



## CONFERENCE PROGRAMME

### SPEAKERS



Mathilde Chevignard



Lynne Turner-Stokes



Bronwyn Hemsley



Beth Armstrong



Juli Coffin



Caroline Fisher



Eddie Tsang



Olivier Piguet



Bruce Powell

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**Getting on with the business of living**  
**THURSDAY 5<sup>th</sup> May**

9.00 – 4.00 Workshops	
<b>9.00-12.00 Workshop 1</b> <b>Chair: Michelle Kelly</b> <i>Dr Caroline Fisher and Edmund (Eddie) Tsang</i>	<b>9.00-12.00 Workshop 2</b> <b>Chair: Travis Wearne</b> <i>Prof Bronwyn Hemsley</i> Crafting A Robust Social Media Strategic Plan for Professional Practice: Development, Intervention, and Advocacy Online
10.30-10.45 Morning Break	
12.00-1.00 Lunch break including Poster Session	
12.30-1.00 Registration at Registration Desk	
<b>1.00-4.00 Workshop 3</b> <b>Chair: Barby Singer</b> <i>Prof Lynne Turner-Stokes</i> GAS without tears – finding the right balance for goal setting in rehabilitation	<b>1.00-4.00 Workshop 4</b> <b>Chair: Janet Wagland</b> <i>Profs Beth Armstrong and Juli Coffin</i> What does culturally secure brain injury care look like for Aboriginal Australians?
2.30-2.45 Afternoon Break	
4.00 Workshops CLOSE	

## FRIDAY 6<sup>th</sup> May

**8.30 –11.00 PLENARY 1**

**Chair: Janet Wagland**

**8.30 – 8.45** Welcome to Country will be undertaken by Cheryl Taylor and Kerri Colegate (KM Noongar Consultancy services)

Welcome to the conference Janet Wagland and Michelle Kelly

**8.45 – 9.45 Debate - *Machines are the future: in the assessment, diagnosis, rehabilitation and care of those with brain conditions***

**9.45 – 10.15** Keynote Speaker: **Dr Bruce Powell**

**10.15 – 11.00** ASSBI Presidential Address: **Prof Olivier Piguet**

**11.00 – 11.30** Morning break including Poster Session

**11.30 – 12.30 CONCURRENT SESSIONS 1 – 3**

<b>Concurrent Session 1 Chair: Olivier Piguet Dementia</b>	<b>Concurrent Session 2 Chair: Grahame Simpson Vocation</b>	<b>Concurrent Session 3 Chair: Aishani Bharat Desai How to Session 1</b>
<p>11.30 Kelly, Michelle: START Caring for Carers: Feasibility and Acceptability of a Support Program for Carers of People with Dementia</p> <p>11.45 Wong, Stephanie: Apathy and effort-based decision-making in behavioural-variant frontotemporal dementia</p> <p>12.00 Kumfor, Fiona: Executive dysfunction underpins cognitive apathy in dementia</p> <p>12.15 Hazelton, Jessica: Investigating emotion and interoception in neurodegenerative diseases: A multi-centre international study</p>	<p>11.30 Simpson, Grahame: Participation in competitive employment after moderate to severe traumatic brain injury in NSW: A multi-center study <b>(DB1)</b></p> <p>11.35 Gates, Thomas: Is the Vocational Intervention Program Effective in Enhancing Return to Work after Severe Traumatic Brain Injury? A controlled trial</p> <p>11.50 McRae, Philippa: Participation in competitive employment after moderate to severe traumatic brain injury in NSW: The VIP 2.0 multi-center implementation study</p> <p>12.05 Lukersmith, Sue: What does it take to get somebody back to work after severe traumatic brain injury?: Service inputs within the Vocational Intervention Program (VIP 2.0) <b>(DB2)</b></p> <p>12.10 Christie, Lauren: Client experiences of participating in a specialist vocational intervention partnership program (VIP 2.0) following severe brain injury <b>(DB3)</b></p> <p>12.15 Kobel, Conrad: Cost-benefit analysis of the Vocational Intervention Program (VIP 2.0)</p>	<p>Pierce, John: Creating a Video Abstract for your research</p>

**12.30 – 1.30** Lunch and Poster Session

**1.30 – 3.00 CONCURRENT SESSIONS 4 – 6**

<b>Concurrent Session 4 Chair: Lizzie Beadle Technology</b>	<b>Concurrent Session 5 Chair: Skye McDonald Rehabilitation</b>	<b>Concurrent Session 6 Chair: Curtis Reddell Traumatic Brain Injury</b>
<p>1.30 Brunner, Melissa: Developing social-ABI-lity - an online course to support safe use of social media for connection after brain injury</p> <p>1.45 Gould, Kate: "This group... I felt like I was</p>	<p>1:30 Jenkin, Taylor: "How do you make life work for the family?": Understanding families' experiences of rehabilitation following paediatric acquired brain injury</p>	<p>1.30 Mann, Georgina: Time between acquired brain injury and admission to post-acute brain injury services: differences in sociodemographic factors, and clinical, functional and psychosocial outcomes, 1991-2020</p>

<p>medicating myself from this cyberscam illness that was living with me". A qualitative evaluation of co-designing cybersafety training resources with and for people with acquired brain injury</p> <p>2.00 Stolwyk, Renee: Investigating Clinician Experiences of Teleneuropsychology Service Implementation within Rural Inpatient Rehabilitation Settings: A Mixed Method Approach</p> <p>2.15 Pilli, Kavya: Clinician Use and Experiences with Assistive Technology in Brain Injury Rehabilitation</p> <p>2.30 Sugden, Nicole: Smartphones as prospective memory aids in ADHD: Helpful or problematic?</p>	<p>1.45 Sharp, Vanessa: Perspectives of Major Traumatic Injury Survivors on Accessibility and Quality of Rehabilitation Services in Rural Australia</p> <p>2.00 Fleming, Jennifer: A randomised controlled trial of prospective memory rehabilitation plus metacognitive skills training for adults with traumatic brain injury</p> <p>2.15 Doig, Emma: Prospective memory rehabilitation goals and compensatory strategies used by people with traumatic brain injury</p> <p>Datablitz</p> <p>2.30 Kelly, Crystal: Community-based rehabilitation following traumatic brain injury: A qualitative investigation <b>(DB4)</b></p>	<p>1.45 Ponsford, Jennie: Surviving the 'Silent Epidemic': A Qualitative Exploration of the Long-Term Journey After Traumatic Brain Injury</p> <p>2.00 Kelly, Erin: Improving services for patients with Disorders of Consciousness (DoC): Implementation of family and staff education packages in a Neurosciences Unit</p> <p>Datablitz</p> <p>2.15 Keys, Alison: Getting on with the Business of Community Brain Injury Rehabilitation during Global Pandemic <b>(DB5)</b></p> <p>2.20 Fraser, Elinor: A Single-Case Experimental Evaluation of a Novel Treatment Adapting a Cognitive Behaviour Therapy Approach for Sexuality Problems After Traumatic Brain Injury <b>(DB6)</b></p> <p>2.25 Winkler, Di: Younger people in aged care: Will we achieve the 2022 and 2025 government targets? <b>(DB7)</b></p> <p>2.30 Ponsford, Jennie: "Its Not Only The Injury But Also the Kind of Head." Factors Influencing Outcome after Moderate-Severe TBI <b>(DB8)</b></p> <p>2.35 Mann, Georgina: Gender differences in service utilisation and clinical outcomes of people with acquired brain injury undergoing post-acute neurorehabilitation and disability support, 1991-2020 <b>(DB9)</b></p>
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**2.45 – 3.15** Afternoon Break and Poster Session

**3.15 – 5.15** **PLENARY 2**

**Chair: Dana Wong**

**3.15 – 4.15** International Keynote Speaker: **Prof Lynne Turner-Stokes**

***Tough Decisions around Catastrophic Brain Injury – An International Perspective***

**4.15 – 5.15** International Keynote Speaker: **Prof Mathilde Chevignard**

***Long-term outcomes and transition to adulthood following childhood acquired brain injury***

**5.15 - 6.15** **WESTERN AUSTRALIAN SHOWCASE**

## SATURDAY 7<sup>th</sup> May

**8.30 – 9.30**      **PLENARY 3**

**Chair: Leanne Togher**

**8.30 – 9.00**      National Keynote Speaker: **Prof Bronwyn Hemsley**

*People with Communication Disability Striving, Thriving, and Surviving as Technology Advances*

**9.00 - 9.30**      National Keynote Speaker: **Prof Beth Armstrong and Prof Juli Coffin**

*Improving services for Aboriginal Australians after brain injury: Current initiatives and findings to date*

**9.30 – 10.00**      Morning Break including Posters

**10.00 – 11.30**      **CONCURRENT SESSIONS 7 – 9**

<b>Concurrent Session 7</b> <b>Chair: <a href="#">Tamara Ownsworth</a></b> <b>Behaviour Mood Emotion</b>	<b>Concurrent Session 8</b> <b>Chair: <a href="#">Jennie Ponsford</a></b> <b>Discharge/Community</b>	<b>Concurrent Session 9</b> <b>Chair: Dana Wong</b> <b>How to Session 2</b>
<p>10.00 Gould, Kate: An international transdisciplinary training program for allied therapy students in Positive Behaviour Support: Findings from a pre-post feasibility study</p> <p>10.15 Chuah, Sarah: Are mental health needs of individuals with a traumatic brain injury being met? A cross sectional study</p> <p>10.30 Rose, Alexandra: Assessment of low mood, distress and depression in people with severe brain injury: a systematic review</p> <p>10.45 Quang, Halle: Motivational disorders after traumatic brain injury: Is apathy driven by abnormal sensitivity to foreground and background reward?</p> <p>11.00 Skronamis, Sarah: Social Disinhibition in Acquired Brain Injury and Neurological Disease: A Concept Analysis</p> <p>11.15 Carmichael, Jai: The Hospital Anxiety and Depression Scale Does Not Reliably Differentiate Anxiety and Depression Following Traumatic Brain Injury</p>	<p>10.00 Collins, Jeanette: Adult patient and carer experiences of planning for hospital discharge after a major trauma event</p> <p>10.15 Douglas, Jacinta: Evaluation of outcomes for people with neurological disability and complex needs after moving into new individualised apartments: Preliminary results</p> <p>10.30 Honan, Cynthia: Does Poor Sleep Quality Affect Functional Outcomes in Individuals with Chronic Fatigue Syndrome?</p> <p>10.45 D’Cruz, Kate: “This is better but not fully there”: Experiences of participating in a co-design project from the perspective of adults with neurological disability and facilitators</p> <p>11.00 Topping, Megan: “They treat you like a person, they ask you what you want”: Exploring Factors that Influence the Quality of Paid Disability Support for Adults with Acquired Neurological Disability</p> <p>Datablitz</p> <p>11.15 Nicol, Chelsea: Individuals’ perceptions of their health and well-being in the context of Stereotactic Radiosurgery for benign brain tumour: a longitudinal qualitative investigation <b>(DB10)</b></p> <p>11.20 Honan, Cynthia: Meta-social-cognitive awareness of emotion perception abilities in ABI <b>(DB11)</b></p> <p>11.25 Sansonetti, Danielle: Assessment of online awareness following acquired brain injury: A conceptual analysis and recommendations for practice <b>(DB12)</b></p>	<p>Ziino, Carlo: Behaviour support and the NDIS: Roles, Responsibilities and Regulations</p> <p>Additional Presenters:  Jane Dahm  Bleydy Dimech  Betancourt  Kate Frencham  Sue Sloan  Kim Trezise  Diane Parcell</p>

**11.30-12.30**What is it: *An informal lunchtime workshop for students*Chair: **Danielle Fynn - WA Student Team Leader****Guest Speakers: Chanel Bowen and Chris Thompson****12.30 – 1.30** Lunch break and Posters**1.45 – 2.45 CONCURRENT SESSIONS 10 – 12**

<b>Concurrent Session 10</b> <b>Chair: Clare Ramsden</b> <b>Stroke</b>	<b>Concurrent Session 11</b> <b>Chair: Miriam Poole</b> <b>Social Reintegration</b>	<b>Concurrent Session 12</b> <b>Chair: Robyn Tate</b> <b>How to session 3</b>
<p>1.45 Wong, Dana: What are the best ways to sustain gains following post-stroke memory rehabilitation? Results from the Memory-SuSTAIN pilot randomised controlled trial</p> <p>2.00 Finch, Emma: The Stroke Unmet Needs (SUN) study: A randomised controlled trial</p> <p>2.15 McKay, Adam: Effectiveness of a telehealth-based memory rehabilitation group after stroke</p> <p>Datablitz 2.30 Phyland, Ruby: Factor Structure of the Agitated Behaviour Scale in Traumatic Brain Injury During Post-Traumatic Amnesia <b>(DB13)</b></p> <p>2.35 Pierce, John: How Fatiguing is High Intensity Treatment for People with Aphasia? An Analysis of 140 Participants from the COMPARE Trial <b>(DB14)</b></p> <p>2.40 Rose, Miranda: Feasibility, acceptability, and preliminary efficacy of a hub-and-spoke peer-facilitated community aphasia group program <b>(DB15)</b></p>	<p>1.45 Douglas, Jacinta: Building skills, connecting, belonging and developing confidence: Qualitative evaluation of a Multi-component Community Connection program (M-ComConnect) for people with severe traumatic brain injury (TBI)</p> <p>2.00 McAllister, Meaghan: The development and implementation of the Aboriginal Brain Injury Coordinator service as part of the Healing Right Way randomised control trial</p> <p>2.15 Cubis, Lee: Housing and Support for People with Huntington’s Disease: A scoping review</p> <p>Data Blitz 2.30 Ownsworth, Tamara: Scoping psychological support pathways for adults with primary brain tumour across Australia: A health professional survey <b>(DB16)</b></p> <p>2.35 D’Cruz, Kate: Support in co-located apartments for people with neurological conditions: Co-design of potential solutions <b>(DB17)</b></p>	<p>Savage, Sharon: Practical Recommendations for the Delivery of Language and Psychosocial Interventions in Primary Progressive Aphasia</p>

**2.45 – 3.15** Afternoon Break and Posters

**3.15 – 4.15 CONCURRENT SESSIONS 13 – 15**

<b>Concurrent Session 13</b> <b>Chair: Barbra Zupan</b> <b>Speech/ Language</b>	<b>Concurrent Session 14</b> <b>Chair: Jacinta Douglas</b> <b>How to session 4</b>	<b>Concurrent Session 15</b> <b>Chair: Angelita Martini</b> <b>How to session 5</b>
<p>3.15 Taylor-Rubin, Cathleen: Is word learning enough? Exploring the effects of verb and noun treatment on connected speech production</p> <p>3.30 Power, Emma: NDIS speak up: Speech Pathologists perspectives’ on provision of NDIS services to people with an acquired brain injury</p> <p>3.45 Savage, Sharon: Beyond Primary Progressive Aphasia: A Scoping Review of Spoken Language Impairments in Other Neurodegenerative Dementias</p> <p>4.00 Sekhon, Jasvinder: Preliminary efficacy and feasibility of a counselling education program on speech pathologists’ self-efficacy and self-rated competency for counselling in post-stroke aphasia</p>	<p>Callaway, Libby: ‘How to’ consider the use of technology for executive function support after acquired brain injury (ABI): Development and testing new information and education resources for people with ABI, their families and clinicians working with them</p>	<p>Smith, Kylie: What person-centred care really means for service provision  <i><b>(please have two sheets of A4 paper and something to write with available for this session)</b></i></p>

- 4.20 – 5.00** AWARDS AND CONFERENCE CLOSE  
**Chair Olivier Piguet**  
**4.20 – 4.30** Thanks to Convenor, Committees and Sponsors  
**4.30 – 5.00** **Brain Impairment Douglas Tate Award**  
**ASSBI Student Awards**  
Kevin Walsh Award  
Luria Award  
Travel Award  
**Mindlink Brightwater**  
Award for Interdisciplinary Presentation

6.00 Networking sessions are being organised in hubs where there are no restrictions (Perth, Melbourne, Sydney, Brisbane)

**POSTER LIST**

#	Name	Title
1	Avramovic, Petra	An online multimodal intervention for people with brain injury and their communication partners to improve their conversation skills together: a proof-of-concept study
2	Carrier, Sarah	Effectiveness of non-pharmacological interventions for agitation during post-traumatic amnesia following traumatic brain injury: A systematic review
3		WITHDRAWN
4	Cubis, Lee	One Size Does Not Fit All: A qualitative investigation into the housing needs and preferences of people with Huntington’s Disease
5	De Pauw, Tom	The impact of physical activity on social cognition, cognition and mood following TBI: A randomised controlled trial protocol
6	Filipcikova, Michaela	The relationship between aggression and social disinhibition following severe TBI
7	Fitts, Michelle	The potential benefits of narrative and creative arts approach during the transition phase for Aboriginal and Torres Strait Islander Australians following traumatic brain injury
8	Ford, Amy	The experience of spousal relationships from the perspective of people with aphasia: Results from cross sectional and longitudinal interviews
9	Gertler, Paul	Assessing the impact of NeuroBITE for clinicians, researchers, and decision-makers
10	Gibson, Robyn	Speech language therapists’ perceptions of working with people with aphasia and co-occurring cognitive impairment.
11	Hall,Zali	Targeting aspects of everyday communication in therapy: a systematic review of co-constructed communication
12	McGrath, Andrew	The Flynn effect in estimates of premorbid intellectual functioning in an Australian sample
13	Mcnamara, Anne	Cognitive Testing Accuracy can be Impeded by Vision Loss
14	Nichols, Ashlee	Implementing and evaluating a cognitive rehabilitation group with clients following Acquired Brain Injury (ABI) and its impact on everyday living skills, at a community based residential staged-rehabilitation service in Perth, WA.
15	O’Sullivan, Catherine	Don’t forget to test! Post Traumatic Amnesia testing at Sydney Children’s Hospital
16	Pierce, John	Key Challenges for People Living with Communication Disability after Stroke and Traumatic Brain Injury – Data from Phase I of Communication Connect
17		WITHDRAWN
18	Roseingrave, Eve	Living in Limbo: Navigating the hospital and discharge process for people with disability and complex needs
19	Troeung, Lakkhina	Measuring the complexity and outcomes of Brightwater clients with acquired brain injury: A whole population cohort study, 1991-2020
20	Watter, Kerrin	Developing an Evidence-based Framework for Early, Interdisciplinary ABI Vocational Rehabilitation
21	Winkler, Di	Primary health care needs and service utilisation of NDIS participants with acquired brain injury

## Workshop 1

### Adult ADHD: Assessment, Diagnosis and Intervention

Fisher, Caroline<sup>1</sup>; Grace, Nicci<sup>1</sup>; Castellani, Mary<sup>1</sup> and Tsang, Eddie<sup>1</sup>

<sup>1</sup>Neuropsychology Service, The Melbourne Clinic, Melbourne, Australia

This workshop is targeted at clinicians who are interested in developing clinical knowledge and skills in the assessment and diagnosis of adults with ADHD, as well as ways to support with neurocognitive intervention.

Increasingly, adults of all ages are being referred to neuropsychology for diagnostic clarification of possible ADHD. This is likely due to increased community awareness and greater understanding of this condition. Adults with ADHD typically also present with longstanding challenges with mental health and emotional dysregulation, and this can be a complicating factor when providing diagnostic clarification.

The workshop will be interactive and include case studies. It will cover three main areas:

- 1) Clinical features of ADHD in adults, what to look for and ask about in history taking. How undiagnosed ADHD may have impacted on functioning, as well as common mental health and neurodevelopmental comorbidities.
- 2) Recommendations for conducting a neuropsychology diagnostic assessment including; clinical and cognitive features of ADHD in adults and how to identify these alongside other psychiatric symptoms and presentations, assessments to aid with diagnosis, using a neuropsychological framework, how to provide a supportive diagnosis in adults, particularly those with mental health comorbidities.
- 3) Intervention: Support and therapy, following an adult ADHD diagnosis, an overview of the Adult ADHD neurocognitive skills group at The Melbourne Clinic based on Dr Mary Solanto's CBT group therapy model for adults with ADHD

**Level aimed for:** Intermediate

**Learning objectives:** List at least 2 learning outcomes delegates can expect to obtain after attending this seminar

- Key clinical features to be aware of and targets of neuropsychological assessment in adults with suspected ADHD
- Ways to provide a supportive diagnosis to adults with ADHD
- Pathways for neurocognitive intervention in adults with ADHD

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eddie.tsang@healthscope.com.au

Reference:

aSolanto, V. 2011. Cognitive-Behavioural Therapy for Adult ADHD. Guilford Press ISBN 9781462509638

## Workshop 2

### Crafting a robust social media strategic plan for professional practice: Development, intervention, and advocacy online

Hemsley, Bronwyn Hemsley<sup>1</sup>

<sup>1</sup>The University of Technology Sydney

Health professionals working in the field of traumatic brain injury admit to being unsure about their own strategic use of social media for professional purposes, and both protectively cautious and reticent to support people with traumatic brain injury to use social media during their early rehabilitation. People with traumatic brain injury describe a 'trial and error' approach being necessary to their beginning to use social media again following their injury. This leaves both health professionals and people with traumatic brain injury exposed through (a) under-utilisation of their social networks for positive aspects of rehabilitation, and (b) encountering difficulties without knowing how to avoid or recover from these in ways that reduce their risks of harm in the future.

Lacking confidence and competence in the use of social media, health professionals who avoid the potential harms of social media by restricting use could be reducing their opportunities for developing skills in (a) predicting and avoiding social media harms, and (b) reducing their future risks and impacts of negative events in social media. This workshop focuses on three main uses of social media that should help health professionals, people with traumatic brain injury, and their families and service providers, in building and strengthening supportive social media networks. This practical workshop will involve working in small groups and crafting personalised strategic statements which will see delegates empowered to step into social media use more confidently in their future work in the field of traumatic brain injury. When considering the large number of social media platforms now available, it is important that a strategic plan is developed to help guide staff within an organisation in their purposes of use and ways to minimise risk and maximise benefit for the effort involved in growing and sustaining a social media presence in safe and enjoyable ways.

The first design element of the plan is the strategic use of social media by rehabilitation professionals to build interdisciplinary connections in areas of interest to develop a robust but diverse network. The main benefit of this is the potential for professional development and shared strength in raising awareness and knowledge in the general

public and co-ordinated or concerted campaigns in social media for greater impact.

The second design element is to enable the development of social networks between rehabilitation professionals and people with traumatic brain injury and their families and service providers, to increase the discourse and mutual understanding of roles and experiences, both of which can improve collaboration for person-centred care and could increase the impact of awareness-raising campaigns with aligned messaging and first-person accounts.

The third design element is to increase the capacity of health professionals for supporting people with traumatic brain injury to use social media as part of their rehabilitation, encompassing communication and participation goals in which social media might contribute important elements.

This workshop is an active-learning forum for delegates to develop a personal or organisational social media strategic plan which furthers their goals in relation to traumatic brain injury, and to develop ways to support staff in the implementation of the plan and as their competency and confidence develop over time. It is vital that health professionals consider their use of social media strategically, so that both use and non-use can be supported thoughtfully; in ways that empower rather than restrict a person's autonomy and freedom of expression and access to an important mode of social and professional communication.

