Measuring outcomes in brain injury rehabilitation programs in NSW

An overview

February 2022





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Contents

Summary	3
Introduction	4
Brain injury rehabilitation services in NSW	5
Background	5
Current types of services that are available in the NSW BIRPs	6
Outcome measurement in the NSW BIRPs	8
Frameworks	8
Psychometric properties	13
Current outcome measures collected by BIRP services	13
Processes to collect outcome measures	16
How to choose an outcome measure?	17
How is outcome data used and reported?	18
Data governance	19
References	21
Glossary	22
Acknowledgements	24

Table of Tables

Table 1 Outcome measurement scales mapped to the International Classification of Functioning, Disability and Health ICF domains.

Table of Figures

- Figure 1: Map of NSW Brain Injury Rehabilitation Programs (BIRP) services in NSW
- Figure 2: International Classification of Functioning, Disability and Health ICF framework
- Figure 3: Example of adapted International Consortium for Health Outcomes Measurement (ICHOM) adapted for traumatic brain injury (TBI)
- Figure 4: Routinely collected outcome data in the NSW Brain Injury Rehabilitation (BIRP) Programs
- Figure 5: Flow chart of outcome measurement time points across the rehabilitation continuum
- Figure 6: Data governance components diagram

Summary

This document provides clinicians with a history and overview of outcome measurement in the NSW Brain Injury Rehabilitation Programs (BIRPs).

The measurement of outcomes is essential not only at the level of the individual, to drive clinical practice and goal setting, but also for service and statewide evaluation.

Standardised and patient-reported outcomes provide a holistic view of the rehabilitation journey and should be a priority in the NSW BIRP services. Processes to support the routine collection of outcome measures are highly recommended. These should be put in place at the local level depending on the resources available in each setting.

Other documents are available to NSW BIRP clinicians to supplement this document.

For further information relating to outcome measurement in the NSW BIRP services, please contact the ACI (Agency for Clinical Innovation) BIRD (Brain Injury Rehabilitation Directorate) at aci-braininjuryrehab@health.nsw.gov.au

Introduction

Traumatic brain injury (TBI) is the most common cause of death and disability among young people in NSW. In the most severe forms, TBI can have lifelong consequences on function, social participation, relationships and employment.

The mechanism of the injury in a TBI is itself a key factor in what makes rehabilitation different for people with TBI from other neurological brain injury. Depending on the type and velocity of the force, different areas of the brain are affected.

In the early stages of recovery following brain trauma, there can be a period of confusion and agitation known as post-traumatic amnesia (PTA). The duration of PTA is a determining factor for injury severity. This period is characterised by poor memory and challenging behaviours. Access to specialised brain injury rehabilitation programs is important in this stage to safely and appropriately manage the confusion, agitation and challenging behaviours.

Specialised brain injury services have skilled staff who provide rehabilitation, information and advice to children, young people and adults who have sustained a significant brain injury. Rehabilitation aims to maximise recovery, health and social participation outcomes and improve quality of life. Rehabilitation is guided by person-centred goals and consists of functional retraining to address impairment in the following areas:

- Physical functioning
- Communication
- · Activities of daily living
- Behaviour
- Cognition

This document provides an overview of outcome measurement in brain injury rehabilitation in NSW and the outcome tools currently used in specialised rehabilitation services. It outlines the Patient-Reported Outcomes Measurement Information System® (PROMIS®) measures currently collected, as well as the additional standardised clinical tools used across the services.

Brain injury rehabilitation services in NSW

Background

In 1976, the first unit in Australia to provide specialised rehabilitation for people with traumatic brain injury was established at Lidcombe Hospital.

Later reports identified the need for specialist rehabilitation services and early intervention to maximise recovery following traumatic brain injury and support families during rehabilitation and integration back into the community. It was recognised that the consequences of brain injury extended beyond the clinical setting, often having a profound impact on relationships, vocation, participation in society and overall quality of life.

As a result, the NSW BIRPs were established from 1989 as a best practice model of specialised rehabilitation. Governance of the services was provided by NSW Health governance in partnership with the then called Motor Accident Authority of NSW.

In 2002, the NSW Health Minister identified brain injury rehabilitation as an area where coordination of statewide services were much needed. This led to the development of the Brain Injury Rehabilitation Directorate (BIRD) which oversees the BIRP network and undertakes projects to improve client and service outcomes across NSW.

