

# ***UK Rehabilitation Outcomes Collaborative (UKROCS) -(UK)***

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Successful clinical-government-scientific partnerships:

# UKROC

## The UK Rehabilitation Outcomes Collaborative

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# International Casemix development

- In the last 30 years - health systems around the world
  - Have introduced activity-based costing and payment models
- Casemix design is typically based on diagnosis-related groups (DRGs)
  - Poor indicators of cost in rehabilitation
- 1990s – development of costing and payment models for rehabilitation
  - In US – Uniform Data systems - Function-related groups (FRGs)
    - Based on the Functional Independence Measure (FIM)
  - In Australia – Blended payment model
    - Also based on the FIM
- Value for money – both systems use:
  - FIM scores on admission - as a proxy for casemix complexity
  - FIM on discharge as a proxy for ongoing costs of ongoing care
    - Value for money: Use 'FIM gain /Length of stay' as a measure of 'cost efficiency'

# Problems with FIM as basis for casemix

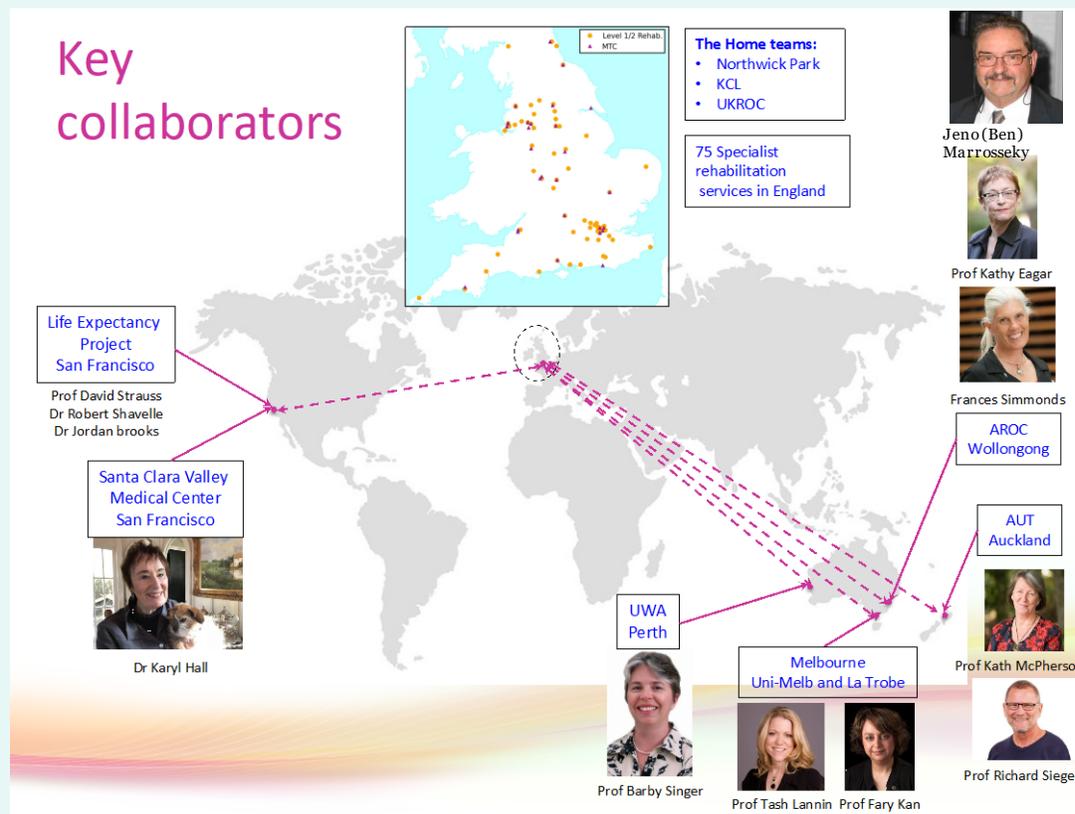
- Generates ordinal data
  - S-shaped curve
    - Floor and ceiling effects
  - “FIM-efficiency”
    - Only works in straight-line part of curve

# Problems with FIM as basis for casemix

- Generates ordinal data
    - S-shaped curve
      - Floor and ceiling effects
    - “FIM-efficiency”
      - Only works in straight-line part of curve
  - Patients who fall
    - Above the ceiling or below the floor
      - Need different measures
        - To capture the full gains
        - And cost-efficiency
- Case mix in the UK started later and learned from these models
  - UKROC model has evolved based on more direct measures of cost
    - Both of rehabilitation and of cost-efficiency