#### **Learning objectives:**

(a) move the evidence base, gathered over the past decade, into their development and implementation of a practice-based and personally meaningful social media strategic plan, and

(b) increase the safety and enjoyment of health professionals using social media as a communication intervention with clients and as a means to advocate for their client groups.

### **Workshop 3**

#### **GAS without tears - finding the right balance for goal setting in rehabilitation**

Turner-Stokes, Lynne<sup>1,2</sup>

<sup>1</sup>The Regional Hyper-Acute Rehabilitation Unit, Northwick Park Hospital, London, UK

<sup>2</sup>The Cicely Saunders Institute, King's College London, London UK

Goal-setting forms the cornerstone of management in rehabilitation programmes, but can be challenging to implement in busy settings.

- Teams sometimes struggle to develop multidisciplinary goals and get bogged down by procedure and rules
- Goal setting should be centred around the individual patient, but some patients and their families can engage more readily than others

- Goal-sets may miss key target areas that may need to be addressed

Most teams now report that they set goals for rehabilitation, but not all actually review them to determine how well they were met. Clinicians report frustration that excessive time spent in setting goals can prevent them from actually delivering the rehabilitation programme. Some disciplines feel excluded from the process as patient rarely chose goals in their particular area of practice.

This workshop will explore the practical implementation of goal-setting in rehabilitation and present a number of solutions to get the best out of it with the minimum of fuss.

Techniques will include:

- Simplified goal attainment scaling using the GAS light model
- Measuring engagement and goal-satisfaction for patients and their families
- An inclusive approach to goal-setting using structured goal sets and goal menus
- Goal setting patients who cannot engage with the process - finding the balance between 'process' and 'outcome' goals
- Using evaluation of goal attainment for team reflection and learning

**Level aimed for:** Intermediate to Experienced

**Learning objectives:** After attending this session, delegates will be familiar with a range of options to help them and their patients to get more out of the goal-setting process for less time and effort

### **Workshop 4**

#### **What does culturally secure brain injury care look like for Aboriginal Australians?**

Armstrong, Beth<sup>1</sup> and Coffin, Juli<sup>2</sup>

<sup>1</sup>Edith Cowan University, Perth, WA, Australia

<sup>2</sup>Telethon Kids Institute, Broome, Australia

This workshop will provide participants with practical ways of implementing culturally secure practice with Aboriginal patients with brain injury in both acute and rehabilitation contexts. It will discuss the concept of cultural security (Coffin, 2007) in relation to brain injury. Cultural security refers to ensuring that Aboriginal cultural values, world views and ways of working are incorporated at each level and stage of the acute and rehabilitation service and that services will not compromise the legitimate cultural rights, values and expectations of Aboriginal people. During the workshop, institutional policies and procedures, team practices and individual attitudes will be discussed as they relate to the care of Aboriginal people after brain injury. Authentic clinical scenarios involving Aboriginal people with brain injury will be provided emanating from the

Missing Voices and Healing Right Way projects. Participants will also be encouraged to present scenarios from their own work contexts and discuss both challenges and facilitators to culturally secure care in the brain injury context.

Outcomes for workshop attendees:

1. Understanding of the concept of cultural security.
2. Practical ways forward for the implementation of culturally secure care for Aboriginal Australians with brain injury.
3. Ability to translate notions of cultural security to their own workplace.

## Plenary Session 1

Bruce Powell

Olivier Piguet

### SESSION 1

#### START Caring for Carers: Feasibility and Acceptability of a Support Program for Carers of People with Dementia

Kelly, Michelle<sup>1</sup>; Kilham, Kaylene<sup>1</sup>; Walter, Alison<sup>1</sup>; Dow, Briony<sup>2</sup>; Rapaport, Penny<sup>3</sup> and Livingston, Gill<sup>3</sup>

<sup>1</sup>University of Newcastle, Australia

<sup>2</sup>National Ageing Research Institute, Australia

<sup>3</sup>University College London, United Kingdom

**Background and Objectives:** The objective of this study was to examine the feasibility and acceptability of the Strategies for Relatives (START) program within the Australian context, for the alleviation of carer distress and burden. Further, we aimed to determine the feasibility and acceptability of the telehealth modality, and the experience from both the therapists and carers perspectives.

**Method:** Twenty-eight family carers were assigned to the START eight-week manualised coping program or cognitive behaviour therapy (CBT). Therapists and carers completed purpose developed *pre-intervention*, *post-session* and *post-intervention* questionnaires to examine aspects of the feasibility of the START program and delivery of START via telehealth. Measures of mood and perceived carer burden were also administered to explore treatment effects.

**Results:** START carers reported higher overall satisfaction and acceptance of the intervention compared to carers in the CBT group. Furthermore, the telehealth modality was shown to be a practical and acceptable method of intervention delivery for carers. Therapists rated their confidence delivering the START program and the relevance of the program to carers higher overall compared to therapists delivering CBT. Therapists rated delivery via telehealth as acceptable, however qualitative

feedback indicated technical difficulties impacted delivery.

**Conclusions:** These pilot findings indicate preliminary evidence for some aspects of feasibility of the START intervention for supporting carers. Delivery of the START program via telehealth is acceptable to therapists and carers however findings suggest technical capacity and infrastructure require consideration. Further investigation is needed to determine intervention efficacy for the treatment of mental health related symptomology via telehealth in a larger sample, though it would be expected these data would support the original UK trial.

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#### Apathy and effort-based decision-making in behavioural-variant frontotemporal dementia

Wong, Stephanie<sup>1,2,3</sup>; Le Heron, Campbell<sup>4</sup>; Wei, Grace<sup>2,3</sup>; Hodges, John R.<sup>2,5</sup>; Husain, Masud<sup>6</sup>; Piguet, Olivier<sup>2,3</sup>; Irish, Muireann<sup>2,3</sup> and Kumfor, Fiona<sup>2,3</sup>

<sup>1</sup>Flinders University, College of Education, Psychology and Social Work, Adelaide, Australia

<sup>2</sup>The University of Sydney, Brain and Mind Centre, Sydney, Australia

<sup>3</sup>The University of Sydney, School of Psychology, Sydney, NSW, Australia

<sup>4</sup>New Zealand Brain Institute, University of Otago, Christchurch, New Zealand

<sup>5</sup>The University of Sydney, Sydney Medical School, Sydney, NSW, Australia

<sup>6</sup>University of Oxford, Department of Experimental Psychology, Oxford, UK

**Background and Objectives:** Apathy is a core diagnostic feature of behavioural-variant frontotemporal dementia (bvFTD). This loss of motivation and pervasive decline in goal-directed behaviour is associated with functional decline, poorer prognosis and carer stress. The neurobiological mechanisms driving these symptoms are poorly understood and treatment options are limited. This study aimed to investigate whether apathy in bvFTD may be driven by changes in effort-based decision-making, a process by which potential rewards and the effort cost required to obtain them are integrated to drive behaviour.

**Method:** Twenty-two patients with probable bvFTD and 20 age-matched controls were assessed using a novel paradigm in which participants decided whether to accept or reject a series of offers to gain different magnitudes of reward by squeezing a handheld dynamometer at varying levels of physical effort. Choice and force metrics were recorded for each of the 6 levels of reward and 6 levels of effort, which were manipulated independently so offers spanned the full range of possible combinations. A computational model of choice was used to estimate each participant's effort sensitivity and reward sensitivity.

**Results:** bvFTD patients showed clinically significant symptoms of apathy, as defined by Dimensional Apathy Scale (DAS). Contrary to our expectations, however, bvFTD patients performed in line with controls on the effort-based decision-making task. The two groups accepted a similar proportion of offers and did not differ in terms of reward or effort sensitivity. Importantly, these measures of task performance were significantly associated with DAS scores in controls, but not in bvFTD patients.

**Conclusions:** These findings demonstrate that effort-based decision-making may remain intact in bvFTD despite clinically significant levels of apathy, and point to potential differences in the roles of extrinsic versus intrinsic motivation in modulating symptoms of apathy in these patients.

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### Executive dysfunction underpins cognitive apathy in dementia

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**Background and Objectives:** Apathy is the most common and disabling non-cognitive feature of dementia, affecting up to 90% of individuals over the disease course. Despite its prevalence, the underlying mechanisms of apathy remain elusive. This study aimed to investigate whether cognitive apathy and executive functioning have a shared cognitive and neural basis.

**Method:** We recruited seventy-one participants (31 variant frontotemporal dementia (bvFTD), 17 Alzheimer's disease (AD) and 23 controls). Participants were assessed on a neuropsychological battery of executive tasks including the Zoo Map Test, Modified Six Elements Test, Tower Test and verbal fluency. The Dimensional Apathy Scale (DAS) was used to quantify cognitive apathy. Principal components analysis identified a single component underpinning performance on the neuropsychological tests, with both bvFTD and AD showing significantly reduced "planning ability" compared to controls.

**Results:** On the DAS, 74% of bvFTD patients and 59% of AD patients showed clinically significant cognitive apathy. Importantly, linear regression revealed that lower planning ability significantly predicted increased cognitive apathy, even after controlling for cognitive impairment and disease duration. Voxel-based morphometry analyses revealed that planning ability and cognitive apathy

were both associated with atrophy of the right frontal pole and orbitofrontal cortex, as well as the thalamus and putamen. Cognitive apathy was uniquely associated with the bilateral inferior frontal gyrus and left postcentral gyrus whereas planning ability was uniquely associated with bilateral posterior temporal regions.

**Conclusions:** From a theoretical perspective, our results reveal a shared mechanism underpinning both cognitive apathy and planning deficits in bvFTD and AD. Clinically, this knowledge will help to improve the identification of apathy in clinical syndromes and inform targeted interventions to improve independence and wellbeing for those affected.

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### Investigating emotion and interoception in neurodegenerative diseases: A multi-centre international study

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**Background and Objectives:** Difficulties in understanding and responding to the emotions of others commonly occurs in neurodegenerative diseases. Indeed, emotion recognition is profoundly impaired in behavioural-variant frontotemporal dementia (bvFTD) and as well as in Parkinson's disease (PD) and Alzheimer's disease (AD) in the later stages. Interoception, the ability to interpret and respond to internal cues (such as feeling one's own heartbeat), has been linked to emotion. To date, however, research investigating the relationship between interoception and emotion recognition in neurodegenerative disease is relatively scant.

**Method:** 170 participants (41 AD, AD; 52 bvFTD; 24 PD; 53 controls) were recruited across three international research centres (Argentina, Australia, and Chile). To measure interoception, participants completed two 2-minute behavioural tasks. Participants were asked to press a button each time they: 1) felt their own heartbeat (Interoception); or 2) heard a recorded heartbeat (Exteroception). Simultaneous ECG was recorded. Accuracy was calculated by comparing the frequency of the event in the task (e.g., actual, or recorded heartbeat) and to the participant's response. To measure emotion recognition participants completed either the Facial Affect Selection Task (Australia) or Ekman faces (Argentina, Chile), with accuracy defined as percentage correct.

**Results:** Our results showed that while all groups had greater exteroception than interoception accuracy (all  $p < .001$ ), only bvFTD patients were significantly worse than controls at interoception ( $p = .001$ ). All patients were worse at emotion recognition than controls (all  $p < .001$ ). Worse interoception was associated with worse emotion recognition ( $p = .001$ ). This association was driven by bvFTD patients ( $p = .046$ ), with no other within-group associations reaching statistical significance.

**Conclusions:** For the first time, we have shown that reduced interoception in bvFTD is related to reduced emotion recognition abilities. Whilst all patient groups were worse at emotion recognition than healthy controls, it appears that in bvFTD the underlying mechanism may be due to a reduced ability to interpret and respond to interoceptive cues. This finding may help to explain the difficulties these patients experience in the emotional realm and opens opportunities for future interventions. Future research is needed to determine the neural mechanisms underlying the interoception and emotion in bvFTD.

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## SESSION 2

### Participation in competitive employment after moderate to severe traumatic brain injury in NSW: A multi-center study

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**Background and Objectives:** Return to work is a key outcome parameter for brain injury rehabilitation. Since the closure of the Commonwealth Rehabilitation Service (CRS) there has been a dearth of specialized providers to deliver vocational rehabilitation programs for people with traumatic

brain injury (TBI). The aim of the current study was to investigate the rate and predictors associated with participation in competitive employment in NSW after moderate to severe TBI in the post-CRS environment.

**Method:** A multi-centre observational study of all active clients with moderate to severe TBI ( $n = 588$ ) from the 11 community rehabilitation services of the New South Wales Brain Injury Rehabilitation Program.

Demographic, injury, clinical and vocational data were collected by treating clinicians employing a purpose-designed protocol.

**Results:** The sample was predominantly male (78% (459/588) with extremely severe injuries (52% > 4 weeks post traumatic amnesia (PTA), 305/588). Over half the sample were more than 2 years post-injury (54%, 318/588) and almost three quarters lived in metropolitan (vs rural) areas (72%, 419/588). Almost 75% (422/564) of clients were employed at the time of injury.

People who never returned to work post-injury were significantly more likely to fall at the two age extremes ( $\leq 19$  years or  $\geq 50$  years) and have had extremely severe injuries (> 4 weeks PTA) or higher levels of challenging behavior.

A total of 43% had ever worked post-injury (250/588) with 63% returning to their pre-injury employment and 37% taking up new employment. Time to first employment data were available for 228 clients. Median return to pre-injury employment was 6 months (IQR 3-9,  $n=147$ ), more rapid than the median of 13 mths (IQR 7-24 months,  $n=81$ ) for clients obtaining new employment. The current employment rate was 29% (173/588), with another 77 having lost their post-injury jobs. Regression analysis found that people in new employment were twice as likely to have lost their jobs (vs people returning to their pre-injury employment; OR 2.03,  $p=.018$ ) and that every additional psychosocial issue also increased the risk of loss of employment (OR 1.78,  $p<.001$ ).

**Conclusions:** Rates of RTW in NSW are in the mid-range among international studies focused on people with moderate to severe TBI. Given the importance of RTW as a rehabilitation goal, there is an urgent need for rebuilding capacity to deliver return to work programs for people with TBI within the vocational rehabilitation sector.

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### Is the Vocational Intervention Program Effective in Enhancing Return to Work after Severe Traumatic Brain Injury? A controlled trial

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**Background and Objectives:** People of working age who sustain a severe Acquired Brain Injury (sABI) have low return to work (RTW) rates, ranging from 16-40%. The Vocational Intervention Program (VIP) was developed to facilitate return to competitive employment after sABI, focusing both on return to pre-injury employment or gaining new employment. The objective of the current study was to conduct a 3-armed trial, evaluating the efficacy of partnering external vocational rehabilitation (VR) providers to deliver the VIP (VIP-VR) compared to the existing direct service model delivered by a specialist unit (VIP-DS) and treatment as usual (TAU) controls.

**Method:** The trial was conducted among the 12 adult community rehabilitation sites of the NSW Brain Injury Rehabilitation Program (BIRP). Six sites delivered the VIP-VR arm in partnership with three external VR providers selected for the trial. One site provided direct vocational services (VIP-DS), and five sites TAU. Competitive employment status (Yes/No) and clinician-rated DEX and SPRS-2 scores were collected pre- and post-intervention and at a 3-month follow-up. Multilevel modelling (with participants at level 2 and study time-point at level 1) was used to assess the impact of each intervention on employment status over the course of the study.

**Results:** A total of 149 people with sABI participated in the trial (VIP-VR, n=75; VIP-DS, n=33; TAU, n=40), of which 65 (60%) completed the VIP. The final model indicated that pre-intervention, the VIP-VR (8%) and VIP-DS groups (6%) were less likely to be employed than TAU (38%) ( $p < .001$ ). However, the VIP-VR (61%) and VIP-DS groups (77%) demonstrated significantly higher rates of RTW post-intervention compared to TAU (56%) ( $p < .001$ ). These differences were maintained at 3-month follow-up (VIP-VR=64%; VIP-DS=81%; TAU=46%) ( $ps > .70$ ). Clinicians rated all three groups as demonstrating lower levels of disability (mean DEX pre-post difference: VIP-VR=-2.80 points; VIP-DS=-1.69; TAU=-3.84) and higher participation rates (mean SPRS-2 pre-post difference: VIP-VR=3.28; VIP-DS=5.74; TAU=1.93) at post-intervention ( $ps < .01$ ). These ratings were largely stable at 3 month follow-up ( $ps > .16$ ).

**Conclusions:** The VIP can be successfully delivered through partnerships between BIRP teams and VR providers. This provides a significant opportunity to build state-wide capability among the VR sector to more effectively facilitate RTW after sABI.

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**Participation in competitive employment after moderate to severe traumatic brain injury in NSW: The VIP 2.0 multi-center implementation study**

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**Background and Objectives:** Building effective pathways to employment for people with severe TBI has been a priority in NSW. A controlled trial had demonstrated the efficacy of the Vocational Intervention Program (VIP), a partnership between the NSW Brain Injury Rehabilitation Program (BIRP) and VR (both private and Disability Employment Service) providers in returning clients to competitive employment compared to usual care. The next stage (VIP 2.0) involved scaling up VIP in a state-wide implementation trial. This paper reports on VIP 2.0 outcomes.

**Method:** This 12-site pre-post implementation study engaged 20 VR providers to deliver two interventions: Fast Track (same employer) and New Track (New Employer). Partnership quality between the BIRP and the VR providers was measured using the VicHealth Partnership Analysis Tool (35 items, total score range 35-175) at two time points (baseline T0, project close T1).

**Results:** The 179 enrolments (47 Fast Track, 132 New Track) comprised 72% male, average age of 37 years, with 72% sustaining a TBI > 7 days PTA. Time post injury differed between the two interventions (mean 8 months, Fast Track participants; mean 18.5 months for New Track).

In total, 72.3% (34/47) of FT participants were supported by VIP to return to their pre-injury employer. A range of outcomes were observed for the 132 New Track participants. Fifty participants completed the program, 44 withdrew and 38 were still continuing their VIP program at the study's end. Paid work was secured for 33/50 and stepping stones to employment completed by another 17 (work trial, n=7; volunteer work, n=7; training course, n=3).

A total of 53 partnerships were established between the 20 VR providers and the 12 BIRP services, with 88.7% (47/53) of the partnerships still intact at project close. Partnership quality grew from baseline to project close as reported by both BIRP teams (T0 mean score 129, range 105-163; T1 mean 137, 105-161) and VR providers (T0 mean score 131, range 105-161; T1 mean 141, range 102-173) with T0 scores falling into the PAT band 'heading in the right direction' and T1 scores as 'genuine collaboration'.

**Conclusions:** The VIP 2.0 demonstrated the

potential of integrating service systems to deliver individualized programs, focused on achieving either return to same employer or new employment pathways. Of the 141 individuals who reached an outcome (excluding the 38 current clients), 84 (60%) were engaged in productive occupation.

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### **What does it take to get somebody back to work after severe traumatic brain injury? : Service inputs within the Vocational Intervention Program (VIP 2.0)**

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#### **Background and Objectives:**

Vocational rehabilitation (VR) programs in traumatic brain injury (TBI) are like a 'black box' - little known about the intervention components, intensity or duration. VR components were captured for the statewide implementation of the Vocational Intervention Program (VIP 2.0) across two pathways: Fast Track (FT, same employer) and New Track (NT, new employer). This paper aims to report on the intensity of the programs (time); describe the actions performed by the service provider and compare the two RTW pathways.

**Method:** VIP 2.0 provided mentoring to 20 Disability Employment Service and private VR providers in delivering RTW programs to clients of the NSW Brain Injury Rehabilitation program. Providers entered hours/minutes of their services into an on-line survey tool for each client, at the end of every month. Time use was categorised using the Case Management Taxonomy (CMTaxonomy), a knowledge map, which identifies the components of case management, their relationship and definition. Analysis employing Mann-Whitney tests or t-tests tested for differences in service delivery across the two pathways.

**Results:** Time data were recorded by the 20 VR providers for 75 VIP 2.0 participants (25 FT and 50 NT). Average intensity of service per completed FT case was 25.1 hours (range 3 to 96 hours) with a median duration of 36 weeks. This was significantly less than the average of 36 hours (median duration 46 weeks) per completed NT case.

For FT participants, the category with the highest proportion of time was documentation (17.7% of total time), followed by collaboration (16.7%) and monitoring (13.5%). There was very little time spent in formal testing and observation and virtually no on-job training, reflecting that participants are resuming familiar work roles and tasks. Similarly, the highest proportion of time for NT participants was in documentation (15.6% of total time), followed by collaboration (13.9%). In comparison to FT, there was more navigation (which includes job seeking) accounting for 8.7% of total time (2.7% for FT) and on-job training (8.8% compared with 0.4% for FT). Like FT, very little time was spent in formal testing and observation (accounting for only 1% of total time).

**Conclusions:** The case management taxonomy provides a useful framework to understand 'what is done' by the case manager and 'how much' in vocational rehabilitation.

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### **Client experiences of participating in a specialist vocational intervention partnership program (VIP 2.0) following severe brain injury**

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**Background and objectives:** Despite high rates of pre-injury employment, clients with severe traumatic or acquired brain injury (TBI/ABI) face significant challenges in resuming employment post injury. The Vocational Intervention Program (VIP 2.0) comprises a novel integrated partnership model between Health (NSW Brain Injury Rehabilitation Program) and VR Providers delivering programs for return to pre-injury (Fast Track) or seeking new employment (New Track). The aim of this study was to explore client experiences of participating in VIP 2.0 to support return to work following acquired brain injury.

**Methods:** VIP 2.0 participants were invited at case closure to participate in a survey about their experiences and satisfaction with VIP. Data were collected using the Client Services Questionnaire-8 (CSQ-8), a self-report measure of service satisfaction comprised of eight questions rated on a 4 point scale (1-4, total score range 8-32) and free-text

comments. Quantitative data were entered into SPSS (version 26) with descriptive statistics and non-parametric analyses performed. Thematic analysis approach was employed to interrogate the free text survey responses, inductively using an open coding process and managed with NVivo Pro version 12. Peer debriefing was used to refine and verify key themes.

**Results:** Clients with ABI/TBI (n=65) completed the CSQ-8 after participating in VIP. Overall satisfaction with VIP was high (median score 29, interquartile range (IQR) 8.5). Greater satisfaction was reported by clients who had returned to their previous employment (Fast Track pathway, median 30.5, IQR 7.3, n=22) than those in new employment (New Track pathway median 26.0, IQR 10.0, n=43). Six key themes were identified that influenced satisfaction with VIP; 1) Taking a person centred approach to the rehabilitation process including tailoring support to individual needs and goals 2) the importance of effective collaboration between BIRP services and vocational providers 3) communication 4) tailoring of work roles to participants needs including consideration of their interests and skills 5) feeling supported to achieve their return to work goals 6) staff knowledge of the sequelae of brain injury and its impact on return to work.

**Conclusion:** The use of an integrated partnership model between Health and VR Providers to deliver vocational rehabilitation post brain injury results in improvements in client employment rates and high levels of client satisfaction.

