

INPA Outcomes Study

Evaluation and recommendations from **INPA** of
a selection of measures used in the independent sector

What is the Independent Neurorehabilitation Providers Alliance?

The Independent Neurorehabilitation Providers Alliance (**INPA**) is a membership organisation for specialist health and social care providers who share the common goal of ensuring the delivery of excellent care in neurorehabilitation. This goal is pursued by **INPA** through a process of setting standards and inspections of member services, through education and training programmes for clinicians, and via research and innovation to improve neurorehabilitation.

INPA members have an agreed set of quality standards to ensure that neurorehabilitation



is delivered in quality environments, by trained and experienced staff in a caring way in order to achieve optimum outcomes.

Impact of brain injury

Outcomes arising from acquired brain injury are wide ranging, diverse and difficult to predict. People with a brain injury can experience a range of physical, cognitive, functional, behavioural, social and emotional changes. Outcomes can change over time, in the days, weeks, months and even years after the injury, all of which can profoundly affect a person's independence.

Neurobehavioural disability

Neurobehavioural disability can present itself in many ways, from profound behavioural changes, such as overt aggression, to disabilities which have more a subtle expression, including lack of empathy, poor

ability to read social cues - leading to 'odd' behaviour, and difficulties engaging in activity. Social handicap that is secondary to neurobehavioural disability takes the form of reduced independence through challenging behaviour. In the longer term, it can lead to a reduced quality of life through reduced social contact and employment opportunities, constraints in education, changes to family roles and dynamics, and reduced living standards. These frequently exert a catastrophic impact on the individual with a brain injury and their friends, families and colleagues, which may result in increased contact with psychiatric and forensic services. Overall, the presence of neurobehavioural disability is associated with a poor prognosis.



Neurobehavioural rehabilitation

Neurobehavioural rehabilitation is a neuropsychological intervention conducted by multidisciplinary teams to address the broad spectrum of neurobehavioural disability. The aim is to alleviate social handicap arising from neurobehavioural disability, to restore as much autonomy to the person with brain injury as possible and to integrate them back into the community.

A complex process of assessment, treatment and management makes up the foundations of neurobehavioural rehabilitation.

Patients (and their families/carers) are supported to achieve their maximum physical, psychological and social potential to maintain and improve their quality of life. It incorporates cognitive, behavioural and social psychology to promote functional and social skills.

Challenges for neurobehavioural rehabilitation services

In order for services to be effective, they must:

- Determine patient needs and the complexity of care they require
- Reliably assess improvements in neurobehavioural disability over time
- Demonstrate neurobehavioural rehabilitation is effective
- Justify the cost-benefits and value of rehabilitation

One way services can achieve this is through the use of outcome measures. Consequently, it is of upmost importance that services have access to a range of outcome measures that are suitable and effective in the context of neurobehavioural rehabilitation.

Outcome measures

What are the options?

Many outcome measures have been developed, usually in the form of questionnaires and rating scales, which have been scientifically determined and have robust psychometric properties (reliability, validity and responsiveness). Due to the wide range of outcomes after brain injury, researchers and rehabilitation services typically incorporate a number of these tools into a basket of outcome measures. However, owing to a lack of guidance specifically tailored for neurobehavioural rehabilitation services, variation inevitably exists across both baskets and services.

What guidance is currently available?

In the UK, guidance is currently offered by the Rehabilitation Outcome Collaborative (UKROC), an initiative funded by the Department of Health. Established to develop a national database for collating case episodes for specialist inpatient neurorehabilitation, UKROC utilises a basket of measures to determine the complexity of patient needs, rehabilitation inputs to meet these needs, and outcomes achieved. A further goal of the collaborative was to develop a multiple level tariff that standardises the fee per patient bed day dependent on the complexity of needs defined by the various measures.

Whilst there is undoubtedly merit in the approach, INPA members felt that there may be shortcomings in applying a 'one size fits all' basket of outcome measures across the diversity of specialised services operated by its members. In particular, INPA members were concerned that measures in the UKROC basket would not necessarily be sensitive to the additional complexities of neurobehavioural rehabilitation, such as how services are staffed and organised.



INPA outcomes study

To address these concerns, **INPA** members formed a collaborative project to explore the measures currently used across their respective services in order to assess both their suitability for capturing the diverse characteristics of neurobehavioural disability, and the effectiveness and outcomes of neurobehavioural rehabilitation. It was hoped that the results of the project could then be used to further inform national initiatives, such as UKROC.

Why is the **INPA** outcomes study important?

