Queensland Health

Moving Towards Awareness

A guide for improving prolonged disorders of consciousness management in Queensland

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Consultation has been conducted through the project Acquired Brain Injury Rehabilitation Working Group and the project Statewide Advisory Committee.

Summary

The Commonwealth-funded Brain and Spinal Cord Injury (BaSCI) Project is working to improve access to safe and quality adult specialist rehabilitation services across the care continuum in Queensland for better consumer outcomes. This paper provides an overview of the specific improvement activities focused on prolonged disorders of consciousness delivered under the acquired brain injury rehabilitation portfolio of BaSCI.

Prolonged disorders of consciousness (PDOC) is the collective term used when patients remain in a state of wakefulness but with absent or reduced awareness beyond four weeks following an acquired brain injury (ABI)[i]. Patients in PDOC lack the capacity to make decisions regarding their own care and treatment and are dependent on others to act in their best interests. While this patient cohort is relatively small, they have a substantial financial, emotional, and societal impact. Due to their extreme vulnerability and complete dependence on others for both care and interaction with the world around them[ii], a particular duty exists to promote their interests and strive towards a quality of life that would be acceptable to them.

At a statewide level, the BaSCI ABI rehabilitation working group has a mandatory deliverable to standardise access pathways and is developing a related model of care for future state service provision for PDOC patients in Queensland. The project has also enabled the testing of actions and interventions for evidence-based quality care in both the acute and rehabilitation care continuum within hospital settings in Metro North Hospital and Health Service (MNHHS).

This paper collates the work from the BaSCI project and outlines a future service modelling concept for continued development. It includes information on international guidelines, research evidence available to date, and considers the Queensland policy context found in the *Statewide adult brain injury health service plan 2016-2026*.

This document will support ongoing engagement and discussion with stakeholders to move towards closing the gap between best practice and the actual experiences of consumers in our care.

Recommendations

A Queensland model delivered through the maturing network of specialist ABI rehabilitation services is required to achieve alignment with PDOC best-practice guidelines. There is also requirement for a specialist in-reach and out-reach service to support local teams, ensuring consistency of intervention, and equity of access to specialist hospital services and community-based review.

Collaboratively deliver the BaSCI project actions related to specialist PDOC care in Queensland:

- Agree standardised service access and design a future service model
- Deliver clinical audit to assess demand for specialist PDOC rehabilitation
- Pursue workforce development opportunities
- Investigate funding opportunities to test the model of care

Pursuing the recovery of a quality of life that is meaningful to them.
- Parent of consumer in PDOC -

Background

Patients who experience a prolonged disorder of consciousness following profound brain injury pose a complex array of clinical and ethical challenges for both the individuals and health care systems responsible for their care[iii].

Medical advances mean that increasing numbers of people are surviving after experiencing neurotrauma, stroke, hypoxia, and brain infections. Consequently, there is a growing population of patients who remain in a vegetative or minimal conscious state following their acquired brain injury, necessitating highly specialist assessment and management through service provisioning that is holistic and lifelong.

Prolonged disorders of consciousness is the collective term used when patients remain in a state of wakefulness but with absent or reduced awareness for more than four weeks following an acquired brain injury (see Table 1). Diagnosis and prognostication are challenging because there is no single clinical sign or investigation for 'awareness'. Its presence must be deduced from a range of behaviours which indicate that an individual can perceive themselves and their surroundings, frame intentions and interact with others. As the patient's condition may change over time, this necessitates repeated skilled assessment by clinicians with specific experience in this area[iv].

Health service modelling has historically clinically prioritised PDOC patients on the assumption that individuals with chronic disorders of consciousness lived for relatively short periods after discharge from inpatient services. Additionally, traditional rehabilitation models were believed to have minimal impact on outcomes. However, a growing number of longitudinal studies are now demonstrating survival rates of around 70% at 8 years[v] with a 'good' recovery rate of approximately 50% for MCS patients and 27% for VS/UWS.