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### **Cost-benefit analysis of the Vocational Intervention Program (VIP 2.0)**

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**Background and Objectives:** Returning to work following a traumatic brain injury is recognised as a key measure of community reintegration. The Vocational Intervention Program (VIP 2.0) is an employment program that aims to achieve successful employment outcomes for people following a traumatic brain injury. It is based on an integrated service model where services are delivered by a team of providers working across organisations and levels of care.

This paper reports on the economic evaluation of the VIP 2.0 which utilized a cost-benefit analysis (CBA) approach to assess the costs of the VIP 2.0 relative to the outcomes and benefits achieved.

**Method:** The Vocational Intervention Program provided mentoring to 20 private and Disability Employment Service VR providers in delivering RTW programs to clients of the 12 adult rehabilitation services of the NSW Brain Injury Rehabilitation program. Data were available on VIP 2.0 participants, program cost structures, and project and vocational providers' staff time. Funding provided to the VIP2.0 was used to establish the cost base for the CBA and the benefits were derived based on the number of participants that achieved competitive employment and the type of their employment. A human capital approach was employed to assign a monetary value to these outcomes. Historical return to work rates were applied as a comparator to calculate the impact of the VIP2.0.

**Results:** During the VIP 2.0, 221 individuals were referred from a NSW Brain Injury Rehabilitation Program (BIRP) unit to a vocational provider. Of these, 173 individuals subsequently participated in the VIP 2.0. Until June 2021, 135 had either completed or withdrawn from the program, 62 of those were in competitive employment and their occupations included labourers (23%), community and personal service workers (18%), technicians and trade workers (18%) and professionals (16%) (according to Australian and New Zealand Standard Classification of Occupations (ANZSCO) major groups). The average annual earnings were estimated to be \$73,672 per participant and the total present value of these earnings was estimated to be \$17,294,795 over a five year period.

The cost of the VIP 2.0 (for program management and coordination) excluding costs associated with the evaluation and time of vocational provider and BIRP unit staff was \$627,181.

VIP2.0 achieved a competitive employment rate that was 17.2 percentage points higher than historical rates for this population and so the additional value created by the VIP 2.0 was \$6,486,943 in dollar terms.

**Conclusions:** Using a conservative approach to the CBA we found that for every \$1 invested in the program the return was \$10.34.

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### **SESSION 3**

#### **Creating a Video Abstract for your research**

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**Synopsis of session:** Research journals require publications to be written in a format that is not accessible to the majority of the population. Many people would not have the interest or necessary knowledge to interpret a published paper, even if it contains important information on a condition they live with, and clinicians repeatedly report time constraints as the biggest barrier to reading journal articles. Video abstracts are a method to briefly summarise research in an accessible and more interesting way. However, creating a video abstract can seem daunting.

This session will cover the basic steps in translating your paper into a video abstract using PowerPoint, with an emphasis on making the video accessible to people with cognitive or communication disability. After an overview of the benefits and process, the method will be demonstrated live as a paper is translated from a standard abstract to a partially completed animation.

**Level aimed for:** Basic knowledge of PowerPoint recommended

**Learning objectives:** Delegates will (1) understand the necessary steps to adapt a formal written abstract to a video; (2) be aware of some simple techniques to create a video abstract; (3) become aware of existing resources for the process.

**Biography:** John recently completed his PhD and now works in the Aphasia CRE as a Post-Doctoral Research Fellow. He is currently coordinator for the Communication Connect project, a \$1.8m government-funded project that aims to improve rehabilitation and self-management for people with communication impairments after stroke and traumatic brain injury. He received the 2020 La Trobe student prize from the Tavistock Trust for excellence in work relating to aphasia. John has a passion for communicating research to other speech pathologists, students and people with aphasia.

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## SESSION 4

### Developing social-ABI-lity - an online course to support safe use of social media for connection after brain injury

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**Background and Objectives:** In 2020 and 2021, people increasingly used the Internet and social media for work, education, and to connect socially.

People with acquired brain injuries lose many of their social connections after their injury. They continue to use social media after their injury yet receive little support to use it safely and experience challenges in using social media. Rehabilitation professionals describe being inadequately prepared to support them in its use and often take a reactive rather than proactive approach. The aim of this research was to use co-design to develop an evidence-based resource that would support safe and enjoyable use of social media after an acquired brain injury (ABI).

**Methods:** social-ABI-lity, an online self-guided course, was developed for people with brain injury to learn skills in using social media safely and meaningfully. Development incorporated (a) a scoping review to identify key features and effective teaching approaches from existing social media skills training programs, (b) co-designing course content with people with lived experience of ABI and other key stakeholders, and (c) a pilot study with five participants who have an ABI.

**Results:** Key recommendations for course design were identified in the scoping review, with training to be interactive and include practical components addressing online safety and wellbeing, and how to use platforms to connect with others. Development of the course incorporated the scoping review recommendations, advice from an expert advisory committee, and followed codesign participants' guidance. The pilot study participant data and feedback further informed subsequent course refinement prior to being launched online.

**Conclusions:** The social-ABI-lity self-directed course is the first of its kind to support people with brain injury in using social media after their injury. Rather than create bespoke, private platforms, this research aimed to support people with an ABI to use mainstream social media in an effort to rebuild, strengthen, and maintain their real-world social connections using online communities. This resource, now freely available online, may also support rehabilitation clinicians in helping people with brain injury to build their social media mastery and participation in supportive online networks.

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**“This group... I felt like I was medicating myself from this cyberscam illness that was living with me”: A qualitative evaluation of co-designing cybersafety training resources with and for people with acquired brain injury**

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**Background and Objectives:** Online scams are increasingly prevalent and distressing. Individuals with acquired brain injury (ABI) may have unique risk factors and vulnerability to online scams for which tailored cyberscam interventions are required. To address this, a co-designed approach was utilised to collaboratively develop cybersafety resources with people with living expertise of ABI and scams. In depth examinations of the co-design experience is needed to inform future utilisation of this methodology within this and other research endeavours.

**Method:** Adults who took part in up to three focus groups to co-design cybersafety training resources were invited to participate. Seven cyberscam survivors with ABI and one ABI carer participated in one-on-one semi-structured qualitative interviews exploring their co-design experiences. Six-phase reflective thematic analysis was conducted to produce an understanding of the key themes and develop a thematic map.

**Results:** All participants shared positive co-design experiences, which were conceptualised across six themes. Group Bonding: An overwhelming sense of support emerged amongst peers and facilitators through a shared purpose. Taking Ownership: Participants felt a sense of ownership by creating their own intervention and felt empowered by their agency in helping others. Validated and Valued: Taking the lead during discussions increased their confidence and self-esteem. Stronger Scam Awareness: Participants learnt about scams and recognised their personal vulnerability. Normalising Scams: their sense of shame was reduced by openly sharing personal stories without judgement and hearing their respected peers talk about being scammed. Staying Connected: Participants identified a desire for ongoing training and involvement in peer-led groups to expand the project outcomes. Considerations for adjustments to support communication, memory impairments and fatigue were recommended.

**Conclusions:** Participant accounts of the co-design experience extended beyond project and resource design and resulted in unanticipated therapeutic benefits relating to increased insight and emotional recovery from feelings of shame. Potential mechanisms underpinning this were the peer group format and opportunities to make genuine contributions. Recommendations for informing future cybersafety interventions and generalising these positive co-design experiences in non-cybersafety projects will be discussed.

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**Investigating Clinician Experiences of  
Teleneuropsychology Service Implementation  
within Rural Inpatient Rehabilitation Settings: A  
Mixed Method Approach**

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**Background and Objective:** The aim of this study was to understand clinicians' experiences of teleneuropsychology service implementation within rural inpatient rehabilitation settings, and the variability of those experiences across rural settings and clinical disciplines.

**Method:** Clinicians ( $n=56$  from four rehabilitation settings) who were involved in a hub-and-spoke teleneuropsychology service completed surveys throughout service implementation. A purposive sample of 16 clinicians then completed semi-structured interviews at the conclusion of the service implementation period. Quantitative data were analysed descriptively and qualitative data were analysed using thematic analysis, prior to the results being converged.

**Results:** Four themes characterising clinicians' experiences were identified. *Pre- and early-implementation considerations* included factors such as early collaboration and consultation, which were identified as important for service integration into rural settings. *Facilitators/barriers* included factors such as technology usability, which positively or negatively influenced service implementation. *Benefits and outcomes* included perceptions on the impact of the service, such as improved equity and quality of care in rural settings. Finally, *future applications* encapsulated what the clinicians envisaged for the future of teleneuropsychology services, such as hybrid teleneuropsychology/in-person services. Some differences were identified in clinicians' experiences across rural settings and disciplines, including preferences for technology infrastructure and satisfaction with teleneuropsychology sessions.

**Conclusions:** Most clinicians reported positive experiences and acceptability of the teleneuropsychology service. Facilitators and barriers which can guide the successful establishment of future teleneuropsychology services were identified. These findings may be used to contribute to improving equity and quality of care for people living with neuropsychological impairments, especially those living in rural areas.

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## Clinician Use and Experiences with Assistive Technology in Brain Injury Rehabilitation

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**Background and Objectives:** The rise in assistive technology (AT) solutions to support people with a brain injury (BI) has foregrounded the role of clinicians to be able to guide their clients in selecting goal-centred AT. The study aims to evaluate (1) clinician capability, attitudes, and barriers with AT for people with a BI, (2) strategies to support clinician AT use within BI rehabilitation, and (3) clinician frequency and type of AT use.

**Method:** An online survey was circulated to BI clinicians within public, private and not-for-profit health sectors across New South Wales (NSW). The survey included a mix of purpose-designed items and the Modified Computer Self-Efficacy Scale (MCSES; possible range 0-100).

**Results:** Clinicians (n=123) were evenly distributed across age groups from 25 years to greater than 55 years. The majority were female (90%, n=111) and occupational therapists (33%, n=45/160) or physiotherapists (20%, n= 28/160) by profession. Other allied health, nursing and medicine were also represented. Over half (52%, n= 84/160) worked primarily in community settings and 76% (n=93) had more than 5 years of experience in BI. Clinicians scored a mean of 75.9 ± 1.2 on the MCSES. Age was a significant predictor (p<0.05) of total MCSES score up to 45 years, suggesting lower technology self-efficacy with increasing age. Whilst most clinicians (92%) were knowledgeable of mainstream technology for personal use, over half (65%) reported having insufficient knowledge of emerging AT for their clients. Only 1 out of 4 (27%) were confident with AT use, set-up, and customisation. Most clinicians had positive attitudes towards AT and believed it should be routinely incorporated into clinical practice (86%). The time required to research, learn to use, set-up and prescribe AT for clients was seen as the primary barrier to using AT (81.3%). The favoured strategy to support AT use was hands-on workshops and in-services to trial AT (72%).

Most clinicians (95%) used at least one AT for their clients in the last 5 years. Commonly used AT included mainstream technology (97%) and computer/phone-based rehabilitation software (63%).

**Conclusions:** Whilst NSW BI clinicians have an overall positive attitude towards AT, there is an evident gap in clinician implementation. There is a

need to support further training and resources to build clinician capability and access to AT.

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## Smartphones as prospective memory aids in ADHD: Helpful or problematic?

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**Background and Objectives:** Prospective memory (PM) utilises attentional, working memory, and executive functioning processes for remembering to carry out daily tasks. Individuals with Attention Deficit Hyperactivity Disorder (ADHD) and those with other brain impairments, where these cognitive functions are impaired, are believed to have difficulty with PM tasks. Smartphones are increasingly being used as memory aids to offload cognitive tasks for those with cognitive impairments. However, the memory aid benefits of these devices may be outweighed by excessive/dependent usage of smartphones, particularly in individuals with ADHD or brain impairments, as entertainment functions of the devices may distract users from PM tasks. We aimed to investigate PM concerns and performance, memory aid usage, and problematic smartphone usage in individuals with ADHD and neurotypical controls.

**Method:** Participants included 139 individuals diagnosed with ADHD and 139 age and gender matched neurotypical controls. Participants completed the Prospective Memory Concerns Questionnaire, an event-based naturalistic prospective memory task, the Problematic Mobile Phone Use Questionnaire-Revised, and a smartphone and memory aid usage checklist.

**Results:** Despite using more memory aids than controls, individuals with ADHD self-reported more memory concerns and had poorer PM performance than controls. Individuals with ADHD reported more problematic smart phone use than controls, with problematic smart phone usage more strongly associated with memory concerns in the ADHD than the control group. Problematic smart phone usage was associated with higher usage of technological and interpersonal aid usage in both groups, and with higher usage of non-technical aids in the control group.

**Conclusions:** Memory concerns were higher amongst individuals with ADHD. While individuals with ADHD used more memory aids than controls, they appear to be less effective for this group. The problematic usage of smartphones, potential for distraction, and their impact on PM functioning

needs to be considered when prescribing devices as memory aids in clinical populations.

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## SESSION 5

### “How do you make life work for the family?”: Understanding families’ experiences of rehabilitation following paediatric acquired brain injury

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**Background and Objectives:** Paediatric acquired brain injury (ABI) can significantly impact children/adolescents and their families and a family-centred approach to rehabilitation is considered best practice. However, families often report unmet needs during rehabilitation and there is little evidence-based guidance regarding how clinicians and services can best involve and support them. This qualitative study aimed to develop a better understanding of family-centred care in rehabilitation from the perspectives of children/adolescents with ABI and their families.

**Method:** Semi-structured interviews were conducted with 10 caregivers, five siblings, and four children/adolescents with ABI who had received rehabilitation within a state-wide paediatric rehabilitation service. Data were analysed using constructivist grounded theory methods.

**Results:** Two themes and sub-themes were developed: (1) Working together as a team: Valuing clinicians’ expert knowledge; Doing rehabilitation together; and Sharing family knowledge; and (2) Navigating rehabilitation as a family: Recognising family needs; Juggling family life; and Making rehabilitation work for the family. Participants perceived that the child/adolescent with ABI was the central focus of rehabilitation.

Participants highlighted the roles of the family and rehabilitation team and described the variable and dynamic nature of family involvement in rehabilitation. They reflected on experiences of working together with the rehabilitation team and sharing family knowledge.

Although participants acknowledged that the central focus of rehabilitation was and should be the needs of the child/adolescent with ABI, they reflected on how the whole family is impacted by ABI and therefore navigate rehabilitation together. The needs of other family members were described

and participants expressed a desire for greater consideration of the family and their needs in rehabilitation.

**Conclusions:** This study contributes to an evidence base to guide clinicians and services in supporting family needs and involvement in rehabilitation following paediatric ABI. Collaboration was central to families’ experiences and the importance of considering the whole family’s needs was highlighted. Clinicians and services should therefore strive to develop an understanding of families’ needs and broader contexts following ABI to determine how to best collaborate with and support them in rehabilitation.

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### Perspectives of Major Traumatic Injury Survivors on Accessibility and Quality of Rehabilitation Services in Rural Australia

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**Background and Objectives:** Major trauma (MT) is a leading cause of disability in Australia. A significant proportion of MT survivors require extended rehabilitation services. This can be more challenging to achieve in regional, rural or remote areas, in which nearly 30% of Australians reside. However, there currently exists little research to understand the experience of accessing rehabilitation services for MT survivors in these locations. This study aimed to explore the experience of non-metropolitan MT survivors accessing rehabilitation services.

**Method:** Using semi-structured interviews, data were collected from 21 adults (*Age* = 47.86; *SD* = 11.35; Range: 21 – 61) who had sustained injury causing brain, spinal cord, orthopaedic or other MT and lived in non-metropolitan Victoria (Australia). Participants were an average of seven years post-injury (*SD* = 3.10; Range: 3.25 – 13.01). Interview data were transcribed and analysed thematically.

**Results:** Four themes were identified: (1) Managing the transition back to local services; (2) Independence and determination to get better; (3) Rehabilitation is an ongoing process; and (4) Limited

service access and quality. Injury-related symptoms persisted for many survivors; however, they displayed a strong determination for independence and self-management of their recovery. Overall, barriers to accessing rehabilitation services included: poor coordination and knowledge of local services, insufficient home-based follow up, financial costs and a lack of local specialist practitioners experienced in MT rehabilitation. By contrast, facilitators to service access included financial and psychological support from compensation bodies, and community and informal supports.

**Conclusions:** Findings highlight the unique rehabilitation needs of rural MT survivors, which can be used to guide future planning and delivery of rehabilitation services in rural areas. Specifically, improved engagement in discharge planning, consideration of factors resulting from living at a distance to services, and harnessing independence to self-manage should be incorporated into future rural service models. Further research is needed to better understand the knowledge and resources available for metropolitan hospitals to facilitate successful discharge back to and ongoing rehabilitation in rural areas.

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#### **A randomised controlled trial of prospective memory rehabilitation plus metacognitive skills training for adults with traumatic brain injury**

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**Background and Objectives:** Prospective memory (PM) impairment following traumatic brain injury (TBI) can limit independence and social and vocational outcomes. Compensatory strategies (e.g., using a mobile phone calendar) may reduce PM failure but require adequate self-awareness for effective use in daily life. Metacognitive skills training (MST) can enhance self-awareness and strategy use, thereby reducing everyday PM failure and enhancing psychosocial integration. This study aimed to evaluate the effectiveness of

compensatory strategy training with an MST component (COMP-MST) in adults with moderate-severe TBI, compared to compensatory strategy training (COMP) alone and a control condition. Primary outcomes were everyday PM failure and psychosocial integration. Secondary outcomes were psychometric PM test scores, strategy use, self-awareness, and level of care.

**Method:** A three-arm assessor and participant-blinded randomized controlled trial was conducted with 52 participants (77% male, mean age = 39.0. SD= 13.6). Participants were allocated to three groups: COMP-MST, COMP, and waitlist control. PM rehabilitation was delivered over 6 weekly sessions. Measures were collected at pre- and post-intervention and 3-month follow-up. Data were analysed using unstructured linear mixed-effects modelling for repeated measures and planned contrasts between time-points for each group.

**Results:** No significant differences were found between the groups on primary or secondary outcome measures using modelling. There were significant pre-post intervention improvements on ratings of everyday PM failure for both intervention groups but not the waitlist control group, with medium to large effect sizes.

**Conclusions:** The findings suggest no significant benefits of MST combined with compensatory PM strategy training, which may reflect the low incidence of impaired self-awareness for the sample. **Correspondence:** Jenny Fleming;  
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#### **Prospective memory rehabilitation goals and compensatory strategies used by people with traumatic brain injury**

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**Background and Objectives:** Following traumatic brain injury (TBI), unreliable prospective memory (PM) may compromise the ability to return to living independently and productive activities. This study aimed to 1) describe the goals set by clients with TBI in an individualised PM rehabilitation program to determine what PM outcomes are meaningful and relevant to clients in everyday life, and 2) document

the compensatory devices, technology and strategies selected by clients and their success in achieving goal outcomes.

**Method:** The sample consisted of 29 clients with moderate-severe TBI who were participants in a randomised controlled trial of a 6-week metacognitive compensatory PM training program. Data were collected from review of occupational therapist's progress notes and coded into categories using N-vivo. A subset of reports were independently coded by a second researcher. Goal outcomes were measured using the Canadian Occupational Performance Measure (COPM).

**Results:** PM goals related to 'communicating reliably with others', 'managing at home', 'looking after myself', 'shopping', 'getting ready to go out', 'working and studying' and 'using memory aids effectively'. Eighty percent (23/29) chose to use their mobile phone as a device to compensate for PM impairment. Other strategies involved syncing their phone with other devices, using a diary, and using a tablet. Strategies for carrying the device and cues to refer to it were highly individualised. Post-intervention, there were clinically significant improvements in COPM performance ratings for 19 participants (65%) and in COPM satisfaction ratings for 21 participants (72%).

**Conclusions:** Clients with TBI have a preference for using existing familiar technology (i.e. mobile phone) to compensate for PM impairments, and identify goals relating to a range of occupations and daily life activities. For compensatory strategies to be adopted in everyday life, clinicians need to use a highly individualised approach to embed new habits into daily routines. Gains in self-awareness arising from metacognitive approaches to strategy training may confound self-rated goal outcomes.

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**Community-based rehabilitation following traumatic brain injury: A qualitative investigation**  
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**Background:** Across Australia and New Zealand, adults who have experienced a traumatic brain injury (TBI) often receive some form of community-based rehabilitation (CBR). Within these services, speech pathologists provide assessment and treatment for a range of acquired communication conditions including cognitive-communication disorders (CCDs) which affects the majority of adults following TBI. There is currently limited research that explores the experiences of this client population when receiving CBR services and their perspectives of how models of care can be improved in the future.

**Aims:** To explore the perspectives of adults with CCDs following TBI when receiving CBR services. In

addition, for participants to identify key factors to consider when designing future models of care for this population.

**Methods & Procedures:** A qualitative descriptive approach grounded in phenomenology was used which involved one-on-one interviews with each of the participants (n=16) to further explore their lived experiences and perspectives of CBR services.

**Results:** Thematic analysis was used to identify a range of factors adults who have CCDs following TBI consider to be integral components of CBR services. The overarching theme and subthemes that emerged from the data provide speech pathologists working with this client group with recommendations to improve management approaches implemented to ensure a high level of service delivery is provided.

**Conclusions:** This study highlighted the importance of careful consideration when designing CBR services for this population across Australia and New Zealand. Further exploration is required to identify the insights of other key stakeholders including the significant others of adults following TBI who have received these services.

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## SESSION 6

**Time between acquired brain injury and admission to post-acute brain injury services: differences in sociodemographic factors, and clinical, functional and psychosocial outcomes, 1991-2020**

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**Background and Objectives:** Time taken to access post-acute care and disability support services can significantly influence outcomes following an acquired brain injury (ABI). This study evaluated differences in functional and psychosocial outcomes at discharge from post-acute care based on the time between injury and admission to post-acute care services.

**Methods:** A retrospective whole-population cohort study with 1,011 individuals who received post-acute neurorehabilitation and disability support services through Brightwater Care Group in Western Australia (WA), 1991–2020. The study used internal clinical and rehabilitation data, and linked hospital, emergency department and mortality data from the WA Data Linkage System. The cohort was categorised into three groups based on time between injury and admission to services: Early (<1 year, n=466), Middle (1-2 years, n=161), and Late (>2 years, n=311). Sociodemographic data, clinical, functional and psychosocial outcomes, and risk of death during post-acute care were evaluated across groups to inform best practice for admission to brain injury services.

**Results:** Early admissions to post-acute services demonstrated significantly improved functional independence at discharge relative to those admitted late ( $p=0.004$ ). Individuals admitted early were significantly more likely to be readmitted to services for more than one episode of care relative to individuals in the middle or late cohorts ( $p=0.001$ ), although individuals from early, middle and late admissions had a similar length of stay in services ( $p=0.498$ ). However, individuals admitted late reported better psychosocial functioning on admission ( $p=0.001$ ), better quality of life during their stay in post-acute services ( $p<0.001$ ), and were significantly more likely to have met their goals on discharge ( $p<0.001$ ). Individuals admitted late were significantly more likely to experience death during care ( $p=0.003$ ).