Ensuring the appropriate measures are selected will assist commissioners in judging and benchmarking services. This will help ensure patients are getting what they need and in determining best value when spending public funds. In addition, **INPA** believes the information generated by the study can further be used to help commissioners, service providers, clinicians and families gain a better understanding of the strengths, limitations and scope of each measure. **INPA** explored the validity, reliability and responsiveness of each measure so services that use these measures can easily be identified to commissioners as providing an accurate representation of their services.

Summary of findings

Detailed findings are available here www.in-pa.org.uk/research

Aims of study

- To review the validity, reliability and responsiveness of outcome measures used in neurobehavioural rehabilitation
- To advise on what measures can meaningfully be used to determine needs, rehabilitation inputs and outputs arising from neurobehavioural rehabilitation

What measures were studied?

Data was collected from four outcome measures used for determining change over time in levels of impairments and disability through repeated assessment, especially in rehabilitation:

- UK Functional Independence Measure & Functional Assessment Measure (UK FIM + FAM)
- St Andrews-Swansea Neurobehavioural Outcome Scale (SASNOS)
- Health of the Nation Outcome Scale (HoNOS-ABI)
- Mayo-Portland Adaptability Inventory-4 (MPAI-4)

Data was also collected for measures of complexity and rehabilitation inputs:

- Rehabilitation Complexity Scale – Extended (RCS-E)
- Supervision Rating Scale (SRS)

Who participated?

- 14 **INPA** services
- Repeated measures were available for 123 individuals
- Age range 18-79, average 43.9 years
- Time since injury ranged from 0-21 years, with 65.9% being admitted within 12 months or less
- 78.9%, (97) males vs. 21.1% (26) females
- Primary type of brain injury was traumatic brain injury (44.7% of total sample), with cardiovascular accident accounting for a large number of diagnoses (20.3%)



What did we find?

- All outcome measures demonstrated that they were a valid means of tracking change in levels of impairment and disability attributable to participation in neurobehavioural rehabilitation, especially UK FIM+FAM, SASNOS and MPAI-4.
- The relationship between measures of clinical complexity and input with those tracking change achieved through neurobehavioural rehabilitation was variable. In particular, ratings on the RCS-E tended to underestimate the level of need actually provided.

What are our main preliminary recommendations?

- The four outcome measures concerned with tracking change through repeated assessment are valid and useful in determining outcomes in neurobehavioural rehabilitation as they differ in what they measure; each can be used to answer different questions.
- The variable relationship between the measures of input and change is of concern, especially if these are used to classify the complexity of needs services manage and the rehabilitation inputs, as this is likely to underestimate costs. It is recommended a measure is constructed specifically for this purpose – this will be a future **INPA** project.

Further information and the results of the full analysis of the outcomes study can be found at www.in-pa.org.uk/research.

Functional Independence Measure and Functional Assessment Measure UK



What is it? FIM is a global measure of disability, which can be scored alone or alongside FAM as an additional measure, addressing cognitive and psychosocial functioning. The combination of the two (UK FIM+FAM) is designed to measure disability in individuals with brain injury.

What is in it? 30 items cover a range of everyday functions and competencies (e.g. eating, comprehension, memory) to create a total score as well as motor and cognitive/psychosocial subscales. An additional six items relate to extended activities of daily living (EADL; e.g. meal preparation, housework).

How to use it

UK FIM+FAM should be completed by a multidisciplinary team upon admission, with a goal score option, and before discharge (see figure 1). Items are scored from 0 (total assistance) to 7 (complete independence) with lower scores indicating greater disability. Training is recommended and is compulsory for members of UKROC.

Turner-Stokes, L., Nyein, K., Turner-Stokes, T., & Gatehouse, C. (1999). The UK FIM+FAM: development and evaluation. *Clinical rehabilitation*, 13(4), 277-287.
www.kcl.ac.uk/nursing/departments/cicelysaunders/resources/tools/fimfam.aspx

