroke
Poster presentation, Society for Research in Rehabilitation, Newcastle, June 2015
Proceedings published in **Clinical Rehabilitation.**

Ashford S. Alexandrescu R. Siegert RJ. Turner-Stokes L. (2014)
Functional outcomes and efficiency of rehabilitation in a national cohort of patients with Guillain- Barré Syndrome and other inflammatory polyneuropathies,
Poster presentation, Society for Research in Rehabilitation, Newcastle, June 2015
Proceedings published in **Clinical Rehabilitation.**

Turner-Stokes L, Bill A, Williams H Sephton K·
Estimated life time savings from specialist rehabilitation following acquired brain injury: a large multi-centre cohort analysis from the UK.
Poster presentation: International Brain Injury Association, The Hague, March 2016.
Proceedings published Abstract 0683 Brain Injury Vol. 30, Iss. 5-6, 2016

Turner-Stokes L, Bill A, Williams H, Sephton K.
Cost-efficiency of in-patient specialist rehabilitation following acquired brain injury: a large multi-centre cohort analysis from the UK.
Oral presentation: International Brain Injury Association, The Hague, March 2016.
Proceedings published in Abstract 0684 Brain Injury Vol. 30, Iss. 5-6, 2016

Nayar M, Bhatti F, Williams, H, Pick A, Turner-Stokes L
To quantify and describe medical resource requirements in a Prolonged Disorders of Consciousness (PDOC) sub-group in a tertiary hyper-acute rehabilitation service in the UK.
Poster presentation: International Brain Injury Association, The Hague, March 2016.
Proceedings published in **Brain Injury 2016**

Jackson DM, Seaman K, Sharp K, Singer R, Wagland J, Turner-Stokes L.
A Comparison Of Functional Gains At Different Stages Of Recovery In Adults With Acquired Brain Injuries Participating In A Residential Community Rehabilitation Programme
Poster presentation: International Brain Injury Association, The Hague, March 2016.
Proceedings published in **Brain Injury 2016**

Jackson DM, Seaman K, Sharp K, Singer R, Rose H, Chantelle Pieterse C, Williams H, Turner-Stokes L.
Extending functional outcome measurement to support international comparison across different rehabilitation settings for patients with acquired brain injury: a UK-Australian pilot study
Poster presentation: International Brain Injury Association, The Hague, March 2016.
Proceedings published in **Brain Injury 2016**

Turner-Stokes L, Bill A, Williams H, Sephton K.
Cost-efficiency of in-patient specialist rehabilitation for patients with complex disability following stroke: a large multi-centre cohort analysis from the UK
Oral Presentation. World Congress in Neurorehabilitation, Philadelphia. May 2016
Proceedings published in **Neurorehabilitation and Neural Repair.**

Turner-Stokes L, Bill A, Williams H, Sephton K.
Estimated life-time savings in care costs from in-patient specialist rehabilitation in patients with complex disability following traumatic brain injury: a large multi-centre cohort analysis
Poster Presentation. World Congress in Neurorehabilitation, Philadelphia. May 2016
Proceedings published in **Neurorehabilitation and Neural Repair.**

Jackson DM, Seaman K, Sharp K, Singer R, Wagland J, Turner-Stokes L.
A comparison of functional change rated on the UK FIM+FAM and Mayo-Portland Adaptability Inventory in brain injured adults receiving rehabilitation
Poster Presentation. World Congress in Neurorehabilitation, Philadelphia. May 2016
Proceedings published in **Neurorehabilitation and Neural Repair.**

Turner-Stokes L, Bill A, Williams H Sephton K.
Estimated Life Time Savings From Specialist Rehabilitation Following Traumatic Brain Injury: A Large Multi-Centre Cohort Analysis From The UK Rehabilitation Outcomes Collaborative (UK ROC) Database.
Poster Presentation selected for Research Spotlight e-poster session: American Academy of Physical Medicine and Rehabilitation, Denver. October 2017 Proceedings published in **Physical Medicine and Rehabilitation.** PM R 9 (2017) S136 (Best Poster Presentations in Neurorehabilitation)

Lakra C, Rose H, Ashford S Turner-Stokes L, (2017)

Goal-setting for patients in Prolonged Disorders of Consciousness (PDOC).
Platform Poster Presentation session. British Society of Rehabilitation Medicine Annual Scientific Meeting. Cambridge. September. 2017.