Table 1: Definitions of disorders of consciousness

Coma *Absent wakefulness and absent awareness*	A state of unrousable unresponsiveness, lasting more than 6 hours in which a person: • Is unconscious and cannot be awakened • Fails to respond normally to painful stimuli, light or sound • Lacks a normal sleep/wake cycle • Does not initiate voluntary actions
Vegetative State (VS) / Unresponsive Wakefulness State (UWS) *Wakefulness with absent awareness*	A state of wakefulness without awareness in which there is preserved capacity for spontaneous or stimulus induced arousal – evidenced by sleep / wake cycles and a range of reflexive and spontaneous behaviours. VS / UWS is characterised by absence of behavioural evidence for self or environmental awareness.
Minimal conscious state (MCS) *Wakefulness with minimal awareness*	A state of severely altered consciousness in which minimal but clearly discernible behavioural evidence of self or environmental awareness is demonstrated. MCS is characterised by *inconsistent, but reproducible,* responses above the level of spontaneous or reflexive behaviour, which indicate some degree of interaction with their surroundings.

Reproduced from Royal College of Physician PDOC Guideline[vi]

Over the past two decades, considerable progress has been made in research regarding PDOC, leading to changes in diagnostic criteria, predictive factors to guide prognostication, and development of tools for assessment and rehabilitation. This has led to the development of the following international guidelines which outline current best practice recommendations for whole of life management.

- Royal College of Physicians (RCP) 2020. Prolonged disorders of consciousness following sudden onset brain injury: National clinical guidelines[vii]
- American Congress of Rehabilitation Medicine (ACRM). Minimum competency recommendations for programs that provide rehabilitation services for persons with disorders of consciousness[viii].
- European Academy of Neurology (EAN) 2020. Guideline on the diagnosis of coma and other disorders of consciousness[ix].

The principles of standard PDOC care outlined in these guidelines include the need for:

- Accurate assessment and diagnosis of the level of disorder of consciousness (DOC) at key time points through effective and timely neuro-behavioural assessment.
- Specialised care provided in all phases of the continuum from intensive care unit (ICU) to community by an interdisciplinary team skilled in the assessment and management of disorders of consciousness.
- Early and ongoing facilitation of treatment planning in consultation with the family, with the patient's best interests as the primary consideration.
- Sensory instigative rehabilitation to optimise chances of emergence and functional recovery.

Legislative Consideration

Patients in PDOC lack the capacity to make decisions regarding their own care and treatment and are dependent on others to act in their best interests. The exact nature of these interests varies from one individual to another, creating significant complexity around decision making and communication with loved ones across the continuum of care. The provisions afforded Queenslanders within the Power of Attorney Act (1998)(QLD), and the Guardianship Act (2000)(QLD) mean the law relating to futile or non-beneficial treatment is different from the other States and Territories. Specifically, substitute decision makers for Queenslanders experiencing PDOC, must consent to both the provision and withholding of treatments, even if deemed futile by health professionals. The need to provide adequate specialist advice and education to both families and health professionals at each stage of the care continuum is imperative to ensure a collaborative best interest's approach to care.

Emerging Evidence

In countries such as the United Kingdom (UK), the Netherlands[x], and Spain, where a networked model of care centred on specialist PDOC inpatient rehabilitation services has been adopted, health economic data is beginning to emerge. A multicentre cohort analysis study from the United Kingdom (UK) published in 2023 highlights that patients with a prolonged disorder of consciousness, treated in specialist rehabilitation facilities, demonstrated a mean net lifetime care cost saving of £167,774 when averaged across the vegetative, minimally conscious, and emerged cohorts. Emerged patients demonstrated mean net savings of £436,000 per patient per year of life. The identification of potential for emergence and provision of timely sensory instigative neurorehabilitation can generate net life-time cost savings that far exceed the costs of the evaluation and rehabilitation program. UK Rehabilitation Outcomes Collaborative (UKROC) data utilised for this study revealed an average of 365 PDOC patients were admitted to specialist rehabilitation services per year[xi]. This is still considered an underrepresentation of the overall UK PDOC patient population. Locally within Australia, the Australian Rehabilitation Outcomes Centre (AROC) has requested identified brain injury sites to submit PDOC data since 2020, but submissions are not mandatory, low in completion and reliant on patients being admitted to these specialist services.

The data challenge

At both state and national levels in Australia there is currently no systematic data collection to identify patients in PDOC. The National Health and Medical Research Council (NHMRC) recommended the establishment of a clinical registry to provide more accurate data on incidence in their 2008 guideline; however, this recommendation has yet to be implemented[xii]. This lack of data poses challenges for modelling services to support this vulnerable patient cohort.