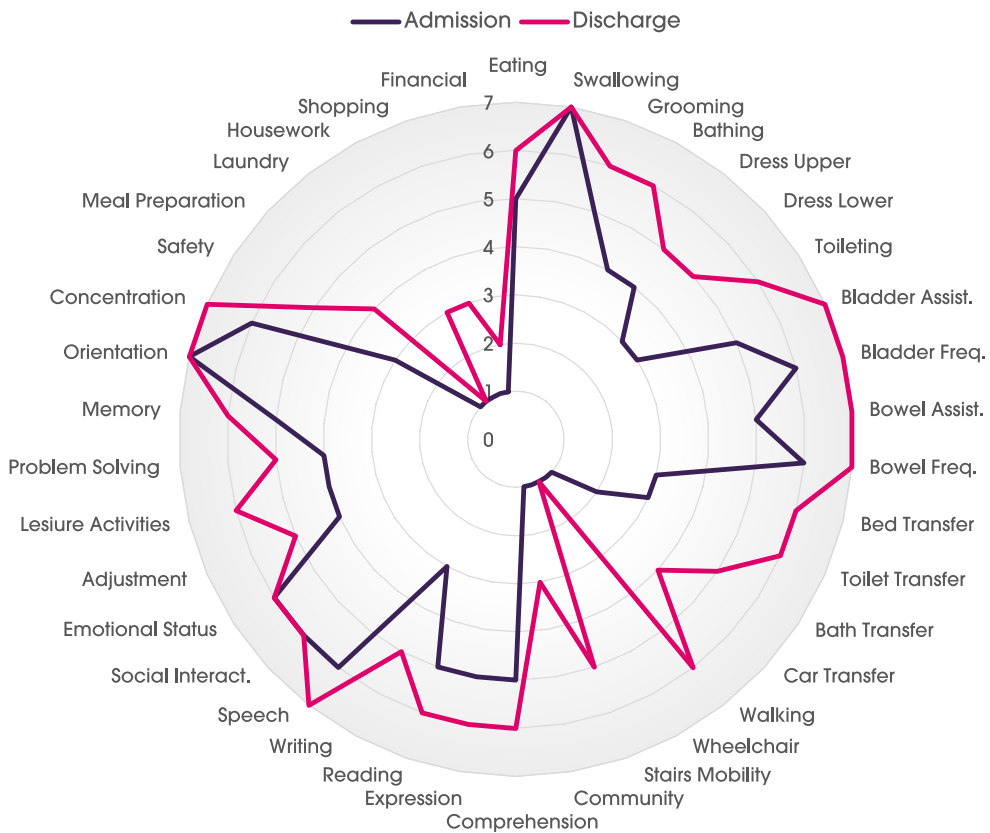


Figure 1. Radar chart of admission and discharge scores for each item of the UK FIM+FAM

St. Andrews-Swansea Neurobehavioural Outcome Scale

What is it? The SASNOS was developed specifically for use in brain injury as a meaningful measurement of neurobehavioural disability that could be used in both clinical and research settings.

What is in it? 49 items capture 5 major domains (cognition, inhibition, aggression, interpersonal behaviour and communication), with each major domain containing 2-3 sub-domains. Each item is rated on 7-point scale from 'never' to 'always'.

How to use it

Assessment follows observation of a two week period with both 'self' and 'proxy' versions available. All scores are converted into standardised T scores, with higher scores indicating a greater perception of ability (see figures 2 & 3).

Alderman, N., Wood, R. L., & Williams, C. (2011). The development of the St Andrews-Swansea Neurobehavioural Outcome Scale: Validity and reliability of a new measure of neurobehavioural disability and social handicap. *Brain injury*, 25(1), 83-100.
<https://projects.swan.ac.uk/sasnos/>

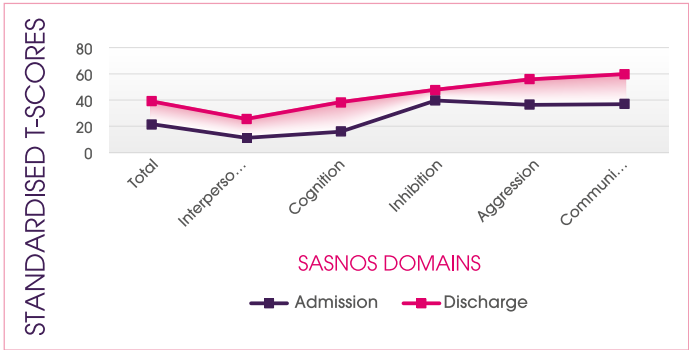


Figure 2. Admission and discharge standardised T-scores for the major domains of the SASNOS

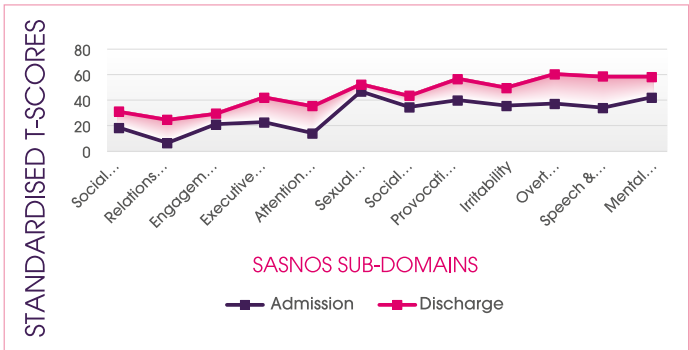


Figure 3. Admission and discharge standardised T-scores for the subdomains of the SASNOS

Health of the Nation Outcome Scale – ABI

What is it? The HoNOS-ABI was adapted from the Health of the Nation Outcomes Scale to assess neuropsychiatric sequelae of brain injury.

