Institution: Swansea University

Unit of Assessment: 04

Title of case study: Improving Outcome Assessment in Acquired Brain Injury: The St Andrew's – Swansea Neurobehavioural Outcome Scale

Period when the underpinning research was undertaken: 2008 – 2018

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:
Claire Williams	Research Assistant, Research Officer, Lecturer, Senior Lecturer, Associate Professor	01.10.2007-present
Rodger Ll Wood	Professor, Emeritus Professor	20.08.2001-present
Nick Alderman	Honorary Senior Lecturer, Honorary Professor	01.11.2003-present.

Period when the claimed impact occurred: August 2013 – July 2020

Is this case study continued from a case study submitted in 2014? No

1. Summary of the impact

The St Andrew's - Swansea Neurobehavioural Outcome Scale (SASNOS), a research collaboration between Swansea University and St Andrew's Healthcare, is a unique tool supporting health professionals to reliably detect neurobehavioural disability after acquired brain injury; a condition affecting over 1,300,000 people in the UK alone. Filling a significant gap, the SASNOS supports patient care by providing health professionals with the means to identify a person's rehabilitation needs, monitor changes, and evaluate progress over time. SASNOS has been embedded into electronic patient record systems, endorsed by professional/medical organisations, and used by large providers of neurorehabilitation. It is used in at least 18 countries and has been translated into seven languages. It has been requested over 300 times since 2017 by professionals from all sectors and service types. The SASNOS has also supported the establishment of Bangladesh's only Brain Injury Clinic.

2. Underpinning research

More than 1,300,000 people in the UK live with the devastating long-term effects of acquired brain injury (ABI), affecting approximately one family in 300 and representing a cost to the UK economy of around GBP15,000,000,000 a year; equivalent to 0.75% of Britain's Gross Domestic Product or 10% of the annual National Health Service (NHS) budget. ABI has many causes (e.g., road traffic accidents, falls, tumour, stroke, haemorrhage) and can result in a complex pattern of disability comprising disturbances of cognition, mood, and behaviour. The term *neurobehavioural disability* (NBD) is used to capture the range of disabilities that often result in wholesale changes to a person's character or personality. NBD is associated with poor rehabilitation outcomes, social handicap, and reduced quality of life, as well as an increased risk of offender behaviour and contact with forensic services. Consequently, having an assessment tool that can reliably identify specific features of NBD in the early-intermediate stages of recovery, when support is most readily available, helps guide clinical decision making and treatment planning throughout the course of rehabilitation. It also allows the effectiveness of treatment to be evaluated, which is vitally important to establishing cost-effectiveness.

However, owing to a paucity of reliable and sensitive assessment tools, this task has proven challenging for medical and health professionals. A comprehensive review by Williams and Wood (Swansea) and Alderman (Swansea and St Andrew's Healthcare) found that existing tools were plagued by serious psychometric weaknesses. Measures were often based on subjective impressions rather than objective observations, without an underlying theoretical

structure. Consequently, data derived from such tools could not reliably be used in a meaningful way to make a prognosis, or to monitor responses to rehabilitation. The benchmarks that a new tool would have to encompass to accurately identify, and monitor NBD were outlined **[R1]**, with the paper receiving a prestigious Henry Stonnington Award from *Brain Injury*, the official research journal of the International Brain Injury Association.

Williams, Wood and Alderman went on to develop the St Andrew's–Swansea Neurobehavioural Outcome Scale (SASNOS) **[R2]** – a 49-item tool capturing five major domains of NBD (Interpersonal Relationships; Cognition; Inhibition; Aggression; and Communication - each with several sub-domains). In the early development phase (2008-2011), an initial pool of items was generated, based on the World Health Organisation International Classification of Functioning, Disability and Health (WHO-ICF), which was further refined by a content analysis of semi-structured interviews with relatives of ABI patients. Thus, SASNOS differed from existing NBD tools in that it was designed specifically for ABI, aligned with contemporary models of neurorehabilitation, and focused on the objective measurement of a person's behaviour. As the SASNOS does not require highly specialised experts (a neuropsychologist/neurologist) for administration, a multidisciplinary mix of professionals then rated patients with ABI on the refined item set. Comprehensive statistical methods were then applied, including Rasch analysis – a novel approach that had not been applied to NBD previously **[R2]**. A normative data set was also created to aid clinical diagnosis and to allow clinicians to produce a meaningful profile of strengths/weaknesses – an essential feature present in fewer than 40% of existing NBD tools **[R1]**. Utilising 336 sets of ratings, multiple indicators of validity demonstrated that SASNOS ratings recorded perceived symptoms of NBD and could reliably distinguish between individuals with and without ABI. Unlike existing NBD tools, the stability and consistency of ratings over time was also evidenced via multiple indices – inter-rater reliability, test-re-test reliability and Rasch analysis. Thus, two critical psychometric properties of the tool, namely, its validity and reliability, were established.

