The St Andrew's – Swansea Neurobehavioural Outcome Scale (SASNOS): End-User Experience Survey

Dr Claire Williams[1], Professor Nick Alderman[12] and Menai Richards[1]

[1] Department of Psychology, College of Human and Health Sciences, Swansea University, Swansea, UK
[2] Elysium Neurological Services, The Avalon Centre, Edison Park Hindle Way, Swindon, Wiltshire, UK

E-mail: claire.williams@swansea.ac.uk

Abstract

The St Andrew's-Swansea Neurobehavioural Outcome Scale (SASNOS) was developed to support health professionals to reliably detect neurobehavioural disability after acquired brain injury. Since its creation, the SASNOS has seen widespread adoption and is routinely used in practice. However, to ensure that the SASNOS continues to meet the needs of its end-users and individuals with ABI, it is important to continually seek end-user feedback regarding its adoption, usage, and utility. To this end, an on-line survey was sent to known users of the SASNOS, with 44 participants completing the questionnaire. Results confirmed that SASNOS is used by a variety of professionals, across a range of service contexts and sector types, and in multiple countries worldwide. It is also used to support individuals with many different forms of ABI, is often part of a services standardised basket of outcome measures, and it is commonly employed to support neurorehabilitation in the broadest form. Additionally, participants free-text responses highlighted a range of benefits from using the SASNOS, evidencing how the tool is having a demonstrable positive impact on both clinical and research practice, and in turn, patient care.

Keywords: Neurobehavioural Disability; Outcome Tools; Assessment; Head Injury; Acquired Brain Injury; Rehabilitation

1. Introduction

Neurobehavioural disability (NBD) after acquired brain injury (ABI) is the product complex interactions between damaged neural systems, neurocognitive functions, and environmental factors, further modified by premorbid personality traits and post-injury learning (Wood, 2001). NBD can take many forms, often comprising elements of executive and attentional dysfunction, poor impulse control, altered emotional expression, labile mood, poor insight, problems of social judgment and awareness, and a plethora of personality changes that impede psychosocial recovery (Kreutzer, Marwitz, Seel, and Serio, 1996; Williams, Wood, Alderman and Worthington, 2020). Behaviour disorders associated with NBD are also enduring, often posing a greater impediment to community reintegration than physical impairments (Alderman and Wood, 2013; Kelly, Brown, Todd, and Kremer, 2008).

Fortunately, there is now a substantial body of high-quality evidence demonstrating the clinical and cost effectiveness of post-acute neurobehavioural rehabilitation (NbR) for reducing NBD and associated social handicap (e.g., Ylvisaker, Turkstra, Coehlo, Yorkston, Kennedy, Moore et al, 2007; Alderman and Wood, 2013; Alderman, Knight and Brooks, 2013; Oddy and da Silva Ramos, 2013). However, whilst effective means of managing NBD have been demonstrated, methods for accurately assessing and measuring NBD must also be available (see Wood, Alderman and Williams, 2008). To this end, the St Andrew's-Swansea Neurobehavioural Disability Scale (SASNOS) was developed (see Alderman, Wood and Williams, 2011) to provide clinicians with a unique basis for treatment planning and evaluation, allowing rapid identification of rehabilitative goals, the detection of meaningful change on repeat assessment, and for the impact of context-dependent support received on ratings of NBD to

be captured (Alderman, Williams, Knight, and Wood, 2017; Alderman, Williams and Wood, 2018).

The SASNOS contains 49 items that capture five major domains of NBD: Interpersonal Relationships; Cognition; Inhibition; Aggression; and Communication. Each domain has two to three subdomains (for example, Aggression consists of Provocative Behaviour, Irritability, and Overt Aggression), with 12 in total. Items comprise a statement regarding a symptom of NBD, rated using a seven-point scale with written anchors ('never' to 'always'). Self- and proxy-versions are available. Total, domain and subdomain ratings are transformed to standard T scores (mean = 50, standard deviation = 10), enabling a balanced assessment of NBD and meaningful comparison of the range of difficulties captured. Higher scores reflect greater perception of ability and fewer symptoms of NBD, with scores below 40 considered exceptional and indicative of potential rehabilitation goals. The SASNOS has robust psychometric properties; inter-rater and test reliability have been established, multiple indices of validity demonstrated (including content, construct, divergent, convergent and discriminant validity) (Alderman et al., 2011), and a number of responsiveness indicators to assist interpretation of change in scores on repeat assessment have been reported (Alderman et al, 2017).