**Conclusions:** Findings indicate differential outcomes at discharge from post-acute care based on time between injury and access to post-acute brain injury care is an important factor, and may influence the trajectory of recovery. The extent to which individuals are able to relearn functional skills and achieve rehabilitation goals to live independently is impacted by the stage at which they enter rehabilitation and disability services. Implications for service delivery for individuals at varying stages of post-acute recovery will be discussed.

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### **Surviving the 'Silent Epidemic': A Qualitative Exploration of the Long-Term Journey After Traumatic Brain Injury**

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**Background:** Previous studies examining life after traumatic brain injury (TBI) have taken a predominantly short-term and quantitative perspective, with generally narrow focus, and have not specifically investigated changes in experience over time post-injury to gain a uniquely long-term perspective.

**Aims:** This study therefore aimed to qualitatively explore the broad long-term experience of living for 10 years or more with moderate to severe TBI.

**Methods:** Thirty participants (60% male) aged 35 to 86 ( $m = 56$  years,  $SD = 15$ ) who were on average 22 years post moderate to severe TBI (range=10-31 years) were purposively sampled from a Longitudinal Head Injury Outcome Study database. They completed semi-structured interviews investigating the impact of TBI on various life domains, the rehabilitation experience and support received, and overall perspectives of the long-term journey after TBI. Data were analysed using Braun

and Clarke's six-stage thematic analysis.

**Results:** Results demonstrated that: a) although some participants reported full recovery, several experienced persistent physical, cognitive and emotional problems that impacted their independence, employment and interpersonal relationships; b) early rehabilitation was very helpful, but some participants experienced difficulties accessing ongoing services; c) family and social support were crucial to recovery; d) most participants drew upon inner strength to find positives in their experience.

**Conclusions:** These findings have identified factors that facilitate and impede long-term recovery from TBI, which may inform better support and care for injured individuals over the years after injury to improve their quality of life.

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### **Improving services for patients with Disorders of Consciousness (DoC): Implementation of family and staff education packages in a Neurosciences Unit**

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**Background and Objectives:** Disorders of consciousness (DoC) are a spectrum of neurological disorders which occur post severe acquired brain injury (ABI) encompassing coma, unresponsive wakefulness state (UWS) and minimally conscious state (MCS). DoC are characterised by impairments in wakefulness (sleep/wake cycle) and awareness (degree of interaction with surroundings, ability to communicate/recognise environment). To optimise outcomes post-ABI, a specialised, multidisciplinary team (MDT) approach is imperative, with family education the cornerstone of management. Despite this, education provision to families is inconsistent and families possess limited understanding of DoC and available interventions. Equally, MDT staff have reduced confidence and skills in the specialised assessment and management of patients with DoC. Little is known about the effects of timely education regarding DoC and sensory stimulation (SS) on family knowledge/satisfaction, nor on staff skill/confidence.

The aim of this study was to evaluate the effectiveness of a family and staff education package in enhancing knowledge, confidence and skills of staff and families surrounding DoC and SS.

**Method:** A standardised education package was developed and delivered to: 1. Staff on a

Neurosciences Ward, and 2. families of patients with DoC. Pre- and post-education surveys were used to measure family knowledge/satisfaction and staff confidence/skill in management of patients with DoC.

**Results:** 26 family member participants (FM: parents n= 10, spouse n= 10, siblings = 4, children n= 2) and 86 health professionals (professions: nurses n= 56, allied health n= 30) were recruited. Due to difficulties with follow up, only 14 family member participants and 69 health service participants completed post-education surveys. Non-parametric statistics (Median, IQR, Wilcoxon Signed Ranks Test) were utilised to analyse the data collected from the pre and post education surveys.

There was a statistically significant improvement across all areas of knowledge, confidence, and skill for both family and staff pre and post implementation of the education packages (all p <.05).

**Conclusions:** Data suggests that a newly developed family and staff education package has the potential to enhance family and staff knowledge and satisfaction surrounding management of patients with DoC.

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### **Getting on with the Business of Community Brain Injury Rehabilitation during a Global Pandemic**

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**Background:** The covid disease pandemic represented an unprecedented challenge for healthcare systems internationally. Services came to a standstill during the global pandemic in March 2020 leaving some of our most vulnerable clients without access to services. This required rapid and more wide-reaching innovation to ensure services could continue.

**Objectives:** Covid 19 presented an opportunity to reflect on current service delivery within Community Brain Injury rehabilitation and look at new ways of working, utilising digital technology and resources with a view to increasing efficiency and productivity.

**Methods:** Clinicians piloted a menu of remote interventions using the Zoom web-based platform. Co-production, self-management and involvement of carers were central to this model of service delivery. Individual and group interventions were delivered addressing issues of fatigue, memory and communication difficulties post brain injury. Questionnaires and interviews were used to evaluate this model of service delivery.

**Results:** Community brain injury rehabilitation was able to be delivered and maintained throughout the pandemic with no waiting lists for intervention. Service users were able to remain in their familiar

environment, health deterioration was prevented and individuals and carers reported reduced isolation and feeling valued and supported. Challenges identified with this model included, access to IT resources, staff confidence with new technology and suitability for clients with severe brain injury.

**Conclusion:** This proved to be an efficient and productive method of service delivery, providing a broad choice of intervention to service users. It continues to be utilised post pandemic in a blended model of service delivery.

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### **A Single-Case Experimental Evaluation of a Novel Treatment Adapting a Cognitive Behaviour Therapy Approach for Sexuality Problems After Traumatic Brain Injury**

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**Background and Objective:** Despite an array of sexuality changes occurring in many individuals following TBI, no interventions have been shown to improve sexuality after TBI. This study aimed to evaluate the preliminary efficacy of an individualised intervention using a cognitive behavioural therapy (CBT) framework to treat sexuality problems after TBI.

**Method:** A nonconcurrent multiple baseline single-case experimental design (SCED) with an 8-week follow-up phase and randomisation to multiple baseline lengths (5, 4, or 6 weeks) was repeated across nine participants (44% male) with moderate-severe TBI (mean age=40.44-years (SD=14.15), mean PTA=34.50-days (SD=29.25), mean time post-injury=7.92-years (SD=11.09)). Treatment consisted of eight weekly, individual therapy sessions, combining behavioural, cognitive, and educational strategies to address a diverse range of sexuality problems. Clinical psychologists adopted a patient-centred and goal-orientated approach whilst following a treatment guide and accommodating TBI-related impairments. Target behaviour was individuals' subjective ratings of satisfaction with sexuality, measured 3 times weekly over 22 weeks. Secondary outcomes included measures of sexuality, mood, and self-esteem. Goal attainment scaling was used to measure personally meaningful goals. Data were analysed visually and statistically. Qualitative appraisals of the intervention were also obtained from participants.

**Results:** The results provide preliminary support for the effectiveness of the individualised sexuality treatment program with most cases reporting

improved subjective sexuality satisfaction and attaining functional goals, maintained at follow-up. Intervention delivery was feasible with high acceptability ratings.

**Conclusions:** This research will assist clinicians and services providers improve their knowledge and skills around the treatment of sexuality problems follow TBI. The findings will further inform the development of practical guidelines that support the proactive management of sexuality changes across the continuum of TBI care.

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### **Younger people in aged care: Will we achieve the 2022 and 2025 government targets?**

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**Background and objectives:** In 2019, the Australian Government announced new Younger People in Aged Care (YPIRAC) targets and policy changes that seek to ensure that (apart from in exceptional circumstances) there are no people under the age of 65 entering residential aged care (RAC) by 2022 and no people under the age of 65 living in RAC by 2025. A government Joint Agency Taskforce was set up to develop and implement a national YPIRAC strategy (2020-2025) which involves a series of initiatives across the aged care, disability and health sectors. Most younger people are admitted to RAC from hospitals. In order to solve the issue of YPIRAC, the disability service system needs to be as effective as aged care in assessing eligibility, approving funding and providing age-appropriate housing and support.

**Method:** Using aged care and disability data, trends in admissions to RAC and exits from RAC were analysed. Data was also drawn from a range of Summer Foundation research projects to provide insights into trends related to YPIRAC targets. Analysis included trends in the time taken for hospitals to identify NDIS eligible patients and submit an access request form, the time it takes for the NDIA to get the level of funding needed in plans for discharge and how quickly the disability sector can transition young people at risk of RAC from hospital to age-appropriate housing. Trends analysed include the number of YPIRAC with Specialist Disability Accommodation (SDA) payments in their NDIS plans and the time it takes the NDIA to approve SDA payments and funding for support.

**Results:** There have been significant decreases in the number of younger people living in RAC and in admissions of younger people to RAC. While there have been some improvements in the efficiency of hospital and NDIA processes for people with disability and high support needs, the disability service system is still a long way from being as effective as the aged care system in supporting a timely discharge. The most common reasons for

delayed discharge are related to NDIS plans, sourcing suitable housing and arranging disability supports upon discharge.

**Conclusions:** Based on current trends and data, if radical changes are not made in the efficiency of NDIS allocating funding and securing age-appropriate housing and support for young people at risk of RAC, the federal government YPIRAC targets will not be met.

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### **"Its Not Only The Injury But Also the Kind of Head." Factors Influencing Outcome after Moderate-Severe TBI**

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**Background and Objectives:** Traumatic brain injury (TBI) has significant physical, cognitive, behavioural and emotional consequences that continue over many years and impact return to functional independence, work, study and psychosocial reintegration. Various factors have been associated with outcomes post-TBI, including injury severity variables, age and education. However a significant amount of variance in outcomes remains unaccounted for. Relatively few studies have included a comprehensive range of pre-injury factors as predictors in large samples. This study aimed to examine factors associated with functional outcome at one year after moderate-severe TBI, including pre-injury and injury-related factors

**Methods:** 1028 participants (71.6% males) were recruited prospectively into the Longitudinal Head Injury Outcome Study and followed up at one year post-injury. They had a mean age at injury of 36 years (SD=18.39 years), mean education of 11.3 years (SD=2.48 years), mean days in PTA 26.98 days (SD=30.68 years), mean GCS score of 8.29 (SD=4.35), 64.9% were single, 15.6% were from a culturally and linguistically diverse (CALD) background, 19.5% had psychiatric issues pre-injury and 17.6% had alcohol issues pre-injury. Functional outcome was measured one year post-injury using the Glasgow Outcome Scale – Extended (GOSE). Scores of 1-6 were combined to represent 'poor recovery', and scores of 7 and 8 represented 'good recovery'. Variables examined as predictors included sex, age at injury, years of education, being from a CALD background, marital status at injury, pre-injury psychiatric disorder, pre-injury alcohol issues, days in PTA, and presence of spinal, chest, abdomen, limb, or facial injuries at time of TBI. Binary logistic regressions were conducted to examine factors associated with good recovery on the GOSE at one year post-injury.

**Results:** At one year post-injury, good recovery, representing return to previous activities on the

GOSE (Score 7-8), was present in 32% of participants. This was significantly associated with: more years of education ( $p=.005$ ), not being from a CALD background ( $p=.03$ ), less days in PTA ( $p<.001$ ), not having psychiatric issues pre-injury ( $p<.001$ ) and absence of spinal ( $p=.01$ ) abdomen ( $p=.008$ ), and limb injuries ( $p<.001$ ).

**Conclusions:** Functional outcomes are determined as much by pre-injury background as they are by injury-related factors. Consideration of such factors may inform prognostication and rehabilitation planning.

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### **Gender differences in service utilisation and clinical outcomes of people with acquired brain injury undergoing post-acute neurorehabilitation and disability support , 1991-2020**

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**Background and Objectives:** Women and men have different patterns of healthcare utilisation after acquired brain injury. Women are at risk of poorer outcomes, have a greater number of cognitive difficulties, and are vulnerable to having unmet health needs relative to men following injury. The objective of this presentation is to describe differences in service use and outcomes for female and male clients at a post-acute brain injury rehabilitation and disability support organisation, and consider the implications of differing service use patterns.

**Methods:** A retrospective whole-population cohort study with 1,011 individuals who received post-acute neurorehabilitation and disability services through Brightwater Care Group in Western Australia (WA), 1991–2020. The study used both internal clinical and rehabilitation data, and linked hospital, emergency department and mortality data from the WA Data Linkage System. Gender differences were examined across a number of categories including service access and utilisation, functional independence (Functional Independence and Assessment Measure), quality of life (Quality of Life After Brain Injury Inventory), and ten-year post-discharge mortality.

**Results:** There were a number of systematic differences between male and female clients. Female clients ( $M=44.6$  years,  $SD=18.2$ ) were significantly older than male clients ( $M=41.3$  years,  $SD=15.5$ ) when they acquired their injury ( $p=0.006$ ) and also at admission to post-acute services,  $M_{Female}=47.9$  years ( $SD=17.1$ ) vs  $M_{Male}=44.2$  years ( $SD=14.6$ ),  $p=0.004$ . Female clients presented to services with lower levels of functional independence ( $p=0.018$ ) and quality of life ( $p=0.039$ ) than male clients, though both male and female clients demonstrated significant improvements in

functional independence as a result of services. Female clients were 1.4x more likely than male clients to have more than one episode of care ( $p=0.017$ ), and had a 40% greater risk of death in the ten years following discharge ( $p=0.039$ ). Of accidental and self-harm deaths post-discharge, female clients represented the majority (61.5%).

**Conclusions:** There are a number of systematic differences in service access, service utilisation, and clinical outcomes for female and male clients with acquired brain injury accessing post-acute care, with female clients demonstrating poorer outcomes in some cases. A review of in-service and post-discharge care for women with brain injury is urgently needed.

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## **PLENARY 2**

### **Tough Decisions around Catastrophic Brain Injury – An International Perspective**

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**Synopsis:** Following catastrophic brain injury, life-sustaining treatments are initiated in the early phases of care, in the hope of a good recovery. But, unfortunately, some patients will remain profoundly disabled or in a prolonged disorder or consciousness. If it becomes clear that there is no realistic hope of returning to a quality of life that they would value, some would prefer not to continue to receive life-sustaining treatments, including clinically-assisted nutrition and hydration (CANH). Clinicians and patients' families may be faced with tough decisions about their on-ongoing care and treatment.

Decisions to give / not give life-sustaining treatment pose a number of ethical/legal and practical challenges at the interface between rehabilitation and palliative care. This lecture will explore these alongside some of the solutions that different countries have come up with to address them.

It will cover:

- The range of life sustaining treatment that are given along the care pathway
- How decisions are made and who makes them
- Some of the legal procedures and frameworks that govern these decisions in the UK, Australia and some other countries
- Practical guidance on how to go about decision-making – supporting patient's families
- Management of end of life care after treatment is withdrawn

It will address questions such as

- Is there an ethical / legal distinction between withdrawing life sustaining treatment and hastening death?
- Is clinically assisted nutrition and hydration (CANH) a medical treatment or part of basic care?
- What is it like to die following withdrawal of CANH?
- Should patients be offered assisted dying in this situation?

### **Long-term outcomes and transition to adulthood following childhood acquired brain injury**

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Childhood acquired brain injury (ABI) is a leading cause of death and lifelong acquired disability. The aim of this presentation will be to rapidly introduce common causes of childhood ABI, such as traumatic brain injury, brain tumours or childhood stroke, and their frequent medium- and long-term outcomes. Neurological, cognitive and behavioural outcomes will be approached, and their consequences on subsequent education and academic achievement, overall participation, and quality of life. Important outcomes, such as fatigue, their determinants and consequences on overall participation will be addressed.

Results drawn from the 7-year comprehensive follow-up of the Traumatisme Grave de l'Enfant (TGE) cohort of children who sustained severe traumatic brain injury will be presented (n=39), including early predictors of long-term outcomes. In this study, the 7-year follow-up was performed when one third of participants had reached adult age, and patients were compared for significant or situation-based outcomes to a control group, matched for age, sex, and parental education. Studies including other populations, such as childhood brain tumours will be presented, including follow-up in adulthood of a cohort of patients treated for childhood medulloblastoma. Finally, important issues of transition to adulthood in this population will be discussed, using results of a large survey performed in France and in Belgium, in various structures working with adults who sustained ABI (e.g. sheltered work, vocational programs, etc.). In this qualitative study, 68 professionals working in 12 medico-social structures answered a questionnaire regarding the age at injury /diagnosis of the persons they cared for (n=1049). They also gave their opinion on any difference they had noticed regarding cognitive

development, independence, behaviour, peer relationships, and implication in their life project, between those who had sustained their ABI in childhood / adolescence, versus adulthood. Specific difficulties faced by those young adults will be discussed, as well as possible solutions and interventions for those major issues.

## **SATURDAY**

### **Plenary 3**

#### **People with Communication Disability Striving, Thriving, and Surviving as Technology Advances**

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**Background and objectives:** Mainstream technologies, including smart home devices, virtual and augmented reality devices, social media platforms, and 3D food printing, promise to improve the participation, inclusion, and safety of people with a range of disabilities, and with communication disability or dysphagia. And yet, there is little evidence that these technologies are designed with people with disability in mind, or that any considerations have been made for their access to the devices or the additional supports needed for successful use and benefit. Indeed, some mainstream technologies explicitly note that they should not be used by people with physical or cognitive impairments.

**Method:** A critical analysis of several disruptive innovations, promising advantages to people with disability will be presented. Device affordances, evidence relating to claims of benefit, and usability will be considered to identify how these innovations could be improved to deliver on expansive claims. Barriers and facilitators to the technologies being used to the advantage of people with traumatic brain injury will be considered in relation to operational, strategic, and linguistic demands associated with use of the devices, along with any supports needed to use the devices.

**Results:** Outcomes of usability device trials for (a) a voice-activated smart home device, (b) virtual and augmented reality devices, and (c) a 3D food printer will be presented to illustrate the problematic gap between what is promised and what is delivered in terms of usability and benefit of these devices. Implications for people with disability and health professionals who are considering use of these devices during rehabilitation will be considered in the light of inclusive design principles and accessibility. The results of recent research on the use of social media platforms by people with communication disability will illustrate a potential pathway for enhancing the access of people with disability to mainstream technologies for a range of purposes.

**Conclusion:** Mainstream disruptive innovations promise much but deliver little in terms of usability

or accessibility by people with disability. Inclusive design principles should guide strategies for increasing the application and usability of innovative technologies to improve participation and inclusion for people with traumatic brain injury.

### **Improving services for Aboriginal Australians after brain injury: Current initiatives and findings to date**

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Recent research has provided insights from Aboriginal people with brain injury and their families around their journeys of recovery that involve geographical, cultural and linguistically diverse issues. One of the biggest barriers is communication, and without a culturally secure care in place, many Aboriginal Australians are simply not recovering to their full potential. The keynote address will explore the journeys of Aboriginal Australians after stroke and traumatic brain injury, highlighting ongoing challenges faced, as well as family and community resources that assist recovery, and new service initiatives aimed at improving access to rehabilitation. The presentation will also outline a program of research informed by Aboriginal people with brain injury and their families. The research involves the co-design of all new initiatives by Aboriginal and non-Aboriginal researchers, clinicians and Aboriginal community members. The presentation will provide the background to, findings to date and current initiatives to improve service delivery including the WA based Healing Right Way clinical trial – the first of its kind in brain injury involving Aboriginal people specifically. The role of cultural security training of hospital staff and the employment of Aboriginal Brain Injury Coordinators throughout WA will be discussed, with implications for national practice proposed.

## **SESSION 7**

### **An international transdisciplinary training program for allied therapy students in Positive Behaviour Support: Findings from a pre-post feasibility study**

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**Background and Objectives:** Challenging behaviours are prevalent, distressing and enduring after acquired brain injury (ABI). Despite this, neurorehabilitation clinicians report feeling inexperienced and inadequately trained in effective behaviour support interventions. Specifically, clinicians report low levels of understanding and confidence in Positive Behaviour Support (PBS), for

which there is growing evidence and support from national funders. We have designed and evaluated a flexible, multi-component and person-driven intervention combining PBS and cognitive-executive strategies for ABI, called PBS+PLUS. We developed post-graduate experiential training to address this knowledge-practice gap and translate PBS+PLUS into clinical practice. The objective of this pilot study is to evaluate the training program for feasibility and identify opportunities for refinement.

**Method:** Pre-post intervention design. Allied therapy students on placement at two clinical services were recruited to participate (Monash University, Melbourne, Australia, neuropsychology trainees,  $n=3$ ; The College of Saint Rose, New York, USA, speech and language therapist trainees,  $n=3$ ). Participants completed a one semester placement which included direct clinical experience with adult clients with ABI, four workshops, case discussion, individual and group supervision, set reading and written assignments. Pre- and post-training self-evaluation was completed by all trainees using a survey of knowledge, competence and skill in PBS+PLUS. Expert independent reviews of a random selection of participant session recordings were available for two trainees. Due to the small sample size, descriptive and summary data was visually analysed.

**Results:** In regards to feasibility, attendance and active participation in the training program by all participants was high. Qualitatively, participants were very positive about the educational need and quality of the training provided. Participants at both services demonstrated marked improvement on all aspects of self-rated competency. Findings of the expert independent reviews will be discussed.

**Conclusions:** The measures selected are sensitive in detecting clinically meaningful changes. The pilot findings provide support for ongoing development and expansion of the clinical training program. Larger sample sizes and follow-up within occupational settings are needed to empirically evaluate the benefit and impact of training on future clinical service delivery.

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### **Are mental health needs of individuals with a traumatic brain injury being met? A cross sectional study**

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**Background and Objectives:** Psychological distress is frequently reported amongst individuals with a traumatic brain injury (TBI), and can persist for several years post-injury. The current study assessed psychological distress and examined level of treatment uptake and satisfaction with psychological support services. The aim was to identify whether unmet mental health needs exist for individuals with a TBI living in the community across NSW.

**Method:** Participants, aged 18-65 years, with a moderate to severe TBI (N=114) acquired within the past five years were recruited from various sites across the NSW Brain Injury Rehabilitation Program. Participants were assessed for psychological distress using the DASS-21 and completed project specific questions about their current linkage with psychological services.

**Results:** General psychological distress amongst the sample was relatively high (M=18.4; SD=15.2). Across the sample, 32 participants (28.1%) reported currently seeing a psychologist for regular, ongoing therapy. Of those reporting clinical levels of distress (n=32, 28.1%), many were not accessing any psychological support services (n=25; 78.1%). Majority of participants were referred to clinically endorsed psychologists for treatment (n=19, 73.1%) and were most frequently referred by their case manager (n=15, 13.2%) among other health professionals. The primary reason for referral was post-injury adjustment (n=16, 14%) but reasons also included post-trauma (n=4, 3.5%), depression/mood (n=2, 1.8%), and stress management (n=2, 1.8%). Uptake of psychology services and levels of clinical distress did not differ across geographic location (metropolitan or regional NSW). Overall, levels of satisfaction with psychology services received was high as rated on a five-point Likert scale (M=4.6; SD=.72).

**Conclusions:** Psychological support services play an integral role in supporting individuals with a TBI who are experiencing psychological distress post-injury. Though, nearly a third of participants were engaged with a psychologist, only one-third of those with clinical levels of distress reported receiving psychological treatment. These findings indicate ongoing unmet mental health needs amongst individuals with a moderate to severe TBI and suggest a need for regular screening of psychological distress in the first five years post-injury.

