Institution: King's College London		
Unit of Assessment: 3		
Title of case study: Transforming specialist rehabilitation services by demonstrating that they provide value for money		
Period when the underpinning research was undertaken: 2001 – 2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	**Role(s) (e.g. job title):**	**Period(s) employed by submitting HEI:**
Prof Lynne Turner-Stokes	Professor of Rehabilitation Medicine	2001- to date
Dr Mendwas Dzingina	Lecturer in Health Services Research and economics	May 2018 – Sep 2019
Dr Stephen Ashford	NIHR Clinical Lecturer (Honorary at KCL)	2012 – to date
Period when the claimed impact occurred: 1 August 2013 – 31 December 2020		
Is this case study continued from a case study submitted in 2014? N		

1. Summary of the impact

As acute NHS services get ever better at saving lives, so more patients with very severe neurological illness or injury are surviving. Sadly, some will require care for the rest their lives. Prior to our research, attention and funding were focused on acute frontline services. The NHS had no systematic information to identify patients requiring complex rehabilitation, nor to quantify the cost and benefits derived from it. King's developed and validated a novel method for evaluating cost-efficiency of rehabilitation, and a robust set of tools for use in routine clinical care to identify and match rehabilitation programmes to individual patient needs, measure outcomes and demonstrate value for money. We found that specialist in-patient rehabilitation for profoundly disabled patients is highly cost-efficient, with average net life-time savings in care costs exceeding £670,000 per patient. Our tools are now incorporated into the NHS national mandated clinical database to benchmark quality and outcomes for all specialist rehabilitation services in England. This work transformed NHS commissioning of specialist rehabilitation services; replaced the payment model to improve provision of services for patients with complex needs; underpinned calls for a substantial increase in rehabilitation beds. It led to the first national audit of specialist rehabilitation service provision; and increased NHS funding and service capacity for this most vulnerable group of patients. Our tools have been adopted internationally, and adapted for the rehabilitation of patients following intensive care during the COVID-19 pandemic.

2. Underpinning research

Specialist rehabilitation for patients with profound neurological disability can be expensive but, by improving their ability to function independently, it can provide the NHS value for money by reducing the costs of long-term care in the community. However, patients vary widely in their needs for rehabilitation – there is no 'one-size-fits-all'. For effective commissioning the NHS needs to be able to match rehabilitation to individual patient needs and measure the cost-savings directly. King's researchers set out to develop a system to evaluate the cost-efficiency of rehabilitation in terms of reduction in long term care costs, and to build ongoing evaluation into NHS data collection in routine clinical practice. This major research programme was led by Professor Lynne Turner-Stokes from 2001 to 2020, conducted in partnership with Northwick Park Hospital.

The need to match rehabilitation inputs to complexity of needs. First, in a proof-of-principle study we developed a novel method for evaluating cost-efficiency of rehabilitation based on our tool The Northwick Park Care Needs Assessment (NPCNA). This single centre cohort analysis of nearly 300 patients admitted for specialist rehabilitation following acquired brain injury established, for the first time, that highly dependent patients with the most complex needs were in fact the most cost-efficient group to treat, despite longer lengths of stay and higher rehabilitation costs, due to the greater reduction of care costs **[1]**. The study emphasised the requirement to match

rehabilitation to the complexity of needs in order to optimise outcomes, and to measure savings in care costs as well as functional ability. This was an important result as these highly dependent patients often fall below the floor of standard functional independence measures, and so would not get into rehabilitation programmes in many countries (e.g. USA, Australia).

Refining of simple tools to measure needs, inputs and outcomes in routine practice. We then set up the UK Rehabilitation Outcomes Collaborative (UKROC) (with a 7-year NIHR Programme Grant, 2008-2015) in partnership with collaborators in the US, Australia and New Zealand. The programme initially involved psychometric validation and further iterative development of a robust set of tools **[2]** to measure (at individual patient-level):

- a patient's needs for rehabilitation (The Rehabilitation Complexity Scale (RCS-E))
- the inputs provided to meet them (The Northwick Park Nursing and Therapy Dependency Scales)
- outcomes and cost-efficiency (The UK Functional Assessment Measure and the NPCNA)

Importantly, these tools were designed to be simple and timely for use in routine clinical practice **[2]**. They were then incorporated into the national UKROC clinical database. Subsequently, we used these tools to systematically collect consecutive case-episode data for all patients admitted to specialist inpatient rehabilitation services in England, to determine whether our proof of principle study findings **[1]** were replicable across centres and conditions other than acquired brain injury.