Since its creation, the SASNOS has seen widespread adoption worldwide. It has been embedded into Electronic Patient Record systems, endorsed by professional/medical organisations, and it is routinely used by large providers of neurorehabilitation. It has also supported the establishment of the only Brain Injury Clinic in Bangladesh, has been translated into 7 languages (English, Welsh, Spanish, French, German, Danish, and Bengali), has been requested ca. ~350 times since 2017 alone, and has seen usage in at least 14 countries (UK, Australia, Canada, New Zealand, USA, Chile, Denmark, Bangladesh, the Netherlands, Belgium, France, Ireland, Spain, Sweden). The SASNOS has also been used as a key outcome measure in research examining the prevalence, nature, and biopsychosocial associations of NBD in both ABI and stroke populations (e.g., Brodtmann et al., 2014; Soendergaard, Siert, Poulsen, Wood, & Norup, 2019; Stolwyk, O'Connell, Lawson, Thrift, & New, 2018).

1.1 Study Aims

To ensure that the SASNOS continues to meet the needs of its end-users and individuals with ABI, it is important to continually seek feedback regarding its adoption, usage, and utility in practice. To this end, an end-user experience survey was organised to (1) determine the extent to which the SASNOS is being used by health professionals and service providers around the world; (2) determine the range of contexts and purposes in which the SASNOS is used; (3) determine the primary reasons it is being used to support research and clinical practice; (4) gather views about the tools perceived strengths, weaknesses and benefits, and (5) identify any unmet end-user needs and suggestions to guide future developments.

2. Method

2.1 Recruitment

An online survey (Qualtrics) was sent to approximately 220 individuals by email between June-November 2019. Contacts included individuals who were known end-users (e.g., prior contact with the project team; marketing collateral/website information confirming use of the tool in services; authors of published research where the SASNOS was used), as well as those who had enquired about the SASNOS and/or registered to use the tool on the project website (https://projects.swan.ac.uk/sasnos - established in February 2017). The email contained information about the survey, and a link to the survey itself. This link took potential participants to further information about the survey, and if participants consented, took them to the questions.

2.2 Participants

From those contacted, 63 individuals accessed the survey. However, of these 63 cases, 15 (23.8%) consented to participate but did not go on to complete the survey, and 4 (6.3%) reported never having used the SASNOS. After excluding these cases, the final sample for formal analysis consisted of 44 (76.2%) participants.

Of these 44 participants, 30 (68.2%) reported being active users, whilst 14 (31.8%) had used the tool previously. Most participants reported having used the SASNOS between 1-30 times (N = 32; 72.7%), with the remaining estimating that they had used it between 31-50 (N = 5, 11.3%) or 51+ times (N = 6, 13.6%). For the latter group, usage estimates ranged from 8 to 200 administrations. Data for one participant (2.3%) was unavailable.

Geographically, 33 (75%) participants were based in the United Kingdom (5 Wales, 11 England, 17 unspecified), 4 (9.1%) in Australia, 3 (6.8%) in Canada, 1 (2.3%) in Denmark, 2 (4.5%) in Ireland, and 1 (2.3%) in Bangladesh. Participants were drawn from a variety of professions, with self-reported occupations including: Clinical Psychologist, Hospital Director, Ward Manager, Occupational Therapist, Consultant Neuropsychologist, Research Officer, Therapy Technician; Behavioural Therapist; Trainee/Assistant Clinical Psychologist; Home Manager; Clinical Nurse Specialist; Psychiatrist; Registered Manager, Behavioural Support Practitioner, Clinical Lead, Counselling Psychologist, and Clinical Nurse Specialist.

In sum, the sample consisted of an experienced, international, and diverse set of end-users who were well positioned to comment on the tool's usage and utility, as well as its strengths, weaknesses, and benefits.

2.3 Materials

The questions in the survey were developed by the SASNOS team and were designed to capture information across three broad areas: (1) the extent to which the tool is used, by whom, where, and for what purposes; (2) end-user feedback to establish how and why the SASNOS is used, including its strengths and benefits, and (3) suggestions and feedback to guide future developments (see Box 1).

2.4 Procedure

Known end-users of the SASNOS received an invitation to take part in the study via emails sent out by the research team. A link to the study survey was also sent to potential new users at the point they registered to obtain the tool, as well as being listed on the SASNOS project website. On clicking on the link, participants were taken to the Qualtrics survey and were presented with a detailed information page covering the purpose of the study, what would happen to them if they took part, and how their data would be managed and kept confidential. It also explained how the study would take approximately 10-15 minutes to complete but would naturally vary depending on how much detail and information they wanted to share. The information page also gave details of participant's withdrawal rights and reiterated that participation was entirely voluntary. An electronic consent page followed, where participants were asked to indicate their consent and agreement with a series of statements by clicking 'Yes' or 'No'. If consent was provided, participants were presented with the survey questions. Participants who did not consent to participate were directed to the end of the survey and thanked for their time.

No time limit was given for responses to be made, and the survey could be completed without responding to all the questions (i.e., no forced choice options). In addition to the survey questions presented in Box 1, participants were also asked to indicate whether they were willing for their role and/or organisation to be recorded against their free text responses/quotes on the SASNOS website and in written project reports. On completion, participants were presented with a detailed debrief page, which thanked them for their contribution, and went into further detail about the purpose and aims of the study.

