

Botulinum Toxin A Transition project

**Working together: A collaboration between paediatric
and adult rehabilitation services**

August 2020

The Agency for Clinical Innovation (ACI) is the lead agency for innovation in clinical care.

We bring consumers, clinicians and healthcare managers together to support the design, assessment and implementation of clinical innovations across the NSW public health system to change the way that care is delivered.

The ACI's clinical networks, institutes and taskforces are chaired by senior clinicians and consumers who have a keen interest and track record in innovative clinical care.

We also work closely with the Ministry of Health and the four other pillars of NSW Health to pilot, scale and spread solutions to healthcare system-wide challenges. We seek to improve the care and outcomes for patients by re-designing and transforming the NSW public health system.

Our innovations are:

- person-centred
- clinically-led
- evidence-based
- value-driven.

www.aci.health.nsw.gov.au

AGENCY FOR CLINICAL INNOVATION

1 Reserve Road St Leonards NSW 2065
Locked Bag 2030, St Leonards NSW 1590

T +61 2 9464 4666 | F +61 2 9464 4728

E aci-info@nsw.gov.au | aci.health.nsw.gov.au

(ACI) 200497, ISBN 978-1-76081-459-5

Produced by: Sydney Children's Hospital Network and ACI Transition Care Network

Further copies of this publication can be obtained from
the Agency for Clinical Innovation website at www.aci.health.nsw.gov.au

Disclaimer: Content within this publication was accurate at the time of publication. This work is copyright. It may be reproduced in whole or part for study or training purposes subject to the inclusion of an acknowledgment of the source. It may not be reproduced for commercial usage or sale. Reproduction for purposes other than those indicated above, requires written permission from the Agency for Clinical Innovation.

Version: 1 Trim: ACI/D20/2129

Date amended: August 2020

© Agency for Clinical Innovation 2020

Executive summary

Investment in improving the health of adolescents has been identified as a priority, described by the Lancet Commission on Adolescent Health and Wellbeing as providing a triple dividend that improves adolescents' health now, in their future, and the health of our next generations.(1) For young people with chronic health conditions and disability, adolescent development includes transition from child-centred to adult-orientated health systems. It is essential that their transition is supported to ensure that young people remain engaged in the health system and health-promoting activities.

Transition for young people with neurological conditions such as cerebral palsy, acquired brain injury and spinal cord injury can be challenging. Spasticity management required as part of these conditions often requires the use of botulinum toxin A; transfer between paediatric to adult botulinum toxin services is often identified as a particular challenge in effective transition.

The Botulinum Toxin A Transition project describes the current landscape for young people who transition between paediatric to adult botulinum toxin services in NSW and ACT. This report provides:

- summaries of the numbers of young people with these conditions in NSW and ACT, their diagnoses, and healthcare needs
- the experiences of clinicians working with this patient group with respect to transition
- the experiences of young people and their families and carers who have experienced transition
- mapping of NSW/ACT adult botulinum toxin A services in the public health system and their capacity for managing young people with complex health needs.

As such the report identifies key areas that could be enhanced to improve patient outcomes and experience for these young people and their families and carers; and can be used as a resource for service planning and development.

Contents

Background	1
Purpose	3
Question 1 - What are the characteristics and health service needs of young people who are expected to transition from child to adult spasticity management BoNT-A services in NSW and ACT during 2018 to 2023?	4
Key findings	4
Methods.....	4
Results.....	6
Question 2. What are the experiences of young people and their families and carers during transition from child to adult spasticity management BoNT-A services in NSW and ACT? ...	8
Key findings	8
Methods.....	8
Results.....	8
Question 3. What do clinicians working in spasticity management BoNT-A services in NSW and ACT identify as barriers to effective transition?	11
Key findings	11
Method.....	11
Results.....	11
Question 4. Where are the available services for botulinum toxin A injections for spasticity in the adult patient population in NSW and ACT?	15
Key findings	15
Method.....	15
Results.....	15
Key recommendations	16
Acknowledgements	17
Document development.....	17
Glossary	18
References	19
Appendices	21
Appendix A – Project management team and project steering committee.....	21
Appendix Ba – Project process timeline: project initiation and planning	23
Appendix Bb – Project process timeline: project execution	24
Appendix C – Focus group and interview questions: Consumer experiences	25
Appendix D – REDCap questionnaire: clinician’s experience.....	27
Appendix E - Botulinum toxin a service mapping questionnaire	30
Appendix F – Botulinum toxin a service listing	33

Background

Collectively, neurological conditions such as cerebral palsy (CP), acquired brain injuries, spinal cord injuries and spina bifida are common causes of physical disability in children. Advances in healthcare mean that most young people (YP) with these conditions now survive into adulthood. Healthcare is transferred from paediatric to adult healthcare settings when YP reach chronological adulthood (typically 18 years of age).

Transition involves the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult oriented healthcare systems.(2) For the young person, it coincides with multiple developments and challenges related to adolescence, such as independence and identity, leaving school, becoming a legal adult and their capacity, the increasing influence of peers, physical and neurocognitive maturation and psychosocial stressors. Many of these YP have chronic and complex health needs that require ongoing use of health services. For example, it is common for YP with CP to have health problems in addition to the management of their physical disability, often involving the neurological, respiratory and gastrointestinal systems. Adults with CP experience higher rates of non-communicable diseases such as cardiovascular disease, chronic pain, mental health problems and osteoporosis.

For health services involved in transition, key principles of care have been developed by the ACI Transition Care Network and Sydney Children's Hospitals Network (SCHN) involving:

- a systematic and formal transition process
- early preparation
- identification of a transition coordinator or facilitator
- good communication
- individual transition plans
- empowering, encouraging and enabling young people to self-manage
- follow up and evaluation.(3)

Other strategies to support transition include close and effective integration with primary healthcare and community teams, a period of joint clinical care with paediatric and adult specialist teams, resource development, and optimisation of psychosocial supports. Effective transition can improve long-term outcomes and experiences for young people.(4) Achieving effective transition is challenging. Research suggests that YP and their families can experience significant stress during healthcare transition.(5-8) YP with CP and their parents have reported difficulties in navigating and accessing the adult health system and linking with adult healthcare professionals who have the knowledge to treat their condition (5, 7-10). YP have requested more and earlier information about transition and better collaboration and communication between paediatric and adult healthcare services.

This project focusses on one particular and challenging area for successful transition of these young people – spasticity management with botulinum toxin A (BoNT-A). BoNT-A is a common treatment for spasticity and involves the periodic intramuscular injection of the drug into multiple muscles. A smooth transfer for BoNT-A treatment is influenced by differences in diagnostic groups including health needs, mobility, intellectual functioning and the models of care between by paediatric and adult BoNT-A services. For example, the injection procedure is painful, and BoNT-A

is typically performed in children using sedation or general anaesthesia, but this is commonly not required and/or less easily available for adults. Whilst there is a literature base to support best practice in transition for YP, there is no literature to report specific best practice for transition of BoNT-A services.(11-13)

During the time this project was undertaken (2018) there were substantial changes to the Pharmaceutical Benefits Scheme (PBS) that have resulted in improved access to BoNT-A for these YP, removing the requirement for eligibility to the Scheme for adults to have received BoNT-A prior to turning 18 years old. Current PBS indications for BoNT-A are shown in Table 1.

Table 1. Current Pharmaceutical Benefits Scheme indications for BoNT-A for spasticity management

Code	Indication	Clinical criteria
5359	Dynamic equinus foot deformity*	<ul style="list-style-type: none"> • The condition must be due to spasticity AND • patient must have cerebral palsy AND • patient must be ambulant AND • patient must be aged from 2 to 17 years inclusive.
8822	Dynamic equinus foot deformity	<ul style="list-style-type: none"> • The condition must be due to spasticity AND • patient must have cerebral palsy, AND • patient must be ambulant AND • patient must be aged 18 years or older.
5178	Moderate to severe spasticity of the upper limb †	<ul style="list-style-type: none"> • Patient must have cerebral palsy AND • patient must be aged from 2 to 17 years inclusive.
8929	Moderate to severe spasticity of the upper limb †	<ul style="list-style-type: none"> • Patient must have cerebral palsy AND • patient must be aged 18 years or older.

* Must be treated by a neurologist, orthopaedic surgeon, paediatrician or rehabilitation specialist.

† Must be treated by a neurologist, orthopaedic surgeon, paediatrician or rehabilitation specialist or plastic surgeon

Purpose

The purpose of this project was to understand the characteristics and needs of YP transitioning from BoNT-A child to adult health services in NSW and ACT.

