ACI NSW Agency for Clinical Innovation

Brain Injury Rehabilitation Directorate

Appendices

Model of Care
NSW Brain Injury Rehabilitation Program

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Appendix A:
List of the Steering Committee Members

First Name	Surname	Role and Organisation
Chris	Shipway	Director, Primary and Chronic Care Services, ACI
Adeline	Hodgkinson	Director, Brain Injury Rehabilitation Unit, Liverpool Hospital/ Director BIRD
Denis	Ginnivan	Manager South West Brain Injury Rehabilitation Service
Indu	Nair	Rehabilitation Specialist, Head of Department, Department of Rehabilitation Medicine
Dominique	Grognard	A/Clinical Stream Nurse Manager, Rehabilitation
John	Estell	Rehabilitation Staff Specialist, St George Hospital
Lyn	Olivetti	Service Development Manager, Rehab and Aged Care
Adrienne	Epps	Rehabilitation Department Head
Vicki	Rose	A/Executive Director Allied Health and Chronic Care
Barbara	Strettles	Manager, Brain Injury Rehabilitation Directorate
Jennifer	Parkin	Implementation Manager, ACI

Appendix B:
List of Stakeholders Consulted

Brain Injury Rehabilitation Services	Westmead
	Liverpool
	Royal Rehab Ryde
	SCHNR_Rehab 2 Kids
	SCHNW_Kids Rehab
	South Western NSW
	Northern NSW
	Hunter
	New England
	John Hunter Kaleidoscope Paediatric BIR Team
	NSW Mid North Coast
	Dubbo
	Mid-Western NSW
	Southern NSW
	Illawarra
LHDs not hosting a specialist brain injury rehabilitation service	Nepean Blue Mountains
	Central Coast
	Sydney
	South Eastern Sydney
Lifetime Care and Support Authority	Suzanne Lulham, Director Service Delivery Neil Mackinnon, Manager Service Co-ordination
Ministry of Health	Roger Holt, Associate Director, Government Relations Branch Sharon Smith, Activity Based Funding Taskforce
Ageing, Disability and Home Care	Samantha Taylor, Executive Director
Acquired Brain Injury Services Inc.	Sarah Watson
Brain Injury Australia/BIRD executive	Nick Rushworth
Brain Injury Association of NSW/BIRD Executive	Angelina Fixter
Carer / BIRD executive	Cheryl Koenig OAM
2 BIRP clients	Participants of the SWBIRS transitional living program

Appendix C:
Diagnostic Project Information Page

NSW Brain Injury Rehabilitation Program Model of Care 'Diagnostic Project'

Aim

Nexus Management Consulting has been engaged by the Agency for Clinical Innovation to undertake a 'diagnostic' of the network of specialised rehabilitation services delivered across NSW for patients with a traumatically acquired brain injury. This review will inform any organisational and service delivery changes for the BIRP Model of Care in the future.

Methods

The project comprises:

1. A review of the literature on Models of Care in other jurisdictions in Australia and internationally.
2. A short survey of the 15 BIRP services across NSW to obtain information on:
   - funding and staffing
   - capacity and utilisation
   - referral pathways and waiting lists
   - discharge planning
   - outcome measures and KPIs.
3. Consultation with the 15 BIRP services to obtain information on:
   - patient journeys and process maps
   - strengths and weaknesses of the existing Model of Care, including identified gaps in service provision
   - key facilitators and barriers to clinical service delivery
   - local Models of Care compared with the findings of the literature review
   - the current funding model and the impact of ABF on service delivery
4. Targeted surveys and consultations with patients and their families/carers, the Ministry of Health, other government departments, authorities and non-government providers.

The project is to be completed by mid-May 2014 with a final report that identifies key themes to guide decision making for revising the BIRP Model of Care.

Appendix D:
Survey Instrument

BRAIN INJURY REHABILITATION PROGRAM MODEL OF CARE

BIRP Service Survey

Nexus has been engaged to identify key issues and themes to inform the development of a revised BIRP Model of Care. This short survey aims to obtain some basic, preliminary information prior to a series of on-site consultations with all BIRP services across NSW.

Please contact Melinda Daley on 0426 104 692 if you have any questions about completing the survey.

Name:

LHD:

Name of BIRP service:

Which of the following brain injury rehabilitation services do you provide?
(please put a tick against the service(s) that you provide)

- ☐ Inpatient services
- ☐ Transitional Living Programs
- ☐ Community services

1. Number of beds

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2. Number and type of staff

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3. Does your BIRP service use a documented or formal care pathway, clinical protocol or Model of Care?

- ☐ Yes
- ☐ No

If yes, please email a copy to Melinda@nexusmc.com
(NB: this will only be available to the Nexus consulting team for the purpose of the project and will not be circulated).

Appendix D:
Survey Instrument

BRAIN INJURY REHABILITATION PROGRAM MODEL OF CARE

BIRP Service Survey

4. What are the strengths of your existing BIRP service that you would wish to see embedded in a state-wide Model of Care?

5. What are the service gaps or weaknesses with your BIRP service?

6. What are the service gaps or weaknesses with the Brain Injury Rehabilitation Program across the state?

7. Please provide details of any outcome measures or KPIs that you report against for the services (if necessary, please email documents to Melinda Daley: mdaley@nexusmc.com)

8. Please feel free to provide any other comments or information useful to the project in identifying key issues for a revised BIRP Model of Care (you can also email relevant documents to Melinda Daley: mdaley@nexusmc.com)

Thanks for your assistance

Appendix E:
Semi-Structured Interview Schedule

BIRP Diagnostic Project

BIRP Service Consultations

Issues for Discussion

1. Welcome and introductions
2. Overview of the project (see attachment 1)
3. Discussion of online survey responses
4. Exploration of current Model of Care
5. Towards a new Model of Care
   - service development/enhancement priorities
   - implications for staffing and funding
   - implications for referral pathways and patient journeys
   - implications for patient outcomes
6. Implementation issues
7. Gathering of information relevant to the diagnostic project
8. Other business

Appendix F:
Literature Review

Agency for Clinical Innovation

Model of Care for Brain Injury Rehabilitation - Diagnostic:

Literature Review

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1. Introduction

NSW Agency for Clinical Innovation (ACI) has engaged Nexus Management Consulting to undertake a diagnostic of the network of specialised rehabilitation services delivered across NSW for patients with a traumatically acquired brain injury (TBI). This review will inform any organisational and service delivery changes for the BIRP Model of Care in the future.

The project comprises five stages:

- project initiation and planning
- literature review
- service mapping
- key stakeholder consultations
- reporting.

This document presents the key findings from a review of literature and is structured as follows:

- **section 2** outlines the approach to the literature review
- **section 3** provides a brief overview of brain injury
- **section 4** provides a review of literature focusing on Models of Care in addition to guiding principles
- **section 5** suggests elements to consider when reviewing NSW BIRP Model of Care and services

The findings and key lessons from this review will be refined and further review undertaken (where appropriate) following consultation with key stakeholders including the ACI project staff.

2. Literature Review Approach

2.1 Sources and Criteria

As outlined in the 'Request for Quotation Response', the literature review involves a selective review of Models of Care in other jurisdictions in Australia and internationally. Rather than a comprehensive literature review, the focus is on best practice and selection of service models guided by stakeholders.

The literature review findings will be compared with the existing BIRP Model of Care to provide an initial gap analysis; that is, to identify potential gaps and areas for service development in NSW.

The literature review was undertaken using health and community health databases PubMed® and Lippincott, Williams and Wilkins search facility. The search was targeted at the focus areas of brain injury rehabilitation and Models of Care. In addition, policy documents and publicly available information were sourced from government and NGO websites in Australia and internationally. The ACI also provided a number of papers.

Limitations: it should be noted that not all of the literature reviewed relates specifically to traumatic brain injury. Given the limited literature, including Models of Care focusing specifically on TBI, literature relating to acquired brain injury was also reviewed. Acquired brain injury includes traumatically acquired brain injury but also includes brain injury associated with stroke, anoxia, inflammation etc.

3. Brain Injury

Acquired Brain Injury (ABI) may be defined as "Injury to the brain which results in deterioration in cognitive, physical, emotional or independent functioning. ABI can occur as a result of trauma, hypoxia, infection, substance abuse, degenerative neurological disease or stroke. These impairments to cognitive abilities or physical functioning may be either temporary or permanent and cause partial or total disability or psychosocial maladjustment." (Commonwealth Department of Human Services and Health, 1994).

Over 600,000 Australians have an acquired brain injury, with 3 out of four of them aged under 65 and as many as 2 out of three of these acquiring their brain injury before the age of 25 (Brain Injury Australia).

In NSW, over 100,000 people currently have a brain injury, with over 1,000 people each year sustaining a traumatic brain injury and experiencing long term disability (Agency for Clinical Innovation). A Traumatic Brain Injury (TBI) is an acquired brain injury as a result of trauma. Causes of traumatic brain injuries include external events such as motor vehicle accidents, falls, assaults, sporting accidents or blows to the head.

