



## PDOC through a different lens 2025

### The Royal Hospital for Neuro-disability, Putney

15 October

Programme

**09:00** Registration and refreshments

**9.30** Welcome and Introduction

Paul Allen, *CEO, RHN*

**Chair (AM)** Dr Sophie Duport, *Associate Director of Research, RHN*

**9.40** Navigating ethical and legal complexities in research involving people with impaired capacity to consent

Dr Victoria Shepherd, *Principal Research Fellow, Centre for Trials Research, Cardiff University*

**10.30** The ethical challenges, reflections and lessons learnt from involving people in disorders of consciousness in research. A novice researchers perspectives.

Teresa Clark, *Consultant Physiotherapist, RHN*

**10.55** Outcome measurement in Severe Brain Injury: the Putney FOCUS tool

Dr Sarah Crawford, *Consultant Clinical Psychologist, RHN*

**11.20** Coffee break

**11.40** Poster Presentations:

- **The views of hospice staff on the management of PDOC patients following the discontinuation of CANH**  
Natalie Priest, *Band 7 Occupational Therapist, Llandough Centre for Specialist Spinal and Neuro Rehabilitation*
- **Developing a PDOC study day to increase staff awareness of national clinical guidelines**  
Claire O'Callaghan, *Occupational Therapist, The Walton Centre NHS Foundation Trust*
- **Challenges and Facilitators Experienced by Family Caregivers of Individuals in a Disorder of Consciousness: A Systematic Review**
- **Healthcare Professional's Experience of Working with Individuals in a Disorder of Consciousness in Acute and Post-Acute Settings: An Interpretive Phenomenological Analysis**  
Dr Caitlin Black, *Clinical Psychologist, Paediatric Cardiology and PICU*
- **Balancing organisational frameworks and the human experience when working with patients in prolonged disorder of consciousness in Switzerland: A Reflexive thematic analysis**  
Solveig Vögelin, *Advanced Physiotherapist, The Wellington Hospital*



**12.00 Challenging Behaviour in Patients who Emerge from Prolonged Disorders of Consciousness**

Dr M. Areli Tejada Condemayta, *Clinical and Research Fellow, RHN*

**12.15 Are we undertreating pain in patients in Prolonged Disorders of Consciousness? Insights from an observational prescribing study**

Dr Nina Dalton, *Clinical and Research Fellow, RHN*

**12:30 Biozoon demonstration and posters over lunch**

**Chair (PM) Dr Sophie Duport, RHN**

**13.30 Assessing communication in patients emerging from PDOC – using Linguistic Ethnography to identify how patients interact in context.**

Dr Amy Pundole, *Clinical Lead Speech and Language Therapist, RHN*

**14.15 Managing Lack of Response to Pain-Related Questions in Patients with Disorders of Consciousness**

Dr Annesofie Ishøy Nielsen, SLT, PhD, *Postdoctoral Researcher, University of Copenhagen, Denmark*

**15:00 Coffee**

**15.20 Prelim: Exploration of Differing Levels of Engagement, Facial and Bodily in Patients with Prolonged Disorders of Consciousness**

Laura Connolly, *PhD Candidate, UCL, ICN*

**15:35 Did you see her eyes?: The negotiation of hope amid uncertainty**

Dr Ann Guernon, *Associate Professor in the speech-language pathology program at Lewis University and Interim Associate Dean for the College of Nursing and Health Sciences*

Dr Christina Papadimitriou, *Sociologist Professor, Department of Interdisciplinary Health Sciences, Oakland University*

Dr Jennifer Weaver, *Director of the Meaningful Measurement in Rehabilitation Research (METEOR) Lab and Director of Implementation Research of the Translational Neurological Lab*

**16.15 Close**



## A bit about our speakers:

### **Teresa Clark**

*Consultant Physiotherapist, RHN*

Teresa Clark is a Consultant Physiotherapist at the RHN. She has worked with people in DOC and their families for approximately 15 years. Her clinical and teaching practice focuses on areas that increase complexity within a disorder of conscious, including; spasticity and contracture, postural management, tracheostomy, and sialorrhea.