This project was structured around four questions and six sub questions.

- 1. What are the characteristics and health service needs of YP who are expected to transition from child to adult spasticity management BoNT-A services in NSW and ACT during 2018 to 2023?**
 - 1.1. How many YP are expected to transition from child to adult spasticity management BoNT-A services in NSW and ACT during 2018 to 2023?
 - 1.2. What are the characteristics of these YP (diagnosis, functional classification, intellectual disability) and their impact on service requirements?
- 2. What are the experiences of YP and their families and carers during transition from child to adult spasticity management BoNT-A services in NSW and ACT?**
 - 2.1. What do YP and their families and carers report as barriers to successful transition from child to adult spasticity management BoNT-A services?
 - 2.2. What do YP and their families and carers report as interventions that could improve success of transition from child to adult spasticity management BoNT-A services?
- 3. What do clinicians working in spasticity management BoNT-A services in NSW and ACT identify as barriers to effective transition for YP?**
 - 3.1. What do clinicians identify that would improve the BoNT-A transition?
- 4. Where are the available services for Botulinum Toxin A injections for spasticity in the adult patient population in NSW and ACT?**
 - 4.1. What are the characteristics of the available services (i.e. clinic structure, funding, referral criteria, sedation options, accessibility)?

Question 1 - What are the characteristics and health service needs of young people who are expected to transition from child to adult spasticity management BoNT-A services in NSW and ACT during 2018 to 2023?

Key findings

- During 2018 to 2023, we estimate an average of fifty YP per year will transition from NSW paediatric BoNT-A services and require treatment in adult NSW/ACT BoNT-A services.
- These YP reside throughout NSW and ACT and will require BoNT-A services either provided by their local health district (LHD) or through partnership with other LHDs.

Of these:

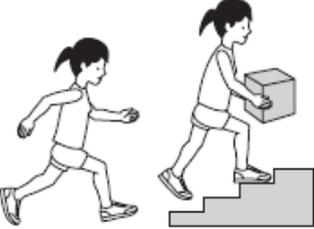
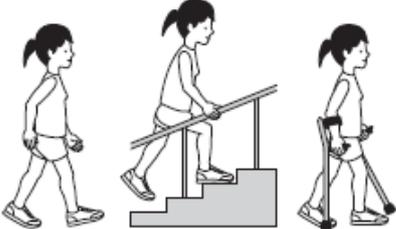
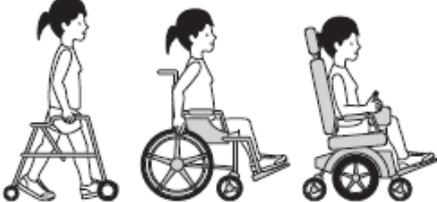
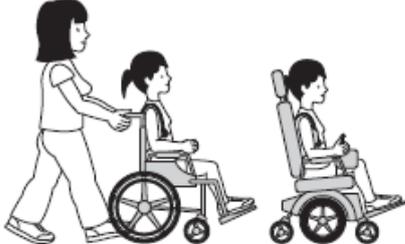
- sixteen YP per year will have significant mobility limitations and will require wheelchair accessible facilities and clinic spaces, and may require a hoist for transfers to clinic examination and procedural beds
- twenty-two YP per year will have intellectual disability and will require healthcare services that acknowledge and support their complex healthcare needs to ensure quality of care for this vulnerable group.
- fourteen YP per year are still using general anaesthetic and/or inhaled sedation for BoNT-A injection at the time of transition; there may be ongoing need for sedation for some of these people in adult BoNT-A services.

Methods

Young people expected to transition from paediatric to adult BoNT-A services in NSW and ACT during 2018 to 2023 were identified by reviewing the details of all YP (birth years 2000 to 2004 inclusive) who had attended BoNT-A clinics at the three major paediatric NSW children's hospitals in NSW (the Children's Hospital at Westmead (CHW), Sydney Children's Hospital (SCH) Randwick, and John Hunter Children's Hospital (JHCH)) during the period from 23/5/2016 to 21/05/2018. Characteristics and health service needs of these YP were assessed using data extracted from electronic medical records and internal databases, kept by the paediatric rehabilitation departments and pharmacies at each hospital. Where information was not easily available, details were checked with clinicians familiar with the child. Mobility and need for supportive clinical environments and equipment was classified using the Gross Motor Function Classification System (GMFCS) or equivalent (for YP without CP) (Figure 1).

Figure 1. Gross Motor Function Classification System (12-18 years of age)

GMFCS E & R between 12th and 18th birthday: Descriptors and illustrations

	<p>GMFCS Level I</p> <p>Youth walk at home, school, outdoors and in the community. Youth are able to climb curbs and stairs without physical assistance or a railing. They perform gross motor skills such as running and jumping but speed, balance and coordination are limited.</p>
	<p>GMFCS Level II</p> <p>Youth walk in most settings but environmental factors and personal choice influence mobility choices. At school or work they may require a hand held mobility device for safety and climb stairs holding onto a railing. Outdoors and in the community youth may use wheeled mobility when traveling long distances.</p>
	<p>GMFCS Level III</p> <p>Youth are capable of walking using a hand-held mobility device. Youth may climb stairs holding onto a railing with supervision or assistance. At school they may self-propel a manual wheelchair or use powered mobility. Outdoors and in the community youth are transported in a wheelchair or use powered mobility.</p>
	<p>GMFCS Level IV</p> <p>Youth use wheeled mobility in most settings. Physical assistance of 1-2 people is required for transfers. Indoors, youth may walk short distances with physical assistance, use wheeled mobility or a body support walker when positioned. They may operate a powered chair, otherwise are transported in a manual wheelchair.</p>
	<p>GMFCS Level V</p> <p>Youth are transported in a manual wheelchair in all settings. Youth are limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements. Self-mobility is severely limited, even with the use of assistive technology.</p>

GMFCS descriptors: Palisano et al. (1997) Dev Med Child Neurol 39:214-23
CanChild: www.canchild.ca

Illustrations Version 2 © Bill Reid, Kate Willoughby, Adrienne Harvey and Kerr Graham, The Royal Children's Hospital Melbourne ERC151050

Results

We identified 253 YP who will transition to adult BoNT-A services during 2018-2023, an average of 50 YP per year. One-hundred and twenty-eight YP were being treated at CHW, 84 at SCH, and 41 at JHCH. One-hundred and thirty-one (52%) were male. Diagnoses for these YP are shown in table 2.

Table 2. Diagnosis in 253 YP expected to transition to adult BoNT-A spasticity clinics

Diagnosis	Number of YP (%)
Cerebral palsy	200 (79%)
Acquired brain injury	30 (12%)
Spinal cord injury	2 (1%)
Other neurological conditions with spasticity / dystonia	21 (8%)

Young people expected to transition resided in all metropolitan, regional and rural LHDs in NSW and in ACT (table 3). Each LHD had a small but regular number of YP expected to transition in each or most years we measured. This suggests that each LHD will have to ensure that it supports appropriate services to treat this group of YP, or alternatively partner with other LHDs for those who require more specialised services, e.g. YP with higher needs.

230 YP (91% of total) had a GMFCS classification or equivalent documented in their records. Eighty YP (35%) were classified GMFCS IV or V indicating severe mobility limitations. This suggests that, on average, 16 transitioning YP per year will require facilities and clinic spaces that are wheelchair accessible with assistive technologies, e.g. hoists, to enable examination and/or treatment.

Data supporting identification of intellectual disability was available in 246 (97%) of YP's records. Intellectual disability was identified in 108 (44%) YP who will transition to adult BoNT-A services over the next five years, an average of 22 YP per year.

BoNT-A injections in children are often performed using sedation or anaesthesia to assist with the pain and distress of multiple injections, and these may be less available in adult healthcare settings. Identifying an ongoing need for sedation for BoNT-A at transition is important for a smooth transfer of care to an adult clinic that provides these resources. Details of sedation requirements at their most recent BoNT-A injection were available for 251 YP. Inhalation sedation (nitrous oxide) was used by 183 (73%) YP, oral sedation (midazolam) by 3 (1%) and general anaesthetic by 25 (10%) YP. Forty (16%) YP used no sedation or topical anaesthesia only.

These results suggest that many YP are still using sedation for BoNT-A injections at the time of transition. Paediatric services may improve transition experience for YP by exploring alternative strategies to manage pain and discomfort during BoNT-A injection in the years before transfer of care. There is likely to be an ongoing need for sedation during BoNT-A for some YP after leaving paediatric services.