The BIRD is one of the clinical networks of the NSW ACI. The underlying principle of the BIRD is to engage health professionals, managers, consumers and the wider community in the process of designing and providing high quality, safe and cost-effective specialised rehabilitation services to meet the needs of children, young people and adults with primarily severe, traumatically-acquired brain injuries.

There are now 15 dedicated specialised traumatic brain injury rehabilitation services for the population of NSW. Figure 1 depicts the BIRP locations across NSW.

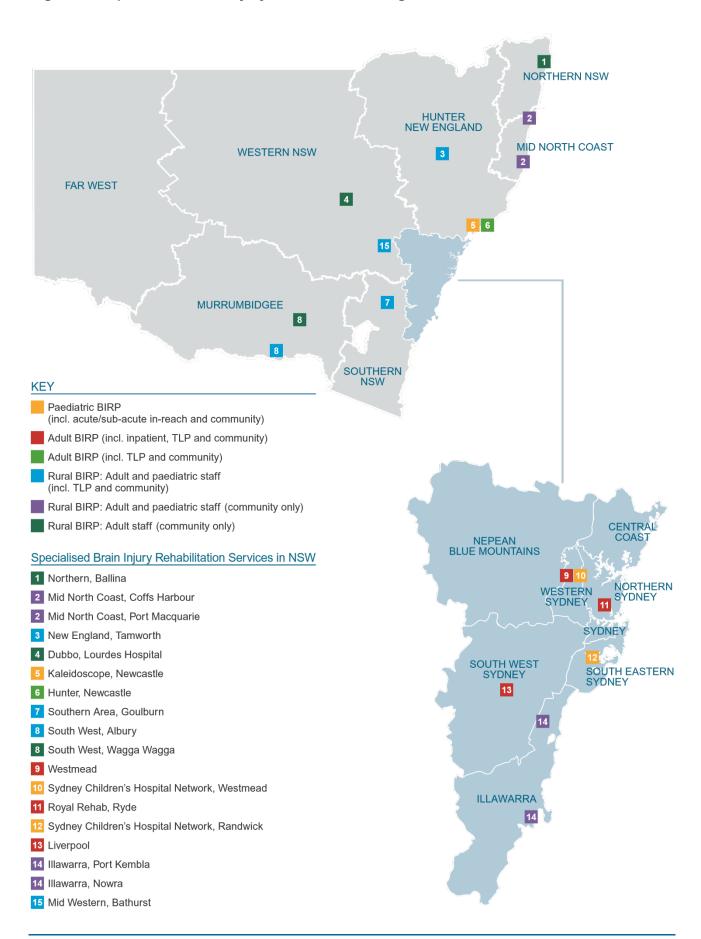
The BIRPs are in specific local health districts (LHDs) and operate for defined geographical regions of NSW. The three adult inpatient services and the three paediatric in-reach services cover about a third of the state each, with one of the adult metropolitan BIRPs also supporting inpatient admissions from the Australian Capital Territory. Local LHDs provide governance and financial management for the BIRPs located in their district, although the service may be supra-regional.

Recovery from a brain injury can have many different trajectories, with variability driven by a range of factors including age at injury, pre-morbid function, life stage, severity of the injury, functional recovery and the availability of support and resources. These factors, along with the availability of and ability to access services, also influences the rehabilitation pathway that an individual may take.

Current types of services that are available in the NSW BIRPs

- Adult specialist brain injury inpatient rehabilitation for adults who are medically stable and
 require a high level of care, have had a severe or very severe brain injury and may still be
 in a state of confusion (post-traumatic amnesia). The units operate 24/7 with doctors,
 nurses, allied health and support staff. Most admissions are received from trauma hospitals
 after an acute admission.
- Adult rehabilitation provided in a transitional living program (TLP) contextually based rehabilitation with a community reintegration and social participation focus. There are dedicated staff who provide formal and informal support and feedback about performance.
- Adult community rehabilitation (including outpatient services) provides contextually-based therapy and case management services. Outpatient medical and multidisciplinary clinics are provided in metropolitan and some rural areas. This includes the case management model devoted to the coordination, rehabilitation, care and support of people with complex clinical needs.
- Paediatric specialist brain injury inpatient rehabilitation is provided in the metropolitan children's hospitals for children who require a high level of care, or who have had a severe or very severe brain injury. Paediatric community rehabilitation is generally community-based rehabilitation. Therapy is delivered and practiced in everyday environments within the child's home, school and community, and at times in a day hospital setting. Case management is integral to the specialist paediatric brain injury rehabilitation.

