AUT TRAUMATIC BRAIN INJURY NETWORK

PREVENTION. CARE. RECOVERY.
Te Kaporeihana Āwhina Hunga Whara

the Rehab Network

Summary of Rehabilitation Outcome Measurement Workshop

Collaboration of TBI Network, ACC and the NRPG

Thursday 12th November, Online Zoom link

Attendees:

Anaru Fraser, Ashleigh Blair, Dianne Mains, Emma Bisset, Jayanthi Mohanakrishnan, Kevin Henshall, Kevin Boyle, Kimberlea Lemon, Kimberley Pilbrow, Kristin Gozdzikowska, Louise Kelly, Lynda Strathdee, Mary Chung, May Wu, Megan Bishop, Mel Rea, Natoya Rose Odette Philander, Pauline Owens, Penny McGarry, Randal Southee, Rebecca Ferguson, Sarah Stevens, Sarah Lillas, Rachael Reid, Sharon Taylor, Vicki Luff.

Facilitators:

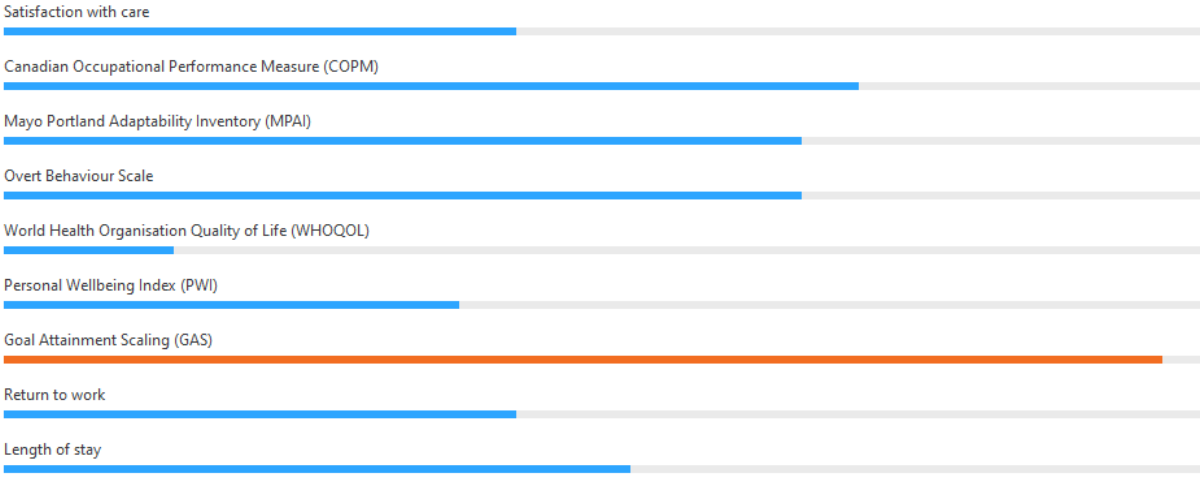
Anand Desai, Alice Theadom, George Arnold, Kris Fernando, Ipsita Sircar, Jan Henry, Estelle Borer, Tony Young, Angela Davenport.

Content:

Estelle thanked everyone for attending the workshop and for their interest in this area on behalf of the NRPG. Anand Desai then gave a presentation on the ACC Outcomes Framework and Alice Theadom provided some context and research evidence on outcome measurement in rehabilitation.

Participants were invited to respond to three poll questions;

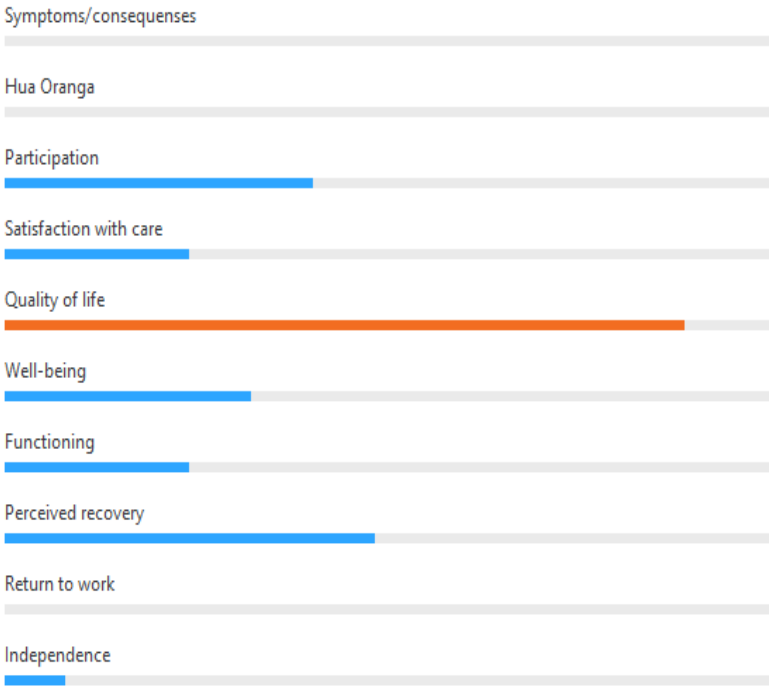
The first poll asked participants “What outcome measures are you currently using?” Participants were able to indicate as many options as relevant (options were drawn from previous smaller online discussion with rehabilitation service managers).



