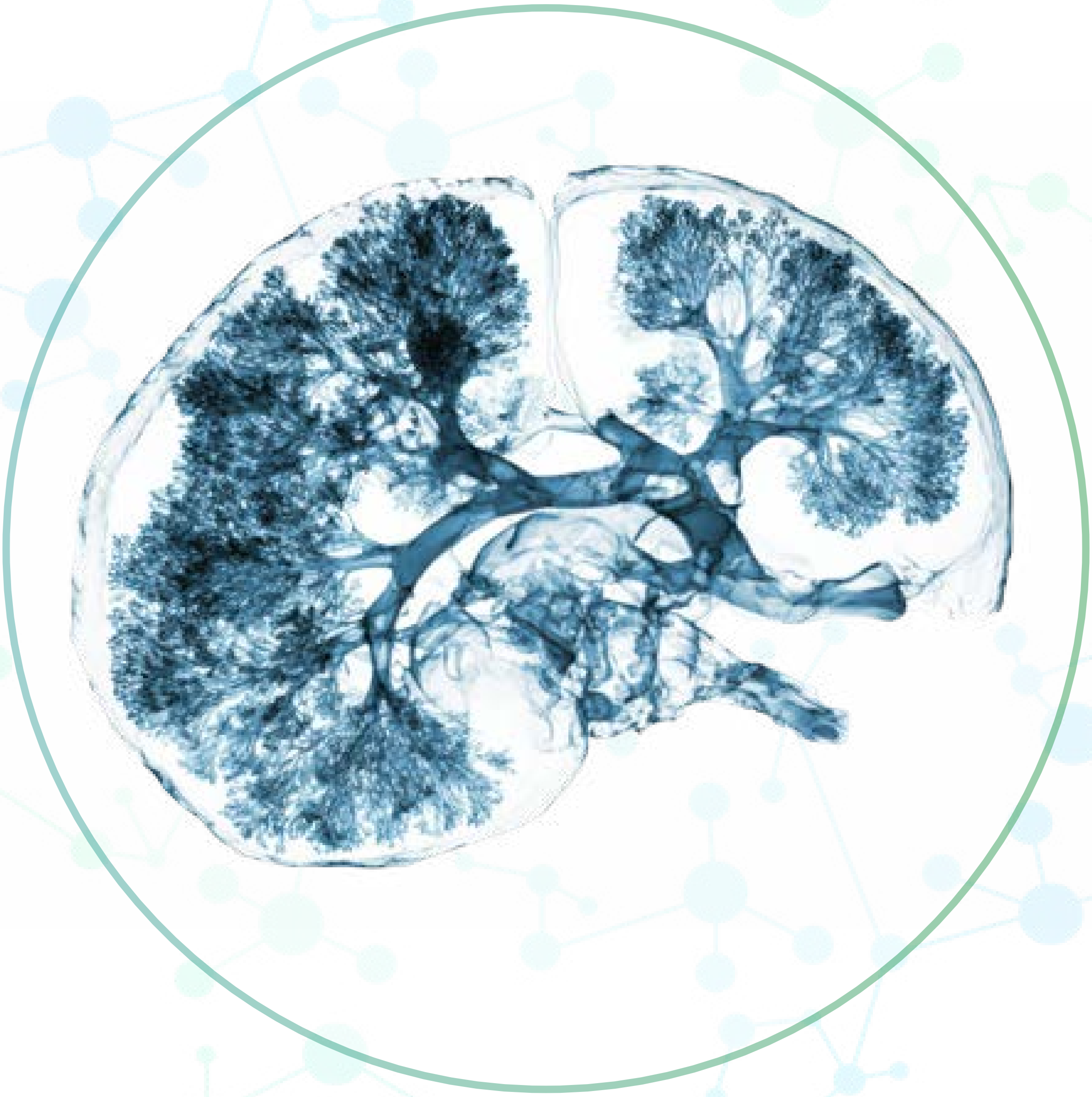
Brainwaves



March 2026 Edition

Research Newsletter from the Royal Hospital for Neuro-disability

Royal Hospital for
Neuro-disability

Chief Executive's introduction

Research and innovation remain at the heart of the Royal Hospital for Neuro-disability's mission, underpinning our continued commitment to delivering outstanding, evidence-based care for our patients. The breadth of work showcased in this edition reflects not only the depth of expertise across the organisation, but also our determination to remain at the forefront of neuro-disability research and clinical practice.