Owing to its robustness, ease of use, and usefulness to clinical practice, the self-report and proxy-rated versions of SASNOS were soon adopted by several large providers specialising in ABI rehabilitation (e.g., Priory, Partnerships in Care, St Andrew's Healthcare), and were further strengthened by the SASNOS team (2012-2018) by adding a supplementary scoring system to convey the impact of support received on ratings of NBD **[R3]** and by fulfilling the final component of the triumvirate of psychometric properties; responsiveness **[R4]**.

3. References to the research

Internationally, this research has made important contributions, likely to have lasting influence on both the academic field and clinical practice. All papers have been peer reviewed.

R1 - Wood R Ll, Alderman N & **Williams C.** (2008). Assessment of neurobehavioural disability: a review of existing measures and recommendations for a comprehensive assessment tool. Brain Injury, 22, 905-918. DOI: 10.1080/02699050802491271. This publication received a Henry Stonnington Award in 2008, an annual publication prize for the Best Review Articles published in the international Bain Injury journal.
R2 - Alderman N, Wood R Ll & **Williams C.** (2011). The development of the St Andrew's-Swansea Neurobehavioural Outcome Scale: validity and reliability of a new measure of neurobehavioural disability and social handicap. Brain Injury, 25(1), 83-100. DOI: 10.3109/02699052.2010.532849
R3 - Alderman N, **Williams C** & Wood R Ll. (2018). When normal scores don't equate to independence: recalibrating ratings of neurobehavioural disability from the 'St Andrew's – Swansea Neurobehavioural Outcome Scale' to reflect context-dependent support. Brain Injury, 1-12. DOI: 10.1080/02699052.2017.1406989
R4 - Alderman N, **Williams C**, Knight C & Wood R Ll. (2017). Measuring Change in Symptoms of Neurobehavioural Disability: Responsiveness of the St Andrew's - Swansea

Neurobehavioural Outcome Scale. Archives of Clinical Neuropsychology, 1-12. DOI: 10.1093/arclin/acx026

Funding: Development of the St Andrew's–Swansea Neurobehavioural Outcome Scale was underpinned by the following project funding: (1) Wood, Quantitative evaluation of the long-term outcome of neurobehavioural disability and social handicap: Producing a new tool for quantifying cognitive, emotional, behavioural and personality changes resulting from traumatic brain injury, Jul 2006-Mar 2012, GBP82,000 from St Andrew's Healthcare; (2) Williams, SASNOS - Improving outcomes after acquired brain injury, 2016, GBP4,881 from EPSRC Impact Acceleration Account and Swansea University Research Grant Enabler scheme.

4. Details of the impact

The SASNOS has had a demonstrable and wide-ranging impact on clinical practice and patient care. The details surrounding this impact are outlined below:

Widespread National and International Adoption: The SASNOS is used by a diverse set of health professionals (e.g., Psychologists, rehabilitation staff, occupational therapists, nurses, and case managers) to guide care across all ABI treatment pathways **[C1, C2]**. It is also used in medico-legal practice for personal injury and clinical negligence litigation [**C1, C2]**, where it is helping to demonstrate the impact of NBD to inform the courts in relation to compensation payments. It has also been employed as a key outcome measure in research and clinical investigations in Australia, Denmark, and Bangladesh **[C3]**.