Figure 1: Map of NSW Brain Injury Rehabilitation Program services in NSW



Outcome measurement in the NSW Brain Injury Rehabilitation Programs (BIRPs)

Since the establishment of the statewide BIRP services, outcome data has played a key role in clinical decision making and implementation of evidenced-based practice at the level of the individual, as well as collating service level data.

Outcome measures are valuable tools that:

- document the effectiveness of treatment
- measure progress resulting from effort
- provide motivation to the person who has sustained a brain injury
- provide information on change over time.

Historically, outcome measures have consisted of only standardised clinical assessment tools, usually clinician rated. In more recent years, there has been a shift in health outcome measurement to focus not only on the disease or health condition, but also to measure health outcomes and experiences that matter to patients.

NSW Health has a vision for integrated, better value care which is being implemented through the Leading Better Value Care initiative, Patient reported measures program and by using innovative technology such as the Health Outcomes and Patient Experience (HOPE) platform.²⁻⁴

This has meant broadening the traditional biometric and functional outcome measures assessed by clinicians to include patient-reported measures (PRMs). The PRMs recommended for collection in the NSW BIRPs are the PROMIS® measures and the Brain Injury Experience Questionnaire (BREQ).

Frameworks

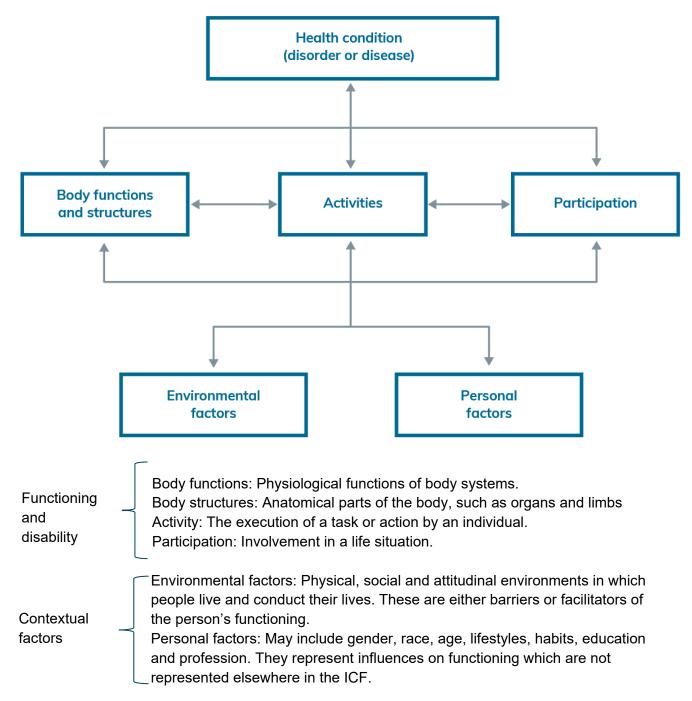
The mapping of outcomes to standardised frameworks, such as the International Classification of Functioning, Disability and Health (ICF) and the International Consortium for Health Outcomes Measurement (ICHOM) is beneficial. These frameworks provide a structure for the outcome measures, ensure all relevant domains of interest are captured and allow for benchmarking through harmonisation of data.^{5, 6} Examples of commonly-used frameworks in brain injury rehabilitation are described below.

International Classification of Functioning, Disability and Health (ICF)

The ICF provides "a standardised language and conceptual basis for the definition and measurement of disability."⁵

Figure 2: International Classification of Functioning, Disability and Health Framework

The ICF organises information into functioning and disability, and contextual factors as summarised below.



Many outcome measures commonly used in brain injury rehabilitation can be organised under the ICF framework. Some measures may not fit discretely into one domain, but rather cross several of the ICF domains. Table 1 is an example of how the ICF can be used to categorise commonly-used outcome measures in brain injury rehabilitation.