Table 3. Number of children transitioning per year per LHD

Local health district	Birth year					Total	%
	2000	2001	2002	2003	2004		
ACT	1	3	3	3	4	14	6%
Nepean Blue Mountains LHD	2	3	0	5	1	11	4%
Western Sydney LHD	5	9	3	7	7	31	12%
South Western Sydney LHD	5	8	7	5	7	32	13%
South Eastern Sydney LHD	2	3	3	2	4	14	6%
Sydney LHD	2	1	3	1	5	12	5%
Northern Sydney LHD	3	3	5	6	5	22	9%
Central Coast LHD	2	3	1	2	4	12	5%
Hunter New England LHD	6	8	5	13	9	41	16%
Mid North Coast and Northern NSW LHDs	0	2	0	6	2	10	4%
Far West and Western LHDs	3	2	4	3	5	17	7%
Illawarra Shoalhaven LHD	5	4	1	2	3	15	6%
Murrumbidgee and Southern NSW LHDs	3	6	4	4	5	22	9%
Total	39	55	39	59	61	253	100%

Question 2. What are the experiences of young people and their families and carers during transition from child to adult spasticity management BoNT-A services in NSW and ACT?

Key findings

- Young people and their families and carers' experiences vary, from positive transition experiences to some people feeling unsupported and unprepared.
- The differences between paediatric and adult services can be a source of major stress for YP and their families and carers.
- Poorer transition experiences were characterised by lack of informed decision-making and choice, minimal information, preparing for transition within a short timeframe, and feeling disempowered or confused by the transition process.
- Better transition experiences were characterised by being told about transition a long time in advance (years), clear detailed information provided at multiple points in time in a number of forms, feeling empowered and an integral part of the team and a more positive experience of adult services.

Methods

Young people and their families and carers who had transitioned from paediatric to adult BoNT-A services during 2013-2018 were invited to take part in a semi-structured interview or focus group. The focus group was facilitated by Caroline Kovacic and interviews were undertaken by staff at CHW and SCH between 21 September and 14 November 2018.

Focus group and interview scripts and questions (see Appendix B) were developed around three questions, and intended to assist the facilitator to explain the purpose, guide the conversation topics and ensure consistency. Consent to participate and record audio was obtained before the interview or focus group. Strategies, such as communication aids, were used to ensure that information and interviews were fully accessible and inclusive.

The audio recordings from the interviews were transcribed by a professional transcription service. Thematic analysis was then conducted by two researchers who:

- individually read each transcript, noting information units, categories and possible themes
- read each transcript together (aloud) and proceeded through the thematic analysis process including condensing (rephrasing) information units, assigning categories to information units and identifying themes.(14, 15)

Results

A total of 18 participants took part in one focus group and 10 interviews (10 parents and carers, 7 YP and 1 carer/young person dyad). Young people with varying diagnoses, including CP and acquired brain injury, were represented. Most (12, 67%) had been through the transition process in the last three years.

Experience of current BoNT-A transition processes

Participants reported mixed experiences with transition from paediatric to adult BoNT-A services. Reported experiences were grouped into four main themes: preparation (information and time), choice (shared decision making, location, doctors and clinics or hospitals), changing relationships (diminishing role of the parent and interaction with the healthcare team) and coordination between healthcare teams.

Preparation

Information

The most frequent suggestion for improvement was a need for more information regarding transition and adult services, before transitioning to the adult service. Specifically, information was needed about:

- different adult BoNT-A services available
- pros and cons of the services
- details about adult services including location, who to contact, and referral processes.

Suggestions for ways to communicate this included pamphlets and fact sheets, presentations and education sessions for patients and families and treating health professionals providing timely information to patients and their families and carers.

Time

Some participants described how they were prepared well in advance, even up to two years prior to transition. They were reminded of the pending transition at each clinic visit and viewed this positively. Other interviewees reported not receiving information about transition in advance. The importance of preparation for transition well in advance was a strong theme across all interviews.

Choice

Shared decision making

Another common problem that participants described was a feeling of exclusion from decision making and lack of true teamwork. They described feeling 'clueless' or 'not respected' in the decision-making process relating to transition. Having a choice and being treated as an integral part of the team was valued by interviewees.

Location

Being able to receive treatment close to home was reported to be preferred by some participants, others were willing to travel further, depending on the process of BoNT-A injections at different adult services.

Doctors

Choice in adult services and doctors was important to most participants. On occasion, patients and their families were only referred to or given the contact details of one service and/or doctor and would have preferred multiple contacts.

Clinics and hospitals

Participants reported that they would have liked more information about how various adult BoNT-A services are different, for example, the accessibility to anaesthetic and sedation. Sedation was often very important in the selection of adult services, with some patients unwilling to undergo BoNT-A injections without sedation.

Changing relationships

Diminishing role of the parent

Young people interviewed reported that they appreciated doctors in adult services communicating directly to them and not to their parents. They reported enjoying being treated as an adult. However, this did not suit one family, where the patient had a severe intellectual disability. The parent reported that the move from paediatric services was difficult and attributed this to the discrepancy between the patient's chronological age and developmental age.

Interaction with healthcare team

The majority of participants reported gratitude towards the staff from paediatric services. A number of participants reported that adult services were less welcoming. Approximately half of interviewees preferred paediatric services, whilst the other half preferred adult services. Preference for one service over another appeared to be related to the staff or service at the adult service. One patient suggested that doctors need to 'introduce themselves properly' when meeting patients and take time to get to know the patient. Others acknowledged specific individuals due to their positive experiences.

Coordination between healthcare teams

Good communication between paediatric and adult services was highlighted as a need throughout the transition period. Patients, their families and carers were thankful for health information transfer when it had occurred, however a more gradual transition was suggested, including ideas relating to:

- a conference between paediatric and adult services (e.g. using telemedicine)
- more frequent communication between the paediatric and adult services
- a follow-up appointment at the paediatric service after being discharged to the adult service.

Most interviewees described a need for better communication between doctors and with other services, as patients feel more responsible for communication between specialists in the adult setting where access to multidisciplinary care in a single setting is less common.

Question 3. What do clinicians working in spasticity management BoNT-A services in NSW and ACT identify as barriers to effective transition?

Key findings

- Clinicians identify that current transition processes can be improved.
- Key areas of improvement highlighted are:
 - communication between adult and paediatric services
 - sedation pathways for BoNT-A.

Method

Clinicians (physicians, nurses and allied health professionals) working in paediatric and adult spasticity management BoNT-A services in NSW and ACT were invited to participate in an online questionnaire designed to identify clinicians' perceptions of barriers to effective transition for BoNT-A services and what additional support and/or resources could improve transition. Participants were recruited through various methods, including newsletters produced by the ACI Rehabilitation Network, Royal Australasian College of Physicians and the Rehabilitation Medicine Society of Australia and New Zealand. The questionnaire was delivered via REDCap[‡], hosted by University of Sydney.

Results

There were 37 responses from clinicians in adult (n=20, 54%) and paediatric (n=17, 46%) settings (table 4). Twenty-eight (76%) respondents reported working in a metro public BoNT-A service, five (14%) in a rural public service, two (5%) in a private clinic and one (3%) in a free-standing public clinic.

Respondents stated that the transition process should be initiated by the age of 16, or at least one to two years prior to leaving paediatric services. The transition should trial injections with reduced sedation, allow time to find an appropriate adult service and include a period of overlap in adult and child services to enable effective handover.

Table 4. Occupation and service setting of respondents to the online questionnaire

Occupation	Adult service	Paediatric service	Total
Medical doctor	15	7	22
Nurse	0	1	1
Physiotherapist	2	5	7
Occupational therapist	3	1	4
Other [§]	0	3	3

[‡] REDCap is a secure web application used to build and manage online surveys and databases.

[§] Other: orthotists n=2, child life therapist n=1.