Project response

Commencing in August 2024 BaSCI is facilitating a prospective audit of all PDOC inpatients able to be identified via the project teams. This coupled with an understanding of the community dwelling PDOC patient cohort supported by the National Injury Insurance Service Queensland (NIISQ) and National Disability Insurance Scheme (NDIS) will help to inform and mature a business case for future service models.

Current State

Within the Australian healthcare context there is insufficient translation of PDOC research and knowledge into national guidelines. The NHMRC ethical guidelines for the care of people in post-coma unresponsiveness (vegetative state) or in minimally conscious state published in 2008[xiii] contains relevant underlying principles for care provisioning, however the terminology and diagnostic criteria taken from the Post coma-unresponsiveness (vegetative state): a clinical framework for diagnosis[xiv] report are not aligned with the current international evidence-base.

In Queensland, the landscape for specialist ABI rehabilitation is evolving with a growing number and distribution of brain injury services. Within this, the current state of healthcare services for adult consumers in PDOC has been found to be characterised by fragmentation, inadequate coordination, clinical variation and limited access to specialist assessment and management. As a result, there are cases of both under and over treatment. Some patients are not identified as being able to benefit from a specialist PDOC sensory instigative rehabilitation approach; while others continue to be managed for decades in a state that would not be acceptable to them.

This document does not address the current state of paediatric PDOC-related services or care. However, it is recognised that adolescents and young adults (15-25) are likely to receive their acute and subacute care in adult facilities. It is also acknowledged that additional considerations for the complexities of care in this age group will be necessary in future planning and that opportunity exists for improvements in quality care to be leveraged across adult and paediatric services.

Services in Queensland

PDOC patients in Queensland encounter challenges accessing appropriate healthcare services. Due to the nature of their clinical presentation, patients in PDOC are often ineligible for local sub-acute rehabilitation units due to established admission or exclusion criteria. The *Statewide adult brain injury rehabilitation health service plan 2016–2026* did not reference this patient cohort and their sensory instigative rehabilitation care needs as a subgroup within the 'extremely severe' ABI category.

The tertiary Brain Injury Rehabilitation Service (BIRS) at Metro South Hospital and Health Service (MSHHS) was, until 2022, the designated statewide service for adult ABI rehabilitation in Queensland. The range of services spans the continuum from inpatient rehabilitation across transitional rehabilitation services to specialist community rehabilitation. Consumers in PDOC do not meet the current admission criteria for inpatient rehabilitation in the MSHHS specialist Brain Injury Rehabilitation Unit (BIRU).

In response, organic service development has occurred outside a strategic planning agenda. Some Hospital and Health Services (HHSs), for example Gold Coast HHS, have developed some capability to provide specialist care in a general rehabilitation setting with small numbers of clinicians who possess the specialist skills required for PDOC assessment and management. This dependence on the special interest and skill of individuals has risk

of not being sustained in the absence of an integrated model of care. Best practice guidelines around patient critical mass and clinician expertise are also unlikely to be met in the absence of a Statewide service element.

Additionally, Brighton Brain Injury Service in Metro North HHS (MNHHS) became a dedicated inpatient BIRU with the expertise to assess and manage PDOC patients. Operationally, the service accepted referrals from across the state regardless of the referring health service district or the consumers usual home residence.

The data presented below (see Table 2) represents the flow of PDOC patients accessing the Brighton Brain Injury Service over four (4) financial years. Based on proportional population data, the number of patients accessing specialist PDOC rehabilitation at the facility likely significantly underrepresents the whole-of-state need for these services. The lack of robust data collection at a statewide and national level for this population group makes identification of diagnostic level, locality and services accessed a significant challenge.

Table 2: Admission to the Brighton Brain Injury Service, MNHHS, by Patient Home HHS

	2023-2024	2021-2022	2020-2021	2019-2020
Metro South	38%	0%	50%	57%
Metro North	13%	0%	33%	29%
Sunshine Coast	12%	0%	0%	0%
West Moreton	13%	50%	0%	0%
Darling Downs	12%	50%	17%	0%
Central Queensland	0%	0%	0%	14%
International	12%	0%	0%	0%

BaSCI Project Activities

The BaSCI Project has three (3) mandatory deliverables across the entire project:

1. Data and KPIs: improved collection of meaningful data to understand access, outcomes, quality & safety for monitoring service performance, ensuring continuous improvement and informing future planning.
2. Access Pathways: development of pathways for both ABI rehabilitation and SCI services, supported by robust processes to ensure patients and treating teams can access clinically appropriate care, irrespective of where patients live or sustain their injury or when they commence their rehabilitation journey.
3. Service Pilots: the testing or scaling of models and/or interventions that increase access to high quality, specialist rehabilitation closer to home, where appropriate.