3.1 Severity of brain injury

The severity and resulting impact can vary greatly. Severity of brain injury may be classified using a range of methods and tools. Common methods include the Glasgow Coma Scale (GCS) and Post Traumatic Amnesia (PTA).

The Glasgow Coma Scale focuses on elements such as eye response, verbal response and motor response with scores ranging between 3 and 15 with 3 being the worst and 15 being the best.

PTA classifies severity based on the duration of post-traumatic amnesia. PTA is the interval from injury until the patient is orientated, and can form and later recall new memories.

The Westmead PTA Scale (Marosszeky 1997), is a tool developed to assess PTA. The authors suggest that it is important to know whether a patient is experiencing PTA for four reasons:

- *Patient Care* - the behaviours associated with PTA include agitation, irritability and restlessness, therefore measuring PTA monitors the patient's mental state during this acute recovery stage
- *Rehabilitation* - as new learning ability is impaired during PTA, conventional forms of therapy which require the patient to retain information over time are not viable
- *Neuropsychological testing* - the neuropsychological testing of patients in PTA will have little validity
- *Index of severity* - the duration of PTA is used as an index of severity for prognosis, medico-legal and scientific purposes

The table below provides GCS and PTA scores aligned to severity of brain injury (Acquired Brain Injury National Management Clinical Network, 2009).

TABLE 1 Severity of Brain Injury

	Duration of unconsciousness	GCS score	PTA
Mild	<15 minutes	13-15	< 60 minutes
Moderate	15mins.-6 hours	9-12	1-24 hours
Severe	>6 hours	3-8	> 24 hours

The relationship between these proxy measures of severity and the actual long term outcome for patients is variable as "some patients categorised as 'severe' at the time of injury will go on to make a complete and rapid recovery, while in others an apparently 'mild' brain injury will lead to long-lasting and eventually catastrophic effects on family relationships and societal participation" (BSRM 2003). Where there is a 'mis-match' between GCS and PTA, the PTA is generally the preferred index (ABINMCN, 2009).

The duration of PTA and its relationship to severity is itself variable with some referring to mild TBI as PTA less than 24 hours (WHO 1992) and moderate TBI as extending beyond 24 hours. Friedland and Hutchinson (2013) suggest that given the range of different classification systems, it is important to be clear about the classification system used.

3.2 Health Consequences

Traumatic brain injury can negatively impact physical, emotional, social, marital and vocational functioning (Zasler & Martelli, 2003). This can impact on ability to manage aspects of one's own care as well as the ability to communicate and socialise with people and can adversely affect personal and social relationships. The consequence of brain injury is far reaching, not only posing challenges for the individual affected but also impacting on the lives of partners, other family members, friends, neighbours and work colleagues.

Whilst impaired physical function may result in the need for assistance with activities of daily living such as feeding, bathing and dressing, cognitive functioning may also be altered resulting in problems with executive function of impairments such as concentration, memory and social behaviour.

People with an ABI are more likely to suffer from mental health problems in comparison to the general population. These problems may present as anxiety, depression or drug and alcohol addiction (Victorian Government Department of Human Services, 2004). There may be psychosocial and emotional issues associated with changes to personality and behaviour which in some cases can present as challenging behaviour (Conzen et al, 1992). Kelly et al describes 9 behavioural domains, these being verbal aggression, physical aggression against objects, physical acts against self, physical aggression against people, inappropriate sexual behaviour, perseverative/ repetitive behaviour, wandering/absconding, inappropriate social behaviour and lack of initiation.

In some cases the individual becomes 'a different person' to whom they were pre-brain injury. It can result in loss of employment, loss of friends and marital breakdown. The once carer may become the cared for and the decision maker now not able to make the same level of decision and the 'bread winner' may now be unable to work and support their family in the way they once did. This can put huge pressures on the individual, their family and their relationships, with people having to re-adjust to a new way of living, a new way of thinking and a new way of approaching aspects of everyday life. As with other effects of brain injury the psychosocial impact may be moderate or severe and may result in social isolation affecting the ability to lead a fulfilling life.

As discussed above, the impact of brain injury has the ability to cut across all aspects of a person's life. The British Society of Rehabilitation Medicine (BSRM, 2003) has categorised problems associated with ABI into 4 broad categories. Some of the deficits arising from ABI and relevant categories are presented in table 2.

TABLE 2 ABI associated categories

Physical	Communicative	Cognitive	Behavioural/ emotional
Motor deficits	Language deficits	Impairment of	Emotional liability
• paralysis	• expression	• memory	Poor initiation
• abnormal muscle tone	• comprehension	• attention	Mood change
• ataxia/coordination	Dysarthria	• perception	Adjustment problems
Sensory deficits	Dyslexia	• problem solving	Aggressive outbursts
Visual/hearing loss	Dysgraphia	• social judgement	Disinhibition
Symptoms e.g. headaches, fatigue, pain			Inappropriate sexual behaviour
Dysphagia			Poor motivation
Seizures			Psychosis

In addition to physical, psychosocial and emotional aspects of brain injury, the impact of the brain injury can affect the hopes, dreams and plans for the future. The person and their families, often have to deal with changes and disruption to routine as a result of the need to attend hospital appointments or have visits to the home by a range of health and social care professionals.

Given that a high proportion of people are young and will live a normal lifespan, the level of support required poses a challenge to the economy.

3.3 Rehabilitation

The World Health Organisation defines rehabilitation as "A set of measures that assist individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environment". The benefits of rehabilitation, as widely documented, can be improved when services are coordinated by multi-disciplinary teams. Recovery for brain injury can occur over months and years with clients requiring different levels and types of support at different times during recovery. As such it is essential that services are delivered based on the individual needs of the clients so that they have access to the care they need at the time they need it.

Whilst rehabilitation should start as soon as possible, with elements such as reducing impairment occurring in the acute hospitalisation stage, as previously discussed, this review focuses mainly on the post-acute stage.

4. Brain Injury Rehabilitation Models of Care

A "Model of Care" broadly defines the way health services are delivered. It outlines best practice care and services for a person, population group or patient cohort as they progress through the stages of a condition, injury or event. It aims to ensure people get the right care, at the right time, by the right team and in the right place (Government of Western Australia Department of Health, 2012). Models of care are often guided by principles or standards which offer direction.

One of the challenges is that whilst traumatic brain injury rehabilitation services operate in a number of countries, information on Models of Care is limited with a number of countries and services simply describing some of the service elements as opposed to a complete system.

Given the limited literature on Models of Care, this section discusses general rehabilitation models, including some of the guiding principles and standards, as well as models specific to traumatic brain injury rehabilitation.

4.1 Australian Faculty of Rehabilitation Medicine

The Australian Faculty for Rehabilitation Medicine (AFRM) developed standards for the provision of 'Inpatient Adult Rehabilitation Medical Services in Public and Private Hospitals' (2011). These standards are for specialist rehabilitation medicine units and not for medical rehabilitation programs conducted by other physicians who are not specialists in rehabilitation medicine. Whilst the standards are also applicable to tertiary level highly specialised inpatient rehabilitation programs (e.g. brain injury, spinal cord injury or burns rehabilitation) it is stated that these tertiary rehabilitation programs may have requirements which are beyond the scope of the general Standards document. The AFRM also point out that whilst the standards are for specialist medical inpatient services and not designed specifically for use in alternate settings such as community based settings, day hospital settings etc. they may be used as a guide. The standards focus on six aspects of service provision:

Governance

Rehabilitation services focus on preventing and reducing functional loss and the management of disability in the physical, psychosocial and vocations. There is a focus on assisting people to achieve optimum levels of independence via a coordinated approach from a range of medical, nursing and allied health professionals.

Staffing

A team approach consisting of medical, nursing and allied health and support staff. The AFRM suggest a ratio of 0.625 rehabilitation physicians (Stroke, Neurology, Traumatic Brain Injury, Spinal Cord Dysfunction) to each 10 inpatient beds. Nursing staff will be qualified/ experienced in rehabilitation medicine with sufficient numbers to deliver a safe and effective service. The table below suggests staffing ratios for allied health staff. As previously stated, the standards and therefore staffing ratios relate to inpatient services only.

TABLE 3 Suggested Ratios for Allied Health Staff

Allied health staff ratios to each 10 patients	
Impairment type occupational	1.5
Physiotherapist	1.5
Allied Health Assistant	0.2
Speech pathologist	1.5
Clinical psychologist	0.2
Neuro-psychologist	1.0
Podiatry	Consult
Dietician	0.5
Social work	1.2
Exercise physiologist	consult

Facilities and equipment

The physical environment should be appropriate to the needs of the client (e.g. the presence of hand rails, ramps and wheelchairs). There should also be the space to conduct group therapy sessions, physical therapy assessments and access to relevant technical equipment such as scanners etc.

Policies and procedures

There should be procedures relating to aspects of individual care such as assessment, progress, case management meetings, discharge planning and liaison with other support services.

Quality improvement and risk management activities

Medical rehabilitation services have a risk management framework addressing consumer involvement, access, appropriateness, effectiveness, safety and efficiency.

Education and research

Services should be actively engaged in education activities such as supporting undergraduate teaching and promoting research.

