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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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'

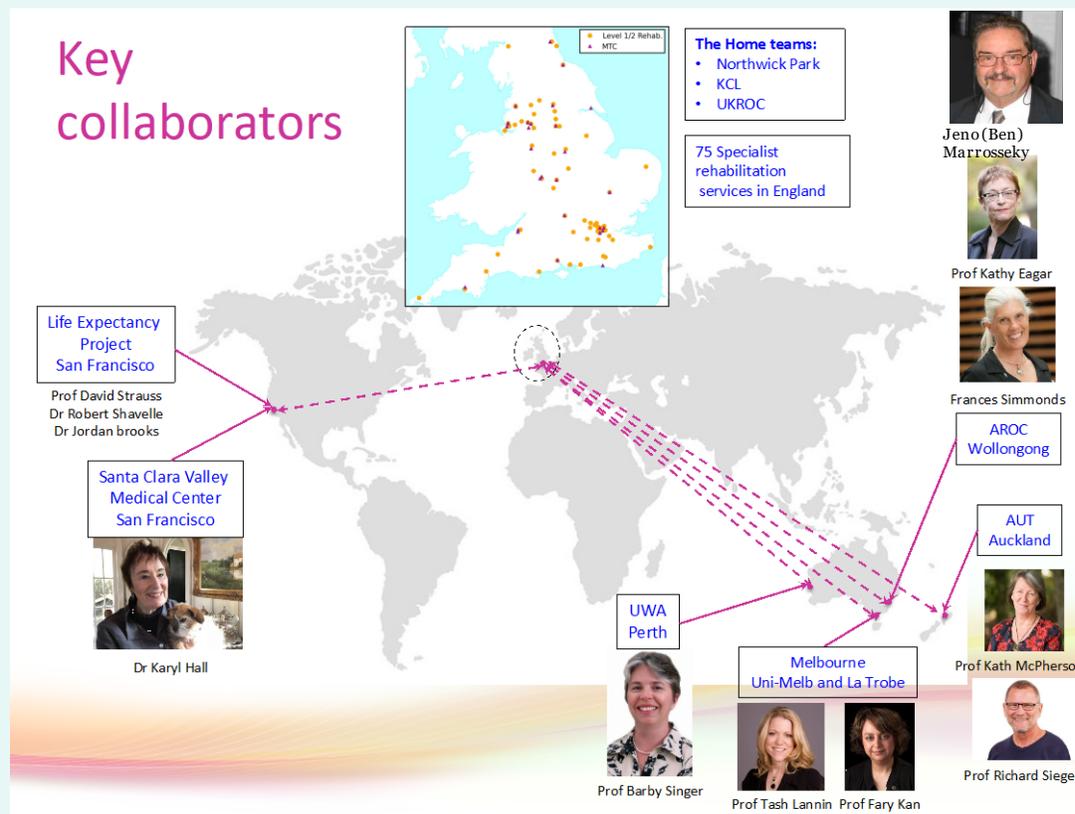# Problems with FIM as basis for casemix

- 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

Key collaborators

The Home teams:
- Northwick Park
- KCL
- UKROC

75 Specialist rehabilitation services in England

Life Expectancy Project San Francisco
Prof David Strauss
Dr Robert Shavelle
Dr Jordan brooks

Santa Clara Valley Medical Center San Francisco
Dr Karyl Hall

UWA Perth
Prof Barby Singer

Melbourne Uni-Melb and La Trobe
Prof Tash Lannin Prof Fary Kan

AROC Wollongong

AUT Auckland

Prof Kath McPherson

Prof Richard Siegert

Jeno (Ben) Marrosseky

Prof Kathy Eagar

Frances Simmonds

UKROC Extended Dataset

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

Parameter	Measure
Complexity of needs for rehabilitation	The Rehabilitation Complexity Scale (RCS-E)
Inputs provided to meet those needs	The Northwick Park nursing and therapy Dependency Scales (NPDS / NPCNA, NPTDA)
Outcomes	The UK FIM+FAM Reduction in care needs and costs
Episode costs	Complexity-weighted bed-day cost Based on the Rehabilitation Complexity Scale
Cost-efficiency	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	• Basic self care • Special nursing needs
Therapy Needs	• No. of different disciplines • Intensity of input • Special facilities / equipment
Additional medical needs	• Medical support environment • (eg 24 hour emergency care) • Procedures / investigations
Length of programme	• Bed days

Item	Description	Range
C	Basic care needs	0-4
N	Special nursing needs	0-4
T	Therapy needs • No of disciplines • Intensity of treatment	0-4 0-4
M	Medical needs	0-4
E	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
After		
1 live-in carer (£1250 / week)	}	(= £5,000/month)

- 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

Turner Stokes et al BMJ Open. 2016 :e011157

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)
	Mean Value		
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

OPEN

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

Lynne Turner-Stokes, DM, FRCP; Mendwas Dzingina, PhD; Robert Shavelle, PhD; Alan Bill, BCom; Heather Williams, MSc; Keith Sephton, BSc(Eng), ACGI

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

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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

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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