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#### **Assessment of low mood, distress and depression in people with severe brain injury: a systematic review**

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**Background and Objectives:** Low mood, distress and depression after acquired brain injury (ABI) are thought to be common. Clinical guidelines recommend routine screening of patients to ascertain whether intervention is required. In ABI research, severity is often defined by the Glasgow Coma Scale (GCS) score or duration of Post traumatic amnesia (PTA), which do not necessarily reflect severity of ongoing cognitive impairment. This review focuses on people with severe ABI with persisting cognitive and communication impairments that affect their ability to complete self-report measures and impact the presentation of their symptoms. The purpose of this review is to identify, collate and synthesise literature examining the validity of mood and depression assessments in people with severe ABI.

**Method:** Databases were systematically searched for articles examining the validity of screens or assessments of mood after severe ABI. Psychometric properties of each study were extracted using the Consensus-based standards for the selection of health measurement instruments (COSMIN) risk of bias checklist. The inclusion criteria relating to participants was extracted for each study to assess the relevance of the results to those with severe ABI.

**Results:** 19 papers detailing the psychometric properties of 21 measures were included. Results could not be pooled due to heterogeneity of participants and lack of agreement in gold standard choice. Regarding psychometric properties, six measures showed low risk of bias in their studies and sufficient validity. Papers were inconsistent in reporting injury severity and cognitive impairments of participants. In a small study including those with severe cognitive and communication impairment, the validity of the Aphasia Depression Rating scale (ADRS) and Stroke Aphasic Depression Questionnaire (SADQ-10) were found to be sufficient and of high quality.

**Conclusion:** The SADQ-10 and ADRS can tentatively be recommended for screening low mood in patients with severe ABI. No self-report measures could confidently be recommended. Further research with consistency in reporting of results would be beneficial. Assessors are advised to take a formulation based approach using multiple sources of information when assessing low mood after severe ABI. Clinicians should employ screening tools with care, and consider the organic nature of the brain injury and the patients' cognitive impairments, insight and consistency when completing assessments.

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**Motivational disorders after traumatic brain injury: Is apathy driven by abnormal sensitivity to foreground and background reward?**

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**Background and Objectives:** Apathy is a common, yet difficult-to-assess behavioural sequela of traumatic brain injury (TBI). Experimental assessment of effort and reward processing may be crucial for understanding the mechanisms that cause apathy. In real-world settings, reward can be further classified into foreground (what can be gained right now) and background (what else could be gained in the broader environment) components, that are dissociable neurobiologically. Here we applied a foraging framework to investigate these components in people post-TBI, hypothesising that apathy would be associated with disrupted sensitivity to background rewards.

**Method:** Forty-five patients with TBI (25 without apathy–TBI-A; 20 with apathy–TBI+A) and 37 matched healthy controls completed a patch-leaving style foraging task. In the task, administered on desktop computer, participants were asked to collect as much reward (milk from cows in fields) as they could, within 14 minutes. Foreground reward rate was manipulated by using fields that differed in the initial yield of milk available per second (low, medium and high yield). In all fields, reward rate reduced exponentially the longer a participant remained in that field. Background reward rate was manipulated by changing the proportion of low and high yield fields between two blocks, or environments (rich environment: 50% high yield, 30% medium yield and 20% low yield fields and poor environment: 20% high yield, 30% medium yield and 50% low yield fields). Participants made decisions as to when they should leave their current field based on the foreground and background reward rates.

**Results:** There was a significant interaction between the effect of background reward rate and apathy on leaving time ( $p < 0.005$ ). This was driven by TBI+A patients showing a reduced sensitivity to changes in background reward rate than both TBI-A patients and healthy controls. These changes were associated with the TBI-A group collecting more reward than the TBI+A group from the rich environment ( $p = 0.046$ ). In contrast, there was no

significant interaction between foreground reward rate and apathy.

**Conclusions:** Apathy following TBI was associated with reduced background, but not foreground, reward sensitivity. Clinical interventions which enhance the ability to process background reward values – or bypass this deficit – show potential to treat motivational disorders and improve patients' and carers' psychosocial outcomes.

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**Social Disinhibition in Acquired Brain Injury and Neurological Disease: A Concept Analysis**

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**Background and objectives:** Social disinhibition is becoming increasingly recognised in the neuropsychological literature as a complex and debilitating sequelae associated with acquired frontal lobe damage. Despite this, the term has been inconsistently defined and described in both clinical and research contexts. The purpose of this paper was to explore and examine the concept of social disinhibition in the context of brain injury and other organic neurological conditions.

**Method:** A literature search for articles published in the English language from journal inception to June 2021 was conducted using MEDLINE, PsycInfo, Embase, CINAHL and Web of Science. A 'concept analysis' was conducted on the identified literature using Walker and Avant's (2019) framework.

**Results:** The analysis suggested that while several terms are often used interchangeably with social disinhibition, including impulsivity and behavioural dysregulation, these terms may be differentiated and defined separately within the broader domain of 'behaviours of concern'. Attributes, antecedents and consequences of social disinhibition were also identified and discussed. **Conclusions:** Clarifying the concept of social disinhibition has important implications in both clinical and research contexts, including increased understanding of the behaviours, more accurate estimates of incidence and prevalence, and the development and implementation of targeted rehabilitation programs.

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**The Hospital Anxiety and Depression Scale Does Not Reliably Differentiate Anxiety and Depression Following Traumatic Brain Injury**

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**Background and Objectives:** Given their high prevalence and co-occurrence, it is vital that anxiety and depression are routinely screened amongst individuals with traumatic brain injury (TBI). The Hospital Anxiety and Depression Scale (HADS) is the most popular measure in the TBI literature for assessing anxiety and depression. However, it is unclear whether this scale can reliably discriminate the constructs it purports to measure as opposed to simply measuring general distress. Using bifactor analysis, our objective was to evaluate whether scores on the HADS following TBI reflect specific factors of anxiety and depression or rather only a single factor of general distress.

**Method:** 873 individuals hospitalised for moderate-to-severe TBI completed the HADS approximately one year after their injury. A subsample (n=187) was also administered the Structured Clinical Interview for DSM Disorders (SCID). We fitted a confirmatory bifactor model to the HADS and derived a series of statistical indices, including omega hierarchical reliability coefficients and average relative parameter bias. We also compared HADS total and subscale scores between participants with formal SCID diagnoses of anxiety and depressive disorders.

**Results:** We found a very dominant general distress factor underlying the HADS, explaining 84% of the systematic variance in total scores. When holding this general factor constant, the specific anxiety and depression factors accounted for very little residual variance in their subscale scores (12% and 19%, respectively). Item loadings on the general factor changed, on average, by only 8% when removing the specific factors, suggesting minimal bias in treating the HADS as a unidimensional instrument. Moreover, the HADS anxiety and depression subscales did not discriminate formal diagnoses of anxiety and depressive disorders on the SCID.

**Conclusions:** In this large TBI cohort, HADS total scores overwhelmingly reflected variance due to a single underlying latent variable. The subscale scores were unreliable and ambiguous since most of their variance reflected the general factor. We therefore advise that the HADS subscales be abandoned in favour of the total score in TBI research and clinical practice. Measures of psychopathology that can yield dissociable, homogenous symptom dimensions should be validated for TBI.

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## SESSION 8

### Adult patient and carer experiences of planning for hospital discharge after a major trauma event

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**Objective & Background:** The objective of this systematic review was to synthesise the best available evidence on patient and carer experiences of hospital discharge planning after a major trauma event. Major trauma is an event that can affect anyone at any time of their lives despite their health status and is a significant contributor towards disability. The transition from hospital to home after a traumatic event is an important stage for both patient and carer. The patient is adjusting to a disability whilst preparing to transition into previous life roles and family are caring for their loved one and adopting vacant life roles.

**Methods:** The systematic review was conducted in accordance with the JBI methodology for systematic reviews of qualitative evidence. Systematic review included qualitative studies that explored the experiences of adults (aged 18 to 65 years) and their carers related to hospital discharge planning following a major trauma event. Relevant studies were identified through a thorough search of relevant databases including grey literature sources. JBI tools were used for methodological quality appraisal and data extraction. Extracted data were analysed and grouped into categories, then developed into a set of synthesised findings. These assisted in creating evidence-based recommendations for practice in relation to the review objective.

**Results:** 14 papers from 13 studies included data relating to patient and carer experiences of discharge planning. Four synthesised findings were developed from the categories: 1) Patients and carers feel generally unprepared to manage at home after discharge from hospital; 2) Early identification of patients' post discharge needs allows for appropriate referrals and supports to be organised prior to discharge; 3) Patients and carers value their participation in the discharge planning process to facilitate an organised discharge from the hospital; 4) The timely presentation, delivery method and relevancy of information impacts how patients and carers manage their discharge.

**Conclusion:** The findings indicate that generally patients and carers do not have positive experiences in the discharge planning process following a major traumatic event. The synthesised qualitative data indicated that the application of patient and family-centred principles will improve patient and carer experience of the discharge planning and provide skills to prepare patients and carers to reintegrate in the community.

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### Evaluation of outcomes for People with neurological disability and complex needs after moving into new individualised apartments: Preliminary results

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**Background and Objectives:** Despite growth in individualised models of housing for people with disability, little research has investigated the outcomes of this housing on residents. This is particularly the case for adults with complex disability such as acquired brain injury (ABI), spinal cord injury (SCI) and multiple sclerosis (MS). The aim of this study was to investigate change in outcomes for people with neurological disability and complex needs who move into individualised housing. Hypotheses guiding analysis of the data were that significant improvements would be demonstrated in individual outcomes (health, wellbeing, community participation, support needs) after moving into an individualised housing option, when compared to their prior living arrangement.

**Method:** This study is part of a larger longitudinal, mixed-methods project designed to evaluate individual experiences and outcomes of moving to individualised models of housing for people with disability. We report the outcomes of the first 15 participants from the larger project. These participants had high support needs and specialist disability accommodation (SDA) in their National Disability Insurance Scheme plan. They had all moved into SDA funded apartments and completed data collection over the first two time points (1: pre-move and 2: 6-24 months post-move). Participants were aged 18-67 years with a variety of disability types (ABI, SCI, MS). Pre-move living environments included group homes, residential aged care, vulnerable housing, private rentals and living with parents. Health (EuroQol visual analog scale), wellbeing (Warwick-Edinburgh Mental Well-being Scale), community integration (Community Integration Questionnaire-Revised) and support needs (Care and Needs Scale) were compared across pre- and post-move timepoints.

**Results:** Paired sample t-tests showed significant improvements with large effects in health ( $p=.039$ ,  $Eta^2=.21$ ), wellbeing ( $p=.016$ ,  $Eta^2=.29$ ) and community integration ( $p=.004$ ,  $Eta^2=.41$ ) after living in individualised apartments for 6-24 months. A Wilcoxon signed rank test demonstrated a trend towards reduced support needs ( $z=-1.941$ ,  $p=.052$ ) consistent with a medium effect (.35) and an average decrease of 2.4 support hours per participant per day.

**Conclusions:** Individualised apartments that are well-located with appropriate design and support provision allow for increased health, wellbeing, and community integration for people with disability and complex needs.

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## Does Poor Sleep Quality Affect Functional Outcomes in Individuals with Chronic Fatigue Syndrome?

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**Background and Objectives:** Chronic Fatigue Syndrome (CFS) is a debilitating disease that is known to affect health and lifestyle. It reduces sleep quality and quality of life, and results in poor everyday functioning. However, it is the relationship between these health and lifestyle factors that is poorly understood. This study examined the relationship between sleep quality and both health related quality of life (HRQoL) and psychosocial community integration outcomes in individuals with CFS. How the relationship between sleep quality and HRQoL differed across CFS and healthy individuals without CFS, was also examined.

**Method:** The sample consisted of 176 participants with CFS (89% female) and 85 healthy control participants (82% female) aged between 18 and 65 years. CFS participants met the requirements of the Institute of Medicine diagnostic case criteria definition. Eligible participants completed questions from the DePaul Symptom Questionnaire to assess diagnostic status, Hospital Anxiety and Depression Scale, Pittsburgh Sleep Quality Index, Short Form Health Survey-36 to assess HRQoL (in the domains of physical and mental health), and Sydney Psychosocial Reintegration Scale to assess psychosocial community integration (CFS participants only).

**Results:** Individuals with CFS experienced substantially lower levels of sleep quality and quality of life than the healthy individuals. Poor sleep quality was associated with poor quality of life, although this relationship was stronger in healthy individuals than in CFS participants. While poor sleep quality was also associated with poor overall psychosocial community integration, it was not associated with the separate psychosocial domains of work and leisure, interpersonal relationships, and independent living skills. Anxiety and depression accounted for all relationships, except for the relationship between sleep quality and the HRQoL physical health domain.

**Conclusions:** This study demonstrates the importance of sleep quality to HRQoL and functional outcomes in CFS. Future research may explore the link between more specific aspects of sleep quality and functional outcomes in CFS, and the manner in which sleep may interact with other key symptom domains of CFS (including post exertional malaise, cognitive difficulties, and autonomic/neuroendocrine/immune dysfunction) to affect psychosocial outcomes.

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## "This is better but not fully there": Experiences of participating in a co-design project from the perspective of adults with neurological disability and facilitators

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**Background and objectives:** Co-design is a collaborative process of knowledge sharing, problem solving and creating solutions, underpinned by lived experience. In healthcare, there are increasing opportunities for people with disability to participate in co-design. However, there is limited understanding of best approaches to co-design engagement for people with complex neurological conditions, especially those with cognitive and communication challenges. The purpose of this study was to evaluate a co-design project, seeking to better understand the experience of contributors with neurological conditions, as well as facilitators. The co-design project itself centred around the creation of capacity building tools, informed by lived experience, to be shared with young people with disability living in residential aged care.

**Method:** Using a qualitative research design, interviews were conducted with nine participants; six contributors with neurological conditions and three co-design facilitators. Interviews were conducted pre and post participation in the co-design project. The focus of this presentation is post participation interviews, capturing reflections about the co-design experience. Interview transcripts were analysed using constructivist grounded theory, following a process of open and focused coding, with exploration of relationships between emergent themes. Satisfaction ratings of the produced tools were also completed by each of the participants.

**Results:** Data analysis resulted in three key themes:

*Making sense of co-design; Being employed and contributing to society; Creating meaningful tools.*

All participants valued the co-design opportunity, while recognising areas for improvement to tailor the process to better meet the skills and needs of people with cognitive and communication challenges. Suggested improvements included a need for better role clarity, peer buddies, more time for reflection and targeted facilitation. Overall, the experience fostered learning and personal growth for the contributors, with reports of increased confidence in work capacity. All participants rated a high level of satisfaction with the produced tools.

**Conclusions:** This study provides valuable new learning to guide future co-design work with people with complex neurological conditions. Central to this learning is the development of key principles to support co-design engagement for people with cognitive and communication challenges.

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## "They treat you like a person, they ask you what you want": Exploring Factors that Influence the Quality of Paid Disability Support for Adults with Acquired Neurological Disability

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**Background and Objectives:** Adults with acquired neurological disability experience a range of cognitive, communication and physical impairments and therefore often require paid disability support to live an ordinary life. Despite the importance of the support worker role, little is known about what influences the quality of support. This study aims to understand the factors and identify the skills that influence the quality of support from the perspective of adults with acquired neurological disability.

**Method:** Guided by constructivist grounded theory, in-depth interviews were conducted with 12 adults with acquired neurological disability, who receive one-to-one paid disability support. Qualitative analysis of interview transcripts followed an iterative process of open and focused coding, identification of emergent themes and sub-themes, and explorations of relations between themes.

**Results:** Three key interrelated themes pertaining to factors and associated skills that influence the quality of support were developed. With a primary focus on the interactional space, participants emphasised the importance of 1) being recognised as an individual, 2) feeling in control, and 3) being the right fit with their support worker. Beyond the interactional space, broader systemic factors (i.e., support arrangements and the support environment) were identified as potentially influential factors.

**Conclusions:** This study provides valuable insights into how disability support workers can provide quality support to adults with acquired neurological disability by prioritising the wants and needs of the individual. Furthermore, the findings can inform recommendations for allied health professionals to support disability support workers to deliver best practice.

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## Individuals' perceptions of their health and well-being in the context of Stereotactic Radiosurgery for benign brain tumour: a longitudinal qualitative investigation

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**Background and objectives:** Treatment-related outcomes after Gamma Knife Stereotactic Radiosurgery (GKSRS) for benign brain tumour are well-established; yet patient reported outcomes have been largely overlooked. This study explored individuals' perspectives of their health and well-being prior to and following GKSRS.

**Method:** Adults with benign brain tumour were recruited from the Gamma Knife® Clinic, The Princess Alexandra Hospital. 20 participants (65% female, 19-84 years) were recruited and assessed approximately 1 week prior to GKSRS, 2 weeks post GKSRS, and at 3 months follow-up. They completed a telephone-based interview focusing on general health, symptoms and well-being and anxiety and depression measures. Interviews were transcribed and analysed using Braun and Clarke's thematic framework (2013).

**Results:** Rates of clinically elevated distress were high both prior to (36-53%) and 2-weeks post GKSRS (31-58%) but decreased at follow-up (15-40%). Diverse physical, cognitive and emotional effects of the illness and GKSRS were reported. Three major themes emerging from the interview data were: sense-making, expected versus unexpected outcomes, and adjusting one's mindset. "Sense-making" reflected efforts to understand one's illness to reduce ambiguity and increase sense of control. "Expected versus unexpected outcomes" related to self-realizations of one's functioning as being better or worse post-procedure than anticipated. "Adjusting one's mindset" characterised how people altered their approach to coping with their illness.

**Conclusions:** Coping and adjustment is highly individualistic in the context of GKSRS. Over time, most individuals were better able to make sense of their illness, accommodate unexpected outcomes, and adjust their mindset to cope with the long-term effects.

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### **Meta-social-cognitive awareness of emotion perception abilities in ABI**

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**Background and Objectives:** A common outcome of acquired brain injury is difficulties in the ability to perceive the emotions of others. What is less understood is difficulties in meta-social-cognitive awareness about these abilities. This awareness is important as it may facilitate appropriate monitoring of difficulties and allow for individuals to adjust their social responding, thereby improving

social communication. This study aimed to replicate prior findings of difficulties in emotion perception ability that invariably occur across emotional types displayed at various emotion intensities. It also aimed to extend on prior findings by examining meta-social-cognitive awareness of these difficulties.

**Method:** Twelve individuals with ABI were compared to 12 demographically matched healthy participants on general tests of cognitive functioning and the Emotion Recognition Task, assessing the ability to accurately perceive facial emotional expressions across various emotion types displayed at various intensity levels. Both anticipatory awareness (judgements of expected performance) and emergent awareness (judgements of performance as the task is being completed) were also assessed using confidence ratings of performance accuracy.

**Results:** While no significant differences between groups on measures of general cognitive functioning were found, ABI participants were less accurate in identifying surprise and disgust displayed at high intensities than healthy participants. ABI participants also demonstrated select meta-social-cognitive anticipatory and emergent awareness difficulties for the perception of surprise and disgust.

**Conclusions:** The results provide novel insights into how awareness of social-cognitive abilities pertaining to the perception of emotions in others may be impaired following ABI. Future studies may seek to examine the extent to which these difficulties in social-cognitive-awareness may contribute to poor communication.

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### **Assessment of online awareness following acquired brain injury: A conceptual analysis and recommendations for practice**

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**Background and objectives:** Self-awareness following acquired brain injury (ABI) is an essential consideration throughout the rehabilitation process, and can impact engagement in rehabilitation and associated functional outcomes. Theoretical accounts identify two main constructs associated with self-awareness; intellectual awareness and online awareness. Most self-awareness assessment methods measure intellectual awareness, with a lack of established standardized measures of online awareness. Identification of methods of online awareness assessment that have utility in both

clinical and empirical contexts is essential to progress this area of cognitive rehabilitation. The aim of this conceptual analysis is to provide a background to online awareness assessment, including a summary of outcomes of a conceptual analysis of online awareness definitions and assessment approaches.

**Method:** Systematic review combined with conceptual analysis methodology to identify online awareness definitions and assessment approaches. Search strategy included Medline, CINAHL, EMBASE, PsycINFO, Cochrane database searches, reference screening and expert recommendation. Papers were included if they provided a definition of online awareness and/or described a method of online awareness assessment for adults with ABI. Data were analysed using thematic analysis.

**Results:** A total of 45 papers were included in this review, which identified 29 online awareness assessment methods. Online awareness definitions comprised five main components: 1/ monitoring and self-regulation; 2/ anticipation and prediction; 3/ strategies; 4/ self-evaluation; and 5/ task factors. Online awareness assessment approaches demonstrated considerable variation in alignment with the online awareness definition components. Assessments comprised a broad range of processes and rating systems that varied considerably across assessments. Key recommendations for online awareness assessment will be outlined.

**Conclusions:** Consensus around the important components of online awareness for inclusion in an assessment approach is required to advance practice in cognitive rehabilitation for adults with ABI.

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## SESSION 9

### Behaviour support and the NDIS: Roles, Responsibilities and Regulations.

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**Synopsis of session:** The delivery of behaviour support services, including the role of therapists delivering behaviour support, has undergone significant change under the NDIS. There is uncertainty amongst people with disability receiving NDIS funding, their families and disability service providers about the NDIS Restrictive Practices and Behaviour Support Rules (2018). This uncertainty can have a negative impact on team dynamics/effectiveness, lead to an inadvertent

breach of rules, and ultimately have an adverse impact on safeguarding the dignity of the person with disability and their quality of life. This presentation aims to support providers working with people with an acquired brain injury to build their understanding of NDIS-funded behaviour support service delivery, including exploring when behaviour support input is required, who can deliver behaviour support, and the role of the behaviour support practitioner and others working with the client.

**Level aimed for:** Basic

**Learning objectives:**

- Understand when and what type of NDIS funding should be requested for behaviour support input for people with disability being discharged from hospital or living in the community.
- Understand NDIS rules relating to restrictive practices and behaviour support, including the input provided by the behaviour support practitioner.
- Understand the role of, and implications for, the NDIS client, their family, and the broader team working with clients receiving behaviour support.

**Biography:** *Alexandra Armstrong* is a neuropsychology registrar at Victorian Neuropsychology Rehabilitation Services who provides psychological services, including behaviour support, to NDIS participants. *Jane Dahm* is a community-based neuropsychologist in private practice. She provides specialist behaviour support for NDIS participants as well as rehabilitation, assessment, and counselling for clients with an acquired brain injury. *Bleydy Dimech-Betancourt* is a Neuropsychologist at Victorian Neuropsychology Rehabilitation Services with a research background in rehabilitation following ABI and who provides behaviour support to NDIS participants. *Kate Frencham* is a neuropsychologist in Private Practice with a special interest in community rehabilitation for people with ABI. With VNRS, she provides behaviour support for NDIS participants with ABI and complex needs. *Di Parcell* is a neuropsychologist in Private Practice with a special interest in community rehabilitation for people with ABI. With VNRS, she provides behaviour support for NDIS participants with ABI and complex needs. *Sue Sloan* is an Occupational Therapist and Neuropsychologist in Private Practice with a special interest in providing training in the area of behaviour support and participation. *Kim Trezise* is a neuropsychologist in Private Practice with special interests in working with adults with developmental disability and in community ABI rehabilitation. With VNRS, she provides behaviour support for clients with developmental disabilities including intellectual disability and autism. *Carlo Ziino* is a neuropsychologist and director of Victorian Neuropsychology Rehabilitation Services, with a

special interest in behaviour support for clients with ABI and complex needs.