Box 1. Survey questions across the three broad areas of interest

Area One
1. In which country are you currently based?
2. What is your formal job title/role?
3. Have you ever used SASNOS?
4. Are you currently using SASNOS?
5. Approximately how many times have you used the SASNOS?
6. Is your organistaion in the priate or public sector?
7. In which service context are you currently using SASNOS? (tick all that apply)
8. For what purpose/s are you primarily using SASNOS?
9. In any given year, approximately how many patients with Acquired Brain Injury reside in your service and/or are on your caseload?
10. If you use the tool for clinical and/or audit purposes, please estimate the percentage of your caseload/patients that you/your service use SASNOS with in a given year
11. What group do you predominently use SASNOS with (e.g., neurorehabilitation in the broadest form; challenging behaviour; progressive neurological conditions)
12. For what population do you typically use the SASNOS with?
13. Does your service/organisation/workplace have a standardised basket of outcome measures? If so, is SASNOS part of this standardised basket of measures?
14. Is SASNOS a mandatory or optional outcome measure in your organisation/service/workplace?

Area Two
15. What are the primary reasons that you use SASNOS?
16. How and why do you use SASNOS? In what way does it benefit you?
17. Does SASNOS allow you to do something that you could not do previously?
18. Compared to other tools in your basket of outcome measures/research protocol, what does SASNOS allow you to do that other measures cannot?
19. How and why has SASNOS benefited your patients/clients and your service?

Area Three
20. Do you have any suggestions/feedback about improvements and/or developments we could make to the SASNOS?

3. Results

3.1 The SASNOS: Extent of Usage

In addition to confirming that the SASNOS is used by a range of professionals and across multiple countries (see Participants section), participants reported using the tool across a variety of sectors and service types, across multiple populations, and for multiple purposes.

Sector: Participants were drawn from both the public (N = 18, 40.9%) and private (N = 24, 54.5%) sectors. 2 [4.5%] participants did not specify whether their organisation/service was in the public or private sector.

Service Type: Participants were asked to indicate all the services/contexts where they were using the SASNOS, resulting in reported usage across nine areas of research and clinical practice:

1. Inpatient Rehabilitation: N = 25 (56.8%)
2. Outpatient Rehabilitation: N = 7 (15.9%)
3. Community Rehabilitation: N = 9 (20.5%)
4. Medico-Legal Practice: N = 9 (20.5%)
5. Research/Academia: N = 3 (6.8%)
6. Case Managerment: N = 3 (6.8%)
7. Family Based Rehabilitation: N = 1 (2.3%)
8. Forensic Mental Health: N = 1 (2.3%)
9. Transitional Brain Injury: N = 1 (2.3%)

Primary Purpose: Participants confirmed that they use the SASNOS to fulfil a range of purposes and activities, including: Clinical (N = 38, 86.4%); Research (N = 7, 15.9%), and Service Evaluation/Audit (N = 8, 18.2%) (N.B., participants could select more than one option).

Population and Group: The majority (N = 24, 54.6%) of participants reported using the SASNOS for 'Neurorehabilitation in the broadest form' or for managing 'Challenging Behaviour' (N = 17, 38.6%). Three participants did not answer (6.8%).

Participants were also asked to indicate all the population/s where they used the SASNOS, with results confirming that it is used to support individuals with many different forms of ABI:

1. Traumatic Brain Injury: N = 38 (86.4%)
2. Stroke: N = 16 (36.4%)
3. Anoxia: N = 11 (25.0%)
4. Encephalitis: N = 7 (15.9%)
5. Progressive Neurological Conditions: N = 6 (13.6%)
6. Epilepsy: N = 6 (13.6%)
7. Tumour: N = 5 (11.4%)

8. Alcohol Related Brain Injury: N = 2 (4.6%)
9. Cerebral Palsy: N = 1 (2.3%)
10. Hypoglycaemic Brain Injury: N = 1 (2.3%)
11. Neurodevelopmental: 1 (2.3%)

Extent of Usage: First, it is important to note here that the personal usage data reported previously (see Participants section) is not necessarily indicative of, or consistent with, usage rates across end-users services or patient numbers as a whole (e.g., patients on an individual's caseload may be assessed on the SASNOS by members of their multidisciplinary team, not just by the individual respondent).

To gauge extent of usage, participants who used the tool for clinical and/or clinical audit/evaluation purposes were asked (if possible) to record approximately how many patients with ABI (and therefore likely eligible for a SASNOS assessment) reside in their service and/or were currently under their caseload. Given the range of professionals who took part and the breadth of contexts/services involved, estimates varied considerably as expected (range 1 – 170, M = 43.42, SD = 44.39).