Across the wide range of studies that are outlined, spanning disorders of consciousness to advancements in anti-seizure medications, our teams are advancing knowledge and integrating scientific enquiry with day-to-day care. This is ensuring that innovation translates into meaningful improvements in our patients' quality of life.

Many of these projects were presented at our annual research conference, held at the hospital in February. The conference provided an important platform to share learning, recognise achievement, and reinforce our unwavering focus on shaping the future of care through innovation, partnership, and clinical excellence. I hope you enjoy reading about the many inspiring projects featured in this edition.

Paul Allen

Chief Executive Officer

Developing an AAC nursing training programme based on the perspectives of patients and nursing staff in long-term care.

Helen Paterson, Compass Advanced Specialist SLT, RHN

This mixed-methods research project, undertaken between 2017 and 2025, aims to challenge the effectiveness of current training provided to nursing staff on Augmentative and Alternative Communication (AAC) use. AAC is essential in providing communication, improving connection and regaining identity for individuals with communication difficulties. However, there is a lack of evidence-base in how to effectively train nursing staff (registered nurses and health care assistants (HCAs), in set up and use of AAC, and nursing staff report lack of confidence and a desire for more training in using AAC technologies.

Previous training provided at the RHN which attempted to train staff through videos and wall signage, had mixed results. This project instead aimed to collect feedback on how AAC users and nursing staff feel about their communication methods, about the current training they receive on AAC, and to use this feedback to develop an improved nursing staff training intervention. The methodology involved interviews and Talking Mats, an evidence-based visual framework which helps individuals with or without communication difficulties to express their feelings and views.

Phase 1 involved 3 AAC users (in long-term care and ventilation wards) and 12 nursing staff, separated into four focus groups of 3 to 4 individuals. The results indicated shared agreement from staff and AAC users that a practical approach during training is more effective than visual guidelines alone. Participants also emphasised that their ideal training would involve more real-time practice with AAC users on the ward and learning from each other (train the trainer). These results were supported in existing literature on this topic. The resulting training intervention followed the framework by the National Institute of Health Research (NIHR) and the Medical Research Council (MRC) for developing and evaluating complex interventions. It involved the following processes which utilised Gagné's (1985) instructional design model: providing learning guidance to the learners on safe and correct AAC set-up, eliciting the performance, giving feedback and utilising train-the-trainer processes to enable carry over to other nursing staff.

Phase 2 aimed to evaluate the impact of the training intervention on nursing staff confidence and knowledge in using AAC, and to determine the feasibility and acceptability of the intervention. This involved 30 nursing staff and 3 AAC users, across 11 sessions conducted from June to July 2024, evaluated using pre- and post-intervention surveys and Talking Mats. The results demonstrated an overall increase in staff knowledge and confidence in AAC interaction, and safe and effective technology setup. AAC users and nursing staff reported finding learning from the AAC users and their nursing colleagues, as well as competency checklists particularly effective training methods.

Limitations included the researcher themselves working within the hospital, which required her throughout the study to ensure she reflected on her positionality as a researcher and therapist. The sample sizes were small, and the study did not analyse behaviour change pre- and post- intervention. However, the research strongly supports the integration of practical training for nursing staff which is delivered with AAC users, and involves elements of train-the-trainer, together with clear strategy instruction and competency checklists.

Update on the Putney FOCUS tool – outcome measure for PDOC

Dr Sarah Crawford, Consultant Clinical Psychologist, RHN

The Putney FOCUS tool was developed to address the difficulty in demonstrating meaningful clinical outcomes in patients who remain in PDOC. Traditional measures such as FIM+FAM are not designed for this patient population and lack the sensitivity to measure small changes. This is important as we need to demonstrate the value of our services to families, clinicians and commissioners.