# UK Rehabilitation Outcomes Collaborative

- Founded in 2008
  - NIHR Programme grant in applied research
  - To develop a national clinical database and registry
    - Building on the US and Australian model
    - Developing and introducing other tools
- Since 2015:
  - UKROC database is funded by NHS England
    - Commissioning dataset
      - Patient-level episode data
      - For all specialist rehabilitation services (n=75)
      - Now over 80,000 episodes
  - Since 2017 – Registry status
    - Identifiable data (NHS number) for tracking patients and linkage with other datasets



# UKROC Extended Dataset

UKROC collects data on needs, inputs and outcomes  
All gathered in routine clinical practice

Parameter	Measure
<b>Complexity of needs</b> for rehabilitation	The Rehabilitation Complexity Scale (RCS-E)
<b>Inputs</b> provided to meet those needs	The Northwick Park nursing and therapy Dependency Scales (NPDS / NPCNA, NPTDA)
<b>Outcomes</b>	The UK FIM+FAM Reduction in care needs and costs
Episode costs	Complexity-weighted bed-day cost Based on the Rehabilitation Complexity Scale
<b>Cost-efficiency</b>	Time taken to offset the cost of rehabilitation by savings in ongoing care needs Life-time savings

# Embed measurement into clinical practice

- Requires simple practical tools – useful to clinicians
  - First priority = needs and costs

## The Rehabilitation Complexity Scale

### Principal determinants of costs

Basic support and nursing needs	<ul style="list-style-type: none"> <li>• Basic self care</li> <li>• Special nursing needs</li> </ul>
Therapy Needs	<ul style="list-style-type: none"> <li>• No. of different disciplines</li> <li>• Intensity of input</li> <li>• Special facilities / equipment</li> </ul>
Additional medical needs	<ul style="list-style-type: none"> <li>• Medical support environment</li> <li>• (eg 24 hour emergency care)</li> <li>• Procedures / investigations</li> </ul>
Length of programme	<ul style="list-style-type: none"> <li>• Bed days</li> </ul>

Item	Description	Range
<b>C</b>	Basic care needs	0-4
<b>N</b>	Special nursing needs	0-4
<b>T</b>	Therapy needs <ul style="list-style-type: none"> <li>• No of disciplines</li> <li>• Intensity of treatment</li> </ul>	0-4 0-4
<b>M</b>	Medical needs	0-4
<b>E</b>	Equipment	0-2

### Simple and quick to score

Recorded serially over time  
 Capture changing needs as the patient progresses through the programme  
 Basis for complexity-weighted tariffs

# Challenge for very severe disability

- Many patients will remain dependent
  - Reduction of care costs is still important - for example:
    - A patient with severe brain injury
    - Admitted for a 4-month programme of specialist rehabilitation

Care package	
Before rehabilitation: 2 live-in carers (£2500 / week)*	} Saving £1250 / week (= £5,000/month)
After 1 live-in carer (£1250 / week)	

- Cost of rehabilitation episode £50,000
    - Cost offset within 10 months
  - Powerful argument for providing the rehabilitation
    - But we needed the measures to record this routinely in the course of clinical practice
- \*NB: This is just a model – they are not real figures*

# Directly costable measures

- Northwick Park Dependency Scale / Care Needs Assessment
  - Direct assessment of care needs
    - No. of carers and time taken
  - Translated by computerised algorithm
  - Outputs
    - Time-table of care needs in the community
      - The care package required
      - Approximate weekly cost (£)
- Cost efficiency
  - Time to offset the costs of rehabilitation
    - By savings in on-going care
  - Life-time savings
    - Annual saving in care costs x remaining years of life
      - Allowing for reduced life expectancy



*Turner-Stokes et al 1998, 1999*  
*Williams et al 2007, 2009*  
*Siegert et al 2010*  
*Turner-Stokes et al 2018*

# Cost efficiency of rehabilitation

- Data extract 2010-2015
  - All neuro-rehab episodes (n=5739)
    - Brain injury, SCI, progressive conditions
    - With complete data
      - NPDS/NPCNA
      - FIM+FAM

Parameter	Mean
Length of stay	90 days
Cost of rehabilitation programme	£39,381
Reduction in care costs	£496 /week
Time to offset cost of rehabilitation	18 months

Open Access Research

## BMJ Open Cost-efficiency of specialist inpatient rehabilitation for working-aged adults with complex neurological disabilities: a multicentre cohort analysis of a national clinical data set

Lynne Turner-Stokes,<sup>1,2</sup> Heather Williams,<sup>2</sup> Alan Bill,<sup>2</sup> Paul Bassett,<sup>3</sup> Keith Sephton<sup>2</sup>

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Health systems that provide tertiary specialist rehabilitation services.