Table 1: Outcome measurement scales mapped to International Classification of Functioning, Disability and Health (ICF) domains

ICF components	Domain	Example of outcome measure
Body functions	Consciousness and orientation	Glasgow Coma Scale (GCS) Western Neuro Sensory Stimulation Profile (WNSSP) Delirium Rating Scale – Revised – 98 (DRS-R-98) Galveston Orientation and Amnesia Test (GOAT) Westmead Post-traumatic Amnesia Scale (WPTAS) Modified Oxford Post-traumatic Amnesia Scale (MOPTAS)
	General cognitive function	Mini-Mental State Examination (MMSE) Rowland Universal Dementia Assessment Scale (RUDAS) Montreal Cognitive Assessment (MoCA)
	Regulation of behaviour, thought and emotion	Agitated Behaviour Scale (ABS) Overt Behaviour Scale (OBS) Fatigue Severity Score (FSS)
	Sensory, ingestion and motor functions	Visual Analogue Scale (VAS) McGill Pain Questionnaire (MPQ) Tardieu Scale Motor Assessment Scale (MAS) High Level Mobility Assessment Tool (HiMAT)
Activity and participation	Daily living	Functional Independence Measure (FIM or WeeFIM for children) Functional Autonomy Measurement System (SMAF) Activities of Daily Living Questionnaire (ADLQ)
	Participation and social role	Child and adolescent scale of participation (CASP) Community Integration Questionnaire (CIQ-R) Sydney Psychosocial Reintegration Scale (SPRS)
Environmental factors		Care and Needs Scale (CANS) Supervision Rating Scale (SRS)
Multi-domain Scales	Global Scales	Glasgow Outcome Scale (GOS) Modified Rankin Scale (mRS)
	Multidimensional and quality of life scales	Disability Rating Scale (DRS) Mayo Portland Adaptability Inventory – 4 (MPAS-4) World Health Organization Quality of Life (WHOQOL) Quality of Life in Neurological Disorder (Neuro-QOL) Patient-Reported Outcomes Measurement Information System (PROMIS®)

International Consortium for Health Outcomes Measurement (ICHOM)

ICHOM develops standardised sets of outcome measures that are most relevant to patients for specific medical conditions or population groups, including stroke, diabetes, or overall paediatric health. The standard sets have been developed using data driven by different perspectives: providers, patients and consumers, funders and registries. ICHOM's measurement of health outcomes focuses on what matters most to patients, and this is usually collected through patient reported outcomes (PROMs).

PROMs capture a patient's perspective on how illness and care impact their health and wellbeing. Standardised and validated tools measure patient outcomes, including quality of life or symptoms related to a specific disease or condition. This information can be used for care planning and decision making to ensure timely person-centred care. PROMIS® is a set of person-centred measures that evaluates and monitors physical, mental and social health in adults and children from the perspective of the person with a brain injury.⁷

Figure 3 provides an example of how, in the value-based healthcare scenario, the child, young person or adult is at the centre of the model with selected measures providing insights into function and progress across various domains in the rehabilitation continuum.

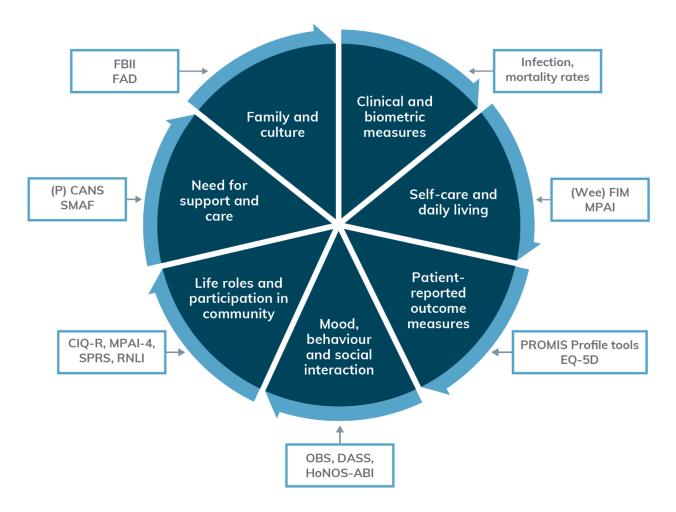


Figure 3: Example of an adapted ICHOM standard outcome set for traumatic brain injury