There is currently no suitable metric available to measure PDOC treatment outcomes. Researchers therefore conducted staff focus groups to identify clinically meaningful but undocumented changes, collaborating with clinicians and service leads to design an appropriate outcome measure.

The 'FOCUS' acronym encompasses the following four areas of interest:

- F - Facilitate (e.g., wakefulness)
- OC - Optimise Care
- U - Understand (e.g., diagnosis)
- S - Support (support for families)

The scoring is on a 4 point scale per domains. A higher score means higher level of need. Scores were calculated at admission, after six weeks and at discharge for 23 patients. Results demonstrated significantly higher scores at admission and lower scores at discharge, confirming that the FOCUS measure captures meaningful changes not reflected in FIM+FAM scores.

FOCUS user manual was developed and distributed to the RHN PDOC 2025 conference attendees. Their feedback will be sought later this year. The tool is being piloted on Devonshire.

There and back again. A PhD tale

Teresa Clark, Consultant Physiotherapist, RHN

“What supports the making of individualised and value-congruent healthcare decisions on behalf of the person in PDOC?“. For most patients, treatment choices are made via a ‘risk-taking’ decision making process. Clinicians interpret the available evidence to offer treatment options. The patient evaluates the risks and benefits of the options (specifically to them) and decides. Differently in PDOC, clinical decisions resemble a ‘risk-making’ decision making process, where the relative risks and benefits are evaluated by another person on their behalf. The person in a PDOC has limited agency in this process, which places it at risk of straying from what the person in a PDOC may have wanted.

Using critical ethnography and deep reflection, this research aims to improve our understanding of how decisions are made on behalf of people in a PDOC and develop ideas that would strengthen values congruent decision-making processes, to keep the person in a PDOC at the centre of decisions made on their behalf.Early findings have suggested that clinicians appear to formulate decisions via an objective lens which forms and tests hypotheses about the person in a PDOC’s awareness and probable experience.

Families appear to formulate their decisions through a social lens, which is guided by what they know of the person before and their current possible experience – evidenced by signs of emerging identity/personhood and feelings of social connection. Getting to a ‘good’ decision (which resembles what the person in a PDOC might have chosen) is a complex process, which appears to be related to relationships (within the family and between the clinical team and family), PDOC specific clinical expertise, and an expert healthcare context, and balancing possibilities and probabilities.

The next phase of this research is to travel to the United States of America, to compare and contrast decision making processes between two very different healthcare contexts.

Autonomy And Interaction In Patients Emerging From PDOC :The Return Of Preferences, Opinions, And Personality.

Dr Amy Pundole, Clinical Lead Speech and Language Therapy SLT, RHN

The current process of identifying the return of communication as patients emerge from a Prolonged Disorders of Consciousness (PDOC) requires them to complete specific tasks with 100% accuracy. They are required to answer 6/6 yes/no questions on two occasions or match a spoken word to a picture or object from a choice of two. In a UK wide survey, clinicians reported that those criteria were too narrow and that they, instead, were looking for evidence of breadth of communicative behaviours in context.

This research used Linguistic Ethnography combining Ethnography and Conversation analysis to examine how patients emerging from PDOC interacted in a variety of activities. Patients were observed during physiotherapy sessions, tooth brushing and family visit. Detailed field notes and video recordings were collected and analysed.

Although patients did not meet the current specific emergence criteria, they all demonstrated a range of interaction behaviours including yes/no responses, following instructions, making choices, greetings, talking, mouthing, turn taking, using objects, smiling, winking, blowing kisses, engaging with task and using humour. They were able to respond to others, change the direction of an interaction and indicate awareness of subtle social norms such as appropriate proxemics.

Despite significant impairments, patients were able to demonstrate the return of autonomy and act with agency in context. They were also able to indicate aspects of their pre-injury personalities.

In this schematic picture, a patient is shown anticipating tooth brushing by open his mouth and avoiding eye contact.

Despite significant impairments, patients were able to demonstrate the return of autonomy and act with agency in context. They were also able to indicate aspects of their pre-injury personalities.