The SASNOS can be obtained from a dedicated website and has been requested over 300 times since 2017 (a single request is usually made on behalf of multiple users/a whole service) **[C2]**. It is available in seven languages (English, Welsh, Spanish, French, German, Danish, and Bengali) and has registered users in at least 18 countries – UK, Australia, Canada, New Zealand, USA, Chile, Denmark, Bangladesh, Belgium, the Netherlands, Germany, Norway, India, France, Ireland, Spain, Switzerland and Sweden **[C1 - C4]**. For example, in 2017 the SASNOS was adopted by the only Brain Injury Clinic in Dhaka, Bangladesh. As the only such outcome tool available in Bengali, it is used with 90% of patients (~60-70 per annum) where it is helping to raise "*awareness among stakeholders"* and *"by showing a patient's recovery visually/graphically"* **[C4]**.

The SASNOS has registered users from over 150 public sector services and private health providers in the UK alone, including over 60 NHS Trusts **[C1]**. Lancashire and South Cumbria NHS Trust (ABI service) use the SASNOS for goal setting and to ensure interventions are effective **[C5]** and Accomplish use it (>four years) to monitor progress and outcomes across their ABI residential services (~10 sites, ~80 beds) and to support those with ABI across their Dual Diagnosis and Supported Living pathways (>nine sites, 70+ beds) [C6]. Likewise, Ariya NeuroCare use the SASNOS to monitor rehabilitation progress across their residential, transitional, and community support services **[C7]**.

Supporting Uptake via Training and Dissemination: Complementing instructional/training materials on the SASNOS website, an annual conference was launched in 2016 **[C8]** to provide training with the SASNOS and the assessment/management of ABI. Approximately 450 delegates have benefitted, with independent CPD accredited points awarded since 2018. Examples of delegate feedback include: *"I have learnt a great deal today", "Very useful – thank you very much!"* and *"SASNOS is a useful tool for exploring neurocog difficulties with staff and patents (particularly in groups where there is limited knowledge of the impact)"*.

Filling Clinical Practice Gaps: Unique in its ABI specific design and aligned with contemporary models of neurorehabilitation, the SASNOS provides health professionals with the unique means to identify needs, plan, and monitor change. As reported by the lead for the Community Brain Injury Service at Abertawe Bro Morgannwg University Health Board,

SASNOS *"has filled a significant gap in that it has helped to better identify the less measurable but often more disabling neurobehavioral aspects of traumatic brain injury"* [C9].

Responses from an international survey of SASNOS users (44 respondents from six countries, nine service types, and a range of professions) further highlights how SASNOS is meeting clinical needs **[C2]**:

- Australia - *"Unlike other tools I've tried, the SASNOS allows for self-rating measures"* (Clinical Neurologist, Public Sector).
- UK - *"No other outcome measures are as effective at identifying the often-nuanced difficulties that ABI patients suffer in terms of CB [Challenging Behaviour]"* (Assistant Psychologist, Private Sector).
- Australia - *"It is a validated and standardised measure of NBD for ABI. We are unaware of any other measure that has established reliability and validity in this field"* (Academic and Clinical Neuropsychologist, Public Sector).
- UK - *"It gives a more accurate reading of the difficulties that my clients face on a daily basis"* (Home Manager, Private Sector).

Benefitting Clinical Practice and Patient Outcomes: The SASNOS has demonstrably benefitted clinical practice, with the Clinical Director of Headwise reporting that it is *"the only measure that captures the neurobehavioral legacies of brain injury which undermine social activity and participation, thus providing a unique basis for treatment planning and evaluation".* It *"allows for more accurate clinical decision making, allows for a single metric to be adopted in a service rather than a multiplicity of tools, and helps our services to be more efficient in directing resources and more accurate in predicting outcome"* **[C10]**.

Large providers of neurorehabilitation have also invested considerable resource in using and integrating the SASNOS into their electronic patient record systems as a mandatory assessment. The lead Psychologist & Consultant Clinical Neuropsychologist for St Andrew's Healthcare, who administers the SASNOS ~130 times per year (benefitting ~325 patients since 2011) reports - *"I am not currently aware of another tool that could take its place and its level of integration within our service is now such that it is available to complete on the patient electronic record system"* **[C10]**.