Legend: FIM: Functional Independence Measure (WeeFIM in children); MPAI-4: Mayo Portland Adaptability Inventory – 4; PROMIS: Patient-Reported Outcome Measurement Information System; EQ-5D: EuroQoI-5 Dimension; OBS: Overt Behaviour Scale; DASS: Depression Anxiety Stress Scales; HoNOS-ABI: Health of Nation Outcome Scale – Acquired Brain Injury; CIQ-R: Community Integration Questionnaire- Revised; SPRS: Sydney Psychosocial Reintegration Scale; CASP: Child and Adolescent Scale of Participation; CANS: Care and Needs Scale (PCANS paediatric); SMAF: Functional Autonomy Measurement System; FBII: Family Burden Injury Interview; FAD: Family Assessment Device.

Other important considerations when selecting a tool to measure outcomes in rehabilitation include the psychometric properties of the tool.

Psychometric properties

Psychometric properties are characteristics of tests that identify and describe attributes of an instrument. Some common psychometric properties of measurement scales frequently reported are described below.

Validity

The extent to which a test measures what it is designed to measure.

Content Does the tool capture or represent all relevant aspects of the construct to be

measured?

Construct How well the test measures the construct that it was designed to measure.

Construct validity considers whether the scores produced by the instrument are consistent with the hypothesis of how the tool should behave, assuming

the tool is valid.

Criterion Do scores on one instrument correspond to scores on another instrument,

measuring the same thing?

Reliability

Reliability is the degree to which the tool is free from measurement error.

Internal Measures the extent that separate items on the same scale, that are consistency designed to be measuring the same thing, produce similar results.

Test-retest The degree to which the score of a patient who has not changed remains

reliability the same under repeated measurements.

Responsiveness

The responsiveness of a tool demonstrates the ability of the instrument to detect clinically important changes in a patient, over time, when changes in the construct being measured occur.

Interpretability

Interpretability is considered important for the usability of the measurement tool rather than as a psychometric property. It is the degree to which a clinician or researcher can equate a qualitative meaning to an instrument's quantitative score.

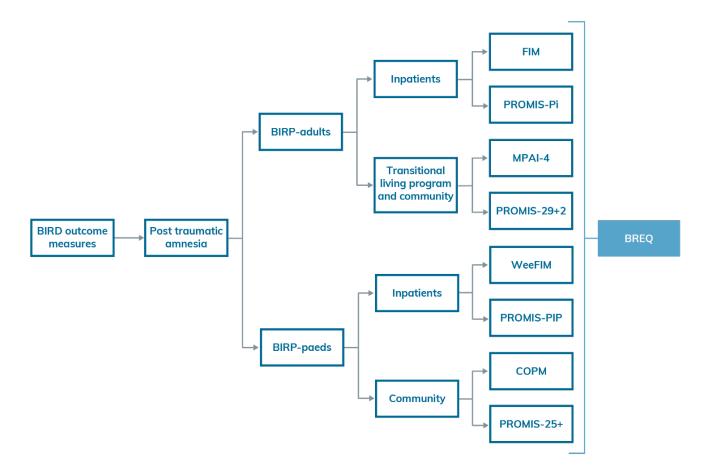
These psychometric dimensions of scales are important considerations, as is ensuring the cultural, gender and age appropriateness of the scales used.

Current outcome measures collected by BIRP services

The outcome measures currently collected by the BIRP services are specific to the rehabilitation population and service setting. Patient-reported measures are collected across all services. Due to the heterogeneity in outcomes in the traumatic brain injury population, measurements cover broad domains and can serve a variety of purposes from evaluating function at an individual level,

provide a baseline to compare with future change, inform treatment planning and decisions as well as identify areas of need and justify services. Figure 4 provides a breakdown of these outcome measures.

Figure 4: Routinely collected outcome data in the NSW Brain Injury Rehabilitation Programs BIRPs



Legend: FIM: Functional Independence Measure (WeeFIM in children); PROMIS-Pi: Patient-Reported Outcomes Measurement Information System - pilot for inpatient setting; MPAI-4: Mayo Portland Adaptability Inventory – 4; PROMIS-29+2: Patient-Reported Outcome Measurement Information System standard tool; PROMIS-PIP: Patient-Reported Outcomes Measurement Information System – paediatric inpatient pilot; COPM: Canadian Occupational Performance Measure; PROMIS 25+: Patient-Reported Outcome Measurement Information System Paediatric/Parent proxy profile instrument; BREQ: Brain Injury Rehabilitation Experience Questionnaire.