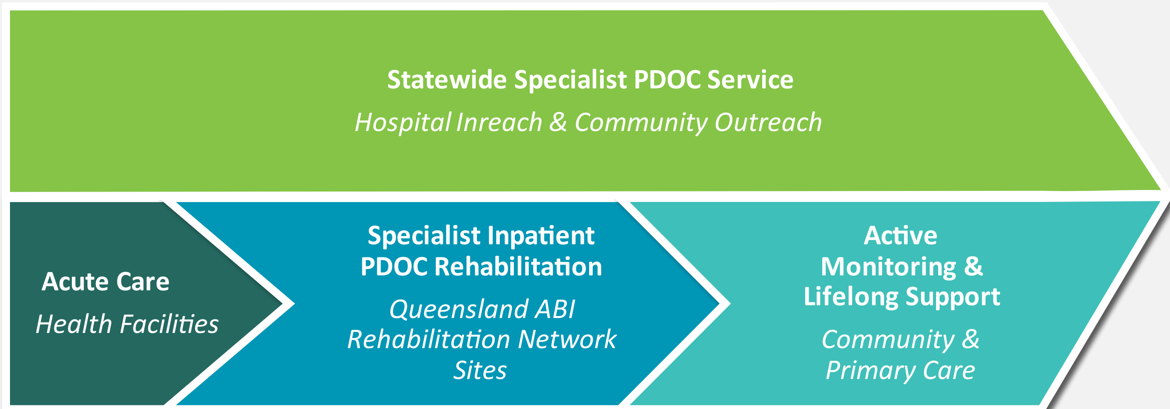
Under the project's ABI rehabilitation portfolio actions specific to patients in PDOC and their specialist care needs are progressing.

Data	Pathways	Pilots
• Local service data sharing and analysis • Self assessed workorce and service capability • Statewide clinlcal audit for PDOC	• Statewide PDOC pathway workshops • Future model of care development • Workforce capability strategies • Consumer Principles of Care	• Implementation of a 12-week assessment and management framework in subacute rehabilitation (MNHHS) • Acute Disorders of consciousness (MNHHS)

In focus: Future Model of Care

In translating evidence to the Queensland context, the BaSCI project has facilitated focused sessions to develop a future PDOC networked model of care. This is underpinned by international guidelines outlining the phases of care, key components within those phases and specific considerations for clinician and service requirements (See Appendix 1). The potential service model illustrated below, incorporates components in line with PDOC clinical guidelines for service provision. This needs further development and broad consultation which will be further facilitated through the BaSCI project.

Potential Service Model



Potential service model features

- Specialist PDOC service providing in-reach to acute settings and delivering outreach to non-specialist settings, and vigilant monitoring and review for community-based consumers. Aims to ensure equitable access to quality care across Queensland.
- Designated bedded services across the ABI Rehabilitation Network deliver admitted PDOC specialist rehabilitation closer to home supported by the expertise of the Statewide Service.

In Focus: Statewide Audit

Contributing to the lack of data on this consumer cohort is Queensland Health's current use of International Classification of Diseases (ICD) 10AM coding. This edition does not contain the codes relevant for disorders of consciousness (DOC). Encouragingly, ICD-11, when adopted, will overcome this hurdle to some extent, with an ongoing need for appropriately-skilled clinicians to assess and diagnose the level of DOC accurately.

The BaSCI project is working to improve the visibility of PDOC consumers across the system by conducting a prospective audit to determine the number of patients across Queensland for a 10-month period from August 2024. This information will be used to establish service needs and understand patient flow while informing the development of an appropriate model of care for the state.

In Focus: Pilots

Reflecting the HHSs' interest in PDOC, the Metro North BaSCI project team delivered two discrete funded service pilots that demonstrated significant successes in both the acute[xv] and sub-acute[xvi] settings.

Acute Disorders of Consciousness

This 12-month pilot introduced DOC specific education, training, and resources for clinicians in the Royal Brisbane and Women's Hospital neurosurgical service.

Results:

- Significant improvements (50%) in staff knowledge and confidence in managing this patient cohort.
- Significant increased compliance with assessment and diagnosis requirements.
- Establishment of discipline specific DOC champions.
- Agreement of ward-based processes aligned with international guidelines.