Whilst these standards aren't specifically for TBI rehabilitation, some elements may still be relevant and so have been included in this paper.

4.2 National Service Framework for Long Term Conditions – UK

In 2003, the Royal College of Physicians (RCP) and British Society of Rehabilitation Medicine (BSRM) published national clinical guidelines to act as a framework for the management of people with acquired brain injury. The guidelines focused on post-acute rehabilitation and longer term care so as to complement the guidelines on the management of head injuries, published by the National Institute for Clinical Excellence (NICE) in June 2003, which focused on the management in the first 48 hours after head injury.

The guidelines also served to inform the development of the National Service Framework (NSF) for long term conditions.

The RCP & BSRM recommended that rehabilitation services should be based on the following principles:

- patient centred care - recognising that different patients require different services and that patients require different services at different times
- joint planning, commissioning and development of services to coordinate care between health and social services and linking with other government and non-government services to maximise resources and reduce burden on services
- the development of rehabilitation service networks including specialist regional services for more complex cases, local hospital and community rehabilitation teams, social services, voluntary agencies and specialist brain injury vocational rehabilitation services
- coordination of rehabilitation to ensure a smooth transition between services
- timing, intensity and duration of treatment should be appropriate to the needs of the individual. Early rehabilitation has been found to have better outcomes and specialist intensive rehabilitation is both effective and cost effective (Prigitano & Pliskin 2003; Cullen et al 2013)
- the number and experience of staff within rehabilitation support services should be appropriate to meet the requirements of the caseload.

This National Service Framework (NSF) for Long-term Conditions (DoH, UK 2005) was developed to improve health and social care services for people with long term neurological conditions and their carers.

A 'long-term neurological condition' results from disease, injury or damage to the body's nervous system (i.e. the brain, spinal cord and/or their peripheral nerve connections) which will affect the individual and their family in one way or another for the rest of their life. However, whilst the term 'long-term neurological condition' can be applied to acquired brain injury (including TBI) it refers to a number of conditions categorised as:

- sudden onset conditions, for example ***acquired brain injury*** or spinal cord injury, followed by a partial recovery.
- intermittent and unpredictable conditions, for example epilepsy, certain types of headache or early multiple sclerosis, where relapses and remissions lead to marked variation in the care needed;
- progressive conditions, for example motor neurone disease, Parkinson's disease or later stages of multiple sclerosis, where progressive deterioration in neurological function leads to increasing dependence on help and care from others. For some conditions (e.g. motor neurone disease) deterioration can be rapid;
- stable neurological conditions, but with changing needs due to development or ageing, for example post-polio syndrome or cerebral palsy in adults.

Within the NSF, it is suggested that much of what is contained in the guidance can be applied to anyone living with a long-term condition (and therefore would be relevant to TBI).

11 Quality Requirements (QRs) were developed which are designed to put individuals at the heart of care, taking into consideration their needs and choices with the aim of providing coordinated care to maximise independence and promote quality of life. A summary of each of the QRs is provided below.

QR 1: A person centred service

QR 2: Early recognition, prompt diagnosis and treatment

QR 3: Emergency and acute management

QR 4: Early and specialist rehabilitation

QR 5: Community rehabilitation and support

QR 6: Vocational rehabilitation

QR 7: Providing equipment and accommodation

QR 8: Providing personal care and support

QR 9: Palliative care

QR 10: Supporting family and carers

QR 11: Caring for people with neurological conditions in hospital or other health and social care settings

In 2006, the NSF Advisory Group recommended that relevant societies undertook a mapping exercise to relate their existing standards to the NSF recommendations to produce a more clearly defined set of national benchmark standards. As a result of this the BSRM mapped existing BSRM standards and other guidelines relevant to rehabilitation to the NSF for Long-term Conditions Quality Requirements. 51 standards were mapped to 4 quality requirements:

QR 4: Early and specialist rehabilitation

To support clients in management of their condition with a focus on maintaining independence. A key element of this recommendation is an integrated approach to assessment and planning to ensure people have access to appropriate services whilst at the same time avoiding unnecessary duplication. Assessment and planning should take into account the holistic needs of the person including housing, transport, benefits, education, careers advice, employment and leisure.

QR 5: Community rehabilitation and support

Rehabilitation has been found to have a positive impact with intensive day rehabilitation helping people to cope better at home and in the community and community rehabilitation helping people to maintain independence enabling social participation. Rehabilitation has been found to be most effective when health and social care organisations work in collaboration (Sander & Kreutzer, 1999).

QR 6: Vocational rehabilitation

To enable people with a long-term neurological condition to return to work or training or to engage in alternative work or training.

QR 7: Providing equipment and accommodation

To support independence, people should have access to equipment and resources such as those that help with mobility and sensory impairment (bathing, walking); specialist equipment (computer equipment, electronic assistive devices) and equipment to help to prevent deterioration (seating or standing aids).

4.3 Traumatic Brain Injury Model Systems

The United States Model Systems (MSs) of care for TBI was initiated by the National Institute on Disability and Rehabilitation Research (NIDRR) in 1987 to improve care and outcomes for individuals with TBI (Dijkers M. P. et al 2010). The TBI Model Systems comprises 16 centres of excellence from various states across the US (Simpson & Strettles, 2014).

In line with specifications outlined in the initial grant funding policies, the core elements of each system were to be a trauma hospital and rehabilitation unit or hospital with links to emergency services, vocational rehabilitation, social services, outpatient programs and follow up. The TBI MSs were required to:

- demonstrate and evaluate the costs and benefits of a comprehensive service delivery system for individuals with TBI
- establish a research program to develop a new database and conduct innovative analyses
- demonstrate and evaluate the development and application of improved methods essential to the care and rehabilitation of individuals with TBI; and
- participate in national studies of the TBI MS by contribution to a national database.

Required system components were emergency medical services, acute neurosurgical care, comprehensive rehabilitation services and long term interdisciplinary follow up. Behaviour modification programs, rehabilitation services at home and community living opportunities were optional elements. Research and TBI National Data Base (NDB) are other key components of the US TBI MSs.

Most of the researchers are clinician researchers dedicating their time to clinical care, administration, research and education and model system activities. The number of units within the TBI MS provides access to a large number of cases which supports opportunities for collaborative research.

MSs are required to enter information on cases that meet inclusion criteria into the NDB. Data entered includes demographics, injury and admission date, severity of injury, GCS, functional status pre-injury as well as at admission to rehabilitation and discharge using Functional Independence Measure (FIM). Follow up data is entered at the 1, 2, 5 and 10 year anniversary of injury and every 5 years thereafter. Follow up data includes FIM, substance abuse, psychiatric problems, re-hospitalisations and the Satisfaction with Life Scale (Diener et al 1985), however accessing follow up data can be problematic due to inability to trace clients or their unwillingness to cooperate over time.

Dijkers (2010) discusses that whilst MSs have contributed to TBI rehabilitation research, it is difficult to quantify the impacts of the program. Outcomes of the TBIMS include advances in practice (supported employment for individuals with TBI, changes in policy, advances in outcome measurement (confusion assessment, family needs questionnaire etc.) and advances in clinical care, to name a few. A study conducted to measure functional outcomes across TBIMS centres (Dadah et al 2013) found significant variation. The researchers suggest that the differences may be due to institutional structures or elements of care such as type and intensity of therapeutic intervention, number of goal planning sessions, access to resources and education, discharge planning and changes to practice during the 10 year study period. The tools used to measure outcomes were FIM, based on observations by clinicians and therapists and DRS and GOS-E both of which are based on self report. Accuracy of self reporting may also be a contributing factor to variation in outcomes. The authors conclude that “once factors associated with greater functional and cognitive gains can be identified, information regarding the processes of care and/or institutional practices that reliably promote these gains during the inpatient rehabilitation course and following discharge can be shared.”

4.4 Traumatic Brain Injury Rehabilitation in the Netherlands

In the Netherlands an average patient with moderate or severe TBI is referred to a level 1 trauma centre. All of the centres have a consulting psychiatrist who monitors the patient for impairments and initiates immediate rehabilitation strategies and involvement of the family in rehabilitation (Horn et al 1990). Patients are then referred to inpatient rehabilitation when they are assessed as having adequate fitness and cognitive ability to engage in therapy but are too disabled to return home. However, given that it can take time for some patients to get to the stage where they are ‘ready’ for referral to inpatient rehabilitation, combined with capacity issues within the acute hospital, patients are sometimes discharged to nursing homes which lack specialised programs (Ribbers, 2007).