Experience of current BoNT-A transition processes

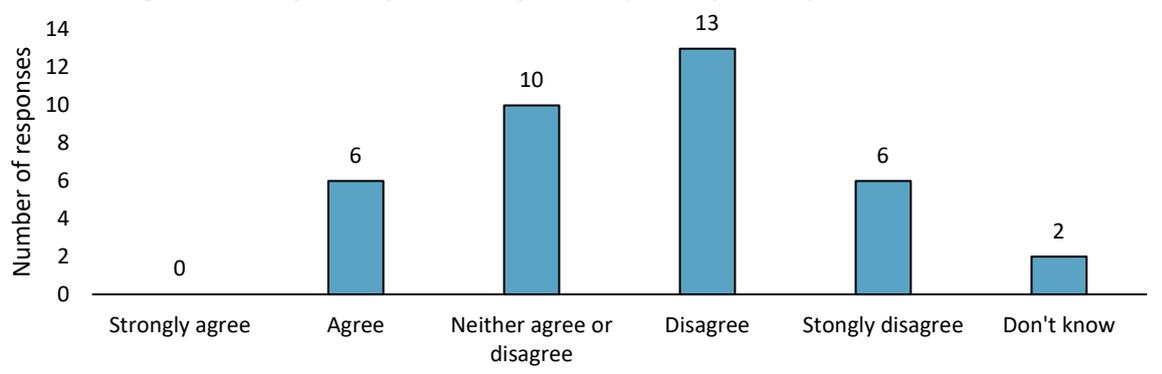
Clinicians were asked about their experiences of BoNT-A transition by rating their agreement with statements using a five-point Likert scale. Clinicians identified a need to improve transition in their answers and comments. Half reported that they were not satisfied (n=19, 51%) with current processes (figure 2a) and that YP and their parents and carers are generally not well prepared for transition (n=9, 28%) (figure 2b). Written comments included: *'parents generally expect the same level of support that they have become accustomed to in the paediatric unit. Adult units are generally not resourced to provide this level of support.'*; *'parents seem to be shocked at how different the experience is/will be in the adult world'*.

Communicating to support effective transition

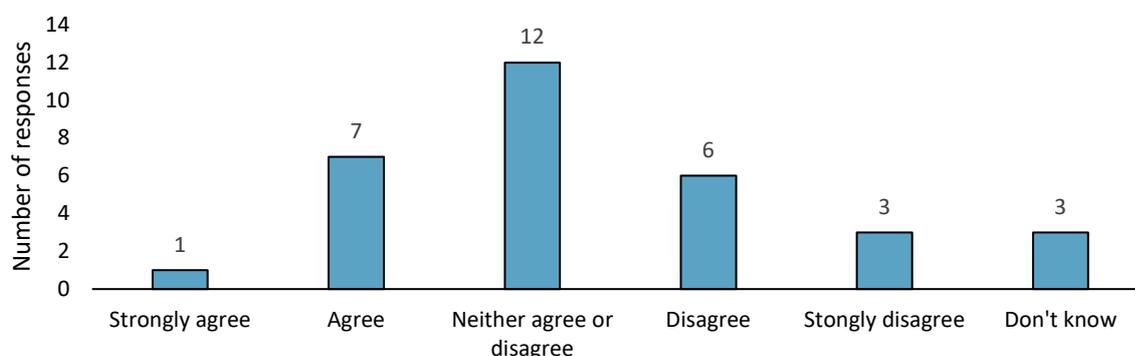
Adult clinicians presented mixed views with respect to the amount and quality of information they received to support BoNT-A transition (figure 2c). Those who were less satisfied suggested in written comments that more information about goals, sites of injections, and intervals between injections would be useful. Clinicians also identified the following information types to be useful to support transition: medical history, previous orthopaedic surgery, current allied health involvement, current therapy goals, past and current sedation needs, expected future sedation needs, previous injection sites and doses, and involvement of a general practitioner.

Figure 2. Clinician reported experience of current BoNT-A transition

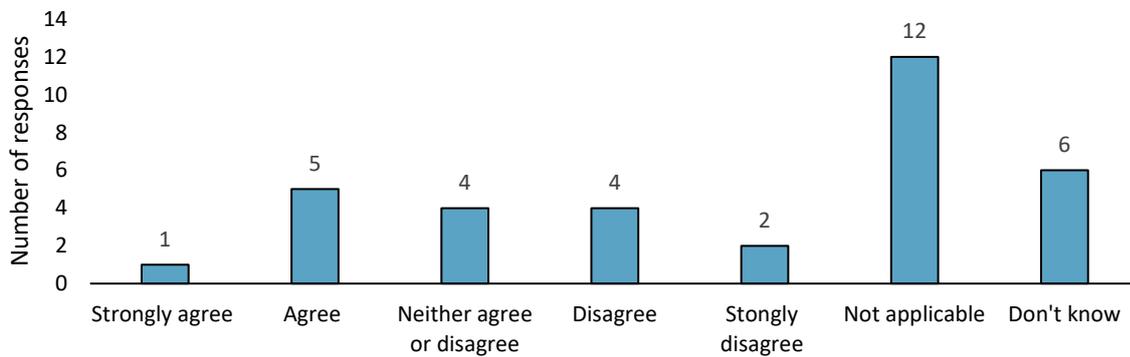
a. *I am satisfied with the current transition process for YP who require BoNT-A for the management of spasticity and/or dystonia (37 responses)*



b. *In my experience, patients and carer and parents are well prepared for BoNT-A transition (32 responses)*



c. *The BoNT-A care transition referrals have provided all the information I need to be able to provide continued BoNT-A care (34 responses)*

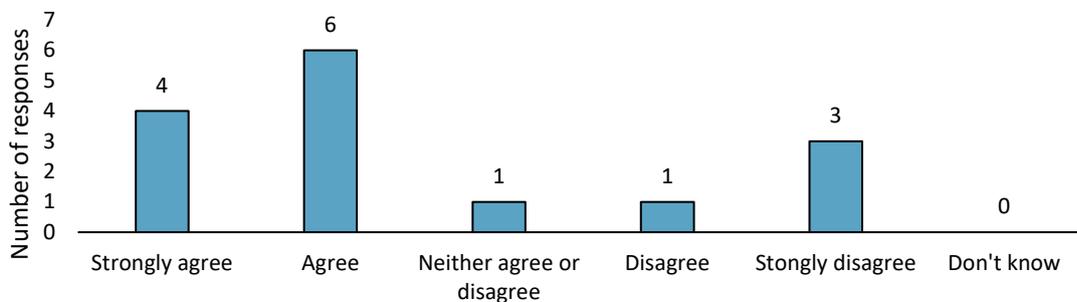


Capacity to support transitioning young people

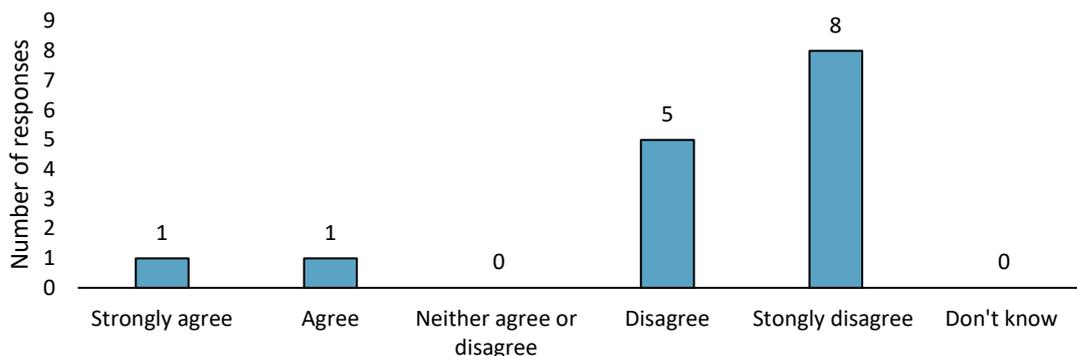
We asked clinicians about their capacity to support the needs of YP during transition. Most (n=10, 67%) adult clinicians who answered this question (n=15) suggested that their service would have the capacity to take on new BoNT-A referrals for YP (figure 3a) but most (n=13, 87%) indicated difficulties in accessing sedation for BoNT-A injections (figure 3b). There was marked variation in reported availability of multidisciplinary team support (figure 3c) and need for improved knowledge and experience in childhood onset conditions (figure 3d).