Interaction partners set up and managed tasks and used scaffolding techniques to facilitate interaction and promote agency. They also collaborated with patients to provide a positive environment through personalised and caring activities that sustained interaction.

This research demonstrates that patients emerging from PDOC are able to exhibit a range of interaction behaviours in context that may not be evident in formal assessment tasks. The study emphasises that context-based insights should be integrated into emergence assessments, to more accurately reflect patients’ returning communication ability.

Anti-seizure medication after acquired brain injury – an ongoing issue

Dr Judith Allanson, Consultant in Rehabilitation Medicine, RHN
Dr Lloyd Bradley, Consultant in Rehabilitation Medicine, RHN

Seizures are defined as uncoordinated activity in the brain, which may be focal or generalised, affecting motor, sensory, visual and consciousness. Following an acquired brain injury, single seizures are common. However, acute symptomatic seizures do not necessarily signify epilepsy (recurrent seizures).

Anti-seizure medications (ASMs) are prescribed after brain injury either to prevent seizures occurring (prophylaxis) or to reduce the risk of further seizures occurring when a person has had a seizure (secondary prevention). There are a limited number of non-seizure related indications including:

- Behavioural management
- Mood disorders
- Spasticity
- Pain management
- Autonomic dysfunction

There may be reluctance to stop ASMs as seizures can significantly affect awareness, aggravate existing brain injuries, cause secondary injury and, in severe cases, lead to death. Recurrent seizures carry substantial implications for independence, including driving, work, and caring responsibilities. The evidence guiding ASM use on a long-term basis is mostly based on research in populations who haven't previously experienced brain injuries.

Conversely, reasons to discontinue ASMs include potentially reduced arousal due to sedative effects (particularly with older medications), as well as negative impacts on cognition and behaviour. This is particularly important when assessing people in PDOC, as ASM may be masking abilities, and thus confounding assessments of levels of awareness.

Previously, we have shown that most patients admitted for rehabilitation at the RHN were on ASMs. Now we looked at ASM prescription for people in the long-term care. A review of 106 patients resident in the long-term care facilities at the RHN found that 61 were on ASMs. Of these, 46 had documented seizures, with only 8 experiencing 1 early seizure. For 12 patients, seizure history over 3-10 years was unknown, while 3 had no documented seizures. This means as many as a third of the group did not need ongoing AMSs.

These findings highlight the need for an evaluation of the benefits and risks of continuing ASM use, particularly given the estimated lifetime care cost of ~£11,964 to cover medication and staff time. The project further aims to develop clear guidelines to support healthcare professionals in making informed decisions regarding ASM continuation.

Supporting MND patients with Tracheostomy ventilation (Service Provision and experiences from a specialist nursing home)

Linda Vardy, Senior Physiotherapist
Mhairi Bartlett, Physiotherapist
Emma Winterson, Clinical Fellow

This analysis is part of a larger project aimed at demonstrating the impacts that long term tracheostomy ventilation, associated interventions and the input of an MDT approach have on life expectancy, function and quality of life.

Since 2020, the RHN has seen 10 admissions, predominantly from acute settings, of individuals with Motor Neurone Disease (MND) and long term tracheostomy ventilation needs, 4 of which are still under our care.

For many of the cases, a tracheostomy was inserted following an acute episode leading to respiratory deterioration. It is unclear how much information had been provided regarding long-term ventilation to the patients and their families before the insertion.

This study found no clear pattern in terms of transfer methods, feeding route (e.g. PEG or oral), primary communication methods (i.e. eye gaze, verbal) or chest clearance techniques. Additionally, post-insertion glycopyrronium dose, and botulinum toxin injection requirements, highlighted how highly individualized secretion management is and illustrate the need for tailored treatment interventions.

Though this analysis involved a small sample group, results demonstrated that tracheostomy insertion can offer meaningful longevity for MND patients whilst reflecting the high variability of trajectories.

Additional patient and family feedback has illustrated that, though a tracheostomy intervention can provide relief from issues such as breathlessness and pulmonary infections, the challenges that may still arise include anxiety relating to adjustments and a lack of control, pain, and rigidity in thinking.