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## SESSION 10

### What are the best ways to sustain gains following post-stroke memory rehabilitation? Results from the Memory-SuSTAIN pilot randomised controlled trial

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**Background & Objectives:** Addressing memory problems after stroke is a priority because of high unmet needs in this area. Compensatory memory skills programs can result in short-term improvements, but difficulties establishing new strategies into everyday routines can reduce longer-term effectiveness. We aimed to evaluate the acceptability and potential effectiveness of 2 maintenance interventions designed to sustain the effects of memory skills training: i) booster sessions delivered via telehealth, and ii) electronic (SMS/email) reminders prompting use of strategies; compared with iii) no active maintenance (usual care).

**Method:** A pilot randomised controlled trial with blinded outcome assessments was conducted with community-dwelling survivors of stroke experiencing everyday memory problems. All participants completed a 6-week memory skills group program, and then after a 6-week waiting period were randomly allocated into one of the three maintenance conditions. Outcome measures included memory-related goal attainment evaluated using Goal Attainment Scaling (GAS) and subjective memory complaints using the Everyday Memory Questionnaire-Revised (EMQ-R), administered pre-memory group (baseline), post-memory group (6 weeks), post-waiting period 1 (12 weeks), post-maintenance intervention (18 weeks), and post-waiting period 2 (24 weeks). Acceptability ratings were collected at 24 weeks.

**Results:** 38 of 41 eligible participants (58% female, mean age 56.1 years, mean time-since-stroke 37.2

months) were randomised. Acceptability ratings were equally high for the 3 maintenance conditions, with all participants saying they would recommend participation to others. Descriptively, satisfaction with the maintenance condition was greater for booster sessions (mean=9.2) than electronic reminders (7.7) and usual care (8.1). GAS t-scores significantly improved and memory complaints on the EMQ significantly decreased between 0-24 weeks for all conditions ( $ps<.001$ ). There were non-significant signals of potentially superior goal attainment for participants receiving booster sessions compared with usual care ( $d=0.2$ ) in this pilot trial.

**Conclusions:** Maintenance interventions appear acceptable and feasible, and a definitive trial is justified to confirm whether they can prolong benefits of memory rehabilitation post-stroke. Identification of clinically relevant maintenance strategies could significantly reduce the long-term impact of memory problems for survivors of stroke.

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### The Stroke Unmet Needs (SUN) study: A randomised controlled trial

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**Background and Objectives:** Increasing evidence suggests that people with minor stroke experience persisting post-stroke impairments and have unmet social and rehabilitation needs that do not resolve spontaneously. The aim of the current study was to determine whether a new multi-component service pathway for minor stroke patients reduced unmet needs compared with usual care 1 and 3 months post-hospital discharge.

**Method:** A parallel, randomised control trial design with 1:1 allocation to the intervention and control groups was used. Sixty-eight people with minor stroke were randomised to either the new intervention or usual care. The intervention group

received a minor stroke self-management pack, minor stroke screening checklist for their general practitioner, and access to minor stroke education sessions. All participants completed T1 (baseline), T2 (1 month post-hospital discharge) and T3 (3 months post-hospital discharge) assessments (including the Survey of Unmet Needs and Service Usage (SUNSU), Mayo-Portland Adaptability Inventory-4 (MPAI-4), Exeter Identity Transition Scales (EXITS), Rand 36-Item Health Survey (SF-36), Stroke Specific Quality of Life Scale (SSQL)).

**Results:** There was no significant difference between the control or intervention groups according to age, gender or work status at T1 (all  $p > .050$ ); however, the intervention group had poorer social functioning ( $p = .048$ ). Unmet needs for both groups decreased significantly over time; however, there was no significant difference between the groups ( $p > .05$ ). The intervention group reported receiving significantly more support than the control group ( $p = .049$ ), with the control group reporting significantly increasing need for support over time ( $p = .040$ ). There was no significant difference between the groups over time according to social group connectedness (all  $p > .05$ ). Ability, adjustment, and participation significantly improved over time; however, there was no difference between the groups ( $p > .05$ ). The intervention group displayed significantly greater improvements in mental health than the control group over time, and significantly greater improvements in social functioning.

**Conclusions:** The new multicomponent intervention led to improvements in support, mental health and social functioning compared to usual care; and adds to the growing evidence base advocating for more support for people with minor stroke.

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#### **Effectiveness of a telehealth-based memory rehabilitation group after stroke**

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**Background and Objectives:** Memory changes are a common problem following stroke yet many stroke survivors have difficulty accessing rehabilitation services to support memory recovery. Telehealth provides a means to increase access to memory rehabilitation, however, evidence on its effectiveness is sparse, particularly using group formats. This study aimed to evaluate a telehealth

adaptation of an existing evidence based memory rehabilitation group in stroke survivors.

**Method:** A single arm trial with pre-post design was used. Participants were eligible if they had a stroke diagnosis and subjective memory complaints and were recruited from the community as part of a larger trial. Participants completed a six-week memory rehabilitation group via telehealth that involved learning internal and external memory strategies, healthy lifestyle tips, and education about memory. Outcomes were measured at baseline, end of treatment, and 6-week follow up. Primary outcome was the achievement of functional memory goals using goal attainment scaling (GAS). Secondary measures included the Everyday Memory Questionnaire-Revised (EMQ-R) and Strategy Checklist.

**Results:** 31 participants completed the telehealth memory group. GAS scores improved significantly from baseline to post intervention, indicating functional memory gains, and remained stable at follow up. Improvements after the group were also seen in everyday memory problems (EMQ-R) and in the use of internal and external memory strategies.

**Conclusions:** These results provide preliminary support for the effectiveness of a telehealth based group for memory rehabilitation after stroke. Further controlled studies are needed to provide a stronger evidence base for telehealth rehabilitation after stroke.

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#### **Factor Structure of the Agitated Behaviour Scale in Traumatic Brain Injury During Post-Traumatic Amnesia**

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**Background and Objectives:** Agitation is observed in approximately one-third of patients with traumatic brain injury (TBI) and is most common during post-traumatic amnesia (PTA). The Agitated Behaviour Scale (ABS) was designed and is commonly used to measure agitation in patients in PTA, however its underlying structure during this phase of recovery remains unclear. The primary objectives of this analysis were to 1) establish the underlying factor structure of the ABS in a sample of patients with TBI during PTA, 2) test this identified structure in a second dataset and 3) compare this factor structure with previously explored one, two- three- and four-factor structures.

**Method:** This retrospective cohort study utilised medical record data from 364 patients aged at least 16 years meeting diagnostic criteria for TBI and PTA admitted for initial inpatient rehabilitation. For these patients, the ABS is measured daily from admission until PTA emergence. Exploratory factor analysis was undertaken to determine the underlying theoretical construct of the ABS, followed by a series of confirmatory factor analyses to compare this model's fit to that of previously identified structures.

**Results:** Exploratory factor analysis uncovered two strongly correlated underlying factors (0.52), labelled Restlessness and Aggression/Lability. Two items failed to demonstrate sufficiently large loadings on either factor. Both factors demonstrated adequate reliability (Cronbach  $\alpha$  = 0.87 and 0.81 for Restlessness and Aggression/Lability, respectively). Linear regression indicated that higher Westmead Post-Traumatic Amnesia Scale (WPTAS) scores predicted lower levels of Restlessness ( $\beta$  = -0.14,  $p$  < 0.001), supporting construct validity. Conversely, WPTAS scores were not a significant predictor of Aggression/Lability ( $\beta$  = -0.12,  $p$  = 0.08). Confirmatory factor analysis indicated superior fit of the identified two-factor solution when compared with previously explored one-, two-, three- and four-factor structures.

**Conclusions:** This study suggests that the latent structure of the ABS is best explained by a single construct of agitation with two discrete facets reflecting Restlessness and Aggression/Lability. These subscales may be used in clinical practice to evaluate the severity of different aspects of agitated behaviour, inform treatment decisions and judge the efficacy of interventions over time. Further research is required to explain low factor loadings demonstrated by two items.

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### How Fatiguing is High Intensity Treatment for People with Aphasia? An Analysis of 140 Participants from the COMPARE Trial

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**Background and Objectives:** The evidence base for high intensity interventions for aphasia continues to grow. However, participant withdrawal rates are typically greater in high intensity interventions. Participant fatigue is presumed to be one explanation for withdrawals. A small amount of data has identified that clinicians believe participant fatigue to be a significant challenge in providing intensive intervention and there are reports of withdrawals due to fatigue (Gunning et al., 2016). Some high intensity programs specify adequate 'stamina' to complete the treatment as an inclusion criterion (Rose et al., 2021). However, there is a lack of direct data on fatigue levels of people with aphasia during high intensity interventions. Patterns of fatigue across interventions are important to guide dose schedules and allow more evidence-based criteria for programs. We aim to examine three hypotheses relating to fatigue during high intensity therapy:

1. Self-reported fatigue will increase from start to the end of each therapy day
2. The magnitude of daily change in self-reported fatigue will increase across the intervention
3. Self-reported fatigue at the start of the day will increase overall across the intervention

**Method:** We will analyse data from the completed COMPARE trial, a three arm randomised control trial of two high intensity interventions for chronic aphasia. Of the 216 participants recruited, 146 were randomised to an intervention arm. Six withdrew *prior* to intervention and thus, data from 140 participants who commenced 30 hours of intervention over two weeks was collected. Participants completed a fatigue scale at the beginning and end of each therapy day. Linear Mixed Models will be used to investigate the impact of intervention time on self-reported fatigue. Withdrawals from intervention will also be examined.

**Results:** The completed analysis of the COMPARE data will provide evidence from a large cohort of people with chronic aphasia (n=140) who were scheduled to receive three hours of treatment per day for ten consecutive business days. Patterns of fatigue over time and withdrawals will be demonstrated.

**Conclusions:** Fatigue is an important consideration

for high intensity intervention and could be a barrier to participation for some people with aphasia. Our analysis provides large scale data on fatigue over time which will inform future therapy design and patient inclusion criteria.

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### **Feasibility, acceptability, and preliminary efficacy of a hub-and-spoke peer-facilitated community aphasia group program**

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**Background and Objectives:** Aphasia is a chronic communication disability negatively impacting relationships, mood, identity, social inclusion, independence, and health. Community support services for people with aphasia and their families are extremely limited. Community aphasia groups (CAGs) are a potentially cost-effective mechanism to support people with aphasia and their families. However, there is an inadequate number of CAGs operating in Australia, currently servicing <1% of the aphasic population, and there are no nationally approved standards or systems to coordinate them. A national program of CAGs could radically improve health, quality of life, reduce carer burden and reduce health care costs. We aimed to investigate the feasibility, acceptability, and preliminary efficacy of a multi-disciplinary hub-and-spoke model of peer-facilitated CAG service provision on quality of life, communication, psychosocial wellbeing, and carer burden.

**Method:** Individuals with and without aphasia (n=6) participated in a CAG facilitation training program tailored to communication disability. Following 2 baseline assessments, participants with aphasia (n=7) and their significant other (n=7) participated in two 12-week community aphasia group programs (2 hrs/week) facilitated by the trained peer with aphasia and a non-aphasic partner. Input from multi-disciplinary staff based in the professional hub was provided on an as-needs basis as requested by group facilitators. Post-program assessments occurred immediately post and at 6-week follow-up for quality of life, depression, anxiety, aphasia severity, multimodal communication, communication confidence, and carer burden.

Group-level pre-post change on outcome measures will be analysed with Wilcoxon signed-rank tests, and individual level changes with Minimal Detectable Change<sub>90</sub> thresholds. Semi-structured in-depth interviews with facilitators, hub staff and group participants will explore perceptions of training, program feasibility, and outcomes, analysed using thematic analysis.

**Results:** The facilitator training program and two 12-week aphasia group programs are complete. All post, follow-up and interview data will be completed by December 2021.

**Conclusions:** This Phase I trial of a novel multi-disciplinary hub-and-spoke peer-led community aphasia group program will provide data on program feasibility, acceptability, and preliminary efficacy. Such data are vital to enable scale-up to a more definitive trial.

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## **SESSION 11**

### **Building skills, connecting, belonging and developing confidence: Qualitative evaluation of a Multi-component Community Connection program (M-ComConnect) for people with severe traumatic brain injury (TBI)**

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**Background and Objectives:** Nearly two thirds of adults with severe TBI have ongoing difficulties developing community connections. M-ComConnect is an individualised intervention with the key objectives of increasing social activity and community integration. It includes individual intervention and group social activity components. We recently evaluated M-ComConnect on three core outcomes (quality of life, wellbeing, community integration). All three measures demonstrated statistically significant change post-intervention with large positive effects maintained at 3 and 6-month follow-up. In this paper we report the results of the qualitative evaluation of the program.

**Method:** M-ComConnect was delivered on 25 occasions over 3 phases. Participants ranged in age from 24-75 years. All had sustained severe TBI (PTA>14 days) and were between 2-36 years postinjury. Post-intervention interviews were transcribed and analysed using thematic analysis (Braun & Clarke, 2009). Core themes were reviewed against the original transcripts to ensure they maintained the voice of participants.

**Results:** Thematic analysis revealed participants' experience of M-ComConnect clustered within 3 domains: i) experience of individual intervention sessions, ii) experience of new social activity and iii) the overall impact on life. Weekly individual intervention sessions led to increased awareness of

skills, limitations and ways to approach them. This developing awareness and skill building occurred for both participants “*good guidance and it felt more like a mentorship*” and support workers who recognised they found “*different approaches on how to deliver something*”. M-ComConnect involved engaging in new activity. Participants’ comments revealed these activities created opportunity for connection “*Feeling connected. Being known by others within the group. That was really rewarding.*” Being socially acknowledged made individuals feel valued, “*I was part of the team, I was the leader so to speak.*” Participants became increasingly confident “*I was recognised as a viable input. I’m used to be sort of head injured and sort of at the last, but with this group I felt to be sort of in a better role, a role of wisdom*”.

**Conclusion:** These results demonstrate that M-ComConnect is a promising intervention to facilitate change in social participation with broader implications for building social connections, confidence and a positive sense of self for people living with the consequences of severe TBI.

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**The development and implementation of the Aboriginal Brain Injury Coordinator service as part of the Healing Right Way randomised control trial**  
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**Background and Objectives:** Acquired brain injury resulting from stroke and traumatic brain injury disproportionately affects Australia’s First Peoples, impacting individuals, families and communities. However, access to rehabilitation services for Aboriginal people is often limited, with very little support following hospital discharge. Aboriginal brain injury survivors and their families have requested a role for Aboriginal health professionals to enable better access to information about brain injury and its impact on daily living, and to support navigation of services after discharge. The Healing Right Way trial (HRW) (NHMRC #1132468) in Western Australia (WA) has created novel Aboriginal

Brain Injury Coordinator (ABIC) roles to enhance cultural security in the rehabilitation journey for Aboriginal people. This paper reports on the development of the role and early implementation.

**Method:** ABICs were employed across eight sites in WA to support Aboriginal brain injury survivors for the first six months post-injury. Activities included liaison, care coordination and linkage, education, and advocacy. ABICs were based in hospitals, Aboriginal Community Controlled Health Services and at the Neurological Council of WA and supported participants in metropolitan, rural and remote locations of WA via face to face and telehealth modalities.

**Results:** Nine ABICs worked with 61 individual participants and their families. Formal evaluation is in progress, however feedback from project partners, participants and the ABICs is positive with success in the role through activities which included care coordination, emotional support and linkage between services and people who were vulnerable to disconnection. ABIC workforce experiences varied; challenges included recognition of the role and staff turnover while facilitators included administrative, personal and cultural support.

**Conclusions:** The implementation of this novel role in a variety of work contexts suggests a way forward to enhance the cultural security of rehabilitation services for Aboriginal people after brain injury. Findings from the HRW study can guide future implementation of such “navigator” roles working to improve the quality of life of Aboriginal people after brain injury.

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**Housing and Support for People with Huntington’s Disease: A scoping review**

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**Background and Objectives:** The Australian Young People in Residential Aged Care (YPIRAC) strategy asserts that no adults under 65 should be living in Residential Aged Care by 2025; however, there is a dearth of alternative options for people with Huntington’s Disease (HD). The aim of this scoping review was to examine the existing literature on effective housing and support models for people with HD internationally.

**Method:** Five major databases (MEDLINE, CINAHL, SCOPUS, PsycINFO and EMBASE) were systematically searched for studies that reported qualitative and/or quantitative findings on housing and support models for people with HD. Key

findings from seven eligible studies provided initial information about housing and support for people with HD.

**Results:** No studies included in the review provided specific data on the effectiveness of housing and support models for people with HD. However, important insights emerged regarding the challenges facing this population in accessing appropriate housing and supports. It was evident from the included studies that finding quality disability and health supports with trained staff was difficult. People with behaviours of concern, poor physical status and psychosocial concerns were more likely to be living in residential aged care than in their own home. The role of supporting caregivers was highlighted as an important consideration.

**Conclusions:** There is limited research on effective housing and support models for people with HD. It is evident that people with HD face unique challenges that need to be identified to establish a best practice framework for housing and support in this population.

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#### **Scoping psychological support pathways for adults with primary brain tumour across Australia: A health professional survey**

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**Background and objectives:** Despite the well-recognized psychosocial impacts of brain tumour, there is limited understanding of the clinical pathways for accessing psychological support in Australia. This study aimed to scope the practices of professionals providing supportive care to adults with primary brain tumour.

**Method:** Health professionals providing supportive care to individuals with primary brain tumour were

recruited from national organisations and state-level cancer support services. They completed an online survey on their demographic and work characteristics, the nature of psychological support provided to adults with brain tumour and family members and perceived barriers or gaps in support.

**Results:** 107 professionals mainly from psychology (42%), nursing (20%), and social work (10%) backgrounds completed the survey. Scope of practice differed according to discipline, with psychologists and nurses most likely to screen for psychological distress (71-76%), whereas psychologists and social workers more typically provided psychological support sessions (78-82%). Psychologists were more likely to screen for cognitive impairment (42%) especially in brain injury or neurosurgery settings, whereas nurses and social workers more commonly provided family-based support (62-73%). Psychological support was more typically provided in the long-term management phase than early post-treatment. Professionals perceived gaps in access to psychological support after initial treatment and identified the need for brain tumour specific training for professionals within psychology/psychiatry.

**Conclusions:** The provision of psychological support for people with brain tumour varies according to discipline, work setting and management phase. There is a need for greater access to psychological support early post-treatment and brain tumour specific training for professionals.

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#### **Support in co-located apartments for people with neurological conditions: Co-design of potential solutions**

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**Background and objectives:** Over the past five years, co-located Specialist Disability Accommodation (SDA) apartments integrated into mainstream residential developments have been pioneered and scaled across Australia. There are over 875 SDA apartments enrolled with the National Disability Insurance Scheme (NDIS). While these apartments are well designed and located to positively impact the quality of life and outcomes of tenants, quality of shared support remains an important consideration. Anecdotal evidence from SDA tenants, SDA providers and support providers suggests that there are a range of approaches and challenges with how support is funded and delivered within these apartments. The aims of this project were to: listen to and document the perspectives of tenants, SDA providers and on-site support (OSS) providers; capture the key challenges; and identify potential solutions to improving the consistency, quality and cost-effectiveness of

disability supports delivered to tenants living in SDA funded apartments.

**Method:** Three co-design workshops and 15 follow-up interviews were conducted with 24 participants including 8 tenants, 8 SDA providers and 8 OSS providers in July-September 2021. All tenants were NDIS participants with neurological conditions and very high support needs. Thematic analysis enabled patterns in the qualitative data to be identified and core themes to be extracted. Summaries of the themes and potential solutions identified by each stakeholder group were provided to participants for feedback and verification.

**Results:** Stakeholders reported that the combination of OSS and 1:1 support delivered in apartments offers tenants cost effective and flexible support and the ability to tailor supports to meet a diverse range of NDIS participant needs and preferences. Stakeholders also agreed that the biggest challenges are getting adequate levels of NDIS funding for housing and support and the inconsistent and limited communication between the NDIS and stakeholders.

**Conclusions:** This project provides a rich evidence base for working with stakeholders to develop a range of potential solutions and resources to address the challenges identified by tenants and providers.

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## SESSION 12

### Practical Recommendations for the Delivery of Language and Psychosocial Interventions in Primary Progressive Aphasia

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#### Synopsis of session:

In this “How to” session, we will present a highly practical series of recommendations and guidelines for implementing 4 types of interventions to assist people living with Primary Progressive Aphasia (PPA). Firstly, we will outline word retrieval interventions, with a specific focus on how to tailor stimuli and practices to enhance maintenance and retention of spoken vocabulary. We will then extend

beyond single word therapies to provide practical strategies and tips to support the implementation of the NARNIA intervention – a discourse intervention to help people with PPA organise and structure their everyday communication (e.g. to give opinions, share personal stories, recount recent events). To address motor speech difficulties which affect the intelligibility of speech and its fluent and rhythmic properties, we will summarise the available evidence regarding approaches for apraxia of speech., discuss principles governing how the motor system (re)learns speech skills, and how therapeutic practice can be structured to optimise this learning and sustain function for as long as possible. Lastly, we will discuss education and support programs which aim to improve quality of life in people living with PPA. Here, we will consider practical advice when providing these programs, both for individuals and for groups, and discuss the differing impacts of the three clinical phenotypes, at various levels of progression. We will address issues regarding service delivery in private and public health settings, supporting caregivers and the development of national education and support resources.

**Level aimed for:** Intermediate

#### Learning objectives:

- Understand how to deliver different therapeutic approaches to people living with the 3 main forms of PPA
- Identify resources to help package communication interventions for people with PPA
- Reflect on challenges to measuring intervention outcomes
- Recognise the importance of tailoring materials to the individual to maximise maintenance and generalisation

#### Biography:

Dr Sharon Savage is a Clinical Neuropsychologist and Lecturer in the School of Psychological Sciences, at the University of Newcastle. Her research focuses on ageing, dementia and cognitive rehabilitation, with a particular interest in the semantic variant of PPA.

Dr Aida Suarez-Gonzalez is a Clinical Neuropsychologist and Senior Researcher in the Dementia Research Centre at University College London (UK). Her research focuses on the diagnosis and neuropsychological treatment and support of people living with PPA, posterior cortical atrophy and behavioural variant frontotemporal dementia. She has led the first set of evidence-led recommendations for the clinical management of semantic variant PPA. Aida holds a UKRI Healthy Ageing Catalyst Award to support the international launch of a multilingual assistive e-reader for people with peripheral alexia.