Figure 3. Clinician reported capacity to support the needs of YP during BoNT-A transition

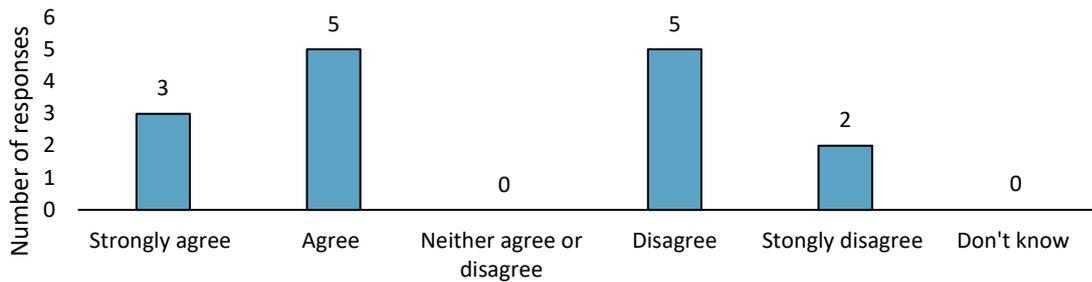
a. *My service has capacity to take on new BoNT-A referrals for transitioning YP (15 responses of adult clinicians)*



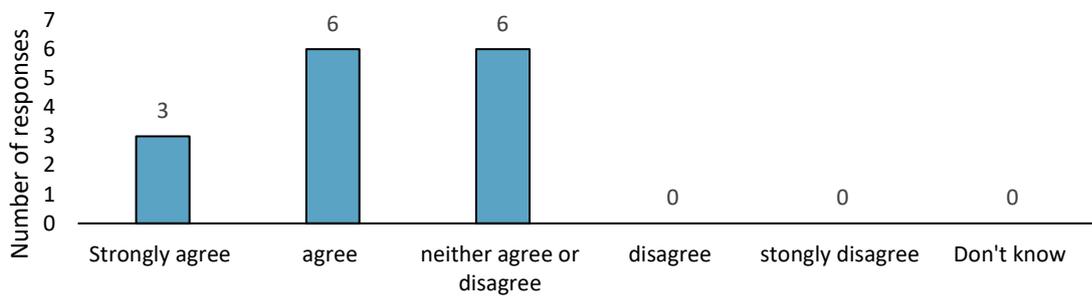
b. *It is easy to access a variety of sedation options (e.g. light sedation, theatre) to use during BoNT-A injections for transitioning YP (15 responses of adult clinicians)*



c. *My BoNT-A service has sufficient access to multidisciplinary support for transitioning YP*
(15 responses of adult clinicians)



d. *I have sufficient knowledge and experience of the YPs' conditions to effectively manage their BoNT-A needs* (15 responses of adult clinicians)



Barriers and suggestions for improvement

Clinicians were offered the opportunity to describe ways health services can improve transition. Suggestions included for paediatric services to trial reduced sedation needs, better prepare YP and families for the difference between the paediatric and adult health systems and increase their skill in goal setting. Clinicians also suggested that services could improve communication and coordination of transition and that adult services could provide more information about how services operate, including whether sedation is available. Clinicians expressed concern about the increasing number of referrals from paediatric services without corresponding increase in support from a multidisciplinary team, inequities of the (now improved) Pharmaceutical Benefits Scheme funding for BoNT-A, and finding other suitable services to support YPs' needs.

Question 4. Where are the available services for botulinum toxin A injections for spasticity in the adult patient population in NSW and ACT?

Key findings

- Across NSW and ACT, there are 26 adult services who are known to take referrals for the ongoing management of spasticity in the transition patient population, using BoNT-A.
- There are likely to be other services available across the state. Future work should focus on establishing and maintaining a working database of available services for referring practitioners.
- Access to a hoist and adequate procedural sedation for BoNT-A injections remain significant challenges for YP transitioning to adult services.

Method

Throughout late 2018 and early 2019, questionnaires (see Appendix E) were sent to possible spasticity management services throughout NSW and ACT.

Services were identified in any of the following ways: previous inclusion in Dr Peter Sturgess's mapping, identification by paediatric rehabilitation services, identification by Trapeze or ACI transition service providers, or identification via 'word-of-mouth'. Questionnaires were either completed in-person, returned via e-mail, or completed over the telephone with a project team member.

Services providing their consent to make information available to clinicians and consumers had their questionnaire results collated, as described below.

Results

Twenty-six services across NSW and ACT provided completed questionnaires with consent to publish their service details, as listed in Appendix F. The services had the following characteristics.

- 18 public services; 8 private services
- 19 rehabilitation-based services; 7 neurology-based services
- 8 services provide procedural sedation of some kind
- All 26 services are wheelchair accessible, and have access to a disabled toilet and disabled parking
- 13 services have hoist access; 8 services have a changing table with hoist.

Services contacted but not listed in Appendix F fell into one of several categories.

- Questionnaire not returned (n=29)
- No existing service on-site (n=28)
- No existing service on-site, but referring to affiliated service (n=13)
- Existing BoNT-A spasticity management services that declined publication of their data due to an inability to accommodate the transition population (n=2)
- Existing BoNT-A service that offers injections only for indications other than those typical for the transition population (n=1).

Key recommendations

- 1. General principles of good transition care should be followed.**

Young people who require transition from paediatric to adult BoNT-A services for spasticity management often have complex health needs involving multiple body systems. The general principles of good transition care should be followed, including, but not limited to, discussing transition from early in adolescence, the use of standardised assessments and resources for transition and involvement of agencies that can support effective transition coordination including Trapeze and the ACI Transition Service. For Aboriginal YP, clinicians involved in their care should try and involve Aboriginal hospital liaison officers where appropriate. A holistic approach to the YP's care needs to be adopted, including engagement of Aboriginal Community Controlled Health Services for primary care needs. Any processes or documents assisting transition should ensure Aboriginal status is recorded in line with NSW Health policy.
- 2. Consideration should be given to developing centres of excellence in BoNT-A.**

The complexity of these YP's health, the relative small numbers and their geographical distribution will make meeting their needs challenging. Consideration should be given to developing centres of excellence in BoNT-A, that have sufficient support to meet these needs including access to a multidisciplinary team, anaesthetics and sedation, and accessible premises. Resources and education will need to be developed to support these centres and establish referral pathways.
- 3. Communication between paediatric BoNT-A services, BoNT-A services, patients and families should be improved to support effective transition.** Examples of such work include the development of resources to support paediatric services' and patients' and families' understanding of individual adult service models of care to improve preparation for transition; information brochures about adult services such as providers, location, accessibility and contacts; joint clinics, using telehealth where appropriate should be considered. A period of overlap, during which the YP sees both paediatric and adult services, should be considered.
- 4. A directory of adult BoNT-A services be made available to all relevant providers and transition coordinators**

The directory, included in this report is a valuable resource. We recommend that this directory be maintained by ACI Transition Network, as it aligns with their priorities.
- 5. Paediatric BoNT-A services should review YPs need for sedation during the transition period**

The aim is to reduce sedation and where required trial alternate methods to support painful procedures before the time of discharge from paediatric care. The use of community resources including access to psychologists should be used to support this aim.

Acknowledgements

First and foremost the project team would like to thank all young adults and their carers and parents who volunteered to share their transition experiences and suggestions for improvement. Sharing your experiences has allowed us to gain a better understanding of the transition experience, and has assisted the project group in developing recommendations for both adult and paediatric botulinum toxin A (BoNT-A) providers with the aim to improve the transition for future patients. We would also like to thank all clinicians who have shared their transition experiences and suggestions for improvement, by completing the online questionnaire.

We would also like to thank Hunter New England (HNE) Kids Rehab, in particular Dr Heather Burnett, and Rehab2Kids at Sydney Children's Hospital, in particular Kerry Hanns, for their collaboration and facilitation of data collection from all children who expected to transition to adult BoNT-A service, between 2018 and 2023, from HNE Kids Rehab in Newcastle, Sydney Children's Hospital in Randwick, and The Children's Hospital at Westmead. We would also like to thank Dr Lani Campbell and Ms Anneliese Blaxland for their thematic analysis of the interviews and focus groups with young people and their families and carers, and Dr Lisa Myers for her work on mapping botulinum toxin services in NSW.

We would also like to thank the NSW Agency for Clinical Innovation, in particular past ACI Transition Care Network Manager Lynne Brodie for sharing her experience and advice and Caroline Kovacic for her assistance in moderating the focus group.

Furthermore, we would like to make a special mention to the contribution of all members of the steering committee: Dr Jane Ho, Dr Alexis Berry, Dr Ann Winkler, Dr Cesar Uy, Dr Helen Redmond, Dr John Estell, Dr Laurence Chu, Dr Peter Sturgess, Dr Rachel McQueen, Dr Rummana Afreen, Dr Simon Chan, Evan Fragiadakis, Jayne Kelderman, and Kerry Hanns. Thank you for providing us with valuable support, expertise and advice during the project.