Understanding post tracheostomy insertion treatment management is essential to set realistic expectations for patients and families, in order to make an informed decision, to tailor symptom-directed interventions and to plan staff and service provisions.

Powering Up Mouth Care After Stroke

Mili Doshi, Dentist, RHN

Poor oral hygiene after a stroke can have significant consequences for both oral and general health. The accumulation of dental plaque and debris increases the risk of dental caries, periodontal disease, oral pain, and infection. Inadequate mouth care is also associated with systemic complications such as aspiration pneumonia, a leading cause of morbidity and mortality among stroke survivors. Poor oral health can also negatively affect speech, nutrition, and overall quality of life. Supporting individuals after a stroke to maintain good oral hygiene is therefore a vital component of rehabilitation, contributing to comfort, dignity, and improved recovery outcomes.

Despite its importance, oral care is often overlooked in stroke rehabilitation. Many settings lack structured oral health protocols, and staff may have limited training or confidence in supporting patients with complex needs. As a result, mouth care practices can be inconsistent, and patients may not receive adequate support. Current guidance recommends twice-daily mouth care and provision of a personal toothbrush, yet practical guidance for patients with physical, cognitive, or sensory impairments remains limited.

Stroke-related challenges such as reduced limb movement, dysphagia, facial weakness, visual deficits, and sensory hypersensitivity can make toothbrushing difficult. Individuals may need assistance with grip, positioning, or posture. Powered toothbrushes may offer advantages, as they can improve plaque removal and require less manual dexterity. Features such as timers and pressure sensors may further support effective brushing, and newer designs may be better tolerated in those with sensory sensitivities.

There is limited research on the use of powered toothbrushes in stroke rehabilitation. This feasibility study aims to evaluate whether introducing powered toothbrushes, alongside staff training and person-centred oral health education, can improve both perceived and actual oral hygiene outcomes for patients recovering from stroke. We will work with around 20 residents at the RHN. This study is sponsored by Oral-B.

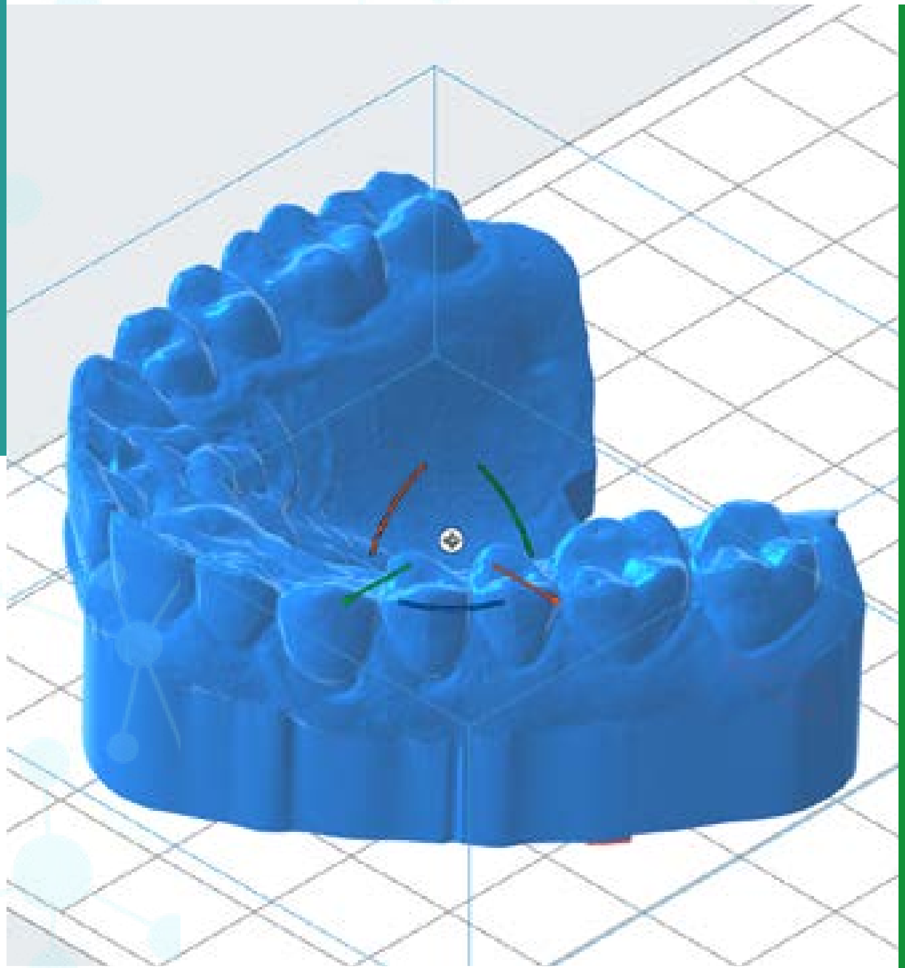
Exploring the tongue's potential: An interaction interface for people with complex disabilities