Patient Reported Outcome Measurement Information System (PROMIS®)

PROMIS® profile instrument is a collection of person-centred short forms containing a fixed number of items from seven PROMIS® domains – physical functioning, depression, anxiety, ability to participate in social roles and activities, fatigue, sleep disturbance, pain interference and intensity.⁷ The PROMIS® system contains standardised 'profile' instruments developed for use with adult (10, 29, 43 or 57 items) and paediatric (25, 37 or 49 items) populations.

The PROMIS® profile instruments were selected as the PROM of choice in the NSW BIRP services for their comprehensive nature and ease of use. Although introduced prior to the NSW Health initiative on PROMS and PREMs, the PROMIS® profile instruments align with the NSW strategy of value-based healthcare.8

In the adult TLP and community settings, the PROMIS-29+2 standard tool has been selected for use as it includes items on cognitive function, which is highly relevant for this population. However, questions such as "Are you able to do chores such as vacuuming and yard work?" do not work well in the context of the BIRP inpatient settings. Using consumer co-design methodology and the PROMIS® bank of items, a range of context-specific PROMIS® tools have been developed specifically for the BIRP inpatient settings. The PROMIS-Pi tool reflects more relevant and appropriate information for an inpatient setting. In the paediatric population, the paediatric PROMIS-25+ tool (including sleep items) is used in community settings and the paediatric PROMIS-PIP was developed for use by paediatric inpatient BIRP services.

Brain Injury Rehabilitation Experience Questionnaire (BREQ)

Patient experience questionnaires have evolved from satisfaction surveys in that they aim to understand the patient experience during the rehabilitation process, rather than patient's satisfaction with the service. The Australian Modified – Client Centred Rehabilitation Questionnaire (AM-CCRQ) was identified as a suitable instrument for measuring client experience, and the BREQ was developed using five of the seven items from the AM-CCQR.⁹

Post traumatic amnesia (PTA)

All people who are admitted to a brain injury service after sustaining a traumatic brain injury undergo standardised testing of orientation and memory. In Australia, the Westmead Post Traumatic Amnesia Scale (WPTAS) and the Modified Oxford Post Traumatic Amnesia Scale (MOPTAS) are commonly used in BIRP settings.^{10, 11} Both tests contain 12 items that assess orientation and memory. There is slight variation in the test items, as well as the procedures for administering the memory items of the tests. The duration of PTA is used as an indicator for injury severity as well as a predictor of long-term global outcome.¹² Paediatric scales measuring PTA have been developed.

Functional Independence Measure (FIM and Wee FIM)

The Functional Independence Measure is a clinician-administered functional assessment of an individual's ability to carry out an activity independently; or if assistance is required, quantifying that assistance.¹³ It is an 18-item measure split into a motor subscale (13 items) and cognitive subscale (five items). The motor subscale consists of eight self-care items and five mobility items. Items are scored on a seven-point ordinal scale from dependence (1) to independence (7) in carrying out that particular item. The Wee FIM can be used in children from six months of age until adulthood.

Mayo Portland Adaptability Index (MPAI-4)

The MPAI-4 is a rating scale consisting of 29 core items measuring domains of physical, cognitive, emotional, behavioural and social function.¹⁴ These domains are grouped into three subscales of ability (12 items focusing on sensory, motor and cognitive ability); adjustment (9 items focusing on mood and interpersonal interactions) and participation (8 items evaluating social contacts, initiation and money management). A fourth subscale, pre-existing and associated conditions, contains six items, however these are not scored. Responses are scored on a five-point scale, with 0 (no

problem) at one end of the scale and 4 (severe problem interfering with activities more than 75% of the time) at the other. The MPAI-4 can be completed by the clinician, proxy or self-rated if cognition enables this. Clinician scoring is often made by consensus of a multidisciplinary team following individual assessments.