Thirty participants who provided approximate patient numbers also provided an estimate for the percentage of those cases where the SASNOS was used: 1-20% of cases (N = 13, 43.3%), 21-40% (N = 4, 13.3%), 41-60 (N = 2, 6.7%), 61-80% (N = 2, 6.7%), and 81-100% (N = 9, 30.0%). For participants reporting over 81% usage, total patient numbers ranged between 7-70 (see Table 1). Taken together, this data illustrates how the SASNOS is used widely across clinical services.

Table 1. Patient numbers against the 81-100% usage group

Approx. Number of Patients with ABI in Service and/or on Caseload	Percentage of Cases where SASNOS is used
70	81%
70	90%
11	90%
50	91%
7	100%
10	100%
10	100%
40	100%
15	100%

Similarly, participants who reported using the SASNOS for research purposes (N=3) were asked to estimate the sample sizes involved, on the basis that a SASNOS assessment would have been completed at least once for each

partipcant. Same size estimates ranged from 80-114 participants.

Standardised Basket of Outcome Tools: 27 (61.4%) participants confirmed that their service/workplace used a standardised basket of outcome measures, with the majority (N = 20, 74%) of these confirming that the SASNOS was part of that basket. This illustrates the level in which the SASNOS is integrated within services to support clinical practice and patient outcomes.

Optional or Mandatory Use in Services: Ten participants (22.7%) reported that the SASNOS was a mandatory outcome tool in their service/workplace.

3.2 End-User Feedback: How and Why Is the SASNOS Used

Information concerning how and why participants use the SASNOS was gleaned from participants free text responses to survey Questions 15-19 (see Box 1). Participants responses to each of these questions are discussed in turn below.

3.2.1 Primary Reasons for Using the SASNOS

Participants were asked to outline the primary reasons why they used the SASNOS (Question 15). Six key themes emerged:

(1) Determining Baseline Functioning: Participants reported that they used the SASNOS as an outcome measure to determine an individual's baseline function on entry to their service and/or at the start of rehabilitation.

"To identify difficulties upon entry into service and to help develop goals" - Clinical Psychologist, Public Sector, Wales

"Baseline measure, evaluate the outcome of service provided and to support patient care – Clinical Lead, Public Sector, Bangladesh

"In the acute setting in patient's early stages of admission to hospital with a acquired brain injury, SASNOS has been used to provide a baseline/indication of level of need" – Occupational therapist, Public Sector, UK

(2) Informing Clinical Decision Making and Monitoring Response to Rehabilitation: Participants indicated that the SASNOS was helpful for formulating rehabilitative goals and for tracking response to treatment.

"Tracking response to behaviourally based rehabilitation on challenging behaviour" – Behavioural Therapist, Private Sector, Canada

"To track/monitor response to intervention, support patient care and service evaluation" – Clinical Nurse Specialist, Public Sector, UK

"To track and monitor response to rehabilitation and to formulate rehabilitation goals" – Assistant Psychologist, Private Sector, UK

(3) Patient Self-Awareness and Insight: Participants indicated that the availability of proxy- and self-rated versions was particularly advantageous, allowing them to compare the degree of congruence between ratings to provide an indication of the extent of patient insight and awareness into their condition.

"I find the self-completion scale the most useful component. It is a useful way of getting a feel of levels of insight. I find the breadth of questions, including formally asking about ability to empathise etc, can yield a understanding of the patient's appreciation (or non-appreciation) of their deficits that wouldn't necessarily be elicited by a non-structured assessment" – Consultant Neuropsychiatrist, Public Sector, UK

"Information re patient insight into condition compared to proxy" – Therapy Technician, Public Sector, UK

(4) Improving Reporting and Feedback: Enhanced reporting to external outside agencies and using results to feedback to relatives was highlighted.

"Provide information to outside agencies to enable them to understand the patients' needs and issues, service evaluation" – Clinical Nurse Specialist, Public Sector, UK

"Demonstrate gains to patients, families and external Commissioners/Funders" – Occupational Therapist, Public Sector, UK

(5) Superior Coverage and Sensitivity: Participants highlighted the tools usefulness for gaining a better understanding of NBD and its superiority over comparable measures.

"When the client's presentation suggests it would be a helpful tool due to the subtleties not being captured on our usual measures" - Consultant Clinical Psychologist, Private Sector, UK

"To better understand nature of neurobehavioural difficulties" – Clinical Neuropsychologist, Public Sector and Medico-Legal Practice, UK

"To improve understanding and awareness of NBD post-stroke" – Academic and Clinical Neuropsychologist, Public Sector, Australia

"Relevant in community settings - has a higher ceiling than other functional measures" – Consultant Clinical Psychologist, Private Sector, UK

(6) Training and Capacity Building: Participants also commented how the SASNOS can play a role in educating professionals without a background in neurology about the nature and prevalence of NBD.

"It 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, UK

3.2.2 How and Why the SASNOS is Used

When asked *"How and why do you use SASNOS?"* (Question 16) participants responses reiterated the six key themes identified in the previous section, as well as an additional theme concerning the tools robust psychometric properties.