Document development

The ACI provided funds to the Sydney Children's Hospital Network to undertake this project to improve the transition of young people who require botulinum toxin A for the treatment of physical disabilities. Dr Simon Paget is the Project Sponsor with Dr Jane Ho the clinical lead. This report was prepared by Dr Paget and Dr Ho.

This report has been endorsed by the ACI Transition Care and Rehabilitation Networks.

Glossary

ACI	Agency for Clinical Innovation
ACT	Australian Capital Territory
AYA	Adolescent and young adult(s)
BoNT-A	Botulinum toxin A
CHW	Children's Hospital at Westmead
CP	Cerebral palsy
GMFCS	Gross Motor Function Classification System
HNE	Hunter New England
JHCH	John Hunter Children's Hospital
LHD	Local health district
NSW	New South Wales
PBS	Pharmaceutical Benefits Scheme
REDCap	REDCap is a secure web application for building and managing online surveys and databases
SCH	Sydney Children's Hospital
TGA	Therapeutic Goods Administration
YP	Young people

References

1. Patton GC, Sawyer SM, Santelli JS, Ross DA, Afifi R, Allen NB, et al. Our future: a Lancet commission on adolescent health and wellbeing. *Lancet*. 2016;387(10036):2423-78.
2. Blum RW, Garell D, Hodgman CH, Jorissen TW, Okinow NA, Orr DP, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *J Adolesc Health*. 1993;14(7):570-6.
3. Agency for Clinical Innovation, Trapeze, The Sydney Children's Hospitals Network. Key principles for transition of young people from paediatric to adult health care. . ACI, SCHN; 2014.
4. Nagra A, McGinnity PM, Davis N, Salmon AP. Implementing transition: Ready Steady Go. *Arch Dis Child Educ Pract Ed*. 2015;100(6):313-20.
5. DiFazio RL, Harris M, Vessey JA, Glader L, Shanske S. Opportunities lost and found: experiences of patients with cerebral palsy and their parents transitioning from pediatric to adult healthcare. *J Pediatr Rehabil Med*. 2014;7(1):17-31.
6. Hopper A, Dokken D, Ahmann E. Transitioning from pediatric to adult health care: the experience of patients and families. *Pediatr Nurs*. 2014;40(5):249-52.
7. Lariviere-Bastien D, Bell E, Majnemer A, Shevell M, Racine E. Perspectives of young adults with cerebral palsy on transitioning from pediatric to adult healthcare systems. *Semin Pediatr Neurol*. 2013;20(2):154-9.
8. Young NL, Barden WS, Mills WA, Burke TA, Law M, Boydell K. Transition to adult-oriented health care: perspectives of youth and adults with complex physical disabilities. *Phys Occup Ther Pediatr*. 2009;29(4):345-61.
9. Bagatell N, Chan D, Rauch KK, Thorpe D. "Thrust into adulthood": Transition experiences of young adults with cerebral palsy. *Disabil Health J*. 2017;10(1):80-6.
10. Carroll EM. Health care transition experiences of young adults with cerebral palsy. *J Pediatr Nurs*. 2015;30(5):e157-64.
11. Binks JA, Barden WS, Burke TA, Young NL. What do we really know about the transition to adult-centered health care? A focus on cerebral palsy and spina bifida. *Arch Phys Med Rehabil*. 2007;88(8):1064-73.
12. Crowley R, Wolfe I, Lock K, McKee M. Improving the transition between paediatric and adult healthcare: a systematic review. *Arch Dis Child*. 2011;96(6):548-53.
13. Howard SW, Zhang Z, Buchanan P, Ambrecht E, Williams C, Wilson G, et al. The effect of a comprehensive care transition model on cost and utilization for medically complex children with cerebral palsy. *J Pediatr Health Care*. 2017;31(6):634-47.
14. Erlingsson C, Brysiewicz P. A hands-on guide to doing content analysis. *Afr J Emerg Med*. 2017;7(3):93-9.
15. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9):1277-88.

Appendices

Appendix A – Project management team and project steering committee

Project management team

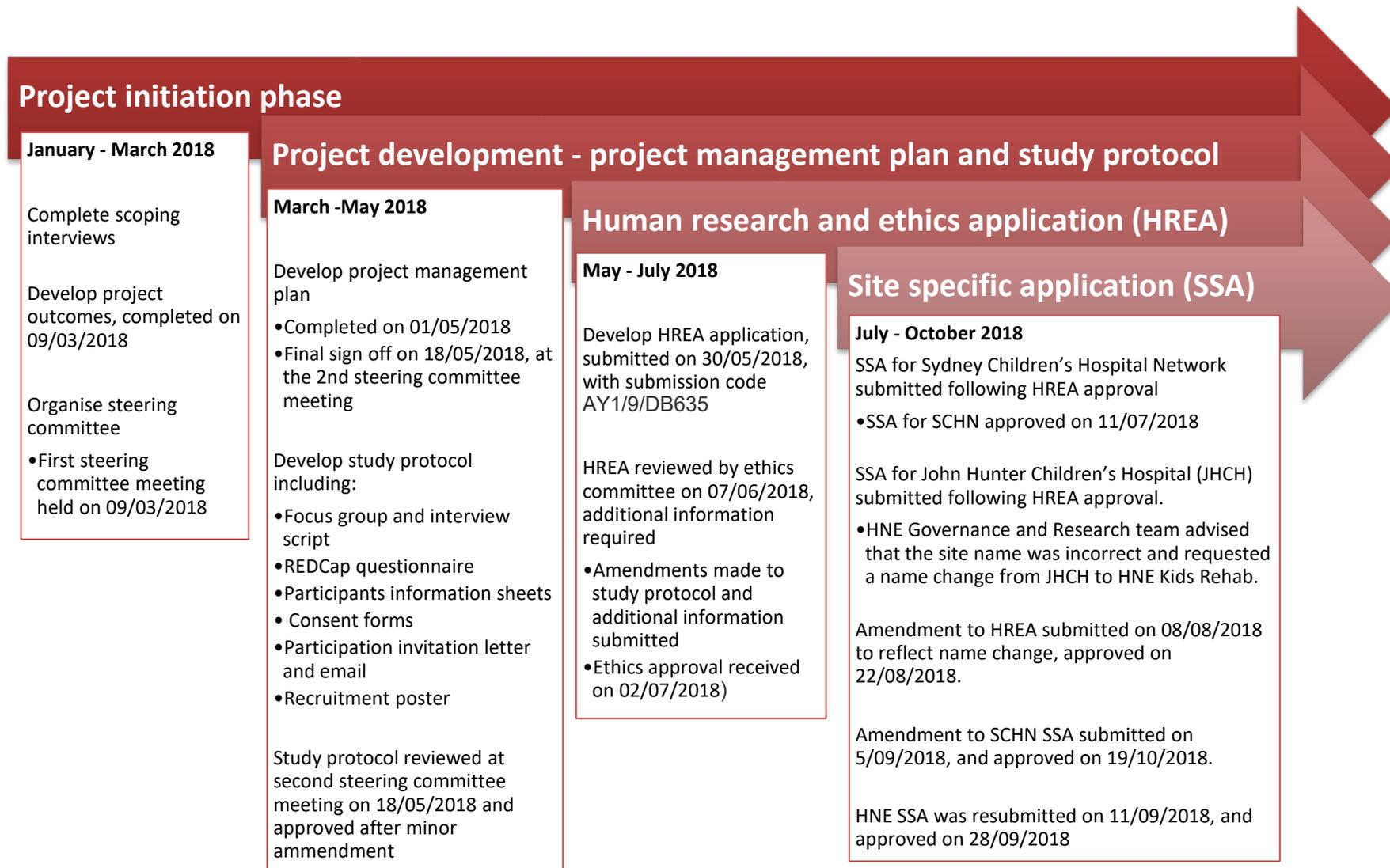
ROLE	NAME	POSITION AND ORGANISATION
Project Sponsor	Dr Simon Paget	Paediatric Rehabilitation Medicine Physician, Head, Cerebral Palsy and Movement Disorders Service, Kids Rehab – The Children’s Hospital Westmead
Clinical Lead	Dr Jane Ho	Staff Specialist, Trapeze – Sydney Children’s Hospital Network
Project Officers	Anneliese Blaxland	Research Assistant, Kids Rehab – The Children’s Hospital Westmead
	Dr Lani Campbell	Research Officer, Kids Rehab – The Children’s Hospital Westmead
	Anne de Groot	Project Officer – Sydney Children’s Hospital Network
	Dr Lisa Myers	Senior Resident Medical Officer, Kids Rehab – The Children’s Hospital Westmead
Project Partner	Lynne Brodie	Network Manager, Transition Care – NSW Agency for Clinical Innovation
	Vanessa Evans	Network Manager, Transition Care – NSW Agency for Clinical Innovation