Turner-Stokes L, Medvedev O, Siegert RJ
A first psychometric evaluation of the Patient Categorisation Tool (PCAT) as a tool to measure complex needs for rehabilitation
Poster Presentation: World Congress in Neurorehabilitation, Mumbai. Feb 2018

Turner-Stokes L, Medvedev O, Siegert RJ
Dimensionality and scaling properties of the Patient Categorisation Tool (PCAT) in patients with complex rehabilitation needs following acquired brain injury
Poster Presentation: World Congress in Neurorehabilitation, Mumbai. Feb 2018

Ashford S, Maddocks M, Fettes L, Wei Gao, Higginson IJ, Turner-Stokes L.
Rehabilitation goals towards the end of life: what matters to people with advanced disease in hospice care?
Society for Research in Rehabilitation Winter Conference, Bristol. 2018

Steed A, Ashford S, Roden P, Turner-Stokes L
Reliability of a Behavioural Pain Assessment tool for patients in a Prolonged Disorder of Consciousness.
Society for Research in Rehabilitation Winter Conference, Bristol. 2018

Williams H, Dungca C
Can care costs rise as patients gain independence through rehabilitation? A post hoc analysis of prospectively collected data
RCN International Nursing Research Conference and Exhibition April 2018

Turner-Stokes L, Rose H, Lakra C, Williams H, Ashford SA, Siegert RJ.
Development of a structured approach to goal setting and goal attainment in Prolonged Disorders of Consciousness
Oral Presentation: International Brain Injury Association, Toronto March 2019

Goal Setting in Prolonged Disorders of Consciousness – How to do it
Invited seminar: Australian Society for the Study of Brain Impairment (ASSBI) and the New Zealand Rehabilitation Association, joint conference Wellington, New Zealand May 2019

Lannin N, Morarty J, Palit M, Crotty M, Ratcliffe J, Jolliffe L, Turner-Stokes L.
Cost-efficiency of inpatient rehabilitation following acquired brain injury. A first Australian adaptation of the UK approach
Rehabilitation Medicine Society of Australia and New Zealand October 2019

Turner-Stokes L, Cardona A, Alfonso E.
Benefits of rehabilitation late after stroke: a multi-centre cohort analysis from the UK Rehabilitation Outcomes Collaborative (UK ROC) database.
Poster Presentation: International Brain Injury Association, Toronto March 2019
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Turner-Stokes L, Dzingia M, Bill A, Williams H, Sephton K
Estimated life time savings from specialist rehabilitation following hypoxic brain injury: a large multi-centre cohort analysis from the UK.
Oral Presentation: International Brain Injury Association, Toronto March 2019

Oral Presentation: British Society of Rehabilitation Medicine and Society of Research in Rehabilitation. Warwick 2019
Poster Presentation: American Academy of Physical Medicine and Rehabilitation (AAPMR) Annual Assembly San Antonio Nov 2019

COVID live presentations

Rehabilitation for the long term effects of COVID-19
Invited lecture: BMJ Live – international webinar conference October 2020

Rehabilitation for the long term effects of COVID-19
Invited lecture: International Foundation for Integrated Care (IFIC) webinar series, Making Integrated Care Happen. December 2020

Appendix 9: UK ROC Oversight Group

UK ROC Oversight Group

Early 2019 the UK ROC Oversight Group was formed. The principal purpose of the group is to provide oversight of the UK ROC database and provide a forum for shared decision-making. The first meeting of the group was on 14th February 2019. Group members include a patient representative, NHSE, UK ROC and Regional Provider representatives.

A key role for the oversight group is to ensure that UK ROC has the various systems in place to meet the quality requirements for commissioning. This includes robust procedures to ensure:

- Correct IG compliance
- Audit of information and algorithms within UK ROC (eg sign-posting)
- Clear protocols covering initial data collection to reported output
- Data quality validation from Providers
- Permissions-based data-access and user generated reporting for both Providers and Commissioners
- Staffing implications

Pre-Covid the Oversight Group would meet 3 or 4 times each year and form sub-groups where necessary in order to discuss specific issues that could not be appropriately handled in the regular Oversight meetings.

Sign-posting sub-group

One such sub-group was the Sign-posting sub-group which comprised UK ROC, NHSE and Provider representatives. The purpose of the sub-group was to better understand and evaluate the process that UK ROC applies in order to 'sign-post' a service to a particular service level. This group met on 25 October 2019 in the UK ROC offices at LNWUH NHS Trust.

A workshop to sign-post several services was undertaken by the group where the group members did not know the service name but simply applied the sign-posting algorithm in order to illustrate the robust nature of the process. Although some minor discrepancies occurred and certain interpretation needed to be explained, it was agreed that the process is accurate based on reported data. Further refinement is gained when local Commissioner knowledge is applied.