(1) Determining Baseline Functioning:

"Help patients and realtives to understand the nature of behaviours and provides a starting point to target rehabilitation" - Clinical Nurse Specialist, Public Sector, UK.

(2) Informing Clinical Decision Making and Response to Rehabilitation:

"It tracks progress successfully" – Occupational Therapist, Private Sector, UK

"It enables us to identify the severity of difficulties within particular domains, and to prioritise areas of intervention. It enables some degree of assessment of risk as part of a broader assessment. It also provides a means to track progress and to ascertain staff views (as completed most often by staff)" – Clinical Psychologist, Public Sector, UK

"It enables us to see progression and regression in the clients" – Care Manager, Private Sector, UK

(3) Patient Self-Awareness and Insight:

"Part of initial assessment, compare with proxy measure. Then used to chart progress/insight gained through both self and proxy measures" – Therapy Technician, Public Sector, UK

(4) Improving Reporting and Feedback:

"It allows families and carers to grasp an understanding of possible problems and put them into perspective. I find that people like to talk around the questions and you can visibly see relief when they know that somebody is really trying to understand their family member - there are also many items that I have found people have not though about before, and been thankful for the prompt and following discussions" – Private Sector, UK

"Overall splat diagram is very accessible for non-Clinicians, family and Commissioners". – Occupational Therapist, Public sector, UK

(5) Superior Coverage and Sensitivity:

"Often identifies observed areas of difficulty not picked up through formal neuropsych testing" – Consultant Psychologist, Private sector, UK

"I find the graphs a helpful visual aid and useful to communicate complex information to multi disciplinary teams [and] helpful in capturing outcomes in less visible/measurable aspects of behaviour" – Clinical Neuropsychologist, Private Sector and Medico-Legal Practice, UK

"The ability to identify difficulties that other measures don't capture; often within the area of higher executive functioning" – Consultant Clinical Psychologist, Private Sector, UK

"It helps us identify areas of challenging behaviour that can be sometimes overlooked and helps us to address these areas with GAS goals and specific interventions" – Assistant Psychology, Private Sector, UK

(6) Training and Capacity Building:

"The graphs are particularly descriptive and self-explanatory when presenting them to people with little psychological knowledge" – Assistant Psychologist, Private Sector, UK

(7) Psychometric Properties: Several participants referred to the robustness of the SASNOS, noting its responsiveness and excellent psychometric properties:

"Bangladesh Version of SASNOS has very good psychometric properties and it shows measurement of a wide number of variables in different area" – Clinical Lead, Public Sector, Bangladesh

"Best neurobehavioural measure available [and] psychometrically based" – Consultant Neuropsychologist, Private Sector, UK

"It is a responsive measure with a number of items which encapsulate the difficulties patients face post ABI" - Assistant Psychologist, Private Sector, UK

3.2.3 Unique Benefits and Enhanced Practice

To further ascertain end-user views of the SASNOS, participants were asked *"Does SASNOS allow you to do something that you could not do previously?" (*Question 17). Here, participants mentioned a range of unique features and benefits, including:

(1) The Availability of Self-and Proxy-Rated Versions:

"Unlike other tools I've tried, the SASNOS allows for self-rating measures" –Public Sector, Australia

"Helps to be able to monitor outcomes for patients who might not be able to complete other outcome measures due to their severe disabilities" – Principal Clinical Psychologist, Private Sector, UK

(2) The Tools Superiority over Comparable Measures (e.g., better breadth of coverage; established psychometric properties):

"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, Australia

"Been using this a long time, hard to remember what couldn't do previously! But yes, it's helpful to quantify neurobehavioural function. Briefer than the NFI" – Consultant Clinical Psychologist, Private Sector, UK

(3) How the SASNOS Ties Together Aspects of Other Measures (i.e., streamlining the assessment process):

"It ties together aspects of other measures with a much-needed neuro-behavioural angle" – Occupational Therapist, Public Sector, UK

(4) The Ability of the SASNOS to Capture the Impact of Support Received on Ratings of NBD:

"Comment on a wide range of neurobehavioural factors and the benefits a structured environment brings" – Private Sector, UK

(5) The Tools Enhanced Sensitivity for Detecting Impairments and Change Over Time:

"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, UK

"Broader medico-legal formulation and more accurate long-term costings for care / intervention. Helpful as treating clinician medico-legally due to Laughlin Setting up neurobehavioural interventions" - Clinical Neuropsychologist, Private Sector and Medico-Legal Practice, UK

"Yes - it is the only neuro-behavioural outcome measure that is used and often assists with applications for funding for longer stay, more complex out of area rehab" – Senior Occupational Therapist, Public Sector, UK

"It gives a more accurate reading of the difficulties that my clients face on a daily basis, and can be very beneficial to monitor deterioration" – Home Manager, Private Sector, UK