Similarly, a third of all neurological cases and 100% of neurobehavioral pathway admissions at Elysium Neurological (>300 beds) are assessed with the SASNOS. Embedded into their electronic patient record and used to provide service level performance indicators, the SASNOS has increased confidence in care plans and enhanced their team's clinical skills by educating them about the diversity/impact of NBD. In this way, the SASNOS has made a major contribution to risk assessment and management to ensure patient safety [C9]. Equipped to monitor change in NBD symptoms over time, clinical decisions are now informed by a reliable instrument rather than clinical judgement alone. Their Medical Director reports that *"this is enormously important to us as a service as we need to confirm to patients, their families and commissioners that the rehabilitation we provide is effective and good value for money. Both are essential in helping us sustain our business as an effective and cost-efficient provider of rehabilitation services"*. They conclude that the SASNOS *"has resulted in us achieving better outcomes for patients than would otherwise have been the case"* **[C10]**.

Further examples of how SASNOS is benefitting clinical practice include **[C2]**:

- UK - *"It [SASNOS] has proved a useful tool in educating and informing medical teams and other professionals that are not trained in neurology regarding neurobehavioral difficulties / impairments"* (Occupational Therapist, Public Sector).
- Canada - *"Helps show the areas where support is required, along with tools to show improvement"* (Behavioural Therapist, Private Sector).
- UK - *"Seeing whether the interventions we are putting in place have a positive outcome or not is very helpful"* (Principal Psychologist, Private Sector).

Endorsed by Professional Bodies: Recognising its many benefits, the Independent Neurorehabilitation Providers Alliance (19 providers, ~58 clinical units) have recommended that the SASNOS is included in the UK Rehabilitation Outcomes Collaborative database [**S9**], which is used by NHS England to inform funding models and to monitor outcomes and quality of rehabilitation. Importantly, the independent sector supplies ~70% of the 4,600 available beds for people requiring specialist neurorehabilitation – the NHS being the chief consumer **[C11]**. In 2018, the Professional Practice Committee of the Physical and Rehabilitation Medicine (this section of the EU Medical Specialists is 1,600,000 strong) also recommended the SASNOS for goal setting and assessment **[C12]**.

5. Sources to corroborate the impact

C1 - The SASNOS is available here and a record is maintained of requests, evidencing 300+ registrations from 18 countries and a range of sectors/organisations and professions.

C2 - SASNOS End-User Experience Survey report, evidencing international adoption by a range of professionals, sectors, and service types, why and how the SASNOS is used, and how it is benefiting clinical practice and patient outcomes.

C3 - Evidence of the SASNOS being used in research/clinical investigations in Australia (Stolwyk RJ et al. 2018; Brodtmann A et al. 2014; O'Connell EL et al. 2019), Denmark (Soendergaard PL et al. 2019) and Bangladesh (Tamanna FH & Hossain S. 2018.

C4 – Testimonial letter from the Clinical Lead for the Brain Injury Clinic in Dhaka, Bangladesh, evidencing SASNOS adoption, scale of service, and impact claims.

C5 - Lancashire and South Cumbria NHS Foundation Trust (ABI service) website documenting use of SASNOS to monitor the effectiveness of treatment (Accessed 29/11/2020).

C6 - Accomplish website and brain injury brochure documenting use of the SASNOS as a key tool across their ABI services (Accessed 28/11/2020).

C7 - Ayria Neurocare website documenting use of the SASNOS to monitor rehabilitation progress across their ABI services (Accessed 29/11/2020).

C8 - Annual brain injury conference flyers (2016-2019) evidencing training and dissemination activities to support adoption of the SASNOS.

C9 – Testimonial letter from the Lead for the Community Brain Injury Service at Abertawe Bro Morgannwg University Health Board (now Swansea Bay University Health Board), evidencing how SASNOS has filled a significant gap in clinical practice.

C10 – A collection of testimonial letters from the Clinical Director of Headwise, a Lead Psychologist & Consultant Clinical Neuropsychologist for St Andrew's Healthcare, and the Regional Director of Neurological Services at Elysium Healthcare, evidencing how the SASNOS is benefitting clinical practice and patient outcomes.

C11 – Testimonial letter from the Chair of the Independent Neurorehabilitation Providers Alliance, evidencing their recommendation for the SASNOS to be included in the UK Rehabilitation Outcomes Collaborative database.

C12 - Evidence Based Position Paper on Physical and Rehabilitation Medicine professional practice for Adults with Acquired Brain Injury (Pages 132-143) recommending SASNOS for goal setting and assessment (Accessed 28/11/2020).