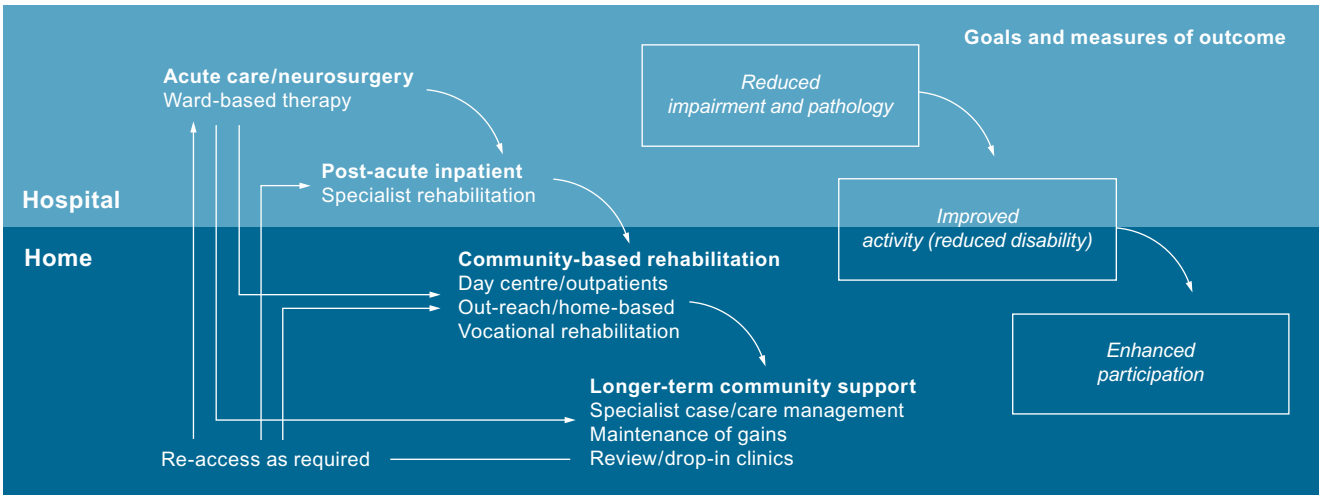
Approximately 90% of patients with TBI in the Netherlands are discharged from rehabilitation centres to their homes with the majority of them receiving outpatient rehabilitation, on average 3 times a week for 6-8 months. Problems exist with coordination between organisations and lack of long term follow up of individuals, especially for those with mild TBI. Many patients with a mild TBI (often associated with injuries such as whiplash and sports injuries) are not referred to emergency departments. Approximately 90% of patients with a TBI who are discharged home do not receive follow up treatment (Van Balen HGG, 1997). It is estimated that approximately 100,000 young patients with TBI living in their home environment have unmet needs (Ribbers, 2007).

Ribbers (2007) highlights national coverage of rehabilitation facilities and compulsory healthcare insurance which includes rehabilitation and coverage of costs associated with long-term nursing as strengths of TBI rehabilitation in the Netherlands but suggest that capacity issues have a negative impact on the ability to deliver a well-coordinated, long term program focusing on the individual and family.

4.5 The Slinky Model

The Slinky model (Turner-Stokes, 2001) in Figure 1 specifies different stages of rehabilitation

FIGURE 1 The Slinky model (Turner-Stokes, 2001)



The 'slinky' analogy is used to communicate the transition through services and the importance of communication between the services to ensure a 'smoothed continuum' (as with a slinky toy).

As can be seen in the slinky model, rehabilitation begins in the acute phase where the focus is on reducing impairment and preventing further complications. Post-acute rehabilitation as an inpatient may be required to aid the transition between hospital and community. Interventions often focus on improving activity and reducing disability. Once back in the community clients may need continued support to maximise function and help them to engage in fulfilling activities. Community based rehabilitation may consist of attendance at day centres and outpatients, out-reach and vocational rehabilitation. In addition to focusing on extended activities of daily living, community based rehabilitation interventions aim to improve quality of life, psychological adjustment and reduce carer stress. Longer term rehabilitation focuses on maintenance of progress and may consist of attendance at drop in clinics for reviews etc.

Regardless of whether services are delivered in a hospital or in the community, the message is the same - 'clients should have access to the services they need at the time they need them'.

4.6 Paediatric Model of Care

Moderate to severe TBI in children and adolescents often results in lasting changes to neurobehavioural and psychosocial functioning (Rivara et al 2011), with the full impact becoming evident over time when the brain fails to mature in line with physical growth and development (Masel, 2006). Cognitive impairments may not be immediately apparent right after injury but when there are additional expectations for a new and independent learning.

Much of the literature on rehabilitation service following TBI for children and young people focusses on problems with service delivery and unmet health needs (Greenspan et al, 2000; De Pompei et al, 2008; Ennis et al, 2013), with factors affecting service provision including lack of trained staff and different approaches to rehabilitation.

It is important that services are able to address the behavioural, social, and emotional needs of both child and family (Cole et al, 2009), with Jaffe (2008) suggesting that "a key venue for the delivery of such services is acute inpatient rehabilitation, in which the goals of intensive, multi-disciplinary efforts are to reduce impairment and disability and to promote a successful transition back to the community. DePompei (2008) suggests that service provision for children should emphasise maximising disability reduction through access to medical treatment, medical rehabilitation, appropriate education, development of social and vocational skills, and the availability of family and community support and services.

The Victorian Paediatric Rehabilitation Service caters for children and adolescents who, as a result of injury, medical/surgical intervention, or functional impairment, will benefit from a program of developmentally-appropriate, time-limited, goal-focused multi-disciplinary rehabilitation. This includes children and adolescents with acquired conditions that can benefit from a defined period of rehabilitation. Whilst not specific to TBI, the Victorian Paediatric Model of Care specifies that this includes conditions "such as ABI" (Victorian Department of Human Services).

The Model of Care is underpinned by the following principles:

- to provide the most appropriate care for the client
- to support a child-and-adolescent-centred and family-focused Model of Care
- to encourage and support continuity of client care
- to encourage appropriate transition from inpatient and ambulatory settings and optimise community reintegration.

It promotes using a regionally coordinated approach to coordinate the care for children requiring specialist rehabilitation. Care is delivered in a range of settings including inpatient, hospital, out-reach, community, community centre, client's home, school and other recreational settings.

Key aspects of care include:

- early assessment
- care planning in association with the client and family as well as regular reviews
- service delivery
- follow-up and where required, re-entry (including ensuring family have details of known point of contact).

4.7 Rural and Remote Model of Care

Residents in rural areas have a higher incidence of TBI and greater mortality associated with TBI than residents of urban areas. A number of studies suggest that they also have poorer access to brain injury rehabilitation resources (Woodward et al, 1984, Glabelle et al, 1997). Poorer outcomes for residents in rural areas, which include increased functional dependency, are thought to be associated with access to specialist rehabilitation services with clients having to travel long distances to access hospital based rehabilitation services and programs (Sample et al, 1998; Johnstone et al, 2003) and poorer access to psychiatric and psychological resources. The NSW report on Developing a Model of Care for Rural and Remote NSW, (ACI, 2011) reports additional challenges for Aboriginal people accessing rehabilitation and support services, with issues such as housing, financial and legal priorities sometimes competing with rehabilitation goals. Aboriginal people also have additional cultural needs.

In contrast to the findings from a number of studies, a NSW study found no significant difference in functional outcomes at 18 months post injury for people between rural and urban patients with TBI in NSW. The researchers suggest that the integrated network of inpatient, outpatient and outreach services provided throughout NSW through the Brain Injury rehabilitation Program provides effective rehabilitation for people with severe TBI regardless of where they live (Harradine et al, 2004).

Nevertheless, delivery of brain injury rehabilitation to some rural and remote areas of NSW may be problematic due to distances and availability of and access to specialist services (Murphy, 2004; Fyffe & McCubbery 1996).

The NSW Acquired Brain Injury Rehabilitation Service Delivery Project: Developing a Model of Care for Rural and Remote NSW (ACI, 2011), made a number of recommendations to enhance the NSW BIRP Model of Care. These included:

- strengthening the Dubbo BIRP so it can operate as a hub for the central-western and northern areas of NSW.
- developing a network of BIRP community workers and ABI champions to be located in the central and western areas of the state.
- supporting the expansion of paediatric ABI services to rural and remote NSW by appointing paediatric coordinators and improving access to metropolitan paediatric medical specialists and clinicians in BIRP services.
- developing a brain injury rehabilitation program at Broken Hill so it can operate as a hub for far-western areas of NSW.
- funding an implementation project officer position at BIRD for a minimum of three years to develop and manage the action plan arising from project recommendations to achieve the identified Model of Care priorities.
- funding a statewide position at Brain Injury Rehabilitation Directorate (BIRD) to identify and support education and training activities for BIRP staff and enhance community ABI knowledge and understanding within rural and remote communities.

4.8 Other Models Reviewed

A number of other 'Models of Care' or 'care pathways' which were reviewed that only presented particular service elements or aspects of care rather than the full model or system. Some of the models had a focus on traumatic brain injury whereas some focused on general rehabilitation which included ABI. Given the challenges associated with the ability to view the model as a whole, rather than attempt to discuss the Models of Care, elements of care which could be identified are presented in the Table 4. It should be noted that some aspects of service delivery may not have been captured.