BMJ

Turner-Stokes L, et al. *BMJ Open* 2016;6:e010238. doi:10.1136/bmjopen-2015-010238

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# Analysis by dependency

Parameter	High (N=3433)	Medium (N=1607)	Low (N=699)
Dependency on admission (NPDS score)	Two carers (≥25)	One carer (10-24)	Self-caring (0-9)
	<b>Mean Value</b>		
Length of stay (days)	102	62	51
Cost of rehabilitation programme	£47,111	£28,473	£23,997
Mean reduction in care costs /wk	£760	£408	£130
Time to offset costs of rehabilitation (months)	14.2	22.3	27.7
FIM efficiency	0.38	0.54	0.37

## Importance:

Severely dependent patients unlikely to receive rehabilitation in some countries

If they require patients to show change in FIM scores

Changes in care needs below the floor of the FIM

# Estimated life-time savings

- US life-Expectancy Project
  - Computes % normal life expectancy in 4 groups
    - Based on FIM Eating and Walking scores at discharge
    - We adjusted for UK mortality statistics
  - Net life-time savings calculated as
    - *Savings in cost of care per year x remaining years – episode cost*
- Analysis of 3259 patients with TBI

Mean Age	49 years
Mean episode cost	£42,894
Mean annual savings	£28,317
Mean further life expectancy	21.6 years
Estimated life-time savings per pt	£679,776
For whole sample	£2.4 billion

J Head Trauma Rehabil  
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OPEN

## Estimated Life-Time Savings in the Cost of Ongoing Care Following Specialist Rehabilitation for Severe Traumatic Brain Injury in the United Kingdom

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**Objectives:** To evaluate cost-efficiency of rehabilitation following severe traumatic brain injury (TBI) and estimate the life-time savings in costs of care. **Setting/Participants:** TBI patients ( $n = 3578/6043$ ) admitted to all 75 specialist rehabilitation services in England 2010–2018. **Design:** A multicenter cohort analysis of prospectively collated clinical data from the UK Rehabilitation Outcomes Collaborative national clinical database. **Main Measures:** Primary outcomes: (a) reduction in dependency (UK Functional Assessment Measure), (b) cost-efficiency, measured in time taken to offset rehabilitation costs by savings in costs of ongoing care estimated by the Northwick Park Dependency Scale/Care Needs Assessment (NPDs/NPCNA), and (c) estimated life-time savings. **Results:** The mean age was 49 years (74% males). Including patients who remained in persistent vegetative state on discharge, the mean episode cost of rehabilitation was £42 894 (95% CI: £41 512, £44 235), which was offset within 18.2 months by NPCNA-estimated savings in ongoing care costs. The mean period life expectancy adjusted for TBI severity was 21.6 years, giving mean net life-time savings in care costs of £679 776/patient (95% CI: £635 972, £722 786). **Conclusions:** Specialist rehabilitation proved highly cost-efficient for severely disabled patients with TBI, despite their reduced life-span, potentially generating over £4 billion savings in the cost of ongoing care for this 8-year national cohort. **Key words:** brain injuries, Economic evaluation, outcome assessment (Healthcare), Rehabilitation, traumatic

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**SEVERE TRAUMATIC BRAIN INJURY (TBI)** can cause life-changing disability. There is now strong evidence from both randomized controlled clinical

study are available free of charge from the authors. Please visit our website for more details and contact information: <http://www.kcl.ac.uk/lm/research/divisions/cicelysaunders/research/studies/ukroc/tools.aspx>. As the UKROC data set is a live clinical data set, for reasons of confidentiality and data protection data sharing is not available at the current time.

Supplemental digital content is available for this article. Direct URL citations appear in the printed text and are provided in the HTML and PDF versions of this article on the journal's Web site ([www.headinjurytraumarehab.com](http://www.headinjurytraumarehab.com)).

The authors declare no conflicts of interest.

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# Prolonged disorders of consciousness

- UKROC
  - Recently developed a PDOC registry (2024)
    - Not yet fully populated
- In the meantime:
  - Used Total FIM+FAM scores as proxy
    - To identify patients in PDOC
    - Single specialist PDOC centre (n=388):
      - <=31: Vegetative state / MCS-minus
      - 32-35: Minimally conscious state-plus
        - Compared with formal PDOC evaluation
        - Identified with 87% sensitivity, 88% specificity
  - Analysis of cost-efficiency from UKROC

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ORIGINAL ARTICLE

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## Prolonged disorders of consciousness: identification using the UK FIM + FAM and cohort analysis of outcomes from a UK national clinical database