Richard Armstrong-Wood, PhD Student, RHN

This early-stage research and development project aims to design a tongue interface to support interaction with technology for people with complex disabilities. It is funded by the Royal Hospital for Neuro-disability, the Frances and Augustus Newman Foundation and led by a researcher at University College London with a background in mechanical engineering, design, and clinical research, with further support from Imperial College London.

In partnership with the hospital's dental and research departments, and in collaboration with technologists, clinicians, and patients, the project places end users at the centre of the design process. The research will explore users' conditions, goals, needs, and abilities, including motivations such as communication, wheelchair control, and creativity. Potential end users include individuals with loss of hand function due to traumatic brain injury, spinal cord injury, cerebral palsy, or neurodegenerative conditions. The project will investigate the design requirements for an intraoral device for these groups, including factors that may affect interaction, such as cognitive ability, involuntary movement, spasticity, salivation, and oral hygiene.

The project will use an iterative design approach based on user-centred design principles. This will include early and frequent prototype testing, feedback sessions, and repeated changes to help shape the device around user needs. Development will begin with a simple design and progress to a more complex system, while considering mechanical, electrical, design, and interaction requirements.



Our initial goal is to create a wearable intraoral device that will be tested first with non-disabled participants before being tested with potential end users. The device will be designed to emulate inputs such as switch presses, joystick control, and swipe gestures. These inputs could support computer access, wheelchair control, or mobile phone use. We will examine the shortcomings of current intraoral devices and explore how different sensing, interaction, and design approaches can allow a degree of personalisation to better meet the needs and goals of people with complex disabilities.

Perceived carer burden at the RHN

Dr Lloyd Bradley, Consultant in Rehabilitation Medicine and Dr Nina Dalton, Clinical Fellow, RHN

Caregiver burden encompasses feelings of stress, distress and strain, which can lead to both physical and emotional challenges, a loss of empathy and a changed attitude towards their profession. These issues can subsequently reduce the quality and safety of care.

Researchers are the University of Leicester developed a 21 items scale (ranked either never, rarely, sometimes or often) to evaluate professional caregiver burden in neurorehabilitation settings

We wanted to use this scale to look at caregiver burden at the RHN. The first aim of this analysis was to determine if working on a particular ward had a significant impact on perceived burden:

- Drapers: patients in “active rehabilitation” and considered “less impaired”
- Wellesley: patients presenting neurobehavioural challenges
- Devonshire: patients considered more impaired
- Jack Emerson: patients on long-term ventilation

The next aim was to determine whether levels of burden were experienced differently according to healthcare role. All staff were asked to fill out a questionnaire twice within 4-month intervals, as they may have different patients after 4 months, but to also identify any changes in perceived burden over time.

Healthcare staff were asked to specify the ward they work on, their professional group, age and years at RHN, as well as time since their qualification. Additional patient factors were considered, including rehabilitation treatment complexity scale, the Northwick Park Care Needs Assessment and patient categorisation tool.

There was a total of 140 responses to the questionnaire with highest response from Allied Health Professionals (AHPs), staff on Devonshire ward and age groups of 25-34 and 35-44 years.