TABLE 4 Service Elements

Models of Care	Service elements
South Australia Statewide Rehabilitation Service Plan 2009-2017 (includes the model for country rehabilitation services)	• care coordination • client focus (holistic) • inpatient/outpatient/ community • multi-disciplinary • telemedicine
New Zealand Integrated Rehabilitation Services for Traumatic Brain Injury	• inpatient/outpatient/ community
A model of rehabilitation service delivery for moderate to severe traumatic brain injury in New Zealand	• client focus • multi-disciplinary • care coordination • inpatient/ outpatient/ community • data management • research
Community Rehabilitation for people with ABI Brain Injury an Irish Model	• community / home / residential / transitional living
ABI Adult Community Care Pathway (Belfast)	• care coordination • client focus • community/ respite • multi-disciplinary and multi-agency • vocational rehabilitation • specialist accommodation and equipment

5. Summary of Key Considerations

Whilst this literature review has limitations, given the number of Models of Care available to review, it does provide information on some of the principles which guide service delivery as well as elements of service delivery relevant to the rehabilitation of people who sustain a traumatic brain injury.

Information contained in this document will be used to undertake a comparative analysis of the NSW Brain Injury Rehabilitation Model of Care. The table below contains some of the issues to consider when reviewing the NSW model.

TABLE 5 Elements to Consider in NSW Model of Care

Elements To Consider	
Guiding principles	• What principles or Model of Care guide the service?
	• Is the approach client centred?
	• Is there multi-disciplinary/ interdisciplinary team involvement?
Governance	• Does the service have a formal Model of Care or care pathway?
	• What are the issues relating to funding?
Policies and procedures	• Are there clear policies and procedures around referral and discharge planning?
Service delivery	• Where is care provided/ service type?
	• Inpatient?
	• Transitional care?
	• Community / outreach?
	• Is it client focused?
	• Is there a focus on goal setting?
	• Vocational rehabilitation
	• Processes e.g. referral
	• Discharge planning
	• Strengths
	• Challenges
Staffing	• Type of staffing providing the service
	• Are there any workforce ratios?
Research	• Any issues relating to research?
Education	• Any issues relating to education?
Facilities and Equipment	• Are these appropriate?
Quality Improvement and Risk Management	• What consumer involvement is there?
	• Is there a risk management framework?
Data and reporting	• Any KPIs/ outcome measures?
	• What data/ reporting arrangements are in place?

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Appendix G:
HEET report

Economic and Data Analysis Report

prepared for the
ACI Brain Injury Rehabilitation Clinical Network

Prepared by: Jennie Pares, Health Economist, ACI Health Economics & Analysis Team

TABLE OF CONTENTS

1. Executive Summary

The ACI clinical network is reviewing the NSW Brain Injury Rehabilitation Program (BIRP) service delivery Model of Care. This report describes the findings of analysis that the ACI Health Economics & Analysis Team has undertaken to support this review.

This paper provides findings on:

1. Analysis of current admitted inpatient sub-acute service utilisation using SNAP classifications and funding under the Activity Based Funding system. The classifications do not specify the type of brain dysfunction so acquired brain injury and traumatic brain injury cannot be separately analysed.
2. Projections for future demand for services

It is important that all BIRP services are appropriately classified to ensure that all activity is identified and that all funding available under the Activity Based Funding system is accessed. In NSW, all sub-acute activity will require a SNAP classification from 1 July 2015 in order to receive payments. It is also important that all non-inpatient activity is appropriately classified.

A second paper will be prepared, if still required by the Network, which review the funding and revenue implications for BIRP with the introduction of sub-acute Activity Based Funding and the Lifetime care and Support scheme. It is anticipated that this paper will inform the solution design phase of the BIRP review.

The key findings of analysis of service utilisation and funding over a 2 year period 2011/12 and 2012/13 and projecting demand for services is as follows:

- In NSW in 2012/13, there were 698 admitted sub-acute episodes of care with a SNAP classification for brain injury. This activity used 20,929 sub-acute bed days, representing an average length of stay (ALOS) of 30 days and totalling $20.79 M in sub-acute ABF funding.
- Activity in 2012/13 represented an increase of 5% in episodes and bed days on 2011/12 (667 episodes, 20,006 beddays). Over the 2 years, ALOS was stable and the level of funding for activity increased by 1%.
- Northern Sydney LHD had the highest volume of activity, beddays and funding for both years.
- Nepean Blue Mountains LHD had the highest ALOS in 2012/13 (44.6 days). Over the 2 year period, Northern Sydney LHD had the greatest increase in beddays in absolute numbers (an increase of 1,019 beddays) while Western NSW LHD had the greatest increase in beddays in percentage terms (96%) over the 2 year period.
- Using SiAM (sub-acute inpatient modelling tool) endorsed by the NSW Ministry of Health, the demand for episodes (activity) is projected to grow at 2% p.a. (2011 to 2022) and the projected supply (beddays) to meet that demand is projected to grow at 3% p.a. for NSW.

Given the lack of an agreed projection methodology for BIRP services, an additional piece of work will be facilitated by the Health Economics & Evaluation Team to address the following:

- confirm the patient cohort to be treated by BIRP services in NSW;
- identify the datasets that will provide the most comprehensive picture possible to reflect current BIRP service activity;
- identify the most appropriate projection methodology to project future service demand to inform service requirements.

This piece of work will be facilitated by the Health Economics & Evaluation team to inform the Solution Design phase for the BIRP project.

2. Purpose

The ACI clinical network is reviewing the BIRP service delivery Model of Care that was established 21 years ago to provide specialised rehabilitation services for children, young people and adults of working age with traumatic and acquired brain injuries. The ACI Health Economics & Analysis Team is supporting this review by undertaking:

1. Analysis of current admitted inpatient sub-acute service utilisation using SNAP classifications and funding under the Activity Based Funding system.
2. Projections for future demand for services
3. A review of funding and revenue implications for BIRP with the introduction of sub-acute Activity Based Funding and the Lifetime Care and Support scheme

This paper addresses the first two activities listed above. The third activity will be dealt with in a separate paper if still required.

3. Method

The application of ABF funding to sub-acute activity in NSW is relatively new. The NSW ABF Taskforce has undertaken analysis of two years sub-acute activity in order to calculate and apply sub-acute NWAUs for funding purposes. This dataset has been used as the basis for this analysis. Activity has been provided for 2011/12 and 2012/13 financial years.

The SNAP classifications used to identify BIRP activity are as follows:

- Brain Dysfunction, FIM motor 14-23
- Brain Dysfunction, FIM motor 24-55
- Brain Dysfunction, FIM motor 56-91, FIM cognition 20-23
- Brain Dysfunction, FIM motor 56-91, FIM cognition 24-31
- Brain Dysfunction, FIM motor 56-91, FIM cognition 32-35
- Brain Dysfunction, FIM motor 56-91, FIM cognition 5-19
- Brain, Neurological, Spinal & Major Multiple Trauma, FIM motor 13

The 2013/14 NSW NWAU price of $4,671 has been applied to the sub-acute NWAUs for this activity to determine the level of funding.

Limitations: This analysis does not include non-SNAP classified sub-acute activity for Brain Injury patients that may have occurred during this period. It excludes paediatric patients as sub-acute NWAUs have not been applied to paediatric activity.

4. Results

In NSW in 2012/13, there were 698 admitted sub-acute episodes of care with a SNAP classification for brain injury. This activity used 20,929 sub-acute beddays, representing an average length of stay (ALOS) of 30 days and totalling $20,790,118 in sub-acute ABF funding.

Activity in 2012/13 represented an increase of 5% in episodes and beddays on 2011/12 (667 episodes, 20,006 beddays). Over the 2 years, ALOS was stable and the level of funding for activity increased by 1%.

Northern Sydney LHD (NSLHD) had the highest volume of activity and total sub-acute beddays for both years in NSW.

Nepean Blue Mountains LHD had the highest ALOS in 2012/13 (44.6 days). Over the 2 year period Northern Sydney LHD had the greatest increase in beddays in absolute numbers (an increase of 1,019 beddays) while Western NSW LHD had the greatest increase in percentage terms (96%) over the 2 year period.

It is important that all BIRP services are appropriately classified to ensure that all activity is identified and therefore funding available under the Activity Based Funding system is accessed. In NSW, all sub-acute activity will require a SNAP classification from 1 July 2015 in order to receive payments. It is also important that all non-inpatient activity is appropriately classified.

In terms of total funding received, NSLHD received the greatest level of funding in 2012/13 of $5.2 M. The greatest increase in absolute $ terms occurred in HNE LHD ($0.505 M) representing 11% on the previous year, while Western NSW had the greatest percentage increase of just over 100% for the two year period, with an increase of $0.404 M which was on a lower starting base in 2011/12.

The following tables provide activity by LHD for 2011/12 and 2012/13.