3.2.4 Benefits of the SASNOS Compared to Other Tools

To directly elicit feedback about how SASNOS compares to other available outcome tools, participants were asked *"Compared to other tools in your basket of outcome measures/research protocol, what does SASNOS allow you to do that other measures cannot?"* (Question 18). Here, participants emphasised the superior depth and breadth of coverage achieved by SASNOS, its ability to show change, and its usefulness for informing team discussions:

"It allows me to measure lots of different things which would previously have taken a few different questionnaires. I find that it informs me which areas to explore further and provides a great basis for discussion with support teams/ families and MDT members" – Private Sector, UK

"Show change (relative to, for example, FIM)" – Psychologist, Public Sector, Canada

"Can quantify aspects of EF [Executive Function] that other formal assessments do not" – Consultant Psychologist, Private Sector, UK

Additionally, participants praised the availability of normative data to aid interpretation of scores, the ease in which SASNOS can be used, and its ability to explore differing perspectives between patients and significant others. For example:

"Comparison with a healthy population, to understand abnormal levels of NBD Examine a range of NBD Examine at activity/participation levels" - Academic and Clinical Neuropsychologist, Public Sector, Australia

"To identify the level of severity of the identified domains, as compared to norms. To have a standardised approach to common neurobehavioural difficulties" – Clinical Psychologist, Public Sector, UK

"Visual recording and very easy to use" – Care Manager, Private Sector, UK

"An overview of the core areas which present as difficulty for people with ABI. The graph 'splat' (as we call it) it particularly helpful when service users describing functioning to support workers, case managers, OTs, Psychologists" – Assistant Psychologist, Private Sector, UK

"Measure and evaluate neurobehvaioural difficulties and differing perspectives between patients and relatives etc" – Clinical Neuropsychologist, Public Sector and Medico-Legal Practice, UK

3.2.5 Service Level Benefits

In addition to benefiting case formulation, treatment planning and clinicians/researchers personally, participants were also asked *"How and why has SASNOS benefited your patients/clients and your service?"* (Question 19). Participants consistently commented on how SASNOS has allowed them to:

(1) More Effectively Evaluate and Demonstrate the Clinical Efficacy of Activities:

"Emphasises our responsiveness, efficacy and validates our therapy" – Occupational Therapist, Public Sector, UK

"It provides evidence of clinical activity" – Counselling Psychologist, Private Practice, UK

"Seeing whether the interventions we are putting in place have a positive outcome or not is very helpful" – Principal Psychologist, Private Sector, UK

(2) Provide Higher Standards of Care by Providing a More Targeted Response:

"Helped the service to provide a targeted response" – Clinical Nurse Specialist, Public Sector, UK

"Higher standards of care and support" - Clinical Neuropsychologist, Private Sector and Medico-Legal Practice, UK

(3) Improve Reporting and Feedback Processes:

"Greater reporting of information relevant to funders about the quality of rehabilitation" – Assistant Psychologist, Private Sector, UK

"Facilitating discussion about less overt deficits" – Consultant Neuropsychiatrist, Public Sector, UK

3.2.6 Client/Patient Benefits

Participants reported that using the SASNOS had led to a number patient/clients benefits, such as by improving communication, providing more accessible means to discuss needs and progress, and by more appropriately tailoring interventions to support patient outcomes:

"Helped them understand their issues better" – Clinical Nurse Specialist, Public Sector, UK

"Assisted with ensuring access to the right services and care" – Senior Occupational Therapist, Public Sector, UK

"Self-feedback of their progress" - Clinical Lead, Public Sector, Bangladesh

"Fostering insight" – Consultant Neuropsychiatrist, Public Sector, UK

"Allows a visual overview diagram of progress and remaining areas of need" – Occupational Therapist, Public Sector, UK

"Implementation of specific interventions aimed at certain items on the SASNOS" – Assistant Psychologist, Private Sector, UK

3.3 End-User Feedback: Suggestions to Guide Future Developments

To identify any unmet end-user needs and suggestions to guide future developments, participants were asked *"Do you have any suggestions/feedback about improvements and/or developments we could make to the SASNOS?"* (Question 20). Three key themes emerged:

(1) Creation of Additional Scoring/Report Tools: Participants made suggestions of additional scoring/report tools that could be developed for end-users:

"Making statistically and clinically significant changes evident on the spreadsheet on re-testing. Allowing overlay of client and sig others graphs" - Clinical Neuropsychologist, Public Sector and Medico-Legal Practice, UK

"It would be useful to have a radar graph (or any other form of graph) that allows us to easily compare repeated scores" - Assistant Psychology, Private Sector, UK

(2) Re-Examination of Items within the Communication Domain: Participants raised the possibility of further developing the 'Communication' domain, noting that items could be more inclusive and provide better coverage of communication problems, as opposed to verbal disinhibition, post ABI:

"I feel that the section on communication could be added to and improved" – Clinical Nurse Speclist, Public Sector, UK

"The Communication dimension is not a communication dimension but a verbal disinhibition one" – Consultant Clinical Psychologist, Private Sector, UK