Using these tools to demonstrate value for money of specialist rehabilitation. Our 2016 national 5-year cohort analysis of 5739 patients **[3]** did indeed replicate our earlier findings on cost-efficiency **[1]**. Conducted across 62 centres and including patients with all neurological diagnoses, we showed that the initial costs of rehabilitation (which averaged £37,158) were offset in just 18 months by savings in the on-going costs of care. Once again, highly dependent patients were the most cost-efficient group to treat, with rehabilitation costs offset in just 14.2 months compared with 22.3 and 27.7 months respectively in medium- and low-dependency patients.

A potential weakness of this argument is that more severely disabled patients have a reduced life-expectancy, and so fewer years in which the NHS benefits from cost savings. We worked with the US Life Expectancy Project to estimate life-time savings allowing for disability-adjusted life expectancy. Our 8-year economic cohort analysis of patients with traumatic brain injury found (i) that specialist rehabilitation led to mean net life-time savings of £679,776 per patient **[4]** with total savings of over £4bn from the population-based sample; and (ii) that the greatest savings are made in the most dependent group *despite* their shorter life span. Few other NHS interventions match these cost-savings. King's thus showed clearly and for the first time that, despite greater resource requirements, treating patients with complex rehabilitation needs provides excellent value for money. This led to the question: given finite NHS resources, how should they be split across patients with different levels of needs, and what constitutes fair payment for treating a more complex caseload of patients?

Translation into commissioning tools. 'Case-mix' classifications are used in healthcare to understand the nature, complexity and differential costs of treating different groups of patients. They form the basis for pricing used by commissioners to provide fair payment to hospitals and other healthcare providers for the patients they treat. The standard NHS case-mix system uses Healthcare Resource Groups (HRGs) based on different diagnoses, but diagnosis is a poor indicator of rehabilitation cost. We developed a new case-mix and payment model based on our Rehabilitation Complexity Scale (RCS-E), to account for complexity of rehabilitation needs **[5]**. We demonstrated that the RCS-E is a valid and reliable measure of rehabilitation resource requirements, that it identifies those patients with complex needs, and quantifies the differential cost of providing for them. We used the RCS-E to develop a costing methodology using a novel complexity-weighted multi-level pricing model **[2]**, which ensures fair payment for purchasers and providers and is also sensitive to change in patient needs over time.

This research focussed on in-patient rehabilitation, but patients with complex needs also require on-going rehabilitation and support in the community. We therefore developed an equivalent tool for community-based rehabilitation - the Needs and Provision Complexity Scale (NPCS). This provides a directly costable measure of both met and unmet needs for rehabilitation and social support in the community, and was shown to be valid and reliable. Funded through an NIHR

Service Development and Organisation grant, we applied the NPCS in a pan-London multicentre cohort study, highlighting significant gaps in community services provision. We demonstrated that the lack of investment in rehabilitation and support in the first year after discharge from hospital (averaging £4110 per person) was associated with increased mean costs in care needs and adapted accommodation amounting to £14,559 per person. Thus the 'saving' of £4K from not providing rehabilitation results in a 2.5 fold net increase (£10K) in expenditure on care costs in that first year alone **[6]**.

3. References to the research

1: Turner-Stokes, L., Paul, S. & Williams, H. (2006). *Efficiency of specialist rehabilitation in reducing dependency and costs of continuing care for adults with complex acquired brain injuries*. Journal of Neurology, Neurosurgery & Psychiatry, 77**,** 634-9. *(Impact factor (IF) 7.144).*

2: Turner-Stokes, L., Vanderstay, R., Eagar, K., Dredge, R. & Siegert, R. J. (2015). *Cost-efficient service provision in neurorehabilitation: defining needs, costs and outcomes for people with long-term neurological conditions*: Programme grant report (RP-PG-0407-10185). London: NIHR.