TABLE 1 SNAP activity for Brain Injury Services 2011/12 by LHD

LHD	Episodes	LOS	ALOS	NWAU13_ sub-acute	Total funding
Grand total	**667**	**20,006**	**30.0**	**4,406**	**$20,580,015**
Northern Sydney LHD	142	4,506	31.7	1,012	$4,726,254
Hunter New England LHD	75	1,627	21.7	341	$1,592,189
South Eastern Sydney LHD	72	2,239	31.1	458	$2,137,262
Western Sydney LHD	69	2,618	37.9	690	$3,220,959
South Western Sydney LHD	51	3,169	62.1	748	$3,495,590
St Vincent's Health Network	40	1,093	27.3	242	$1,128,389
Illawarra Shoalhaven LHD	39	957	24.5	177	$827,787
Sydney LHD	35	865	24.7	179	$837,464
Northern NSW LHD	30	585	19.5	113	$527,566
Nepean Blue Mountains LHD	28	727	26.0	140	$653,061
Western NSW LHD	25	422	16.9	86	$400,716
Central Coast LHD	23	474	20.6	88	$411,382
Mid North Coast LHD	13	268	20.6	47	$291,308
Murrumbidgee LHD	11	153	13.9	29	$135,596
Victoria in-reach to NSW	11	152	13.8	29	$133,919
Southern NSW LHD	3	151	50.3	28	$132,570

TABLE 2 SNAP activity for Brain Injury Services 2012/13 by LHD

LHD	Episodes	LOS	ALOS	NWAU13_ sub-acute	Total funding
Grand total	**698**	**20,929**	**30.0**	**4,451**	**$20,790,118**
Northern Sydney LHD	154	5,525	35.9	1,120	$5,232,210
South Western Sydney LHD	83	3,516	42.4	807	$3,771,792
South Eastern Sydney LHD	78	2,370	30.4	532	$2,485,264
Western Sydney LHD	63	1,961	31.1	503	$2,348,377
Hunter New England LHD	50	1,221	24.4	238	$1,110,624
St Vincent's Health Network	42	845	20.1	166	$773,565
Illawarra Shoalhaven LHD	36	776	21.6	156	$729,595
Sydney LHD	32	707	22.1	148	$690,921
Western NSW LHD	30	826	27.5	172	$804,916
Central Coast LHD	28	699	25.0	136	$637,151
Nepean Blue Mountains LHD	26	1,159	44.6	213	$996,009
Northern NSW LHD	25	428	17.1	88	$413,111
Mid North Coast LHD	20	429	21.5	80	$372,616
Murrumbidgee LHD	15	196	13.1	38	$177,947
Victoria in-reach to NSW	14	246	17.6	50	$231,772
Southern NSW LHD	2	25	12.5	3	$14,249

Of interest and for further investigation, is the fact that some LHDs are recording sub-acute activity for Brain Injury but do not currently have a dedicated BIRP service. These include:-

- South Eastern Sydney LHD
- St Vincent's Health Network
- Sydney LHD
- Nepean Blue Mountains LHD
- Central Coast LHD

5. Projected demand

There is no agreed methodology for determining the incidence and relevance of TBI or ABI in Australia[1,2] however using the sub-acute activity projection tool (SiAM) endorsed by NSW Ministry of Health, the demand for services (episodes) is projected to grow at a modest 2% and the projected supply (beddays) to meet that demand is projected to grow at 3% p.a. for NSW to 2021.

5.1 NSW Ministry of Health, sub-acute Inpatient Modelling (SiAM)

The Health System Planning & Investment Branch of the Ministry of Health commissioned the development of a modelling tool that projects demand and supply for admitted sub-acute services in NSW. The general approach[3] to the development of the projections involves five stages:

Stage 1: Time series regression model based on the previous 11 years to be used to project rates per 100,000 population and average length of stay (ALOS) for each relevant age/sex/ESRG.

Stage 2: Comparison of increases in projected rates and associated episodes with other relevant information to determine whether projected increases are appropriate. For example, projected acute activity for certain clinical services (e.g. stroke and joint replacement and projected cancer deaths). Rates will be aligned with other projections, if this is considered appropriate.

Stage 3: Comparison of the results of the projections in terms of beds per 100,000 population with those implied by the 'planning benchmarks' for rehabilitation, palliative care and GEM. The implications of projected increases will be considered in the context of the commitment to increase activity by 5 per cent annually required through the new National Partnership Agreements for the enhancement of the provision of sub-acute services.

Stage 4: Application of assumptions regarding trends in relative utilisation to projected levels of activity at the LGA (or planning cluster) level. The implications of this to other approaches will be compared to estimate relative differences across geographic populations in the demand for sub-acute care.

Stage 5: Application of the pattern of provision for 2008-09 to 2010-11 to future periods.

The key results of running a Business as Usual scenario using the SiAM modelling tool for Brain Injury activity across NSW to project demand (episodes) and supply (beddays) to 2022 is as follows:

- The total activity in 2022 for NSW is projected to be 600 episodes of care, requiring 12,672 beddays at an ALOS of 21 days
- Activity across NSW is projected to grow at 2% p.a. over the 11 year period, while beddays are projected to grow at 3% p.a.
- In 2022, the LHD with the highest level of demand will be South Western Sydney (121 episodes, 2,999 beddays ALOS 24.8 days) despite this reflecting a decline in demand over the period
- The LHD with the highest growth rate in episodes and beddays is Central Coast (14% and 17%)

A summary of projected demand and supply of services by LHD is provided in the following table.

TABLE 3 Summary of Projections by LHD for ESRG 844-Rehabilitation Brain Dysfunction

	2011		2017		2022		Growth Rate	
LHD	Episodes	Beddays	Episodes	Beddays	Episodes	Beddays	Episodes	Beddays
516 Albury	4	72	4	69	4	68	0%	-1%
690 St. Vincent's Network	9	170	13	270	15	288	6%	6%
700 Sydney	19	322	21	394	23	425	2%	3%
710 South Western Sydney	170	2,684	112	2,878	121	2,999	-3%	1%
720 South Eastern Sydney	44	649	52	1,027	56	1,067	2%	6%
730 Illawarra Shoalhaven	15	280	24	476	27	507	7%	7%
740 Western Sydney	44	1,167	75	1,518	81	1,592	8%	3%
750 Nepean Blue Mountains	14	395	12	232	13	263	0%	-3%
760 Northern Sydney	81	2,281	106	2,541	113	2,598	4%	1%
770 Central Coast	5	84	11	224	13	244	14%	17%
800 Hunter New England	33	652	59	1,199	63	1,247	8%	8%
810 Northern NSW	11	209	22	450	25	483	11%	12%
820 Mid North Coast	9	176	13	246	15	273	6%	5%
830 Southern NSW	4	33	3	50	3	55	-2%	6%
840 Murrumbidgee	5	90	10	176	11	190	11%	10%
850 Western NSW	10	162	16	321	17	335	7%	10%
860 Far West	2	38	2	40	2	39	0%	0%
NSW	**479**	**9,464**	**556**	**12,110**	**600**	**12,672**	**2%**	**3%**

[1] Bid

[2] AIHW, 2007, Disability in Australia: acquired brain injury Bulletin no 255

[3] *Source: Health Policy Analysis Pty Ltd | Commissioned by the NSW Ministry of Health SiAM2012 Data book P a g e | ii*

5.2 Prevalence/incidence rates

Another method of determining future demand for services is analysing the incidence and prevalence rates. However, there is considerable uncertainty about the incidence and prevalence of brain injury in Australia. The use of hospital data to say how many new incidences of traumatic brain injury (TBI) can only be indicative in a given year because:

1. Not all people who suffer a traumatic brain injury are hospitalised and
2. People who are hospitalised more than once for their TBI will be counted more than once.[4]

Notwithstanding these limitations, the ACI has undertaken recent work in this area and analysis using prevalence in NSW has been used to inform Models of Care for Adults with Challenging Behaviours; Children with Challenging Behaviours and; Rural and Remote services (2011).

5.3 Developing a Preferred Approach to developing a Projection Methodology for BIRP services

As can be seen from Table 3, the projected episodes in 2022 (600) using SiAM is almost equivalent to the current (2012/13) SNAP activity recorded for brain injury (698). This discrepancy, combined with the lack of an agreed incidence/prevalence rate, highlights the need for an additional piece of work to be undertaken to firstly confirm the patient cohort to be treated by BIRP services in NSW; identify the datasets that will provide the most comprehensive picture possible to reflect current BIRP service activity; and then identify the most appropriate projection methodology to project future service demand to inform service requirements. This piece of work will be facilitated by the Health Economics & Evaluation team to inform the Solution Design phase for the BIRP project.