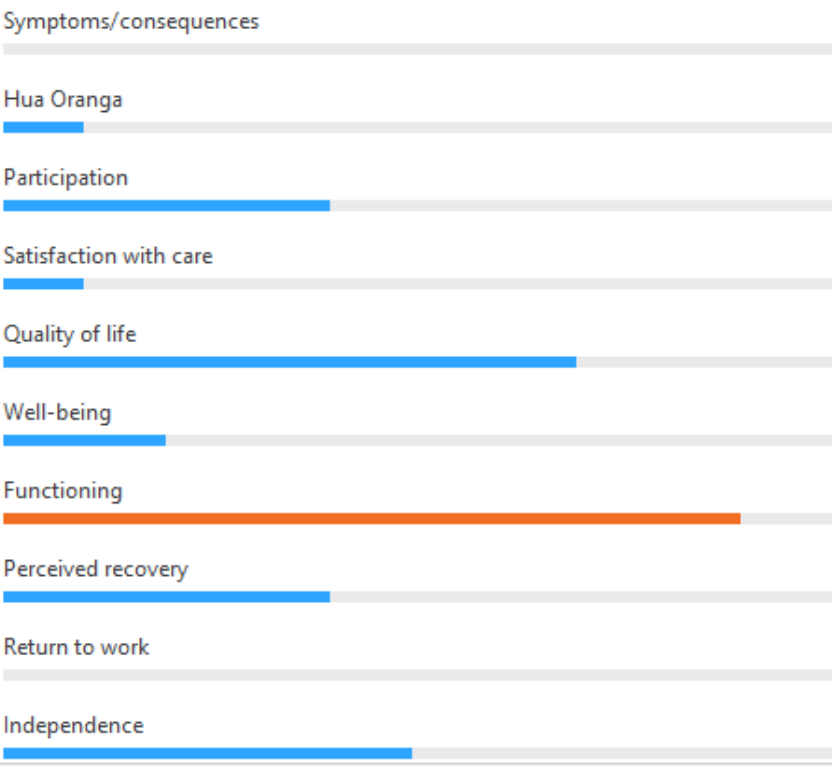
‘Other measures used included; L**awton** Instrumental Activities of Daily Living, Motor Assessment Scale, Modified Fatigue Impact Scale, Personal Wellbeing Index,, inteRAI scale, AusTOMS, DOM, Analog pain scale, Tampa Scale of Kinesiophobia, Patient Health Questionnaire, post-concussion symptoms, Wessex Head Injury Matrix

The following polls asked participants to choose a single choice from the options provided

What is the most important outcome for clients?



What is the most important outcome for clinicians?



Participants were then randomly allocated into groups to discuss the following questions for 40 minutes;

- What makes a good outcome measure and why?
- What is do-able/practical if we were to look at using universal outcome measures across services?
- What is most important for you to get back from collecting outcome data?

The groups then each provided feedback to all attendees. Group feedback and group facilitator notes have been combined to summarise the discussion below

Reasons for assessment

- To reflect change
- Feedback to patient
- Ability to benchmark to share learnings and feed into improvements – although important to be aware of other variables in doing so
- To determine if treatment/intervention is making a difference

Choice of outcome measures

- Need for both a core of 'universal' in addition to clinician/service selected profession specific and client centred outcome measures to ensure measures fit needs of service of client as well as core universal measures. This is because it is important to show clients/whānau we understand their hopes and dreams and that some measures reflect clients goals and what want to achieve – not necessarily same as therapy goals
- Could also have optional modules to take injury/context/ethnicity into account

Would need to measure something that can be changed by rehabilitation services.

1 or 2 universal outcome measures would be do-able potentially

Potentially one functional type tool and one quality of life type tool

Outcome measures chosen would need to;

- Be quick and easy (so don't take up all therapy time) but sensitive enough
- Need to use language that is easy for clients and whānau to understand
- Not require specific training
- Involve the client/whānau (not clinician rated)
- Need to have proven psychometric properties e.g. valid, minimal floor and ceiling effects, reliable (if no changed) but sensitive to change if there is change
- Need to be delivered in same way

  Need to address cultural and social environment factors that can influence outcome.
- Take initial severity and complexity into account
    - sometimes return to normal isn't possible
    - FIM no good for mild injuries
- Need a sense of what life was like before accident
- Would need to span different ages
- Would need to account for different stages in rehabilitation journey e.g. hospital/inpatient – community and change in therapy needs over time

- Provide advice on how to implement these type of measures in those clients with a restricted insight

- There was the suggestion that there is a need for a menu or layers for clinicians to select from outlining the reasons might use each for less experienced practitioners. One or two measures on their own are unlikely to be useful across all conditions and severities and ages seen in rehabilitation. This menu/layers could be based on ICF with 1 or 2 domains assessed by universal outcome measures and other domains assessed by flexible individual measures

Data clinicians would want back

- Ability to learn from data at clients' level but also at service level – where can we improve
- How effective are we being?
- Timely – be good if could interact with data when needed rather than set time once per year

Important considerations

- Need a clear aim for use of universal outcome measures – who are we doing it for?
- Determine how often people want to be assessed e.g. 6 weeks & discharge – research project needed to get client perspective on catching change to show improvements over time whilst not being burdensome.
- Ensuring relevance across journey of recovery – client needs change over time
- Could there be a transition assessment rather than double assessments at exit and entry when moving between services.
- Need to manage risk of loss of services if improve/don't improve – if clients' rate highly will supports be cut?
- Take into account different ACC contracts
- Need to manage underestimation of ability at baseline/setting of easy goals just so services look good
- Annual feedback for services vs case by case – need to know quickly if service not working well for client
- Managing lack of insight
- How to manage risk of over assessing e.g. transferring between services/ACC contracts
    - Could discharge assessment for one service be baseline for next service?

Action points from workshop:

Summary of the discussion to be made publicly available

Summary of the discussion to the shared with the National Trauma Network

Anand Desai to report back on discussion to ACC

Feedback form to participants

Suggested to set up a taskforce to progress the work