Project Steering committee

NAME	POSITION AND ORGANISATION
Dr Rummana Afreen	Senior Staff Specialist in Rehabilitation – Westmead Hospital
Dr Alexis Berry	Staff Specialist in Rehabilitation, Disability Assessment & Rehabilitation Team for Young People, – Concord Hospital
Dr Simon Chan	Senior Staff Specialist, Rehabilitation and Aged Care Service – Hornsby Kuring-gai Hospital
Dr Laurence Chu	Senior Staff Specialist in Rehabilitation – Nepean Hospital
Dr John Estell	Director, Department of Rehabilitation Medicine, Senior Staff Specialist in Rehabilitation – St George Hospital

Evan Fragiadakis	Consumer representative, young adult who has transitioned to adult BoNT-A services
Kerry Hanns	Cerebral Palsy Clinic Coordinator, Rehab 2 Kids – Sydney Children’s Hospital
Jayne Kelderman	Consumer representative, parent of a young adult who has transitioned
Dr Rachael McQueen	Senior Staff Specialist in Rehabilitation – Wagga Wagga Hospital
Dr Helen Redmond	Senior Staff Specialist, Spasticity Management Service, Brain injury Rehabilitation Service – Liverpool Hospital
Dr Peter Sturgess	Staff Specialist in Rehabilitation – Prince of Wales Hospital and Royal North Shore Hospital
Dr Cesar Uy	Senior Staff Specialist, Rehabilitation and Aged Care Service – Hornsby Kuring-gai Hospital
Dr Ann Winkler	Staff Specialist in Rehabilitation – Prince of Wales Hospital

Appendix Ba – Project process timeline: project initiation and planning



Appendix Bb – Project process timeline: project execution

Retrospective data review - Future needs pre-transition

May - December 2018

CHW data report exported on 24/05/2018

Data cross referenced with EMR for identification of ID

All SCH data received on 15/09/2018

▪SCH+CHW data analysed and presented at 3rd steering committee meeting on 24/08/2018

HNE data received on 27/09/2018 and added to data list

All data coded for analysis with SPSS (version 25), October 2018

Data analysis completed and write up of first draft of the 'future needs pre-transition' report.

First draft completed on 16/12/2018

Focus group and single interviews (July-December 2018)

Data list created of all patients who have transitioned from 2013-2018 from both SCH and CHW, July 2018

- Letter with invitation to participate sent to both parents and adults (separate letter) on 01/08/2018
- Email with invitation to participate sent to those of with a known email address.

Phone call follow up on invitations started on 15/08/2018

Focus group dates organised both at Randwick and Westmead.

Focus group completed at Westmead on 21/09/2018 (Randwick got cancelled, only 3 participants)

▪ 7 of 11 confirmed participants attended the focus group on the 21/09/2018

- Audio transcript completed on 4/10/2018

10 additional phone interviews (transcribed) were completed from 31/10/2018 to 14/11/2018.

▪ Complete analysis and write up to be complete in January 2018.

REDCap Questionnaire (July -December 2018)

Project created in REDCap on 06/07/2018.

REDCap questionnaire moved into production on 07/26/2018.

Invitation send to steering committee to complete questionnaire on 26/07/2018

- Closing date extend on 23/08/2018 from 31/08/2018 to 30/09/2018

Questionnaire promoted via

- NSW ACI Rehabilitation network on 8/08/2018
- AFRAM bulletin on 24/08/2018
- Rehabilitation Medicine Society of Australia and New Zealand (RMSANZ) on 06/09/2018 via email
- Royal Australasian College of Physicians, September 2018

Data report extracted for analysis. Drafted the write up of result, October-November 2018

First draft completed and send out for external review on 18/12/18

Mapping of BoNT-A services (Oct 2018 - Dec 2019)

Questionnaire for the mapping of adult BoNT-A service completed on 11/10/2018.

Data list developed with all known public and private rehabilitation and neurology clinics which may provide BoNT-A injections.

- Email sent to known contacts (including steering committee) on the data list.
- 8 completed questionnaires received in 2018.

Mapping put on hold thereafter due to resourcing shortages.

Questionnaire and data list revised (May 2019), and all remaining services contacted thereafter via email and/or telephone; contact attempts completed in September 2019.

Data cleansed and summarised in draft report November to December 2019.

Appendix C – Focus group and interview questions: Consumer experiences

Short questionnaire to define the demographic of the focus group

This is an anonymous questionnaire to help us to define the demographics of this group. The questionnaire provides you with an option to opt out on answering these questions and you won't have to provide us with a reason why.

- I would like to opt out on participating in this short questionnaire
- I understand that this is a short anonymous questionnaire and I am willing to participate and consent for this data to be used to define the demographics of this group.

What is your current postcode: _____

Are you a male/female/other: _____

Are you a carer or patient: _____

If you are a patient, how old are you: _____

What is the main medical diagnosis for which you or your child receives botulinum toxin A?

- Cerebral palsy
- Brain injury
- Spinal cord injury
- Spina Bifida
- Other: _____

What is your or your child's current mobility status, e.g. do you require a wheelchair or a walking aid?

Where are you or your child in the transition process, how many years after leaving children's services?

- Last year
- 1-3 years
- 3-5 years
- Other: _____

Interview questions

QUESTIONS	PROMPTS	PROBES
<p>What is important for us to know about receiving botulinum toxin A injections?</p>		<p>Does anybody else have anything to add?</p>
<p>How would you describe your experience of the transition process for botulinum toxin A injections?</p>	<p>How did you feel about the botulinum toxin A transition process?</p> <p>What were your expectations? Were they met or not met?</p> <p>Who played an important role in preparing you for your transition and how come?</p> <p>What was the level of support like during transition (for botulinum toxin A injections)?</p> <p>What was it like for you the first time you received botulinum toxin A injections at an adult service provider?</p> <p>How did you feel about your level of involvement in the decision making?</p> <p>How did you feel about the communication in the adult Botulinum toxin A clinic?</p>	<p>Has anybody else had a similar experience?</p> <p>Does anybody have anything different to discuss?</p> <p>Can you share an example?</p>
<p>What has gone well during your transition for BoNT-A injections</p>	<p>Did anyone or anything particularly help?</p>	<p>Has anybody else had a similar experience?</p> <p>Does anybody have anything different to discuss?</p> <p>Can you share an example?</p>
<p>What has not gone so well?</p>	<p>What could we do better?</p> <p>What else has affected your transitioning process?</p> <p>Have you experienced any other hurdles or problems that have affected your transition? Could we have helped you with this?</p>	<p>Has anybody else had a similar experience?</p> <p>Does anybody have anything different to discuss?</p> <p>Can you share an example?</p>
<p>What could we do better as a service to improve the experience for young people who will transition in the future?</p>	<p>What doesn't work? How could we improve this?</p> <p>What worked well and what should we keep doing?</p> <p>Is there anything else that helped you during the transition process that is important for us to know?</p> <p>Is there anything else that you would like us to know that could help us improve the experience for future patients?</p>	<p>Does anybody else have anything to add?</p>

Appendix D – REDCap questionnaire: clinician’s experience

Questionnaire questions

Questionnaire

1. What is your position?

- Medical Doctor
- Nurse
- Physiotherapist
- Occupational Therapist
- Speech Pathologist
- Other

Please indicate other profession:

2. I work, or I have worked within the last 5 years in?

- A paediatric BoNT-A service provider for the management of spasticity/dystonia.
- An adult Health BoNT-A service provider for the management of spasticity/dystonia

3. How many years have you worked in BoNT-A service(s)?

- Less than 1 years
- 1-2 years
- 2-5 years
- 5-10 years
- >10 years

4. Type of setting of your current BoNT-A service?

- Within a metropolitan public hospital
- Within a rural public hospital
- Within a free standing public clinic
- Within a private clinic/hospital
- Other

Please indicate other:

5. For how many years has this service existed?

6. I am satisfied with the current transition process for young people who require BoNT-A for the management of spasticity and/or Dystonia.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree
- Don't know

Question 6
Comment (optional):

7. When should the BoNT-A transition process commence?

8. The BoNT-A care transition referrals have provided all the information I need to be able to provide continued BoNT-A care.