Teresa completed a Masters in Clinical Research (at St Georges University London) exploring the feasibility and acceptability of including people with reduced decisional capacity in randomised trials. She is now a PhD candidate at the University of Nottingham, investigating philosophical and methodological methods of improving research participation and equitable research outcomes for those in a DOC.

### **Laura Connolly**

*PhD Candidate, UCL, ICN*

Laura Connolly is a PhD student in her final year at University College London at the Institute of Cognitive Neuroscience. Her focus has primarily been non-linguistic emotional vocalisations for the majority of her PhD. In particular, adult crying and laughter. She obtained her master's at UCL in 2021, in which she focused on laughter. She has a BSc from Royal Holloway where she had a focus in Psychophysics.

### **Dr Sarah Crawford**

*Consultant Clinical Neuropsychologist, RHN*

Dr Sarah Crawford is a Consultant Clinical Neuropsychologist at the Royal Hospital for Neuro-disability in Putney. She is the professional lead for Clinical Psychology within the Brain Injury Service, an NHS England funded Level 1 neuro-rehabilitation service for patients with complex neuro-disability. Dr Crawford has a particular interest in supporting families, and chaired the RHN's steering group for improving services for our patients' and residents' families and friends.

She has previously worked in the NHS, providing specialist outpatient neuropsychological assessments. She has also worked as a Clinical Psychologist within other specialist neuro-rehabilitation settings, including a transitional rehabilitation service and a unit for patients with severe challenging behaviour secondary to brain injury.

Dr Crawford has a BA degree in Experimental Psychology from the University of Oxford, a PhD in Psychology from University College London, and a Doctorate in Clinical Psychology from Kings College London. She has completed post-doctoral training in clinical neuropsychology and is listed on the British Psychological Society's Specialist Register of Clinical Neuropsychologists.

### **Dr Nina Dalton**

*Clinical and Research Fellow, RHN*

Dr Nina Dalton has a Medical degree and a BSc in Neurosciences and Mental from Imperial College London, and completed an MSc by Research in Psychiatry from the University of Oxford, supervised by Professor Paul Harrison. She has been working at the Royal Hospital for Neurodisability as a Clinical and Research fellow for the past 8 months, prior to which she has 7 years of experience working in a range of disciplines in the NHS.



## **Dr Ann Guernon**

*Associate Professor in the speech-language pathology program at Lewis University and Interim Associate Dean for the College of Nursing and Health Sciences*

Ann conducts mixed methods research related to communication and interactions between a variety of end-users and how those interactions influence person-centered care and shared decision-making. Her specific areas of focus are on youth sport-related concussion and individuals with disordered consciousness following severe brain injury.

## **Dr M. Areli Tejada Condemayta**

*Clinical and Research Fellow, RHN*

Dr Areli Tejada holds a Medical degree and a Bachelor's degree in Neuroscience and Psychology. She previously worked as a clinical fellow at the Royal Hospital for Neuro-disability (now an honorary fellow) and is currently an Internal Medicine trainee at NHS Sussex, aiming to expand her knowledge in medicine and neuropsychiatry.

## **Dr Annesofie Ishøy Nielsen**

*Postdoctoral Researcher, University of Copenhagen, Denmark*

Annesofie is a Danish speech and language therapist with extensive experience in a specialized neurorehabilitation unit, working with patients in the subacute phase following severe brain injury. Her clinical focus includes patients with disorders of consciousness, post-traumatic confusion, and severe cognitive-communication disorders. In her PhD research, she involved rehabilitation staff in the development of a tool to document emerging signs of interaction abilities observed in everyday clinical practice. In parallel, she conducted detailed analyses of staff-patient interaction using video recordings and the method of conversation analysis. In this presentation, she will share insights into how professionals ask questions—particularly about pain and discomfort—and how they manage situations when patients do not respond.