The pilot facilitated resource sharing between service providers including the DEAR DOC *'Delivering Education and Resources to staff and families on Disorders of Consciousness'* from researchers at MSHHS.

While the pilot demonstrated success, sustaining impact has been challenging.

Key learning:
Consultation with acute stakeholders and clinical leaders in this space highlighted support for a specialist in-reach service to further improve the quality, consistency, and sustainability of diagnosis and family communication.

Implementation of a 12-week Assessment and Management Framework in Subacute Rehabilitation

Delivered in Brighton Brain Injury Service, this pilot utilised existing rehabilitation staff and inpatient beds within the service to test best practice evidence for patients in PDOC.

Results:

- Seven patients admitted to the PDOC pathway from July 2022 to June 2023.
- 66% compliance in delivering the key PDOC pathway elements as designed.
- Three out of four patients admitted to the pathway transitioned in accordance with the implemented criteria led decision framework.
- 80% of staff concurred that the PDOC pathway is valuable in their clinical practice, with a 90% consensus on its benefit for patients and families
- Compliance with clinical guidelines for PDOC assessment and management improved by approximately 48%, to achieve an overall 69% compliance.
- Improvement 5-fold in compliance with minimum competency recommendations for services that provide sub-acute rehabilitation for patients in PDOC to take it to an overall 86% compliance.

Key learning:
Sustainability of gains is highly reliant on specialist clinical skill and sufficient PDOC patient flow to maintain these skills. This emphasises the importance of advocacy, collaboration, and ongoing evaluation to uphold evidence-based care and ensure the effectiveness of PDOC-related care.

Capturing risk and communicating change

During the planning and consultation phase of the BaSCI PDOC Pathway Workshop in March 2024, a significant change to PDOC service access was noted. Metro North stakeholders reported Brighton Brain Injury Service would no longer accept referrals for patients from outside of the HHS catchment. The workshop facilitated solution focused discussion on the emerging risk, related actions and next steps at both HHS and statewide project level[xvii].

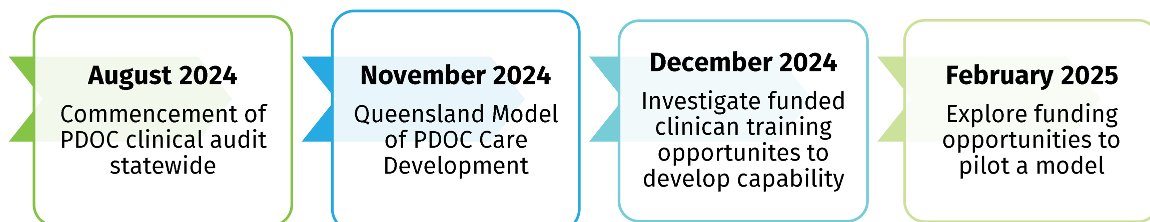
Noting the reliance on Brighton Brain Injury Service for the delivery of specialist PDOC rehabilitation care, particularly in metropolitan Brisbane, the recent changes to referral have had an immediate and significant impact on patient access and flow. In the absence of subacute rehabilitation settings with the capability and capacity to address these patients' needs, repatriation to suboptimal or inappropriate clinical settings can and is occurring.

> The Statewide BaSCI Advisory Committee escalated this change and associated risk to patient safety via the Deputy Director-General, Clinical Excellence Queensland (DDGCEQ), alongside internal briefing through HHSs to their respective executives.

On 23 September 2024, DDGCEQ actioned correspondence to all Health Service Chief Executives, Chairs of Clinical Networks and the Chief Allied Health Officer indicating the changes to service provision and the actions that will be undertaken by the project to 30 June 2025.

Partnering to design a future state

Building on project activities to date BaSCI will continue to deliver PDOC specific actions through the ABI Rehabilitation Working Group and with oversight from the project Advisory Committee through working towards the key milestones below:



Appendix 1

Key requirements of a future service model

The below considerations align to the evidence-base at a system and provider level for a future service model.

System requirements

- Agreement that a centralised networked approach to whole-of-life PDOC patient management would benefit patient outcome and flow in Queensland.

- Acknowledgement that PDOC patients represent a discreet cohort within the wider ABI patient group (by volume and complexity) for whom a specialised approach to management improves outcomes and equity.