Dr Jade Cartwright is a speech pathologist and researcher, committed to optimising communication, participation, and quality of life in

people living with PPA and dementia. Jade's research focuses on the design, evaluation, and translation of evidence-based communication and psychosocial interventions into clinical practice. Jade was awarded a 2019 Dementia Australia Research Foundation Pilot Grant to evaluate the outcomes of a highly novel discourse intervention for people with PPA that moves beyond the word level to target everyday communication. Kirrie Ballard (PhD Northwestern University USA; CCC-SLP, CPSP) is Professor of Speech Motor Control and Disorders at University of Sydney. Her research focuses on nature, diagnosis and treatment of apraxia of speech (AOS) in adults and children, and aphasia in stroke and atypical dementias. She was the first to publish on application of motor learning principles to AOS and has twice chaired the international writing committee on evidence-based guidelines for treatment of AOS. She was Editor-in-Chief for International Journal of Speech-Language Pathology 2014-2019 and is a Fellow of Speech Pathology Australia.

Dr Cathleen Taylor-Rubin is a Speech Pathologist who's clinical and research work focuses on effective behavioural interventions for improving and maintaining communication for individuals with PPA and their families and caregivers. Cathy leads a specialist clinic at Uniting War Memorial Hospital in Sydney, which provides assessment, treatment, education and support for people with PPA across NSW.

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## SESSION 13

### Is word learning enough? Exploring the effects of verb and noun treatment on connected speech production

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**Background and Objectives:** Lexical retrieval impairment is a pervasive and distressing feature of both stroke-induced and progressive aphasia impacting on successful communication. Clinicians, people with aphasia and their families identify improvement in daily communication as an essential treatment outcome. While treatment has been demonstrated to improve lexical retrieval of treated items, evidence of generalisation to connected speech is scarce. In this study we aimed to determine whether, in people with primary progressive aphasia (PPA), when improvements in lexical retrieval are evidenced by improved single word noun and verb picture confrontation naming, these same lexical items can be produced in a verb phrase; a basic unit of connected speech.

**Method:** We systematically examined changes in verb phrase production following lexical retrieval treatment in a series of single case experimental design studies. Four individuals with PPA (three semantic variant, one logopenic variant) undertook a sequence of verb and noun lexical retrieval treatments using Repetition and Reading in the Presence of a Picture. We analysed the effects of treatment on verb naming, noun naming and verb phrase production using Weighted Statistics.

**Results:** Production of treated nouns- and/or verbs- in-isolation significantly improved following treatment for three of the four participants. Verb phrase production did not improve for one participant (logopenic PPA), perhaps due to the relatively small treatment dose. Two participants (semantic variant PPA) did however, demonstrate generalisation, with improvement in treated verbs and also in their use of those verbs in (untreated) verb phrases. For these two participants, verb phrase production improved most after lexical retrieval treatment had been completed for both nouns and verbs.

**Conclusions:** Lexical retrieval treatment offers people with PPA opportunity to regain personally relevant vocabulary items, but the full benefit of treatment can only be realized if those successfully treated vocabulary items can be used in everyday speech. In this study, we demonstrated that a combined approach of lexical retrieval treatment of both verbs and nouns, can result in beneficial generalisation to verb phrase, benefitting production of connected speech for some individuals with semantic variant PPA.

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### NDIS speak up: Speech Pathologists perspectives' on provision of NDIS services to people with an acquired brain injury

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**Background and objectives:** The National Disability Insurance Scheme (NDIS) has altered the landscape of funding and service delivery for people with an Acquired Brain Injury (ABI). Speech Pathologists facilitate access to long-term and person-centred funding and supports for people with ABI. However, navigating the NDIS is reportedly highly complex, and experiences and support needs of speech pathologists are largely unknown. We aimed to understand perspectives and experiences of speech pathologists providing NDIS services for people with ABI to develop critical support resources.

**Method:** Design: A phenomenological qualitative focus group study. Participants: 16 Speech Pathologists with 6+ months clinical experience delivering NDIS-based services to clients with ABI. Participants worked in both public and private

sector rehabilitation services (mean 11 years post-graduate experience) and provided informed consent. Procedure: Three focus groups and three interviews (due to availability) were conducted online covering NDIS-related experiences, barriers/facilitators and training needs. Analysis: Video-recorded data was transcribed and analysed using reflexive thematic analysis. Rigour: Design/reporting followed COREQ guidelines for qualitative research.

**Results:** The first focus group highlighted that *the NDIS is a crucial system for supporting people with ABI with increased access to support and community accommodation. Key facilitators included (i) Respectful Communication between NDIS members (e.g., planners, support coordinators, client and family) and (ii) Speaking the NDIS language in reports and plans. However, overall the NDIS system is very challenging to navigate, with uncertainty on allocating numbers of hours and dollars of funding per person and changing administrative requirements. The complex nature of ABI contributed to further challenges due to frequent comorbidities and insight difficulties, compounded when clients and referrers could not access specialist clinicians with ABI experience. Training specific to ABI and the NDIS is needed to meet these challenges. All data has been collected and finalised themes from the remaining data will be shared at the conference.*

**Conclusion:** Benefits of the NDIS for people with ABI were balanced with many challenges navigating a complex system for individuals who present with complex health conditions. Future training supports specific to ABI and the NDIS are required to address these needs.

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### **Beyond Primary Progressive Aphasia: A Scoping Review of Spoken Language Impairments in Other Neurodegenerative Dementias**

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**Background and Objectives:** While awareness has grown over the last 40 years regarding Primary Progressive Aphasia (PPA) and the debilitating language impairments that may arise in such conditions, it is important to note that progressive language difficulties are not unique to PPA. The aim of this scoping review was to identify the range, severity, and impact of spoken language difficulties

in 8 other forms of dementia, and to critique the research evidence on current language interventions in these conditions.

**Method:** A search was conducted on the following databases: PubMed, MEDLINE, OVID-EMBASE, PsycINFO and SpeechBITE. Dementia types included Parkinson's disease dementia, dementia with Lewy bodies, Progressive supranuclear palsy, Corticobasal syndrome, behaviour variant frontotemporal dementia, early-onset Alzheimer's disease, posterior cortical atrophy and motor neuron disease associated with FTD. Both the QualSyst tool and the PEDro-P scale were used to assess methodological rigor of studies

**Results:** The search revealed 73 eligible studies, of which 64% were rated as good quality according to QualSyst criteria. A range of expressive and receptive language impairments were identified, although only in certain cases was a full aphasic syndrome described. Little information was provided regarding severity. Surprisingly, no papers described the impact of these language impairments on everyday living or presented data regarding language therapies to treat them.

**Conclusions:** There is a need to conduct studies which assess the impact of spoken language impairments on activities of daily living and quality of life for people living with non-language led dementias. The underlying mechanisms (both linguistic and cognitive) should be identified in order to inform effect interventions. Trials of language therapy are then required to support evidence-based treatment for these people.

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### **Preliminary efficacy and feasibility of a counselling education program on speech pathologists' self-efficacy and self-rated competency for counselling in post-stroke aphasia**

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**Background and Objectives:** People affected by post-stroke aphasia experience a range of psychological issues. Speech pathologists have a role in supporting psychological wellbeing but identify that providing counselling to patients and carers is a challenge in aphasia rehabilitation. A literature review identified content, duration, format, and evaluation for an education module that may be effective in improving speech pathologists' knowledge, skills, and confidence in counselling to support psychological wellbeing in post-stroke

aphasia. We aimed to evaluate the preliminary efficacy and feasibility of an online counselling education program delivered over 5 weeks and comprising of 7 hours of self-directed learning via a university Learning Management System and a 3-hour online workshop facilitated by a speech pathologist via Zoom.

**Method:** A two arm pilot randomised controlled trial with a waitlist control condition investigated changes in self-efficacy and self-reported competency for counselling in post-stroke aphasia. Feasibility outcomes included rate of recruitment, workshop attendance, and participant attrition at follow-up. Fifty-two speech pathologists working in post-stroke aphasia were recruited via community, clinical and professional data bases in Australia. After enrolment, 49 participants were randomised and stratified by previous counselling training of more than 1 day, and co-work with psychologists when addressing psychological wellbeing in post-stroke aphasia. Participants were assessed pre-, post program (primary endpoint) and at 5-week follow-up.

**Results:** Statistically significant improvements were seen in speech pathologists' self-efficacy ( $F(1,44) = 23.388, p = .0005, \text{partial } \eta^2 = .347$ ) and self-rated competency for counselling ( $F(1,44) = 24.12, p = .0005, \text{partial } \eta^2 = .354$ ) at post-education compared to wait list control. Effects were maintained at 5-week follow-up. Higher than expected recruitment targets were achieved within 1 month of advertising. There was high attendance to the online workshops ( $n=46$ ) and a low attrition rate with 41 participants completing follow-up measures.

**Conclusions:** This online counselling program improved speech pathologists' self-efficacy and self-rated competency for counselling in post-stroke aphasia. Strong interest, and engagement in this study suggests preliminary feasibility and warrants a definitive trial and possible translation of this program into practice.

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## SESSION 14

**'How to' consider the use of technology for executive function support after acquired brain injury (ABI): Development and testing new information and education resources for people with ABI, their families and clinicians working with them**

Callaway, Libby<sup>1,2</sup>; Simpson, Grahame<sup>3,4,5</sup>; Bould, Em<sup>1</sup>; Licciardi, Lisa<sup>1</sup>; Hurst, Jade<sup>6</sup> and Scott, Jacqueline<sup>7</sup>

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<sup>6</sup>Research and Evaluation Team, Strategy Sectors & Research Division, Transport Accident Commission (TAC), Geelong, Australia

<sup>7</sup>Lifetime Care, icare New South Wales (NSW), Sydney, Australia

### Session Synopsis:

Mainstream and assistive technologies offer opportunity to change the way support is delivered to people with acquired brain injury (ABI). Smart home, wearable and mobile technologies, and associated mobile applications, can offer varied approaches to compensate for executive dysfunction. However, tools to guide consideration and selection of technology for compensatory cognitive support are lacking for both people who may use this technology, and people who advise on its use.

This 'How To' session will present a draft set of information and education resources for evaluating technologies which may be used to compensate for executive dysfunction following ABI. Varied resources have been designed for two audiences: people with ABI and their families and clinicians working with them. Workshop attendees will explore the use of the resources via a case scenario (contributed by our team's lived experience collaborators) to evaluate and consider features of technology that can be customised to a user's goals and support needs. There will be an opportunity to provide structured feedback about the utility of these resources, based on this applied experience.

**Level aimed for:** Basic to Intermediate

### Learning objectives:

At the end of this session, participants will have:

1. Gained a greater understanding of the good practice steps, assessment tools and processes that underpin a clinician's role in advising on assistive technology;
2. Learned about a new set of technology information resources developed by a research team in collaboration with people with lived experience of ABI; health professionals; researchers and social and injury insurers;
3. Been offered an opportunity to test the resources being developed, using a case scenario contributed by lived experience collaborators;
4. Contributed feedback which will further inform the resource design and utility for both people with ABI and their families, as well as people who advise them on technologies used for

executive function support.

#### **Biography:**

Libby, Grahame, Em and Lisa have extensive interdisciplinary experience in disability and rehabilitation research and/or clinical practice across Victoria and NSW. Jade and Jacqueline bring injury insurer expertise from the TAC (Victoria) and icare (NSW). The group is working together on a multi-year research project evaluating smart home, wearable and mobile technologies for cognitive support following ABI.

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### **SESSION 15**

#### **What person-centred care really means for service provision**

Smith, Kylie<sup>1</sup> and Minett, Trudy<sup>1</sup>

<sup>1</sup>Lifetime Support Authority, South Australia, Australia

#### **Synopsis of session:**

Busting the myth that being person-centred is the same as being nice or providing good customer service. Person-centred care is about knowing and understanding a person's hopes, dreams and aspirations, and establishing a relationship that acknowledges and takes account of the uniqueness of that person.

Service provision that effectively utilises person-centred care will:

- Support the person to reach their own level of maximum independence and transition to the community
- Minimise long term over-dependence on service provision
- Optimise health and wellbeing outcomes.

**Level aimed for:** Intermediate

#### **Learning objectives:**

- Explain how a person-centred care approach in service provision contributes to better health and wellbeing outcomes.
- Recognise service provision behaviour that characterises a person-centred care approach

#### **Biography:**

Trudy Minett is the Director Services at the Lifetime Support Authority in South Australia. She is a strategic leader with a focus on strategic leadership, execution and engagement. Trudy has significant experience in personal injury insurance across a diverse range of business functions – strategic and operational management; strategic and operational planning and tactical implementation; support, advice and reporting at Board and Finance/Audit Board Committee level, engagement of stakeholders

and staff in leading transformation and change management projects; and considerable experience in designing, implementing and managing organisational frameworks.

Kylie Smith is the Senior Manager - Service Planning at the Lifetime Support Authority. She has a lifetime of experience in disability, having seen first-hand the contribution people with disability make to the community. Kylie is a dedicated leader and clinician who builds enthusiastic and resourceful teams with a shared purpose. She has a strong track record in developing systems that empower people with a disability to achieve positive outcomes and continues this work at the Lifetime Support Authority.

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### **POSTERS**

#### **An online multimodal intervention for people with brain injury and their communication partners to improve their conversation skills together: a proof-of-concept study**

Avramovic, Petra<sup>1</sup>; Rietdijk, Rachael<sup>1</sup>; Attard, Michelle<sup>1</sup>; Kenny, Belinda<sup>2</sup>; Power, Emma<sup>3</sup>; Lim, Renee<sup>1</sup>; Rushworth, Nick<sup>4</sup>; MacLean, Liza<sup>5</sup> and Togher, Leanne<sup>1</sup>

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**Background and Objectives:** People with traumatic brain injury (TBI) experience communication breakdown in everyday interactions many years after injury. Access to long term services is essential, however it is especially limited in rural locations<sup>1</sup>. Digital health can overcome the challenges of travel, improve cost efficiencies, and improve outcomes<sup>2</sup>. Convers-ABI-lity is a novel multimodal intervention adapted from previous evidence-based programs, TBI Express<sup>3</sup> and TBIconneCT<sup>4</sup>, and has been developed using co-design. The aim of this research was to investigate feasibility of using convers-ABI-lity to improve conversations between people with TBI and their communication partners (CP).

**Method:** This proof-of-concept study included three dyads as participants, consisting of a person with severe TBI and a usual CP. Participants completed convers-ABI-lity, an 8-week conversation skills intervention program consisting of weekly videoconference sessions with a clinician and self-guided online modules. Outcome measures included pre-, post- and follow-up blinded ratings of casual and purposeful conversation samples using the Adapted Kagan Scales<sup>5</sup> and self-report measures

such as the La Trobe Communication Questionnaire<sup>6</sup>. The Adapted Kagan Scales are 9-point rating scales (ranging from 0 to 4) for two core areas (Interaction and Transaction for people with TBI; Acknowledging and Revealing Competence for CPs). An improvement of 0.5 was considered a clinically significant change. Feedback from participants about their experience with the program was analysed qualitatively.

**Results:** In casual conversation, one participant with TBI improved at post training for Transaction and all participants improved at follow up for Interaction. At follow-up, two CPs improved in Acknowledging Competence (AC) and all three improved on Revealing Competence (RC). On purposeful conversation, two participants with TBI improved in both Interaction and Transaction by at least 1.0 at follow up. One CP improved in AC and RC post intervention, and by follow up all CPs improved in these measures. Qualitative feedback indicated the training was positively received. Participants recommended the length of program be extended to provide opportunity for revision of key concepts.

**Conclusion:** convers-ABI-lity may increase accessibility to specialist communication training for people with TBI and their carers. This proof-of-concept study is the foundation of planning a study with a larger participant sample.

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### **Effectiveness of non-pharmacological interventions for agitation during post-traumatic amnesia following traumatic brain injury: A systematic review**

Carrier, Sarah L.<sup>1,2</sup>; Ponsford, Jennie<sup>1,2,3</sup>; Phyland, Ruby K.<sup>1,2</sup>; Hicks, Amelia J.<sup>1,2</sup> and McKay, Adam<sup>1,2,3</sup>

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**Background and Objectives:** Agitation is frequently observed in the early recovery period following traumatic brain injury (TBI), known as post-traumatic amnesia (PTA). Non-pharmacological interventions are commonly used to manage agitation, yet their efficacy is largely unknown. The aim of this systematic review was to synthesise current evidence on the effectiveness of non-pharmacological interventions for agitation during PTA in adults with TBI.

**Method:** Key databases searched included MEDLINE Ovid SP interface, PubMed, CINAHL, Excerpta Medica Database, PsycINFO and CENTRAL, with additional online reviewing of key journals and clinical trial registries to identify published or unpublished studies up to May 2020. Eligible studies

included participants aged 16 years and older, showing agitated behaviours during PTA. Any non-pharmacological interventions for reducing agitation were considered, with any comparator accepted. Eligible studies were critically appraised for methodological quality using Joanna Briggs Institute Critical Appraisal Instruments and findings were reported in narrative form.

**Results:** Twelve studies were included in the review: two randomised cross-over trials, three quasi-experimental studies, four cases series and three case reports. Non-pharmacological interventions included music therapy, behavioural and environmental strategies (such as antecedent modification and contingency management), physical restraints and electroconvulsive therapy. Key methodological concerns included absence of a control group, a lack of formalised agitation measurement and inconsistent concomitant use of pharmacology. Interventions involving music therapy had the highest level of evidence, although study quality was generally moderate to low.

**Conclusions:** Overall, there was a lack of evidence for the effectiveness of any non-pharmacological interventions for managing agitation during the PTA period after TBI. Randomised controlled trials with inclusion of a control group and use of a formal measurement tool for assessing agitation are a critical next step in developing suitable recommendations for the effective non-pharmacological management of agitation after TBI.

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### **One Size Does Not Fit All: A qualitative investigation into the housing needs and preferences of people with Huntington's Disease**

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**Background and Objectives:** Huntington's disease (HD) results in progressive cognitive, physical and psychiatric symptoms, eventually resulting in a prolonged palliative stage and death. Due to the complex interplay of these symptoms, housing and support needs of people with HD change as the disease progresses, often resulting in admission to residential aged care. It remains unclear which housing and support models are effective for people with HD to be able to be supported for their whole lives in the community. The aim of this research was to explore professional and caregiver perspectives on the housing and support needs of people with HD.

**Method:** Qualitative interviews were conducted with 21 professionals internationally who had

expertise in housing and support for people with HD and 11 caregivers of people with HD. Semi-structured interview questions focused on the housing and support models that exist for people with HD in the country they were based, evidence of their effectiveness and opportunities to further improve housing and support.

**Results:** Five overarching themes emerged: 1) *The dynamic and fast changing course of HD*; 2) *Family dynamics* in the context of a hereditary genetic disease; 3) *Access to housing and support* in an environment of very limited options; 4) *Needs and considerations* for complex physical, cognitive and behavioural symptoms; and 5) *Types of housing and support models* that exist internationally. It was evident that no “one size fits all” approach would meet the needs of this heterogeneous population.

**Conclusions:** People with HD require a responsive and flexible system of funding to remain living at home or in specialist housing that matches physical and behavioural needs. Disability, Allied Health, and nursing supports underpinned by expertise in HD are crucial for sustainable disability support and the ability for informal caregivers to maintain their role.

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### **The impact of physical activity on social cognition, cognition and mood following TBI: A randomised controlled trial protocol**

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**Background and Objectives:** Difficulties with various aspects of social cognition following traumatic brain injury (TBI) are well documented. The rapidly expanding focus on social cognition presents an opportunity to explore holistic integrative approaches in rehabilitation. This study aims to explore the impact of a physical activity program on heart rate variability and social cognition for people with TBI. It is known that limited participation in physical activity (PA) puts people with TBI at a significant health risk but increasing PA in this population positively impacts physical health, mood, and cognition. Thus, it is hypothesised that the same improvement can be attained for social cognition. Studies with people without TBI have actually reported a connection between heart rate variability and facial emotion perception, supporting this hypothesis.

**Method:** 20 adults with moderate to severe TBI will be recruited for this randomised controlled trial. Participants are eligible if they are currently engaging in less than 90 minutes of physical activity per week. Participants individually complete a 12-week exercise program, supervised by an accredited exercise physiologist. Pre- and post- intervention measurements will include objective data from the accelerometer, self-report questionnaires

measuring mood and social participation, and researcher-administered assessments to investigate the impact of the exercise program on social cognition, cognition, executive functioning and general physical health (including heart rate variability).

**Results:** This protocol is currently being implemented. The links between social cognition, cognition, mood and physical activity (including heart rate variability) will be discussed. An overview of the protocol will be presented, including rationale, methods, and challenges faced in implementing the protocol to date.

**Conclusion:** This innovative protocol has the potential to improve social cognition, cognition and mood alongside physical health, offering a prospective holistic approach to rehabilitation for people with TBI.

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### **The relationship between aggression and social disinhibition following severe TBI**

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**Background and Objectives:** Both aggression and social disinhibition are common following severe traumatic brain injury (TBI), with similar prevalence rates. While both are linked to damage of the frontal lobes, it is not known whether they represent the same underlying construct and they are usually studied separately. Furthermore, aggression following TBI has been studied extensively and various treatment programs have been trialled whereas research evidence about social disinhibition is limited. Establishing the association between aggression and social disinhibition would facilitate a better conceptualization of these disorders. The aim of the current study was to determine whether social disinhibition and aggression co-occur and correlate in a sample of people with severe TBI.

**Methods:** The Buss-Perry Aggression Questionnaire (BPAQ), Frontal Systems Behavior Scale (FrSBe), and an observational measure of social disinhibition (Social Disinhibition Interview - SDI) were completed by 25 individuals with severe TBI and 25 healthy control participants.

**Results:** In the TBI group, higher levels of observed social disinhibition were associated with higher levels of anger, as measured by BPAQ. No significant correlations were found between FrSBe (informant-report) and any of the BPAQ subscales, or BPAQ total score in the TBI group. In the control group, no significant correlations were found between SDI score and any of the BPAQ subscales, or BPAQ total score. Higher self-reported disinhibition (FrSBe) was associated with higher rates of physical aggression, anger and total score on the BPAQ.

**Conclusion:** These results suggest that people with TBI who are socially disinhibited might also experience unregulated anger (the emotional component of aggression). This might not necessarily translate into aggression towards other people, as it appears to do in healthy individuals without brain injury. One possible reason may be that another frequent sequela of brain injury, i.e. apathy may reduce motivation towards aggressive behaviour.

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### **The potential benefits of narrative and creative arts approach during the transition phase for Aboriginal and Torres Strait Islander Australians following traumatic brain injury**

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#### **Abstract**

**Background and Objectives:** Narrative and creative arts approaches are being used to improve recovery after Traumatic Brain Injury (TBI). Narrative and arts-based approaches are congruent with Indigenous storytelling may therefore provide benefit during the transition from hospital to home for some Indigenous TBI patients. This study explored the use and impact of this approach as part of a study of TBI transition with Indigenous Australians.

**Method:** A combined narrative and arts-based approach was used with one Indigenous Australian artist to describe his transition experiences following TBI. Together with the researchers and filmmaking team, the artist was involved all aspects of the process. The artist contributed two paintings, detailing his story of his life and TBI. Based on the artworks, a film was created. Following the viewing of the film, impacts of the narrative and arts-based process were examined through semi-structured interviews with the artist, a service provider, and a family member.