Canadian Occupational Performance Measure (COPM)

The COPM is an evidence-based outcome measure designed to capture a client's self-perception of performance in everyday living, over time.¹⁵ The COPM uses a semi-structured interview technique to identify and prioritise everyday issues that affect the person who has sustained a brain injury.

Processes to collect outcome measures

The BIRD provides training and recommendations on processes to collect outcome data in the BIRP services. However, each service is required to establish local processes around data collection that best suit their available resources and context. These processes include the logistics of administering the measurement tools, scoring, feedback to the patient and interpretation of the results. An example of some localised differences in processes in the BIRPs is around the collection of the PROMs. Some community services have initiated sending an email or paper copy of PROMIS® profile instruments to their client (or family) to complete prior to their initial appointments. In this way their health professional can review the responses prior to the session, while at other services it is completed during or after a session with the healthcare professional.

Work has also been done to standardise the timepoints during the rehabilitation journey at which outcome measures are administered. These time points are at the commencement of an episode of care, at six months (or discharge from an episode of care), at ongoing plan review times or annually thereafter. The flow chart below (Figure 5) depicts the outcome measurement time points across the rehabilitation continuum.

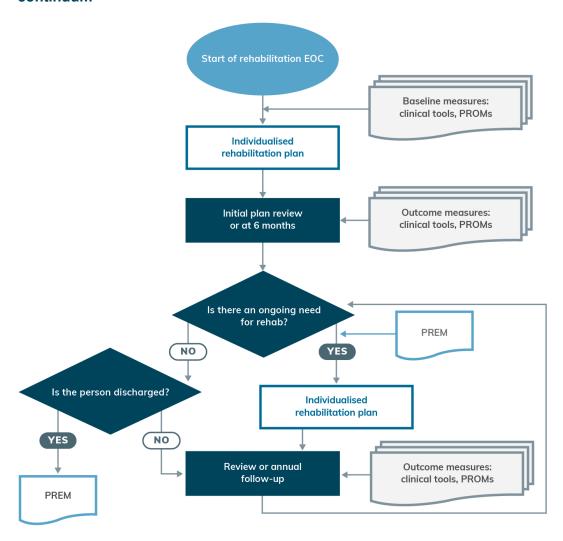


Figure 5: Flow chart of outcome measurement time points across the rehabilitation continuum

How to choose an outcome measure?

Whilst PROMIS® is the PROM instrument of choice, other additional outcome measures will support and monitor the patient diagnosis, journey and goals in the BIRPs. Selection of these additional outcome measures are based on several considerations such as "Why am I measuring this outcome?" and "Who wants me to measure this outcome?"

Outcome measures have many purposes in rehabilitation including:

- Evaluating change at an individual level
- Demonstrating results of effort or practice for the person with a brain injury
- Documenting the effectiveness (or ineffectiveness) of a treatment
- Informing discussions with person with a brain injury and their family
- Reporting to funders with clear outline of progress and ongoing needs
- Monitoring the quality of services
- · Evaluating clinical effectiveness in the different settings of care
- Supporting self-reflection on clinician's own practice.

It is also important to ensure that the outcome that is being measured is of significance to the person with a brain injury as this will influence their motivation and drive toward the task.

Outcome measures can also be administered in several ways. Some instruments require a health professional to administer the test; while others, such as questionnaires, rating scales and interviews require a response from the person with a brain injury. Where it is not possible for a person to respond, a proxy-respondent (generally a family member who has close contact with the person and knew them well prior to their injury) may assist.

There are advantages and disadvantages of collecting data from each source, and a recognition of these should be made by the clinician during administration. For example, a person who has sustained a recent traumatic brain injury may present with confusion. If asked to rate something on a rating scale, their interpretation of this may affect the validity of the score given their confusion. In a clinical context, the clinician should be responsible for selecting the most appropriate tool.

How is outcome data used and reported?

Clinicians utilise outcome measures with individuals daily to monitor change in various domains, develop rehabilitation plans and set goals. The results of outcome measures can also be useful in communicating progress with clients and families. The reporting of progress is a key feature in communicating with funding bodies that are often involved in the care of people after a brain injury. Funding bodies assess the ongoing needs of clients based on recommendations from the treating and supporting evidence.