[4]http://www.abistafftraining.info/Content/1_Intro_d.html

Appendix H:
SNAP classifications

The SNAP classifications used to identify BIRP activity are as follows:
Brain Dysfunction, FIM motor 14-23
Brain Dysfunction, FIM motor 24-55
Brain Dysfunction, FIM motor 56-91, FIM cognition 20-23
Brain Dysfunction, FIM motor 56-91, FIM cognition 24-31
Brain Dysfunction, FIM motor 56-91, FIM cognition 32-35
Brain Dysfunction, FIM motor 56-91, FIM cognition 5-19
Brain, Neurological, Spinal & Major Multiple Trauma, FIM motor 13

Appendix I:
Workshop Agenda

BIRP DIAGNOSTIC PROJECT WORKSHOP

ACI, Yandhai Room,
Level 7, Sage Building,
67 Albert Avenue,
Chatswood NSW 2067
10.00am – 3.00pm Tuesday 8 April 2014

Agenda

1.	**Overview of project** (see attachment 1)	Chris Shipway, Director - Primary Care & Chronic Services, ACI
2.	**Progress to date** • Literature review (see attachment 2) • BIRP service visits • Stakeholder consultations	Greg Masters, Nexus
3.	**Setting the scene:** • BIRP data • A changing context	Jenny Peres, Economics & Analysis Team, ACI General discussion
4.	**Key issues** (see attachment 3)	Greg Masters
5.	**Small group work and plenary**	
6.	**Next steps**	

Appendix J:
List of the Workshop Participants

Organisation	Name	Role
Central Coast LHD	Dr Stephen Chung	Rehabilitation Physician
Hunter New England LHD	Chris Catchpole	A/Service Manager, Hunter Brain Injury Service
Hunter New England LHD	Karen Height	A/Service Manager, Kaleidoscope Paediatric BIR Team
Mid North Coast LHD	Cassandra Carswell	Rehabilitation Co-ordinator, MNC BIRP_Coffs Harbour
Mid North Coast LHD	Vicki Solomon	OT/ Rehabilitation Co-ordinator MNC BIRP_Port Macquarie
Nepean Blue Mountains LHD	Agapito Raul 'Roy' Nario	Staff Specialist, Rehabilitation
Nepean Blue Mountains LHD	Sharryn Byers	CNC Neurosurgery
Northern NSW LHD	Liesel Jeffers	Manager, Northern Brain Injury Rehabilitation Service
Sydney Children's Hospital Network	Virginia Binns	Clinical Program Director
Sydney Children's Hospital Network	Dr Angie Morrow	Staff Specialist, Head of Brain Injury Service
Illawarra Shoalhaven LHD	Jasmine Xavier	Paediatric Co-ordinator, IBIS
Illawarra Shoalhaven LHD	Irena Gordon	Manager, IBIS
Sydney LHD	Dr Indu Nair	Rehabilitation Specialist, HOD Rehabilitation Medicine
Sydney LHD	Karleen Allen	Acting Director Occupational Therapy
Southern NSW LHD	Jeremy Gilchrist	Manager, Southern Brain Injury Service
Western NSW LHD	Narelle Miller	Dubbo Brain Injury Rehabilitation Program
Western NSW LHD	Denise Young	Mid-Western Brain Injury Rehabilitation Service
Western Sydney LHD	Dr Joe Gurka	Director, Rehabilitation Medicine
Western Sydney LHD	Dr Jill Hummell	Manager, Community Integration Program
South Western Sydney LHD	Dr Adeline Hodgkinson	Director Brain Injury Rehabilitation Unit, Liverpool Hospital/ Director BIRD
South Western Sydney LHD	Cara Egan	Senior OT, LBIRU
South Western Sydney LHD	Sandra Krpez	Nurse Unit Manager, LBIRU
Northern Sydney LHD	Dr Clayton King	Medical Director, RR BIRP
Northern Sydney LHD	Jessica Taveira	Nurse Unit Manager, RR BIRP
Murrumbidgee LHD	Denis Ginnivan	Director - South West Brain Injury Rehabilitation Service
South Eastern Sydney LHD	Dr John Estell	Director, Department of Rehabilitation Medicine Staff Specialist in Rehabilitation Medicine St George Hospital
ACI	Jennifer Parkin	Implementation Manager
ACI	Chris Shipway	Director, Primary and Chronic Care Services
ACI	Greg Masters	Nexus Management Consulting
ACI	Melinda Daley	Nexus Management Consulting

Appendix K:
Workshop Issues Paper

BIRP DIAGNOSTIC PROJECT
ISSUES PAPER FOR WORKSHOP

INTRODUCTION

This paper aims to provide a short, sharp analysis of the key issues emerging to date from our consultations and literature review. The paper does not purport to be a comprehensive analysis of these issues; rather it has been prepared to stimulate discussion and to guide the next steps on this diagnostic project.

The paper is structured as follows:

- section 1 provides a list of BIRP principles
- section 2 presents some key issues for BIRP that are grouped according to a continuum of services across various care settings
- section 3 sets out some questions for consideration by small groups in the workshop.

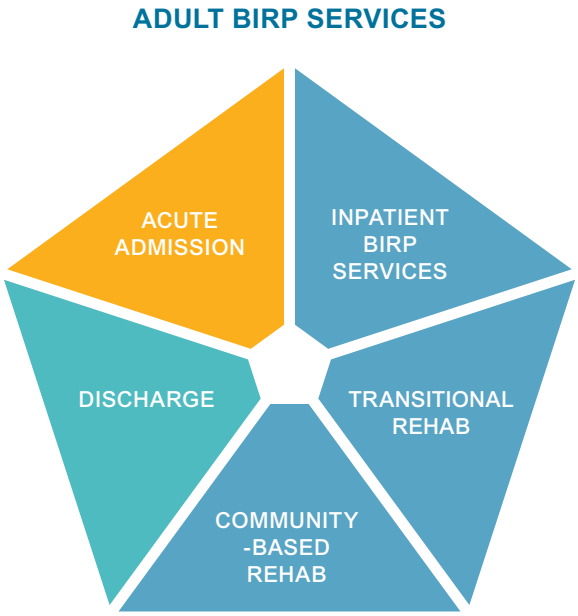
1. BIRP Principles

- **Equity of access to rehabilitation**
  Individuals are unselected, with minimal referral criteria.
- **Early intervention**
  To maximise recovery referral/admission to the specialist brain injury rehabilitation service occurs as soon as possible after injury/admission to hospital
- **Needs-driven rehabilitation**
  Goals of social rehabilitation are not dependent on initial injury severity, but rather the nature and degree of disablement. There are no time limits provided on the length of time support is provided and programs are provided in a flexible manner.
- **Goal-based rehabilitation**
  Goals of social rehabilitation are multi-dimensional, representing the sum of client-expressed need and third-party identified needs.
- **Continuum of care**
  Coordinated transition is provided between the relevant components of the continuum of care from acute inpatient rehabilitation to long-term support.
- **Community rehabilitation approach**
  Rehabilitation is approached as an holistic endeavour informed by biomedical, neuropsychological, neuro-behavioural and community participation paradigms involving a range of medical, clinical and support staff operating together with the client and significant others to maximise outcomes.
- **An enablement approach**
  People are encouraged to reclaim decision-making, responsibility and control over their lives, also known as psychological independence.
- **Contextual-based approach**
  Rehabilitation where possible is conducted within the environment that the person lives.
- **Participation-based approach**
  Outcomes represent the product of the interaction between the individual and their social, physical, service, attitudinal and political environment.
- **Family-centred approach**
  Families are viewed as partners in the rehabilitation process and typically the greatest resource available to the person.
- **Evidence-based approach**
  Rehabilitation is provided with reference to the international best-practice, where possible using evidence-based intervention.

2. The Service Continuum

The following figure sets out a continuum of service settings for BIRP. It should be noted, however, that patients' clinical needs may not require them to proceed along all elements of the continuum; some, for example, may be transferred directly from acute hospital to the community while others may be referred to TLU from the community. Nevertheless, the figure is useful in structuring the key issues discussed in this Section 4.

FIGURE 1 Continuum of Services



2.1 General Issues

Strengths

- client-centred rehabilitation planning
- highly skilled, interdisciplinary teams
- metropolitan and rural specialist teams
- adult and paediatric services in the network
- continuum of services and settings
- family involvement in rehabilitation
- case management is an integral part of the model
- the network provides a vehicle for service development, professional development and information sharing.

Issue	Comments
The Model of Care	• the model is not well documented • significant variation in service across the state • lack of clarity re: patient pathways and knowing where to refer clients • significant changes in governance arrangements since inception of BIRP
Eligibility criteria	• different criteria across the state • some LHDs have flexibility i.e. age (<5 and >65) and severity of BI (moderate) and ABI • some services feel age criteria should be reviewed
Funding complexity & inequities	• resources across the state vary considerably in staffing levels and service types • this is especially true of paediatric services • differential access to services for compensable and non-compensable patients • some services benefit directly from revenue raised whereas others don't • some concerns around ABF and ability to capture all of the work that goes into supporting clients (e.g. non-client facing) • as 'purchaser' of services, LTCSA crucial in contributing to Model of Care • complexity of LTCSA assessment process • LTCSA often contracts private providers
Staffing of services	• variation in staffing of services • difficult to recruit staff especially as there isn't any guidance around types of staff or levels required • staffing levels and delays in recruitment results in lost revenue • what staff/ roles are essential for brain injury rehabilitation services? • communication and service delivery enhanced where staff are co-located
Aboriginal-specific services	• there appears to be a disproportionately low proportion of Aboriginal clients in the service
Needs of 15-24 yr olds	• paediatric and adult services not well matched to this group's needs
Consumer input	• need for increased and more structured consumer input at local and state level
Clinical governance and professional development	• while the network provides some training and professional development, there is lack of formal structures and arrangements • professionals in regional and rural services most isolated • sometimes lack of understanding in how other services operate which can cause issues with referrals
Information Technology	• services see benefits for greater use of IT (e.g. linking with other practitioners, client consultations, client skills) • IT capability limited due to resources and internet access • organisational security hinders potential benefits (i.e. firewalls etc.)
'Profile' of BIRP	• BI and the BIRP seems to have lower 'profile' relative to other clinical groups that have clearer pathways