## **Dr Christina Papadimitriou**

*Sociologist Professor, Department of Interdisciplinary Health Sciences, Oakland University*

Christina is a sociologist and medical rehabilitation researcher interested in how people with disabilities and health professionals make meaning of their healthcare experiences to develop more inclusive and collaborative healthcare practices. She works with interdisciplinary and interprofessional teams to develop relationship-centered assessments for people living with disorders of consciousness to improve shared decision-making. She also studies peer support interventions for people with disabilities to improve community participation and healthcare outcomes. Christina's research has been funded by federal and foundation grants including NIDILRR and AHRQ. She is also the Director of Hermeneutic Resource Development at the Advanced Metrics Lab at The George Washington University where she develops resources that unpack how people make meaning to support inclusive and authentic articulation of their experiences.

Using an equity-based hermeneutic approach, Christina works with both marginalized and dominant cultures to make invisible positions and experiences visible, and to develop inclusive and collaborative assessments that can lead to greater shared benefits for all involved.

## **Dr Courtney Powdrill**

*Orthoptist – Vision Screening Lead, St. George's Hospital*

Courtney graduated from the University of Sheffield with a BMedSci in Orthoptics in 2016 where she then began working at Kingston Hospital (Royal Eye Unit). During her time at Kingston Hospital, Courtney was the Orthoptic Clinical Lead for stroke patients. In 2019, she moved to Moorfields Eye Hospital (mainly based at St. George's Hospital), as the school Vision Screening Lead for the Wandsworth borough. Over the years Courtney has worked in the neuro-ophthalmology and



strabismus clinics, assessing, diagnosing and managing patients post brain injury. In June 2021, the Neuro-Orthoptic service was set up at the RHN. At present, the service runs monthly and referrals include patients with diplopia, field loss and eye movement disorders.

## **Dr Amy Pundole**

*Clinical Lead Speech and Language Therapist, RHN*

Amy Pundole is an experienced Clinical Specialist Speech and Language Therapist working with communication and swallowing disorders in patients with severe and complex acquired neurodisability. Amy graduated from Sheffield University in 2001 and has worked with adults in a range of settings, in the NHS and Charitable sector. Amy's particular interests include complex dysphagia and tracheostomy management and she is an experienced FEES assessor and endoscopist. She uses a holistic approach and is trained in the use of Facial Oral Tract Therapy (FOTT) in the management of swallowing and communication disorders.

Amy is highly skilled in working with adults in a Prolonged Disorder of Consciousness (PDOC) and their families. She is an RCSLT advisor in this field and has contributed to national guidelines. She has completed a PhD at University College London investigating how best to assess patients emerging from PDOC.

## **Dr Victoria Shepherd**

*Principal Research Fellow, Centre for Trials Research, Cardiff University*

Dr Victoria Shepherd is a registered nurse and a Principal Research Fellow at the Centre for Trials Research in Cardiff University where she leads a mixed-methods research programme exploring the ethical, legal, and methodological issues in research involving adults with impaired capacity to consent and developing interventions to address them.

Her work has included exploring decision-making about research participation on behalf of adults who lack capacity to consent, which led to the development of a novel decision support intervention for family members acting as consultees and legal representatives. Her current project (CONSULT) is identifying the barriers and facilitators to the inclusion of adults with impaired capacity, evaluating the decision support intervention in a range of trials and settings, and the development of an online resource on capacity and consent and stakeholder-informed e-learning. She is also exploring the feasibility of advance research planning, and is leading the development of the OPTIMISE principles for designing more inclusive consent processes.

Victoria has a particular interest in the inclusion of under-served groups in research and has a portfolio of methodological research exploring inclusion in clinical trials. She led the development of the NIHR INCLUDE Impaired Capacity to Consent framework to support researchers to design trials that are inclusive of adults with impaired capacity, and is an expert member of an NHS REC.

## **Dr Jennifer Weaver**

*Director of the Meaningful Measurement in Rehabilitation Research (METEOR) Lab and Director of Implementation Research of the Translational Neurological Lab*

Her research interests include facilitating shared decision-making between care partners and rehabilitation practitioners of clients with chronic neurological conditions, such as traumatic brain injury. To support shared decision-making, Jennifer works on creating easy-to-understand assessment result information.