Fleminger S, Leigh E, Eames P, Langrell L, Nagraj R, Logsdail S. (2005). HoNOS-ABI: a reliable outcome measure of neuropsychiatric sequelae to brain injury? *Psychiatric Bulletin*, 29, 53–55.
www.rcpsych.ac.uk/pdf/HoNOS_ABI.pdf

What is in it? 12 items reflect a different domain of symptoms (e.g. depression, relationships, living conditions) and are rated on a 5-point scale from 0 (no problem) to 4 (severe/very severe problem).

How to use it

Ratings are based on the most severe problem that has occurred in the previous 2 weeks. Total scores (0–48) are calculated, with higher scores indicating more severe problems. Ratings should be completed by clinicians who know the individual with brain injury well.



Supervision Rating Scale

What is it? The SRS is a measure of the level of supervision an individual with brain injury receives.

What is in it? The SRS is a 13-point scale that can be ranked into 5 levels from Full Time Direct Supervision to Independent.

How to use it

The SRS was designed to be rated by a clinician based on interviews with the individual with brain injury and an individual who has seen first-hand the

level of supervision the individual has needed, by selecting the rating closest to the individual's level of supervision. Ratings should be made on the supervision received, and not what is predicted to be needed.

Boake, C. (1996). Supervision Rating Scale: a measure of functional outcome from brain injury. *Archives of Physical Medicine and Rehabilitation*, 77(8), 765-772.

Mayo-Portland Adaptability Inventory – 4

What is it? MPAI-4 was designed to: (a) assist in the evaluation of individuals with brain injury; (b) aid the understanding of long term outcomes following brain injury, and (c) assist in the evaluation of rehabilitation programmes.

What is in it? 29 items are organised into 3 subscales; abilities, adjustment and participation. An additional 6 items on special needs and circumstances pre- and post-injury.

How to use it

Completed by the individual with brain injury, a significant other or a rehabilitation professional. Each item is scored from 0 (no problem) to 4 (severe problem) and total and subscale scores are calculated and converted to T-scores. Higher scores indicate greater disability (see figure 4).

Malec, J. F., & Lezak, M. D. (2003). The Mayo-Portland Adaptability Inventory (MPAI-4). www.tbims.org/combi/mpai

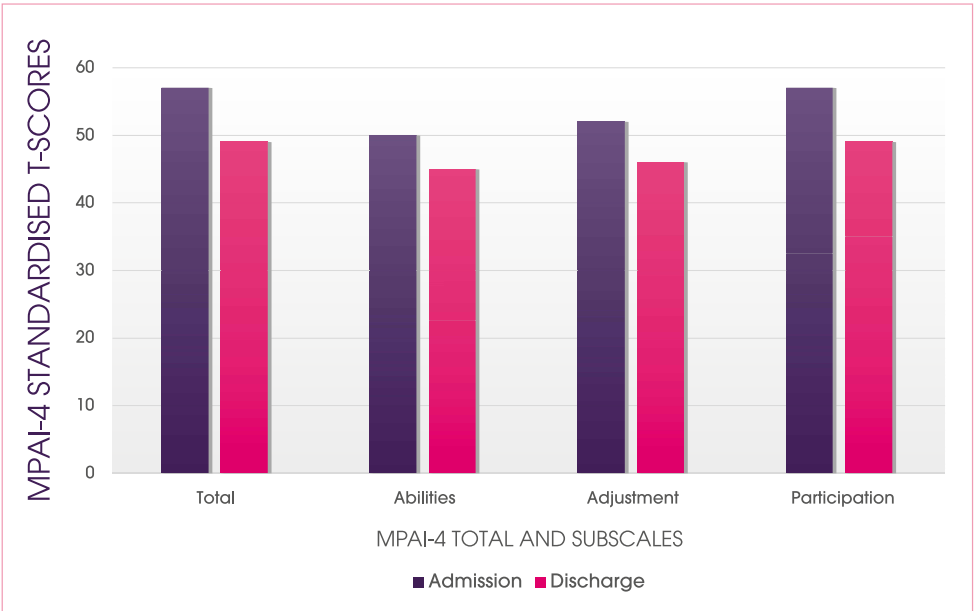


Figure 4. Admission and discharge total and subscale T-scores for the MPAI-4

Rehabilitation Complexity Scale – Extended

What is it? The RCS-E was designed to provide a simple measure of the complexity of rehabilitation needs and/or interventions across a range of rehabilitation services.