3: Turner-Stokes, L., Williams, H., Bill, A., Bassett, P. & Sephton, K. (2016). *Cost-efficiency of specialist inpatient rehabilitation for working-aged adults with complex neurological disabilities: a multicentre cohort analysis of a national clinical data set*. *BMJ open,* 6**,** e010238. *(IF 2.413)*

4: Turner-Stokes, L., Dzingina, M., Shavelle, R., Bill, A., Williams, H. & Sephton, K. (2018). *Estimated life-time savings in the cost of on-going care following specialist rehabilitation for severe traumatic brain injury (TBI) in the UK*. J. Head Trauma Rehabil DOI:10.1097/HTR.0000000000000473. (*IF 3.406*)

5: Turner-Stokes, L., Williams, H. & Siegert, R. J. (2010). *The Rehabilitation Complexity Scale version 2: a clinimetric evaluation in patients with severe complex neurodisability*. Journal of Neurology, Neurosurgery & Psychiatry, 81**,** 146-53. *(IF 7.144)*

6: Turner-Stokes, L., Mccrone, P., Jackson, D. M. & Siegert, R. J. (2013). *The Needs and Provision Complexity Scale (NPCS): a multicentre prospective cohort analysis of met and unmet needs and their cost implications for patients with complex neurological disability*. BMJ Open 3(2). pii: e002353. DOI: 10.1136/bmjopen-2012-002353. *(IF 2.413)*

4. Details of the impact

Until recently, rehabilitation was poorly understood by most clinicians, commissioners and policy makers. The Department of Health had no way to identify which patients required specialist rehabilitation, or whether they got the care needed: while aware of insufficient capacity to meet demand, the NHS could not quantify the shortfall, let alone cost a business case to address it. Before gathering longitudinal outcome data for rehabilitation in routine practice, consensus was first required on what to measure and how to collate data. King's developed a robust toolset for real-life clinical settings, and established the UKROC national clinical database for specialist rehabilitation. These tools were adopted by NHS England (NHSE) to collect data on every patient admitted for specialist rehabilitation. Using this data, King's have built a strong evidence base for the effectiveness and cost-efficiency of rehabilitation, and demonstrated the value of systematic data collection in routine clinical practice to evaluate the long-term benefits of rehabilitation to individuals and society. Our approach has been widely taken up at clinical and policy level, nationally and internationally, and changed UK rehabilitation service commissioning, with ultimate benefit to patients and their families.

Impact on commissioning

The infrastructure for commissioning specialist rehabilitation services has been transformed: In 2013, NHSE's Specialised Services Programme was set up to reduce variation in service provision for patients with complex needs. Our research on cost-efficiency was a key part of the evidence used to justify centralised commissioning of specialised rehabilitation services for patients with very complex needs, to provide more equitable access across the country **[A]**. All 32 tertiary specialised in-patient rehabilitation services in England are now commissioned directly by NHSE **[A]**. These services cater for about 2400 patients a year at annual cost of £130m. In addition, 39 district specialist rehabilitation services now cater for a further 2710 patients/year at a cost of £87m, paid for by the local Clinical Commissioning Groups (CCGs) **[B, C]**.

Adoption of our tools and the UKROC database by NHSE for commissioning: As the NHS had no reliable data on specialist rehabilitation activity or costs, NHSE used our research data from

2013/14 to inform its national commissioning programme. In 2015, the UKROC database was formally adopted by NHSE and is now used directly to provide the national commissioning dataset for specialist rehabilitation across England, creating an invaluable resource **[B]**.