- Agreement as a network of ABI service providers that pathways in and out of any cohorted specialist inpatient settings will be developed and supported to optimise patient flow and outcomes.

- Service provisioning within the system to support:
  - Access to assessment, diagnosis, and ongoing monitoring including arrangement of in-reach and outreach services for whole-of-life PDOC care.
  - Data monitoring of statewide patient flow and ongoing monitoring of community dwelling patients with PDOC.
  - Training/education to local HHSs and community services.
  - Specialist support for active management and vigilant assessment during the first-year post injury. This support may be offered in local general or neuro-rehabilitation centres following a period of PDOC specialist inpatient assessment and management, or in the community.
  - Outreach advisory support extending to insurance bodies providing care for community dwelling PDOC patients.
  - Annual assessment and review in patients' place of residence as required/practical. Annual reviews to include best interests' discussions and review of any treatment escalation plans.
  - Telehealth service delivery and resources for in-reach and out-reach purposes.
  - Integration of palliative care services within the service model to support end-of-life-care and decision making around withdrawal of clinically assisted nutrition and hydration.
  - Responsiveness to the emerging evidence base & contribution to research evidence for PDOC population in collaboration with community stakeholders and other institutes/organisations.
  - Engagement in the development and delivery of a PDOC research and quality improvement (QI) framework across the ABI network and continuum of care to progress towards recommendations outlined in the relevant international guidelines.
    - European Academy of Neurology guideline on the diagnosis of coma and other.pdf
    - ACRM Minimum competency recommendations for rehab of PDOC.pdf
    - RCP Guidelines on the diagnosis and management of PDOC.pdf

Specialist ABI rehabilitation service requirements

- Inpatient PDOC rehabilitation should be delivered in CSCF Level 5/6 facilities that can develop compliance with the ACRM minimum competency standards for facilities offering PDOC rehabilitation.[xviii]
    - ACRM Minimum competency recommendations for rehab of PDOC.pdf

- Ability to deliver (or willingness to progress service competency towards) clinical intervention and care in line with the Royal College of Physicians national clinical guidelines on PDOC following sudden onset brain injury.[xix]
    - RCP Guidelines on the diagnosis and management of PDOC.pdf

- Admission of a critical mass of PDOC patients for maintenance of clinical skills, expertise, and qualifications.

- Sufficient bedded capacity to meet the defined catchment demand (based on trauma catchments and patient flow and consideration of age criteria for paediatric services).

- Patients treated in this setting require access to controlled stimulus environments (including options for lighting and sound control).

- Infrastructure to allow patients the benefit of access to single rooms during their admission

- Access to highly specialist elements of care:
    - Coordinated assessment and management of highly complex physical, cognitive, sensory and communication disorders.
    - Medical management (including stabilisation of dysautonomia, seizures, complex nutritional needs, decannulation and respiratory management).
    - Expert assessment and diagnosis of VS/UWS and MCS+/- (including application of formal diagnostic tools such as Coma Recovery Scale-Revised (CRS-R) and Sensory Modality Assessment and Rehabilitation Technique (SMART).
    - Sensory instigative rehabilitation addressing core PDOC minimum goal set (Detailed in the *BaSCI BBIS assessment and management framework*).
    - Specialist complex and customised equipment prescription (e.g., specialist seating, electronic assistive technology)
    - Best interest decision-making (including treatment escalation planning and support for end-of-life care following decisions to withdraw life sustaining treatment).

- Options for readmittance to specialist centres in circumstances such as:
    - Improvement in level of responsiveness.
    - Community care unable to meet care needs satisfactorily.
    - Specific disability management that requires specialist management (i.e., severe spasticity, marked postural difficulties, pressure injuries).
    - Patient at a critical point for diagnosis and decision making that requires formal re-assessment and management.
    - Complex best interest discussions/ completion of necessary processes for consideration of CANH withdrawal that is unable to practically be provided in the community.

- Recruitment, retention, and development of expert level MDT clinicians skilled in the clinical, ethical, and legal requirements for effective management of the PDOC patient cohort. (See RCP guideline for minimum skill and experience requirements)

- Maintain training / PDOC qualifications of specialist staff, experienced in diagnosis, management, and application of specialised assessments (e.g., CRS-R, SMART).
- PDOC inpatient rehabilitation provision situated within a broader moderate to severe ABI case-mix to minimise risk of staff burnout, support staff retention, and succession planning. [xx]

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