What is in it? 22-point measure comprised of 5 sections (e.g. nursing, equipment, therapy). All sections are scored from 0 (no needs) to 4 (very high level of needs), except equipment which is scored 0 (no equipment needs) to 2 (highly specialist equipment). Lower scores indicate a lower level of complex needs.

How to use it

The RCS-E should be completed by a multidisciplinary team on a fortnightly

basis. The final score is the total of the higher value for either the basic support and care section or the risk section and all subsequent sections (see figure 5). However, it is recommended that individual section scores are reported or the use of two subscales; nursing medical care and therapy.

Turner-Stokes, L., Scott, H., Williams, H., & Siegert, R. (2012). The Rehabilitation Complexity Scale-extended version: detection of patients with highly complex needs. *Disability and rehabilitation*, 34(9), 715-720.
www.kcl.ac.uk/nursing/departments/cicelysaunders/resources/tools/rcse.aspx

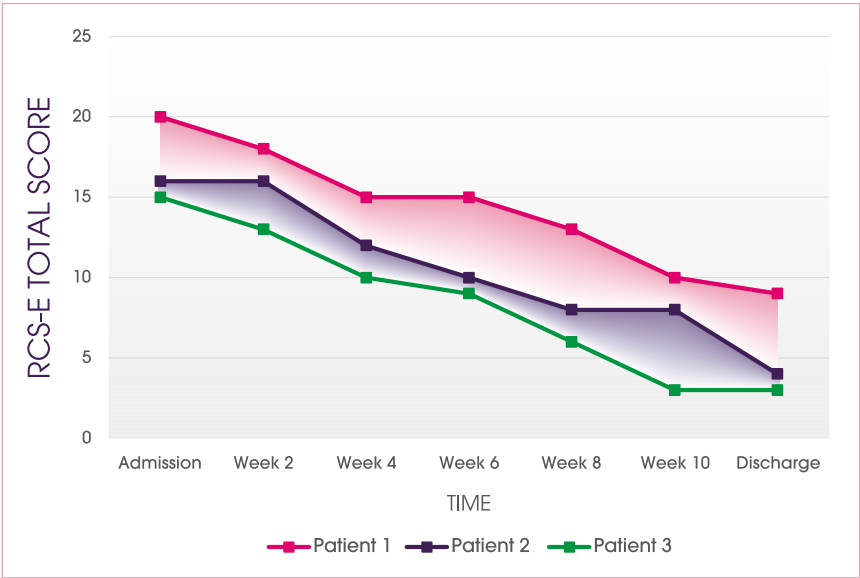


Figure 5. Total scores from admission to discharge for the RCS-E

INPA basket of measures

INPA have reviewed a selection of outcome measures used in neurobehavioural rehabilitation and from this suggests a basket of tools that services may find useful. This basket adds to the suggested measures by UKROC to further capture the effectiveness and outcomes of neurobehavioural rehabilitation.

In addition, this basket has the following benefits:

- Relevant to neurobehavioural rehabilitation
- Captures the rich and varied outcomes after brain injury
- Straightforward to administer and score
- Allows services to select measures that best meet the needs of their patients and service - type, location, setting, population, service goals
- Enables identification of rehabilitative goals
- Allows monitoring of rehabilitation efficacy to ensure patients are getting what they need and in determining 'best value'
- Can detect change through repeated assessment
- Allows rehabilitation progress to be tracked in a standardised manner

Future directions for INPA

- To develop an outcome tool that will capture the clinical input of neurobehavioural rehabilitation.
- To aid the categorisation of specialised neurobehavioural rehabilitation services which describes the level of complexity they could manage and the complexity of their current patients.

INPA welcomes your thoughts about the current outcome measures study as well as the proposed outcome tool. Please share your views via email at info@in-pa.org.uk or on Twitter [@inpalliance](https://twitter.com/inpalliance).

Common abbreviations

ABI	Acquired Brain Injury
INPA	Independent Neurorehabilitation Providers Alliance
NBD	Neurobehavioural Disability
NbR	Neurobehavioural Rehabilitation
UKROC	UK Rehabilitation Outcome Collaborative

Notes

Ensuring the delivery of expert care

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