The administration of regular outcome measures has many benefits, not only at the individual level but also across the state. At the level of the LHD, collated individual level data is used to provide a summary of activity in the BIRP services, look at workforce planning and service developments. This has been facilitated by reporting by the BIRD at the local level and aggregated statewide data. Some of this data is shared with external agencies, such as the Australasian Rehabilitation Outcome Centre (AROC) for comparison with other rehabilitation services in the region.

The BIRD Executive and Data and Information Management Committees oversee reporting of statewide BIRP service activity and outcomes. The *BIRD Minimum Dataset Data Dictionary* and *BIRD Outcomes and Evaluation toolkit* provide information about statewide data collection.

The BIRPs receive outcome data reports from the BIRD when requested. This helps BIRPs to identify trends within their service and provides data to meet local reporting requirements. From 2022, the BIRD will also provide summarised feedback across the state on outcome measures, as well as provide a more detailed look at individual site data. It is envisaged this will become an annual process of feedback to the BIRPs on their collected outcomes.

Data governance

The BIRD data collection is governed by the NSW Health *Data Governance Framework*. ¹⁶ Data governance describes how data-related decisions are made, the organisational roles, decision rights and accountabilities of people and systems as they perform health information-related activities. The framework outlines the roles and responsibilities involved in data governance and the structures required to be in place to ensure effective and consistent management of the BIRD data collection.

Figure 6: Data governance components diagram



The ACI BIRDs data governance structure adheres to the NSW Health Data *Governance Framework*. ¹⁶ It has enacted this framework through processes such as the establishment of a data and information management committee, published data dictionary and minimum dataset and documentation of internal use and disclosure procedures.

Outcome data across the BIRPs are entered on the ACI Research Electronic Data Capture (REDCap) Brain Injury Rehabilitation database. REDCap is a secure web-based portal designed specifically for the electronic recording of data. The REDCap platform is securely hosted within NSW Health servers and complies with rigorous privacy and security standards. Most BIRP services have access to REDCap on which to securely store individual outcome data. Services not using REDCap have their own secured database where their outcome data is stored. The BIRP REDCap database is set up to automatically calculate scores on measures, and in some instances, provide clinical decision flags to help identify priorities with the patients.

Every BIRP service has received individualised training on outcome measurement, familiarisation with the *BIRD Minimum Dataset Data Dictionary* and *BIRD Outcomes and Evaluation toolkit*. All new staff are orientated to outcomes in-house, prior to a more formal education session being provided by the BIRD outcome manager. Training has now evolved from a familiarisation with the measures to assistance with implementation of the measures within the local contexts.

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Glossary

Term	Description
ABI	Acquired brain injury (includes traumatic and non-traumatic injuries)
ACI	Agency for Clinical Innovation
AM-CCRQ	Australian Modified – Client Centred Rehabilitation Questionnaire
AROC	Australasian Rehabilitation Outcomes Centre
BIRD	Brain Injury Rehabilitation Directorate
BIRP	NSW Brain Injury Rehabilitation Program
BREQ	Brain Injury Experience Questionnaire
CANS	Care and Needs Scale
CASP	Child and Adolescent Scale of Participation
CIQ-R	Community Integration Questionnaire Revised
CDS	Clinical Data Set (BIRP Database)
СОРМ	Canadian Occupational Performance Measure
ICF	International Classification of Functioning
ICHOM	International Consortium for Health Outcomes Measurement
FIM	Functional Independence Measure
GCS	Glasgow Coma Scale
HOPE	Health Outcomes and Patient Experience platform
LHD	Local health district
MAS	Motor Assessment Scale
MOPTAS	Modified Oxford Post-Traumatic Amnesia Scale
MPAI-4	Mayo Portland Adaptability Inventory, Version 4
Non-TBI	Non-Traumatic Brain Injury
OBS	Overt Behaviour Scale
PREM	Patient-reported experience measure

PRM Patient-reported measure

PTA Post-traumatic amnesia

PROM Patient-reported outcome measure

PROMIS® Patient Reported Outcome Measurement Information System®

REDCap Research Electronic Data Capture

SMAF Functional Autonomy Measurement System

SPRS Sydney Psychosocial Reintegration Scale

TBI Traumatic brain injury

TLP Transitional Living Program

WeeFIM Functional Independence Measure for children

WPTAS Westmead Post Traumatic Amnesia Scale

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