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**ABSTRACT**  
**Purpose:** 1. To determine whether Total UK FIM + FAM scores can identify patients in VS/MCS. 2. Using the identified cut-off points, to examine outcomes from specialist rehabilitation.  
**Methods:** Part 1: Retrospective analysis of a consecutive clinical cohort (n = 388) presenting to a single specialist PDOC evaluation programme 2007–2021. FIM + FAM scores were analysed by PDOC diagnosis to define cut-off points for vegetative (VS) and minimally conscious states (MCS). Part 2: Multicentre cohort analysis of prospectively-collected clinical outcomes data from the UK Rehabilitation Outcomes Collaborative database of adults in PDOC registered 2011–2020 (n = 2384 in 68 centres).  
**Results:** Cut-off points of <=31 and 32–35 in FIM + FAM total scores respectively identified patients in VS/MCS-Minus and MCS-Plus. Approximately 365 PDOC patients are admitted to specialist rehabilitation units in England each year. By discharge, 43% have emerged into consciousness and demonstrate a wide range of disability. A few reached full independence, but the majority remained severely dependent. Nevertheless, those who emerged generated mean net life-time savings of over £436,000 (£400 million for this cohort).  
**Conclusion:** In absence of a dedicated PDOC registry, FIM + FAM scores can identify patients in VS/MCS at population level. Identifying those who emerge and providing timely rehabilitation generates cost-savings well-exceeding the cost of the evaluation/rehabilitation programme.

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**KEYWORDS**  
Consciousness disorders; rehabilitation; patient outcome assessment; cost-effectiveness; health-care economics

**► IMPLICATIONS FOR REHABILITATION**

- The UK National Health Service currently collects no systematic data to identify patients in PDOC, so we have no accurate information on how many patients there are, where they are managed or what their outcomes are.
- In the absence of more direct data, total FIM + FAM scores of <=31 and 32–35 respectively can be used to identify patients in vegetative and minimally conscious states.
- Of the 365 or so patients admitted to specialist rehabilitation units per year, 43% emerge into consciousness leaving about 150 patients per year in PDOC states that are likely to be permanent.
- Identifying those who emerge and providing timely rehabilitation generates cost-savings that pay for the entire PDOC evaluation/rehabilitation programme many times over.

**Introduction**

As acute services get ever better at saving lives, more patients are surviving with catastrophic brain injury and present to rehabilitation services still in a prolonged disorder of consciousness (PDOC). Some of these individuals will remain in a vegetative or minimally conscious states (VS/MCS) while others emerge into full consciousness.

Although it has been estimated that there may be between 4,000 and 16,000 in VS, and approximately three times that in MCS (1), the UK NHS currently collects no systematic data to identify patients in PDOC, so we have no accurate information on how many patients there are, where they are managed or what their outcomes are. The national clinical guidelines for PDOC (2) have recommended the establishment of a clinical registry to provide more accurate data on incidence, and to monitor the progress of individual patients. In the meantime, however, it is pertinent to explore whether any information on prevalence and outcomes could be gained from existing data.

In England, while the majority of patients with mild-moderate brain injuries receive rehabilitation within their local non-specialist (Level 3) services, those with more complex rehabilitation needs may be referred to specialist Level 1 (tertiary regional) or Level 2 (local secondary) rehabilitation services. The national clinical

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<sup>a</sup>Supplemental data for this article can be accessed here.

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# Cost efficiency – mean values

Parameter	Overall		VS/MCS-Minus	MCS-Plus	Emerged
Length of stay	136		114	129	162
Cost of rehabilitation episode	£79,473		£69,889	£74,167	£91,229
Annual savings in care costs	£10,559		£3,242	£627	£20,972
Time to offset the cost of rehabilitation	6.3 years		6.7 years	7.0 years	6.0 years
Estimated net total life-time savings	£167,774		-£40,597	-£81,691	£436,609
Cost of rehabilitation episode	136		114	129	162

- Negative lifetime savings for patient who remain in PDOC
  - But £436K per patient treated for those who emerge
    - Total saving of >£400 million for this cohort
      - Offsets the negative costs of evaluating those who remain in PDOC
        - Optimises chance of identifying those who will emerge
- Providing this service is cost-efficient overall

# UKROC/NHS England partnership

- UKROC is primarily a clinical registry
  - Tools are timely to collect – and designed to be useful
    - Aid clinical decision-making in real time
      - Teams want to collect data, because it helps them in their daily practice
- Other functions for NHS England:
  - Commissioning database for contract monitoring and payment
  - Audit - National benchmarking of quality and outcomes
  - Research – what works best for which patients?
- Cost-efficiency data collected in real life clinical practice
  - Powerful argument for NHS England and other purchasers of services
  - Has helped to make the case for provision of rehabilitation
    - 32 new rapid access acute rehabilitation beds opened in London this year!

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  - All the members of the UKROC team
  - All of our other collaborators around the world