**Results:** Positive impacts from the process for the artist included: positive challenge; healing and identity; understanding TBI and raising awareness.

**Conclusion:** A creative arts approach may enable the individual to take ownership over their transition story and to make sense of their life pre-

and post-TBI, at a critical point in their recovery. A combined narrative and arts-based approach has potential as a rehabilitation tool for use with Indigenous Australians during the transition period following TBI.

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### **The experience of spousal relationships from the perspective of people with aphasia: Results from cross sectional and longitudinal interviews**

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**Background and Objectives:** Psychosocial difficulties are among the most pervasive and challenging issues for people following stroke and aphasia. Relationships are frequently impacted and in particular the spousal relationship is subject to challenges and changes. This presentation aims to present the experiences of people with aphasia around their spousal relationships using both cross sectional retrospective reports and longitudinal data gathered from participants.

**Method:** This presentation is part of a larger study which investigates the experience of a range of relationship types following aphasia. Two groups of participants were recruited and interviewed. The first group comprised ten adults who were recruited from community aphasia groups and who ranged from five months to nine years post onset. These participants were interviewed on two occasions and were asked to relate their experiences. The second group comprised seven participants who were recruited from inpatient rehabilitation units and who were interviewed on four occasions beginning around the time of their discharge home.

Researchers adopted a constructivist grounded theory approach and data were transcribed and coded and then analysed using a constant comparative method. Analysis is ongoing.

**Results:** Spousal relationships are subject to a range of changes following the onset of aphasia. Spouses deal with significant alterations to life goals, an increase in conflict and vastly changed roles. Spouses are an important source of support and the need for support is acknowledged for both partners. In relation to supporting communication it is important that support is balanced with allowing independence and self-expression for the person with aphasia.

**Conclusions:** Spouses relationships are often central and supportive following the onset of aphasia but are also subject to changes and challenges. These findings have clear practice implications for facilitating more positive relationships for people with aphasia.

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**Assessing the impact of NeuroBITE for clinicians, researchers, and decision-makers**

Gertler, Paul<sup>1</sup>; Doubleday, Janet<sup>1</sup>; Filipcikova, Michaela<sup>1</sup>; Taylor, Christine<sup>2</sup> and Tate, Robyn<sup>1</sup> on behalf of the NeuroBITE board

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**Background and Objectives:** The NeuroBITE resource was established as the PsycBITE evidence database in 2004 with the aim of being the “go-to” source for studies of cognitive, behavioural, and other treatments for psychological problems and issues occurring as a consequence of acquired brain impairment (ABI). Since then, there has been a proliferation of research and the database now holds almost 7,000 studies that have been identified for their relevance to neurorehabilitation.

Randomised controlled trials and single-case experimental design studies are rated for methodological quality. The authors sought to establish who was using the resource, why they were using it and to evaluate the user experience, with the aim to assess the real-world impact of NeuroBITE.

**Method:** An online survey was created by the board of NeuroBITE and was distributed via professional networks, including at an ASSBI national conference.

**Results:** Sixty-seven respondents completed the survey, of whom 29.9% were first-time users of NeuroBITE. The most common workplaces of respondents were hospitals (40.9%) and universities (39.4%). Almost 45% were seeking articles for research projects and 38.8% were seeking ideas for interventions. The three most common disciplines were psychology (40.4%), physiotherapy (32.7%) and occupational therapy (19.2%). Most respondents were working frequently with ABI patients and 75.4% were from Australia. Almost all respondents rated the website and search function positively on ease of use, however only a small proportion gave the highest ratings on usability. In relation to the signature features of NeuroBITE, most users found ratings of the methodological rigour of studies and the rehabilitation summaries useful. Most thought that adding practice guidelines would be useful.

**Conclusions:** Evaluation of NeuroBITE by a user survey found that the current audience are largely researchers and clinicians who are well-versed in ABI who go to NeuroBITE to help identify studies to assist with research and clinical practice. The key features (method quality ratings and rehabilitation summaries) were found to be useful. The survey suggested several avenues for development of NeuroBITE. A major recommendation was to include practice guidelines, thereby increasing the capacity

of clinicians who have less familiarity with ABI. There are now 42 practice guidelines on the database.

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**Speech language therapists’ perceptions of working with people with aphasia and co-occurring cognitive impairment.**

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**Background and Objectives:** Communication and cognitive impairment are often areas of need within a stroke population, both in terms of research and clinical practice, and an evidence-practice gap has been identified for both people with aphasia and those with specific cognitive impairments. This study is part of a bigger doctoral research project investigating the evidence-practice gap from the perspectives of both people with aphasia and SLTs. This presentation will provide participants responses to questions regarding working with people with aphasia and co-occurring cognitive impairment.

**Method:** A questionnaire was distributed through social media networks to SLTs across the world. The questions included a range of demographic questions, multiple choice, and open questions.

**Results:** The majority of respondents were evenly split between those working in New Zealand (n=43), Australia (n=44) and USA (n=44). In response to the question of how SLTs approach the overlap between aphasia and cognitive impairment, the most frequent responses were to liaise with MDT members and to focus on functional tasks. In response to the question of who does cognitive rehabilitation for people with aphasia, 66% reported that the SLT would do this, 35% reported occupational therapy, 15% reported neuropsychology and 6% reported that no one would do cognitive rehabilitation for people with aphasia. Respondents reported that it would make a difference if the cognitive impairment was pre-existing or occurred at the same time as the aphasia, with the most frequent responses were that it would affect the person’s ability to improve, it would affect how interventions were tailored to that person, and it would affect the clinical decisions around taking a rehabilitation or compensatory approach to therapy interventions post-stroke.

**Conclusions:** This study shows that SLTs perceptions of rehabilitation for people with aphasia and co-occurring cognitive impairment vary widely, and that whether that person had pre-existing cognitive impairment may have a significant impact on the rehabilitation that they receive, including a small number of people with aphasia who may not

receive any cognitive rehabilitation at all. This study is small but may provide useful information for those looking at the rehabilitation provided to people with aphasia, and the evidence-practice gap.

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### **Targeting aspects of everyday communication in therapy: a systematic review of co-constructed communication**

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**Background and Objectives:** Successful, meaningful conversation is an important therapy target for adults with acquired brain injury (ABI), due to its importance for social reintegration. Conversation is a multifaceted social activity, often reduced to component parts in therapy protocols; that is, interventions typically target conversation via linguistic skills (via word and sentence level tasks), or as a whole (via connected speech tasks). However, both approaches have limitations: neither capture the complexity of conversation and there is limited evidence supporting treatment generalisation. An alternative option is for intervention to target conversation in replicable, experimental tasks, where an adult with ABI and their communication partner jointly-construct meaning. This is termed 'co-constructed communication'. While such interventions exist, they are variably labelled, target different ABI populations, and have not been synthesised in the literature. This systematic review aimed to identify the nature, scope and effects of intervention studies targeting co-constructed communication in adults with ABI.

**Method:** This systematic review was completed using the PRISMA Guidelines. Six databases (MEDLINE, Embase, CINAHL, Scopus, LLBA, PsychInfo) were searched. After duplicates were removed, 1210 studies were screened (25% screened by a second rater), and 11 met inclusion criteria. Data was extracted and methodological quality was rated using the PEDro-P, ROBINT and JBI Critical Appraisal tools, and treatment reporting was described using the TIDiER checklist.

**Results:** The 11 eligible studies cluster into three sub-categories, based on the specific nature of the intervention: 'language-action games', 'retell and recount therapies', and 'communication training programs'. Quality assessment revealed 3 non-RCTs scored moderately well, 4 single-case designs scored from high-low, and 2 case series and case reports scored moderately well. Most studies were identified as being reported moderately well. Further data will be presented on treatment outcomes.

**Conclusions:** Co-constructed communication interventions may offer clinicians a feasible, replicable way to target aspects of everyday communication. These interventions may be effective for improving conversational outcomes for adults with ABI, however more high-quality research is needed to strengthen this currently limited evidence base.

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### **The Flynn effect in estimates of premorbid intellectual functioning in an Australian sample**

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**Background and objectives:** While the Flynn effect is a well-recognised phenomenon impacting tests of cognitive ability, little research has been conducted into its relevance for tests of premorbid ability. This study aimed to investigate whether estimated FSIQ scores from four commonly used word reading tasks (the NART, NART2, WTAR, and TOPF) were influenced by the Flynn effect.

**Method:** We administered the NART, WTAR, and TOPF to 120 healthy community-dwelling adults. Using these raw scores, we calculated estimated FSIQ scores using the predictive models published in the relevant manuals and compared these with scores obtained on the Wechsler Abbreviated Scale of Intelligence (WASI-II).

**Results:** We found a linear increase in estimated FSIQ, with the oldest reading task, the NART (1981), returning the highest scores and the most recent, the TOPF (2011), the lowest. The NART, WTAR US, and TOPF US overestimated intellectual ability compared with current intellectual functioning measured by the WASI-II.

**Conclusions:** Our findings indicated tests of premorbid functioning appear to be subject to the Flynn effect, and clinicians should exercise caution in using older word reading tasks such as the NART. Our results support the need for Australian standardisations of these instruments.

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### **Cognitive Testing Accuracy can be Impeded by Vision Loss**

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**Background and Objectives:** Assessing cognition is an important part of the diagnosis and management of disorders affecting the brain. However, comorbid conditions in older adults, such as visual impairments, may impact cognitive test performance such that lower test scores may be caused by difficulties seeing the task material. We conducted an experiment to explore the impact of macular degeneration on cognitive testing.

**Method:** Twenty-four normally sighted participants (aged 18–60) completed two cognitive tasks: a vision-dependent reaction time task and vision-independent verbal fluency test. Each task was administered twice, under normal and simulated vision conditions. Macular degeneration was simulated with a ten-degree central scotoma in a set of 6/60 visual acuity goggles.

**Results:** Repeated measures ANOVAs revealed significantly slower responses ( $p < 0.001$ ,  $\eta^2 = 0.14$ ), by up to 25 percentile ranks, for the reaction time task in the simulated macular degeneration condition, compared with normal vision. There was no significant difference ( $p = 0.78$ ) between conditions for the verbal fluency test.

**Conclusions:** Our findings, that simulated visual impairment negatively affects performance in a vision-dependent cognitive test, but not the vision-independent test, corroborates previous paper-and-pencil studies. The findings suggest that low test scores, obtained in tests where sight is essential to the task should be interpreted with caution, as the scores may only partly reflect cognitive impairments. Unless precautionary measures are taken to account for individual differences in vision (e.g., vision screening prior to cognitive assessments), inaccurate test scores could contribute towards the misdiagnosis of conditions such as mild cognitive impairment.

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### **Implementing and evaluating a cognitive rehabilitation group with clients following Acquired Brain Injury (ABI) and its impact on everyday living skills, at a community based residential staged- rehabilitation service in Perth, WA**

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**Background and Objectives:** Evidence suggests that a combination of education, remedial and functional approaches to cognitive rehabilitation results in the greatest improvement for clients following ABI. Additionally, delivery in a group setting has been

demonstrated to develop greater insight and awareness of cognitive difficulties.

The aim was to implement an effective cognitive rehabilitation group encompassing education, remedial and compensatory cognitive strategies, provide opportunity to discuss lived experiences to develop participant's insight and awareness and to assess the benefits of the group and the translation into everyday living skills.

**Method:** The group was delivered to six clients who resided in the moderate care stage of the rehabilitation service and experienced difficulties in primary cognitive domains. The group was conducted twice weekly for a ten week period, facilitated under a multidisciplinary model by two Occupational Therapists and a Speech Pathologist. Data was collected from clients by the group facilitators pre and post intervention using The Addenbrooke's Cognitive Examination Revised (ACE-R) 2006 and the Awareness questionnaire (1998). In addition, qualitative surveys were completed by the client's and their treating allied health team post intervention. The survey included information regarding client's level of independence in everyday living tasks and implementation of learnt compensatory strategies.

**Results:** All participants reported the group resulted in greater acceptance of their ABI, a more positive outlook on cognitive rehabilitation and increased confidence completing daily tasks with high cognitive demands. Treating therapists reported an increased willingness to accept and implement cognitive strategies and more realistic goal setting following the group.

The awareness questionnaire reflected increased insight and awareness for all participants post intervention.

Participants achieved improvements in attention and memory on formal assessment with post intervention scores falling into normative data ranges. The mean ACE-R attention pre and post intervention scores were 14.6 /18 and 16.8 /18 respectively and pre and post intervention memory scores were 18.8 /26 and 22.4/26 respectively. 12-months post intervention the ACE-R mean attention and memory scores were 16.6 /18 and 22.4/26.

**Conclusion:** Engaging in cognitive rehabilitation in a group setting resulted in improved cognitive outcomes for all participants, primarily in the domains of attention, memory, insight and awareness. The improved cognitive outcomes resulted in greater confidence with everyday living tasks and translated to a greater independence within the home and community.

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### **Don't forget to test! Post Traumatic Amnesia testing at Sydney Children's Hospital**

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**Background and Objectives:** Accurate and timely completion of Post Traumatic Amnesia (PTA) testing is crucial in clinical care and ongoing management of children with traumatic closed head injuries. It was identified that there are inconsistencies with PTA testing at SCH and other paediatric hospitals. This has resulted in incorrect / missed administration of assessment.

**Method:** Benchmarking with tertiary children's hospitals in Australia and New Zealand was completed.

1. Current processes at SCH for referrals and administration of PTA testing were reviewed.
2. Survey was completed reviewing staff knowledge and confidence related to referrals and administration of PTA testing at SCH.
3. File audit was completed to determine if appropriate testing was completed and resultant implications of incorrect / missed administration.
4. Development of policy for PTA testing at SCH.
5. Development of educational resources to disseminate to relevant stakeholders.

**Results:** A number of children presenting to SCH who met criteria for PTA testing were not appropriately assessed for PTA. Many of these children continue to demonstrate cognitive sequelae related to their brain injury. Survey results indicated decreased staff awareness and confidence in identifying need for PTA testing and method of referral. Nil formalised pathway existed for screening and referral for PTA testing. More detailed results will be available including results post education to staff.

**Conclusions:** Streamlined processes for PTA administration and referral (plus education to staff) will likely lead to consistent clinical care for children presenting with a traumatic closed head injury. Further conclusions to be provided upon project completion.

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### **Key Challenges for People Living with Communication Disability after Stroke and Traumatic Brain Injury – Data from Phase I of Communication Connect**

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**Background and Objectives:** Over 250,000 Australians live with communication disabilities resulting from stroke and traumatic brain injury. Without well-coordinated rehabilitation and community support programs, this population is at high risk of social, emotional, and physical isolation, and vulnerable to medical and psychosocial complications. Communication Connect is an NHMRC-funded Ideas Grant program that involves co-design by people with lived experiences and clinicians. It will integrate evidence-based interventions into a comprehensive and technology-enabled program of care to address the challenges of living with communication disability after discharge. In this first phase of Communication Connect, we aim to identify key short- and long-term challenges experienced by people with communication disability after discharge from inpatient care.

**Method:** Communication Connect uses the Experience Based Co-Design (EBCD) methodology. EBCD emphasises exploration of the *experiences* of consumers for the design phase. For Phase I (identifying challenges), sampling will include healthcare staff from our three partner sites nationally (n=15) and nine people living with communication disability after stroke or TBI and their significant other, sampled for maximum variation on aetiology (stroke type; TBI), time since injury, sex, and severity (n=18). People with communication disability and their significant other will be interviewed and healthcare staff will participate in a focus group. Thematic analysis will be employed to identify key themes within the data. A workshop with participants from each group will explore and prioritise the challenges.

**Results:** Results of our Phase I data will outline the key challenges of living with communication disability from stroke and TBI in Australia, from the perspectives of people with lived experiences, their close others and health professionals. Challenges will be ranked in priority order, guiding the second phase of Communication Connect – a solution co-designed by end users and to be trialled across multiple sites nationally. Data collection has commenced and analysis should be completed by May 2022.

**Conclusions:** People with communication disability face a range of challenges across aspects of daily life, mental health, employment, social participation, and family functioning. Phase I of

Communication Connect will identify the most important challenges for this group from their experiences.

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### **Living in Limbo: Navigating the Hospital and Discharge Process for People with Disability and Complex Needs**

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**Background and Objectives:** People with acquired neurological disability and complex needs are at risk of lengthy hospital delays and discharge to unsafe or inappropriate housing. Effective discharge planning is crucial to facilitate better health and psychological outcomes; however, there remain components of the hospitalisation and discharge trajectory characterised by delays and inconsistencies that, in turn, negatively impact discharge outcomes. The purpose of this qualitative phenomenological study was to gain an in-depth understanding of the barriers and facilitators to effective hospital discharge for people with acquired neurological disability.

**Method:** People with disability ( $n = 13$ ), close others ( $n = 3$ ) and discharge leads ( $n = 10$ ) completed semi-structured interviews exploring the hospitalisation and discharge trajectory post-discharge. People with disability and close others were followed up at 1 month and 6 months post-discharge. Discharge leads were interviewed 2 weeks following the discharge of the primary participant.

**Results:** Three interrelated themes emerged: *wrangling systems* depicted that consistent coordination was required to navigate complex interfaces between health, disability, and housing sectors throughout discharge. Often this fell to the individual's close others. *Anticipation and early instigation* highlighted the importance of early identification of discharge supports and prompt engagement with the NDIS and service providers. *Post-discharge life* reflected the influence of hospitalization and discharge processes on the experiences of individuals living with acquired disability in the community following discharge.

**Conclusions:** This qualitative study highlights the ways in which components of the hospitalisation and discharge trajectory influence discharge and post-discharge outcomes. These novel findings highlight the need for coordination and consistent processes to ensure timely discharges for people with disability with housing and supports that match their needs and preferences.

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### **Measuring the complexity and outcomes of Brightwater clients with acquired brain injury: A whole population cohort study, 1991-2020**

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**Background and Objectives:** Brightwater Care Group has been a main provider of post-acute neurorehabilitation and disability support services for people with acquired brain injury (ABI) in Western Australia (WA) since 1991. The Acquired Brain Injury Community REhabilitation Services OuTcomes CohoRT (ABI-REStART) study measures the short- and long-term outcomes of all clients of Brightwater's brain injury services from inception on 15 March 1991 to 31 December 2020. This presentation provides an overview of the functional and psychosocial outcomes of the cohort at discharge over a 29-year period, and discusses service strengths and opportunities for enhancement, to inform person-centred care.

**Method:** A retrospective whole-population cohort study comprising all individuals who received post-acute neurorehabilitation and disability services through Brightwater Care Group, 1991–2020. The study used both internal clinical and rehabilitation data, and linked hospital, emergency department and mortality data from the WA Data Linkage System. Outcomes evaluated include functional independence (UK Functional Independence and Assessment Measure; UK FIM+FAM), psychosocial functioning (Mayo-Portland Adaptability Inventory; MPAI-4), and goal attainment (Goal Attainment Scale; GAS).

**Results:** 1,011 individuals with ABI were admitted to post-acute services between 1991-2020. Non-traumatic injuries (e.g. stroke, hypoxia) were the most prevalent (54.9%,  $n=555$ ). Mean age at admission was 45.4 years ( $SD=15.5$ ), and 67.5% of the cohort were male ( $n=682$ ). Median time from injury to admission was 10.5 months. On average, all individuals showed clinically significant functional gains at discharge, with a mean improvement of +18.4 points in FIM+FAM score,  $p=0.020$ . Small improvements in psychosocial functioning were also seen, with a mean reduction of -1.5T points in MPAI-4 score,  $p<0.001$ . Over half (52.2%) of ABI clients achieved their goals at the expected or higher level at discharge.

**Conclusions:** Brightwater's brain injury services showed the strongest impact in helping people with complex brain injuries to relearn functional skills and achieve functional rehabilitation goals to live independently or with minimal support. Greater focus on psychosocial health would further improve outcomes, and additional supports are likely needed to better support the psychosocial needs of this population.

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### Developing an Evidence-based Framework for Early, Interdisciplinary ABI Vocational Rehabilitation

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**Background and Objectives:** Adults with acquired brain injury (ABI) can struggle to access specialised vocational rehabilitation (VR) to support their return to work goals post-injury. Barriers include limitations in service delivery, timing and access to knowledgeable and skilled staff. Providing consistent ABI VR within existing rehabilitation services may improve access and availability to clients and improve future outcomes. Developing an evidence-based framework for ABI VR during early community rehabilitation should improve service quality and consistency and guide service delivery across clinical contexts.

**Method:** Four study phases were undertaken to identify and generate the contextual knowledge and evidence-base; these informed ABI VR framework development (phase five) which occurred using a Knowledge to Action framework. The VR framework was also informed by guidelines for model of care and framework development, Australian national rehabilitation standards and evidence-based practice models.

**Results:** The evidence-based ABI VR framework developed involves aspects of case-coordination and program-based VR, and provides a structure for service delivery by a community rehabilitation team. It details the specific roles and activities to be undertaken across 5 phases of clinical activity (assessment, goal setting and rehabilitation planning, intervention, monitoring and evaluation, discharge) and includes service delivery features of access and timing, using a coordinated interdisciplinary approach, and supporting families.

**Conclusions:** The developed framework has been implemented in clinical practice, increasing consistency of VR service provision and access to components of ABI VR. Translation and implementation to other services / contexts should enable improved access to components of ABI VR for clients.

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### Primary health care needs and service utilisation of NDIS participants with acquired brain injury

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**Background and objectives:** General practitioners play an important role in health management of people with an acquired brain injury (ABI) and early intervention for prevention of comorbidities and health complications. The aims of this paper are twofold. First, to present the results of a scoping review regarding the health care needs and general practice (GP) utilisation of people with ABI. Second, to describe the health care needs and general practice utilisation of National Disability Insurance Scheme (NDIS) participants with ABI and compare them to other NDIS participants and the general population.

**Method:** A scoping review methodological framework was utilised. Six databases (MEDLINE, PsycInfo, CINAHL, Scopus, Embase and the Cochrane Library) were searched. This research utilises de-identified primary care data from Outcome Health's POLAR (POpulation Level Analysis and Reporting tool). POLAR GP health records in the Eastern Melbourne Primary Health Network were linked with National Disability Insurance Agency (NDIA) data to identify 33,767 NDIS participants common to the NDIA and GP dataset. Within this linked dataset there are 1053 NDIS participants with ABI.

**Results:** The scoping literature review found that people who have ABI have distinct health care needs and experience substantially more health problems than the general population. Secondary complications such as chronic pain, bladder and bowel dysfunction, respiratory conditions and pressure ulcers are more common. Preliminary analysis of the linked GP-NDIA data set will compare the frequency of preventative care (e.g. cancer screening, vaccinations) and referrals (e.g. mental health) in GP records for people with ABI with the general population. Analysis will determine if people with ABI are less likely to have a regular GP. We will also compare the most common diagnoses, chronic health conditions and frequency of preventable health conditions across levels of disability severity (low, medium and high) and with the general population.

**Conclusions:** The scoping literature review found that people with ABI are at risk of suboptimal health care. This project provides a rich evidence base for working with stakeholders to co-design potential solutions to improve the primary health experience and outcomes of people with ABI.

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