2.2 Acute Admission

Issue	Comments
BI not identified	• some patients are not referred to the BIRP team because there is no assessment often and BI not identified • lack of skills/knowledge around BI
Referral pathways to BIRUs	• often discharged without referral to BIRP teams: hospital-based or in the community • sometimes discharged to general rehabilitation units, which are often not appropriate for TBI patients • many patients are discharged home without rehabilitation
In-reach	• different models of In-reach operate across the state

2.3 BIRP Inpatient Units

Issue	Comments
Bed availability	• are there sufficient dedicated BIRP beds across NSW? • are the existing beds in the right locations? • some lack of clarity about the relationship between the inpatients units and BIRP services re 'catchments', feeder hospitals and referral pathways • different referral processes to the three units • often difficult to access beds • patients often in general rehab beds which are inappropriate

2.4 Transitional Care

Issue	Comments
Outpatients	• different referral processes across services • lack of access for rural and remote patients especially • lack of knowledge as to whether referrals accepted until post-discharge
Transitional living units	• variation in availability across NSW • is there a preferred model? • viability in regional settings
Day rehabilitation	• lack of day rehab services

2.5 Community-Based Care

Issue	Comments
Role of BIRUs	• diversity of service models: therapy, case management, brokerage, secondary consultation • variety of case management approaches adopted • is there an ideal model or configuration?
Access to specialist & therapy services	• difficulty of accessing rehab specialists, especially in regional and remote areas • shortages in a number of therapies, especially regional areas & paediatrics • non-compensable clients generally have poorer access • difficulty of meeting needs of remote clients
Access to non-health community services	• lack of long term support for clients following discharge results in them being 're-cycled' through service when not always necessary • variation in vocational support
Brokerage funding	• some services have funds for brokerage • difficulty in accessing services and specialists, especially in regional and remote areas

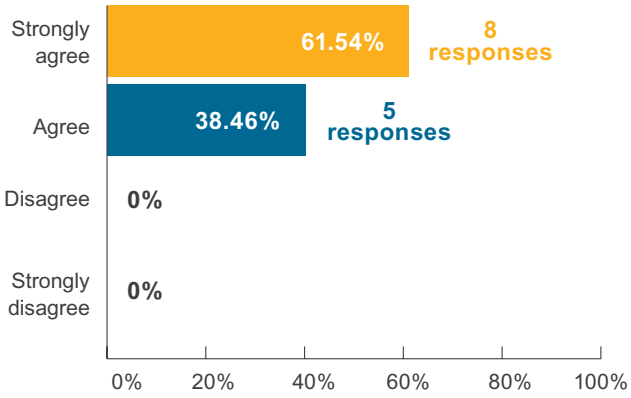
3. Small Group Questions

1. Do you have any quick feedback on the principles (edits, additions, deletions)?
2. Is the continuum useful for structuring the issues in the final report? Any suggested changes (edits, additions, deletions)?
3. For each of the categories of issues across the continuum (plus general):
   - have we identified the issues correctly?
   - are there any significant changes (edits, additions, deletions)?
4. In terms of client outcomes and improved service delivery, what are the top five issues?
5. What other information or analysis would be useful in finalising the report?
6. Any other comments

Appendix L:
Summary of the Post-Workshop Evaluation Results

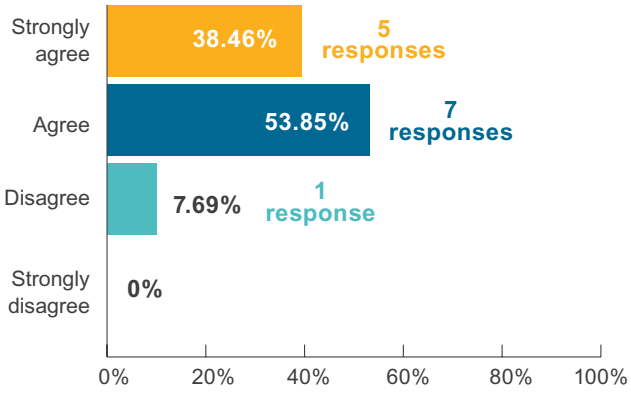
Question 1:
I felt that I had the opportunity to contribute my expertise to the revised Model of Care for the BIRP

Answered: 13
Skipped: 0



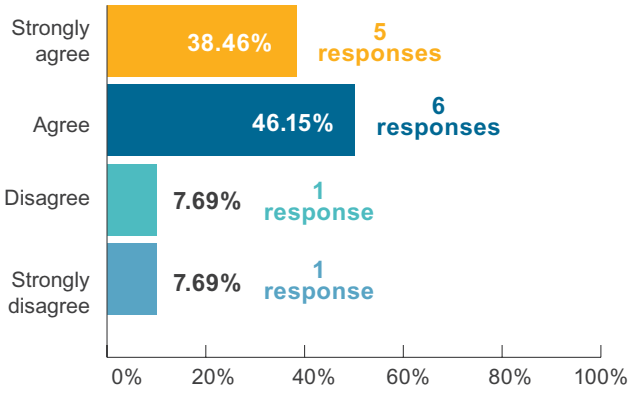
Question 2:
As a result of the workshop, I am clearer about the key issues and priorities for a revised model of care

Answered: 13
Skipped: 0



Question 3:
Overall, the workshop was a useful process in the 'diagnostic' phase of the development of a Model of Care

Answered: 13
Skipped: 0



Appendix L:
Summary of the Post-Workshop Evaluation Results

Question 4:
Any other comments about the workshop or Model of Care?

Answered: 10
Skipped: 3

#	Responses	Date
1	The workshop offered a good opportunity to see the diversity of Models of Care across the state and also highlighted a number of very relevant issues. I think the discussion about focusing on developing a Model of Care based on the needs of the client group rather than the capabilities of the BIRP was a very good point and should be further reinforced in future planning and workshops.	4/14/2014 4:54pm
2	There is an unresolved issue as to whether this project is to review the Model of Care of the BIRP or the Model of Care generally for people with brain impairment. I consider these to be very different tasks and the workshop was confusing for me due to the lack of clarity in this issue. We seem to have interchanged between these 2 potential objectives. I am not sure what is supposed to be happening with the identifies priorities/issues when talking about Model of Care. Overall, I am uncertain as to what the workshop added to work that has already been done and I believe the consultants require more direction from BIRD ACI on what is required because there are potentially 2 very different directions this could go.	4/14/2014 3:34pm
3	Well run and good variety of people involved.	4/14/2014 10:45am
4	Information was tailored to group and summarised to ensure key points were covered.	4/14/2014 9:49am
5	Thank you for the opportunity to participate in person on the day via funding for travel.	4/14/2014 9:21am
6	Paperwork given to us for small group review was a little confusing. More explanation by organisers regarding the worksheet provided for group discussion; (especially on expectations of what the group was actually supposed to do), prior to commencing group discussion would have been useful. For eg: most groups struggled with the “principles” document and were not clear on whether they were being asked to comment on the appropriateness of an existing BIRP overview document OR give feedback on whether the statements presented reflected the existing delivery of service. Overall the workshop was a useful exercise in establishing and prioritising issues; among this group at least. With the addition of other stakeholders such as consumers into the mix, the priorities list might look different.	4/11/2014 4:51pm
7	Nil - Information provided on the day	4/11/2014 4:11pm
8	Well done! Very productive, consultants and ACI staff are all very much across the issues... My only concern is the creative tension between the need to develop and strengthen the state-wide network but without the mandate to implement it, as the LHDs have the autonomy to do with it (the BIRP will always be a low priority in financially stressed acute content) what they wish... I believe that the model will need strong advocacy to ensure that the state-wide model retains its integrity, and develops in the strategic directions that it needs to grow in.	4/11/2014 4:02pm
9	Environment was conducive to interaction/discussion in small group work. Lunch, although tasty was difficult with insufficient seating for the number in the workshop.	4/11/2014 3:51pm
10	A useful step towards the Model of Care document	4/11/2014 3:39pm

Appendix M:
AROC Example Data

Length of Stay (LOS), Functional Independence (FIM) and discharge to private residence for AROC comparisons with Brain Dysfunction groups of different pre-morbid dependency, demographic and impairment shows that specialist units had a greater LOS than non-specialist units, with the biggest difference being for the most severe patients. However, for the same severe patients the specialist units achieved a greater improvement in Functional Independence (FIM) and a higher rate of returning to a private residence.

LOS AN-SNAP S3-214	8 days longer than non-specialist
LOS AN-SNAP S3-215	17 days longer than non-specialist
FIM change AN-SNAP S3-214	50 point gain in specialist units compared to 38 point gain in non-specialist units
FIM change AN-SNAP S3-215	64 point gain in specialist units compared to 50 point gain in non-specialist units
Discharge to private residence	5% higher than non-specialist