"The Speech/Language aspect does not take account of the fact that some patients with brain injury are not able to fully communicate (i.e. due to aphasia etc) - would be helpful if there were other markers like 'does patient over-vocalise' etc" – Principal Clinical Psychologist, Private Sector, UK

(3) **Complexity of Language:** One participant suggested that the accessibility of the tool could be improved by simplifying the language used throughout:

"The language is quite sophisticated and requires a reasonable level of education/fluency in English to understand. It is difficult, as some concepts are quite abstract, but any simplification of language that could be achieved would be great" – Consultant Neuropsychologist, Public Sector, UK

3. Discussion

The principal aims of this study were to (1) determine the extent that the SASNOS is being used by health professionals and service providers around the world; (2) determine the range of contexts and purposes in which it is used; (3) determine the primary reasons why the SASNOS is being used to support research and clinical practice; (4) gather views about the tools perceived strengths, weaknesses and benefits, and (5) identify any unmet end-user needs and suggestions to guide future developments.

Results from our end-user experience survey confirm that the SASNOS is used by a variety of professionals, across a range of service contexts and sector types, and in multiple countries worldwide. It is also used to support individuals with many different forms of ABI, is commonly employed to support neurorehabilitation in the broadest form, and is often part of services standardised basket of outcome measures - often as a mandatory assessment.

Feedback from end-users highlighted that they use the SASNOS for a myriad of reasons, with responses often falling across a set of recurring themes. For instance, when asked to outline the reasons why they used the SASNOS, participants emphasised how the tool is useful for: (1) determining baseline functioning; (2) informing clinical decision making; (3) comparing the congruence between self- and proxy-ratings to gauge patients levels of insight and awareness into their condition; (4) improving reporting and feedback to outside agencies (e.g., funders, commissioners) and families; (5) for gaining a better understanding of NBD over and above what can be achieved with other comparable measures, and (6) in educating professionals without a background in neurology and neuropsychology about the nature and prevalence of NBD post-ABI. Several end-users also commented on the robustness of the SASNOS, praising its responsiveness and excellent psychometric properties.

Further, end-users identified a range of unique benefits of the SASNOS, highlighting its superiority and enhanced clinical utility compared to other comparable measures. For example, when asked to explain what the SASNOS allows them to do that (a) they could not do before, and (b) compared to other measures, several key themes emerged across participants free-text responses. First, participants commented on the tools ability to detect more nuanced difficulties and change over time, noting how it ties together aspects of several other measures and thereby streamlining the assessment process. For example, one participant noted

"It allows me to measure lots of different things which would previously have taken a few different questionnaires". Second, participants frequently praised the availability of normative data, allowing total, domain, and subdomain ratings to be transformed to standard T-scores, enabling a balanced assessment of NBD and meaningful comparison of the range of difficulties captured. Third, several participants commented on the ease in which the SASNOS can be used, noting how its scoring/reporting tools are easy to use, visually based, and useful when describing functioning to other health professionals and to patients themselves. Fourth, the tools robust psychometric properties were recognised, including its reliability, validity, and responsiveness. For instance, one participant reported *"Best neurobehavioural measure available [and] psychometrically based"* and another noted *"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"*. Finally, the availability of self- and proxy-rated versions was considered a strength as it allows differing perspectives between patients and relatives to be examined, providing valuable information regarding levels of patient insight and awareness.

In addition to aiding case formulation, treatment planning and clinicians/researchers personally, participants were also asked *"How and why has SASNOS benefited your patients/clients and your service?"*. In regards to service level benefits, participants reported that the SASNOS (1) helps them to more effectively evaluate and demonstrate the clinical efficacy of their activities; (2) allows them to provide higher standards of care by providing a more targeted response, and (3) supports their clinical work by improving reporting and feedback processes, such as communicating information to funders about the effectiveness and quality of their rehabilitation. For client/patient benefits, participants thought that the SASNOS helps patients to understand their issues more effectively, as well as supporting their recovery by allowing specific interventions to be implemented based on their needs.

Finally, to inform future developments of the SASNOS tool and to ensure it continues to meet end-user needs, participants were asked to share their suggestions/feedback about possible developments and/or improvements that could be made. Three main points were raised. First, participants made suggestions for additional scoring/report tools (e.g., radar graphs; graphs to allow repeated assessments to be captured visually) that could be made available. These supplementary scoring/reporting spreadsheets (e.g., graph packs) are now available by request via the SASNOS project website. Second, simplifying the language used throughout was raised as a suggestion by one participant. Whilst this cannot be actioned in isolation (e.g., because of potential impacts on the tools reliability and validity), it can be considered if/when the tool undergoes revision (i.e., SASNOS-V2). Finally, some participants suggested that items within the 'Communication' domain could be improved to ensure better breadth of coverage of difficulties in this area of function. Further enhancing the breadth of coverage of items within the 'Communication' domain is already part of an on-going work package. As part of this, we have worked with Speech and Language Therapists to generate a pool (approx. 80) of additional 'Communication' items that are currently undergoing validation, including the collection of general population ratings to ensure availability of normative data to aid subsequent interpretation. Once completed, this work will underpin the publication of the SASNOS-V2.