- Registration with UKROC and submission of the full UKROC dataset is now a mandated requirement for all inpatient specialised rehabilitation service commissioned by NHSE **[A]**.
- Recommendations for national clinical standards published by the British Society of Rehabilitation Medicine (BSRM) endorsed the approach, which was also taken up by CCGs for commissioning of local specialist rehabilitation services **[D.1]**. As the BSRM President explained, "(this*) research demonstrating the cost-efficiency of rehabilitation has been pivotal in making the case for further development of rehabilitation services*" **[D.2]**.
- By 2018, all 71 Specialist Level 1/2 rehabilitation services in England were routinely collecting and reporting the UKROC dataset, which now has over 50,000 registered case episodes **[B]**.
- UKROC provides quarterly comparative benchmarking reports on quality, outcomes and cost-efficiency for the NHS, using our tools as the key quality indicators **[A]**.
- Since April 2017, UKROC data flow directly to the National Clinical Data Repository held by NHS Digital with potential for linking with other national datasets **[B]** (see also below).

Adoption of our complexity-weighted payment model and costing data: The lack of a suitably sensitive case-mix and payment model was a significant barrier to providing services for patients with complex needs. From 2013/14, NHSE adopted our multi-level weighted bed day (WBD) payment model as the national mandated commissioning currency for all specialist rehabilitation services in England **[A]**.

- Using costing data derived from the UKROC database, it also published indicative complexity-weighted tariffs based on serial collection of our Rehabilitation Complexity Scale (RCS-E).
- This WBD currency model is mandated under the NHSE contract **[A]** and NHSE with NHS Improvement (NHSI) have recently used updated data from UKROC to publish uplifted tariffs in their 2019/20 NHS pricing guide **[E]**. The uplift of over 10% recognised the extent of under-commissioning in previous years and NHSE/NHSI commitment to address this.
- In 2019, the community equivalent of the RCS-E (the Needs and Provision Complexity scale) was adopted by NHSE/NHSI as basis for community currencies for long term conditions **[F]**.

Impact on NHS Policy, planning and service delivery. Despite these developments, in-patient rehabilitation bed capacity is still insufficient to meet demand, which in turn leads to bed-blockage in acute services. Several high-level policy documents, including NHSE's Commissioning Guidance for Rehabilitation **[C]** and an All Party Parliamentary Group for Acquired Brain Injury **[G]** used our research and cost-efficiency model to call for a substantial increase in rehabilitation beds. However, without a robust national clinical and commissioning database there was no way to quantify the population level shortfall or to estimate the cost of addressing this. In 2012/13 the Major Trauma and Stroke Clinical Networks were established and focused on acute and frontline services, not rehabilitation. This considerable under-investment in rehabilitation, especially for those with highly complex needs, was later acknowledged and in 2014 the NHSE Service specification for Major Trauma centres advocated the use of a Rehabilitation Prescription (RP) for patients requiring on-going rehabilitation. However, they did not define how to develop these. The BSRM Core Standards for Specialist Rehabilitation in the Trauma Pathway (with King's contributing) now recommend these tools, including the RCS-E, as the basis for a Specialist Rehabilitation Prescription to identify patients with complex rehab needs **[H]**.

In 2015, the Health Quality Improvement Partnership (HQIP) commissioned a National Clinical Audit of Specialist Rehabilitation following Major Injury (NCASRI) as part of its government mandated NCAPOP (National Clinical Audit and Patient Outcomes Programme). This used our tools to identify patients leaving the acute major centres with complex needs requiring further specialist rehabilitation, and linked data from the Trauma and Audit Research Network (TARN) database and UKROC to determine whether they got the rehabilitation they needed **[I]**. In 2017, the UKROC database was adopted by NHSE and acquired registry status, enabling collection of identifiable data (via NHS number). The research output became an impact in its own right **[J]** and, for the first time, individual patients could be tracked throughout their rehabilitation journey to see if they got the services they needed. The final (2019) NCASRI report used our tools and

methods to quantify the shortfall in capacity (an estimated 330 beds), and estimate the potential NHS cost savings (over £500m a year), strengthening the argument to meet this unmet need **[I]**.