Results showed no significant effect of time since qualification or RHN employment tenure on perceived burden. Allied Health Professionals reported the highest burden overall, with significantly higher rating among AHPs on Devonshire ward and HCAs on Drapers. Burden was similar amongst nursing staff in all settings.

Future analysis will repeat the scale for consistency, whilst also taking account how caregiver burden relates to patient care-need.

One Year On with Melo: Staff Experiences and Reflections

Dr Natali Farran, Clinical Psychologist, RHN
Presented with:
Pelinsu Aydogan, Honorary Assistant Psychologist, RHN
Jessica Moreno, Assistant Psychologist, RHN

The Neuro-behavioural Service at the Royal Hospital for Neuro-disability (RHN) is a highly specialist inpatient service supporting adults with acquired brain injury or Huntington’s Disease who present with complex Behaviours that Challenge (BtC). The service experiences substantial volumes of dynamic data requiring ongoing recording and synthesis to support clinical decision-making. This can be particularly difficult in demanding, unpredictable, high-risk, and fast-paced clinical environments that also require timely communication between staff members to maintain safety and improve patient outcomes. Melo™ is a Digital Health Technology designed to record and provide insights about behaviours in patients presenting with BtC. The tool was deployed at the service approximately one year ago, with approximately 4,000 data entries made to date. We explored staff experiences of Melo™ during the initial trial phase and after one year of use, and examined perceived clinical and service-level benefits.

Before the introduction of Melo™, behavioural entries were recorded on electronic ABC text forms or on paper-based systems, which required manual transcription into an electronic format and processing of data. Due to the manual nature of these approaches and the large volume of data, these were extremely time consuming, labour-intensive, prone to error, and required exhaustive real-time decision-making to balance behavioural risk and staff deployment. Processed data was also available on a week-by-week basis rather than in real-time. Melo™ was deployed in our service after working carefully with our clinical team to further enhance the platform through a structured and phased implementation, which focused on cultural pre-adoption. Quantitative and qualitative data were collected from staff during a trial phase prior to deployment of Melo™ and after one year of use. Staff feedback was consistently positive across both time points, highlighting ease of use, high data quality, and time efficiency. For instance, in both 2024 and 2025, approximately 80% of staff found Melo™ to be much faster than the previous system, and the rest found it as slightly faster (none of the staff members indicated that there was no difference between both systems, or that the new system is slower). Other gains were also identified such as having real-time insightful visual charts and synthesized information (e.g., common triggers of BtC), and effective information sharing and monitoring of the behaviours. A case example highlighting the efficiency of Melo™ was furthermore shared.

The team expressed excitement about the next phase with Melo™ based on suggestive feedback from the staff, which would include further collaborations to enhance the platform, such as integrating it with the electronic health record system at the RHN, capturing further details on restraint, and recording positive behaviours.

Projects on People in Prolonged Disorders of Consciousness Assessments and Long-term

Dr Judith Allanson on behalf of Drs A Ali, S Antiga, L Bradley, RHN

Patients with Prolonged Disorders of Consciousness (PDOC) can present unpredictable rehabilitation progression trajectories, for which behavioural indicators alone may not reliably reflect underlying neurological activity or inform likely outcomes. Here we present two projects that illustrate this complexity:

- A large international research collaboration of fMRI and EEG investigations of people in PDOC, that involved 61 RHN residents, found that 25% of patients thought to be in a Vegetative or low minimally conscious state (MCS-) after detailed bedside assessments, actually had the ability to change their brain activity in response to specific spoken requests. Ie they were more aware than could be detected by any clinical observations. Furthermore, long term follow up of 72 people in PDOC revealed that 22% had changed very significantly 2- 9 years later, and had achieved independence in many domains, highlighting the potential for very late changes in activities of individuals.
- A review of cases found that of 232 people admitted to the RHN in PDOC, over the last 5 years, 17 emerged later than 6 months after injury, with many demonstrating return to independence in some activities of daily living.
- one detailed case study from this cohort illustrates the challenges of predicting outcome while patients are in rehabilitation, as this person showed no consistent signs of change from PDOC until 12 months after injury but then emerged and continued to recover over the subsequent 12 months becoming well enough to be discharged to a supported living environment 24 months after initial brain injury.