As with all research, this study is not without limitations. First, and given the recruitment method, it is possible that some end-users were not reached. Indeed, we know that the SASNOS is distributed amongst professional networks without formally registering for the tool via the SASNOS website. Similarly, it is not uncommon for end-users to submit a single registration request for the tool on behalf of their service, meaning that a single contact is stored on behalf of a service with multiple end-users. However, as part of our recruitment email, we encouraged contacts to distribute the invitation to other members of their team and service as applicable. Second, our final sample size was relatively small, with only around one-quarter of those invited taking part. However, the design of the end-user survey still ensured that we elicited rich and detailed feedback about the SASNOS, and our final sample comprised a variety of professionals from a range of service contexts, sector types, and countries.

In conclusion, a survey of SASNOS end-users confirms its usage by a variety of professionals from several sectors, service types and countries. It is used to support individuals with many different forms of ABI and is commonly employed to support neurorehabilitation in the broadest form. Feedback from end-users also highlights its many benefits, evidencing the myriad of ways in which the SASNOS is having a demonstrable positive impact on clinical and research practice, and in turn, patient care.

Acknowledgements

References

Alderman, N., & Wood, R. Ll. (2013). Neurobehavioural approaches to the rehabilitation of challenging behaviour. Neurorehabilitation, 32, 761-770. doi:10.3233/NRE-130900

Alderman, N., Knight, C., & Brooks, J. (2013). Rehabilitation approaches to the management of aggressive behaviour disorders after acquired brain injury. Brain Impairment (Special Issue: state of the art reviews on mental health in traumatic brain injury), 14, 5-20. doi: 10.1017/BrImp.2013.7

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, 32(2), 218-229. doi: 10.1080/02699052.2017.1406989

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 Outcomes Scale (SASNOS). Archives of Clinical Neuropsychology, 32(8), 951-962. doi: 10.1093/arclin/acx026

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, 83-100. doi: 10.3109/02699052.2010.532849

Brodtmann, A., Werden, E., Pardoe, H., Li, Q., Jackson, G., Donnan, G., Cowiem T., Bradshaw, J., Darby, D., & Cumming, T (2014). Charting cognitive and volumetric trajectories after stroke: protocol for the Cognition and Neocortical Volume After Stroke (CANVAS) study. International Journal of Stroke, 9(6), 824-828.

Kelly, G., Brown, S., Todd, J., & Kremer, P. (2008). Challenging behaviour profiles of people with acquired brain injury living in community settings. Brain Injury, 22, 457–470. doi: 10.1080/02699050802060647

Kreutzer, J. S., Marwitz, J. H., Seel, R., & Devany Serio, C. (1996). Validation of a neurobehavioral functioning inventory for adults with traumatic brain injury. Archives of Physical Medicine and Rehabilitation, 77(2), 116–124. doi:10.1016/S0003-9993(96)90155-0

Oddy, M., & da Silva Ramos, S. (2013). The clinical and cost-benefits of investing in neurobehavioural rehabilitation: a multi-centre study. Brain Injury, 27, 1500-1507. doi:10.3109/02699052.2013.830332

Soendergaard, P. L., Siert, L., Poulsen, I., Wood, R. Ll., & Norup, A. (2019). Measuring neurobehavioral disabilities among severe brain injury survivors: reports of survivors and proxies in the chronic phase. Frontiers in Neurology, 10, 51. doi:10.3389/fneur.2019.00051

Stolwyk, R. J., O'Connell, E., Lawson, D. W., Thrift, A. G., & New, P. W. (2018). Neurobehavioural disability in stroke patients during subacute inpatient rehabilitation: prevalence and biopsychosocial associations. Topics in Stroke Rehabilitation, 25, 527-534. doi:10.1080/10749357.2018.1499301

Williams C., Wood, R. Ll., Alderman, N., & Worthington, A. (2020). The psychosocial impact of neurobehavioural disability. Frontiers in Neurology, 11, 119. doi:10.3389/fneur.2020.00119

Wood, R. Ll. (2001). Understanding neurobehavioural disability. In R.Ll. Wood, & T.M. McMillan (Eds.), Neurobehavioural disability and social handicap following traumatic brain injury (pp. 3-28). Hove: Psychology Press Ltd.

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

Ylvisaker, M., Turkstra, L., Coehlo, C., Yorkston, K., Kennedy, M., Moore Sohlberg, M., & Avery, J. (2007). Behavioural interventions for children and adults with behaviour disorders after TBI: A systematic review of the evidence. Brain Injury, 21, 769-805. doi:10.1080/02699050701482470