Benefits to patients. Our research is already starting to support national expansion of services, giving more equitable access to the rehabilitation people need. Between 2015 and 2018, NHSE and local commissioners (CCGs) invested a combined total of £16.8m of new money in these services, creating 67 additional beds - of which 40 were provided locally, enabling more patients to have specialist rehabilitation closer to their home and families **[B]**. Over 5000 patients per year now benefit from specialist inpatient rehabilitation **[B]**, and, although this is a relatively small population, our research has reached all of them: the needs of all patients are now systematically captured so that their rehabilitation programme is tailored to their requirements. We have improved the lives of patients by bringing rehabilitation to the forefront of NHS planning. The 2016 NHSE's Commissioning Guidance for Rehabilitation highlights our research on cost efficiency **[C]**, and Sir Bruce Keogh, NHSE National Medical Director, said *"Rehabilitation is now central to the way we deliver health services"* **[C]**. As the BSRM President observes, *"The work of Professor Turner-Stokes has been ground-breaking in placing rehabilitation at the forefront of NHS planning to improve the lives of disabled patients and their families"* **[D2]**.

International impact. Following national implementation in the UK, other countries are increasingly interested in adopting the dataset, its tools or both. The World Health Organisation (WHO) Guidelines for Rehabilitation, published in 2017, rely on our evidence for cost efficiency **[K]**. Our tools have also been translated in languages including Danish and Italian, and shown to maintain validity and inter/intra-rater reliability in other countries **[L]**. For example, our costing algorithm for community care cost savings was adapted to show cost-efficiency in Australia **[L3]**.

Responding to COVID-19. During the COVID-19 pandemic the BSRM released guidelines for rehabilitation of patients recovering from infection, citing our research on cost-benefits and recommending use of the Rehabilitation Prescription incorporating the RCS-E **[M1]**. The tools were also implemented in the *Framework for assessing early rehabilitation needs in patients following treatment in intensive care* published by the National Post-intensive Care Rehabilitation Collaborative hosted by the Intensive Care Society **[M2]**.

5. Sources to corroborate the impact

[A] NHSE Standard Contract D02/S/a For Specialised rehabilitation for patients with highly complex needs. 2013. **[PDF]**
[B] UK Rehabilitation Outcomes Collaborative Triennial report 2015-18. **[PDF]**
[C] Commissioning Guidance for Rehabilitation. NHSE 2016. **[PDF]**
[D] Evidence of BSRM endorsement. **D1** Specialist neurorehabilitation services: providing for patients with complex needs, 2015. **D2** Testimonial from the BSRM President **[PDF]**
[E] The 19/20 National Tariff Payment System. NHSE 2019. AnneX DtC. **[PDF]**
[F] A new approach to supporting community healthcare funding. NHSE 2019 **[PDF]**
[G] Time for Change 2018: All Party Parliamentary Group on Acquired Brain Injury Report
[H] **H1** NHS Standard contract for Major Trauma Services. **H2** Specialist rehabilitation in the Trauma pathway: BSRM core standards **[PDF]**
[I] National Clinical Audit of Specialist Rehabilitation following major Injury: Final Report **[PDF]**
[J] UKROC Database: https://www.kcl.ac.uk/cicelysaunders/research/studies/uk-roc/index
[K] WHO: Rehabilitation in Health Systems 2017 (Refs 12, 39-41,65, pages 56,59, 73) **[PDF]**
[L] International application of UKROC tools: **L1** Maribo et al. *Assessment of primary rehabilitation needs in neurological rehabilitation: translation, adaptation and face validity of the Danish version of Rehabilitation Complexity Scale-Extended.* BMC Neurology 2016.**16**:205 **[PDF]**; **L2** Roda F, et al. *Psychometric validation of the Italian rehabilitation Complexity Scale extended - Verson13*. PLoS One. 2017 Oct 18;12(10). **[PDF]**; **L3** Lannin N et al. *Cost efficiency of inpatient rehabilitation following acquired brain injury. A first Australian adaptation of the UK approach.* Conference abstract. Rehabilitation Medicine Society of Australia & New Zealand. 2019.
[M] Rehabilitation guidance developed during the Covid-19 pandemic: **M1** BSRM, "Rehabilitation in the wake of Covid-19 – A phoenix from the ashes" **[PDF]**; **M2** National Post-Intensive Care Rehabilitation Collaborative COVID-19 Framework **[PDF]**.