These findings emphasise the importance of explaining the limits of behavioural assessments when offering prognostication during best interests meetings.

AI and Data Processing at RHN

Toby Roberts, Associate director of information technology

Safe data processing is essential to RHN's work hence the importance of robust data structure and rigorous data governance systems. There is also added value of data integration to enable seamless data flow. IT has been working alongside clinicians and partners to support the development and integration of a range of new data processing tools:

- MEMORI (in collaboration with Sanome) with BIS and Ventilator Unit teams: for early detection of infection.
- Safeguarding chatbot with the Safeguarding team: to provide decision support for safeguarding questions.
- Melo with the Neuro-behaviour team to record and analyse in real time patients' behaviours
- Working with the Admission team towards an Automation of patient flow pathways.
- Supporting clinicians in integrating an ambient audio transcription for notes and meetings.

Effective data governance and integration is enabling RHN to improve data processing for a more effective service and better care for our patients and residents.

Upcoming Events

Specialist Nursing Conference 2026: Excellence. Innovation. Leadership in Neuro-disability Nursing

Tuesday 28 April

The NHS is advancing a 10-Year Health Plan and a new 10-Year Workforce Plan that will shape the future of nursing. This conference brings together nurses, leaders, commissioners, and educators to strengthen the role of neuro-disability nursing within these plans. It highlights the RHN's experience, innovation, and collaboration in building a resilient, adaptable workforce, while serving as a call to action to empower nurses and safeguard high-quality care for neuro-disability patients.

HealthTech Forum 2026

Tuesday 5 May

This annual event is a dynamic forum where pioneers in the intersection of Information Technology and Healthcare will meet to address pressing challenges and continue to propel the industry forward. The day is for professionals, researchers, and experts dedicated to solving problems and advancing healthcare through seamless data integration. Explore cutting-edge strategies and breakthroughs as we delve into the intricacies of IT in healthcare, focusing on actionable solutions to complex issues. Engage in thought-provoking discussions on data interoperability, security, and analytics, with a focus on improving patient outcomes and operational efficiencies.

RHN Clinical PDOC Conference 2026

Wednesday 14 October

This conference will explore advancements in patient care for Prolonged Disorders of Consciousness (PDOC), featuring expert insights, innovations, and practical approaches to management. The day will also provide a valuable opportunity to network and discuss the clinical realities of delivering care across the full patient pathway.

Our educational events brochure for 2026 is live on our website. Take a look for all our specialist training courses, webinars and conferences. We look forward to welcoming you to one of our upcoming events soon:

www.rhn.org.uk/events

Publications by RHN researchers in 2025

- **A retrospective study of chronic percutaneous gastrostomy site complications and the effect of tube replacement** L McIntyre Gastrointestinal Nursing, Vol 23 No 9 November 2025 S9-14
- **Making Healthcare Decisions on Behalf of People in a Disorder of Consciousness. A "Risk-Making" Theory of Decisional Practices.** Clark T, Edgley A, Kerry R.AJOB Neurosci. 2025 Jul-Sep;16(3):129-145.
- **Do some people with a prolonged disorder of consciousness experience pain? A clinically focused narrative review and synthesis.** Wade DT, Hanrahan A.Clin Rehabil. 2025 Jun;39(6):796-807.
- **The assessment of mood in people with severe cognitive and communication impairments following brain injury: a survey of UK-based professionals.** Rose AE, Cullen B, Crawford S, Evans JJ.Brain Inj. 2025 Aug;39(11):947-962.
- **The Effect of Residential Distance from Inpatient Setting on Outcomes of Rehabilitation Following Acquired Brain Injury.** Bradley L.NeuroRehabilitation. 2025 May;56(3):414-417.
- **The effectiveness and safety of botulinum toxin treatment for sialorrhea due to severe brain injury.** Clark T, Arikan E, Bradley L.Brain Inj. 2025 May 12;39(6):476-481.

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