Current signposted units https://www.kcl.ac.uk/cicelysaunders/research/studies/uk-roc/ukroc-register-of-services-mar2020.pdf

UK ROC Commissioning and Providers workshop

On the 11th of February 2020 a Commissioning and Providers workshop was held at Wellington House, London, with representation from NHSE, UK ROC and Providers.

At that time NHSE was in the process of viewing the various databases that it commissions. The purpose of the workshop was to start a process of taking stock of the data that is currently collected for specialist rehabilitation:

- to ask what data is needed to plan and commission services
- to consider whether the current database is meeting the needs of commissioners and clinicians, and if not, what needs to be changed

Workshop participants broke into groups arranged approximately by region to discuss the purposes for which data is needed. The group agreed that data is needed for several distinct purposes – each requiring a slightly different dataset but with common elements between them.

Uses of data

1. **A Clinical dataset and registry (at individual patient level - identifiable)**
    a. For tracking individual patients as they move between services and progress over time
    b. Monitoring their rehabilitation needs and how well these are met
    c. Measuring complexity and dependency to understand their impact – especially for those with very high level needs including tracheostomy, 1:1 supervision, challenging behaviours
    d. Clinical decision-making, including managing the unit's caseload, admission planning, etc.
    e. Monitoring outcomes – including functional gain and cost efficiency and tracking these longitudinally over time
    f. Linkage with other datasets – for example the Rehabilitation Prescription dataset in TARN – but ideally extending a similar model with the stroke, neurosciences, neuro-critical care, etc.

2. **A commissioning dataset (at individual patient level - identifiable)**
    a. For contracting and contract monitoring using a currency that is meaningful in the context and neutral (ie shares risk between commissioners and providers)
    b. For determining eligibility:
        i. NHS entitlement
        ii. complex rehabilitation needs
    c. For managing waiting lists, monitoring response times
    d. For measuring demand and capacity
    e. For quality and benchmarking – performance against the service specification quality indicators - national comparison – with dashboards for easy vision
    f. For assuring data quality

3. **An improvement dataset – (at service level)**
    a. Costing data – eg service costs, patient level costing
    b. Quality – staffing levels, experience (banding), facilities, etc.
    c. Signposting
    d. Access to own data for local analysis
        i. clinical team review
        ii. local service evaluation and audit

    Local data analysis may be undertaken with a band 4 data entry clerk and a band 7 analyst to monitor data quality, and pull out the data for team reflection

Key identified data requirements include

- **Demographics**
    - NHS no and date of birth – patient identifier for linkage with other datasets
    - Diagnosis - expand current diagnostic classification
    - Referral source
        - Provider code
        - Treatment function code – to identify type or service – eg Major Trauma, neurosurgery, stroke, etc.
    - Gender, Age
    - Date of onset / injury
    - Employment status
    - GP code

- CCG – confirm eligibility for NHS treatment

- **Needs for rehabilitation identified by referrer**
  - Category A/B/C/D - According to Rehab Prescription from referring centre

- **Response and process times**
  - Date of referral
  - Accepted / declined
    - Reason for refusal – eg if rehab not offered or patient declined
  - Date of assessment
  - Date fit for admission
  - Dates of admission
  - Date fit for discharge, actual discharge date and length of stay
  - Delayed transfers of care (DTOC)
    - Length of delay
    - Reason for delay eg CCG / social services funding, housing, waiting for nursing home, etc.
  - Discharge destination – eg home, further rehab, back to acute hospital, died

- **Admission dataset**
  - Eligibility for specialist rehab - confirmation of Category A/B needs
    - PCAT tool
  - Programme type: according to the specification
    - Eg Rehabilitation complex disability management, PDOC assessment, neuropalliative care

- **Change in course of programme**
  - Measure of complexity – resource needs as they change
    - Rehabilitation Complexity Scale - including highly complex needs, trache, 1:1, challenging behaviours, etc.
    - Measured at appropriate intervals for the programme – eg 2-4 weeks to inform changing costs of care for commissioning
  - PDOC patients
    - Change in level of awareness – VS / MCS (minus/plus) / emerged
    - Serial Coma Recovery Scale (CRS-R) and / or WHIM scores
      - See National PDOC guidelines for recommended dataset [https://www.rcplondon.ac.uk/guidelines-policy/prolonged-disorders-consciousness-following-sudden-onset-brain-injury-national-clinical-guidelines]

- **Outcomes - change from admission to discharge**
  - Gains in function
    - physical, cognitive, psychosocial - eg through UK FIM+FAM
  - Reduction of dependency and care costs (especially for highly dependent patients who fall below the floor of the FIM+FAM)
  - Cost-efficiency – makes the argument for service provision
  - Other optional tools – eg Mayo-Portland for more cognitive patients, ASIA for Spinal cord injury, goals and goal attainment scaling

Specific comments regarding current data collection

Core minimum dataset and optional data components

- People found different elements are useful for different purposes
- Not all of the data need be collected all of the time
- Some have relevance for certain types of service only. eg 1a, 1c and hyper-acute services

It would be appropriate to identify a core minimum dataset for each service type, but to have the other more detailed tools available for those who want to use them, or for data collection for specific purposes (eg peer review).

Cloud-based platform and data access

- Many people would like a cloud-based platform with instant access to their data and user-friendly visualisation
- They would also like to be able to see other units' data more readily for comparison

Complexity weighted bed-day currency model

- People generally found the WBD model helpful in that it takes account of patients with different levels of complexity in a way that is fair to commissioners and providers, and most people now understand it
- There was concern that it is not granular enough at the top end, and would be improved if it could reflect the additional impact of patients with the following:
    - Tracheostomy
    - Requiring 1:1 supervision
    - Very challenging behaviours
    - Treatment under section of the Mental Health Act
    - Medical acuity
    - Very distressed / challenging families
    - Multiple conditions, comorbidities

Linkage

- Linkage with other datasets is extremely important
- The National Clinical Audit for Specialist Rehabilitation following major Injury (NCASRI) tested the model for data linkage with TARN to identify:
    - Patients requiring specialist rehabilitation on leaving Major Trauma Centres
    - Those who actually got it, and the shortfall between
- This led to expansion of the mandated data collection for the rehabilitation prescription to include identification of patients with category A and B needs for specialist rehabilitation
- This model works for major trauma and therefore the rehabilitation prescription should be rolled out to other acute services that feed into specialist rehab including stroke, neurosciences, and crucial care

Real-time versus retrospective

- To consider the purpose for which data is required and how quickly it is needed
    - Useful to have real-time data eg for live waiting list management locally
    - But static data more reliable where validity is important – eg payment and outcomes – national comparison and benchmarking
        - Currently updated monthly – need to balance frequency with work involved in data checking and validation

Current UK ROC tools - Comments about the current tools were as follows:

- **Patient Categorisation Tool (PCAT)**
  - Reflects the criteria for patients with complex needs as per the specification, therefore useful for confirming eligibility for NHSE-funded services
  - Some concerns expressed about variable data quality, especially when completed by less experienced staff (NB according to the specification it should be completed by a Rehabilitation Medicine consultant or under their supervision)
  - Needs expanding to reflect requirement for Hyper Acute services

- **Rehabilitation Complexity Scale (RCS-E)**
  - Useful measure of rehabilitation needs in terms of resource requirements
  - Simple and timely to apply
  - Needs expanding to reflect the list of very complex needs above

- **Functional Assessment Measure (UK FIM+FAM)**
  - Useful global measure of disability that includes both physical and cognitive function
  - FAM splat is very useful – a similar pictorial display may be developed for other scales
  - Quite time-consuming to apply but generally appropriate to the population for these services - could it be used just in modules? – eg 1c services to use just the cognitive / psychosocial scale in patients who are physically able

- **Nursing Dependency Scale (NPDS)**
  - Nursing staff often find it useful
    - Some concern about quality of completion but this may reflect patients' different behaviour in therapy sessions vs day-to-day function with nurses
  - Demonstrates change for the very physically dependent patients who may not change on the FIM+FAM – can be important for costs
  - Provides the cost efficiency measure when scored between admission and discharge, or for justifying extension

- **Therapy Dependency Scale (NPTDA)**
  - Time consuming – especially to complete every 2 weeks for 'tranch data'
  - Provides sense check for complexity scoring - might be useful as part of the improvement dataset for a specific peer review but probably not needed every year going forward
  - Some trusts are using therapy contact tools as part of PLICS which could replace this (but not consistently applied across all Trusts so no national comparison, and may not capture indirect patient time which is not face to face)

What is missing (not as core set but optional wish list)?

- A tool to predict outcome - but this is difficult to do using a single structured tool
- Hyper-acuity
  - A tool to capture reasons for hyper-acuity, and input from different specialties
  - (This is the Medical Activities Assessment tool which is developed but not yet integrated into UK ROC)
- Family outcome measure – adjustment
- Measure of Patient / Family Satisfaction
- Medicolegal aspects - best interests, etc.
- 6-month follow-up – eg return to work