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree
- Don't know
- N/A

Question 8
Comment (optional):

9. The following information should be included in the referral to support BoNT-A transition.

	Strongly agree	Agree	Neither agree or disagree	Disagree	Strongly disagree	Don't know
Medical history	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Involvement of the general practitioner	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Current allied health therapy involvement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Current therapy goals	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Past/current sedation used	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Expected sedation requirements in adult care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Orthopaedic surgery documentation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Previous injection sites and doses	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other, (optional)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please indicate others, if applicable

Question 9
Comment (optional):

10. In my experience, patients and carer(s)/parent(s) are well prepared for BoNT-A transition

- Strongly agree
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree
- Don't know

Question 10
Comment (optional):

11. In what ways can paediatric service providers better prepare young people and their carer(s)/parent(s) for transition to adult BoNT-A services?

12. In what ways can adult service providers better assist young people and carer(s)/parent(s) for transition to adult BoNT-A services?

13. Please rate the following statements as they relate to your experience in your current service:

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know
1. My service has capacity to take on new BoNT-A referrals for transitioning young people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. It is easy to access a variety of sedation options (e.g. light sedation, theatre) to use during BoNT-A injections for transitioning young people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. My BoNT-A service has sufficient access to multidisciplinary support for transitioning young people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Transitioning young people have sufficient access to BoNT-A under the Pharmaceutical Benefit Scheme (PBS), for the management of their needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. I have sufficient knowledge and experience of the young persons' conditions to effectively manage their BoNT-A needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Question 13, comment (optional), please refer to statement number if applicable:

14. Have you experienced any other barriers to transition of young people for their management of spasticity and/or dystonia, which have not yet been mentioned?

15. Do you have any other concerns about the transition of young people, for their management of spasticity and/or dystonia with BoNT-A?

16. Do you have anything else that you would like to share with us regards to the transition process for young people receiving BoNT-A for the management of spasticity and/or dystonia?

Appendix E - Botulinum toxin a service mapping questionnaire

Dear botulinum toxin A service providers,

Transition has been a challenge for young people who need botulinum toxin A (BoNT-A) injections as they enter adult health care. Some of the challenges include: inequitable access to injecting services especially in rural and regional areas, eligibility criteria and differences in protocols across services especially around sedation options. This questionnaire seeks to build on the work of Dr Peter Sturgess, who mapped adult BoNT-A services in 2017-2018, to further clarify adult (public and private) service provision in NSW and ACT, eligibility criteria and ease of accessibility. We intend to make this directory publicly available to help people needing BoNT-A injections and the clinicians who support them.

Your input is valuable to us and we thank you for your contribution.

Dr Simon Paget
Staff Specialist and head of the
Cerebral Palsy and Movement
Disorders Service,
Kids Rehab
Children's Hospital at Westmead
Phone: (02) 9845 2820
Email:
Simon.paget@health.nsw.gov.au

Dr Jane Ho
Staff specialist at Trapeze, the
adolescent chronic care and transition
support service Sydney Children's
Hospitals Network
Phone: (02) 9382 5446
Email: Jane.Ho@health.nsw.gov.au

Dr Lisa Myers
SRMO, Kids Rehab
Children's Hospital at Westmead
Phone: (02) 9382 0833
Email:
Lisa.Myers2@health.nsw.gov.au

Please contact Dr Lisa Myers, Lisa.Myers2@health.nsw.gov.au if you have any questions or concerns.

Yours sincerely,

Dr Lisa Myers

On behalf of the Botulinum Toxin A Transition project group.

Consent

My service is aware that the information provided in this questionnaire will be made available to clinicians and consumers. I am aware that this information will be collated into a resource that will map botulinum toxin A services across NSW and ACT and that this resource may be published on the NSW Agency for Clinical Innovation and SCHN Trapeze website.

I hereby agree to the above	<input type="checkbox"/> YES <input type="checkbox"/> NO	Date	
Name			
Position			
Email			
Phone			
Date			

Service details	
Name of the service/Hospital:	
	Tick all that apply: <input type="checkbox"/> Public outpatient clinic <input type="checkbox"/> Public inpatient admission <input type="checkbox"/> Private outpatient clinic <input type="checkbox"/> Private inpatient admission
If private, which patients are offered bulk billing for services?	
Access to the PBS Botulinum Toxin Program?	<input type="checkbox"/> YES <input type="checkbox"/> NO
Access to other sources of funding to offset the cost of BoNT-A for the patient?	<input type="checkbox"/> YES <input type="checkbox"/> NO Comment:
Department	
Address	
Phone	
Fax	
Email	
Website	

Referral criteria	
Local health district	
Accept patients outside LHD?	
Referrals accepted from	
<input type="checkbox"/> General practitioners <input type="checkbox"/> Paediatricians <input type="checkbox"/> Neurologists <input type="checkbox"/> Surgeons <input type="checkbox"/> Other specialists <input type="checkbox"/> Allied health professionals <input type="checkbox"/> Self or family	
Minimum patient age?	
Other eligibility or referral criteria?	

Sedation options	
Procedural sedation options available?	<input type="checkbox"/> YES <input type="checkbox"/> NO
If yes, what are these sedation options?	
Is there access to theatre, i.e. can the procedure be done under general anaesthetic?	<input type="checkbox"/> YES <input type="checkbox"/> NO Comment:
Additional Comments	

Clinic structure	
Clinic type?	<input type="checkbox"/> Medical-only <input type="checkbox"/> Multidisciplinary input at clinic
Nurse involved in clinic?	<input type="checkbox"/> YES <input type="checkbox"/> NO
If multidisciplinary clinic, which professionals are involved in the clinic	
<input type="checkbox"/> Physiotherapy <input type="checkbox"/> Occupational therapy <input type="checkbox"/> Speech pathology <input type="checkbox"/> Clinical psychology <input type="checkbox"/> Orthotist <input type="checkbox"/> Others, please specify: <hr/>	
Referral / Follow Up	
Do you provide coordination or referral for therapy post injection?	
Is therapy provided by the service?	
How long will the procedure visit take (on the day of injections)	

Accessibility & amenities	
Clinic is wheelchair accessible, e.g. ramps, lifts?	<input type="checkbox"/> YES <input type="checkbox"/> NO
Hoist available in clinic room?	<input type="checkbox"/> YES <input type="checkbox"/> NO
Disabled toilet?	<input type="checkbox"/> YES <input type="checkbox"/> NO
Changing table available with hoist?	<input type="checkbox"/> YES <input type="checkbox"/> NO
Disabled parking available?	<input type="checkbox"/> YES <input type="checkbox"/> NO

Appendix F – Botulinum toxin a service listing

Key

✓ Yes | ✗ No | ~ Sometimes | ? Unknown

Illawarra Shoalhaven LHD

Rehab Department, Shoalhaven Hospital Scenic Dr, Nowra NSW 2541 Phone: (02) 4421 3111 Fax: (02) 4423 9277		Services ✓ Public ✗ Private		✗ Inpatient ✓ Outpatient	
Billing and referrals Minimum age: 16 ✓ Non-PBS funding ✗ Referrals outside LHD		Sedation and anaesthetic ✗ Sedation ✗ General anaesthetic ✓ Multidisciplinary team assessment		Accessibility and amenities ✓ Wheelchair accessible ✗ Hoist available ✓ Disabled toilet ✗ Changing table with hoist ✓ Disabled parking	

Neurology Department, Wollongong Hospital 348 Crown St, Wollongong NSW 2500 Phone: (02) 4253 4430 Fax: (02) 4253 4436		Services ✓ Public ✗ Private		✗ Inpatient ✓ Outpatient	
Billing and referrals Minimum age: 16 ✓ Non-PBS funding ✓ Referrals outside LHD		Sedation and anaesthetic ✓ Sedation ✗ General anaesthetic ✗ Multidisciplinary team assessment		Accessibility and amenities ✓ Wheelchair accessible ✗ Hoist available ✓ Disabled toilet ✗ Changing table with hoist ✓ Disabled parking	

Neurology Department, Wollongong Private Hospital Suite 606, Level 6, 360 Crown St, Wollongong NSW 2500 Phone: (02) 4225 1133 Fax: (02) 4253 4430		Services ✗ Public ✓ Private		✗ Inpatient ✓ Outpatient	
Billing and referrals Minimum age: 16 ? Bulk billing ✓ Non-PBS funding ✓ Referrals outside LHD		Sedation and anaesthetic ✓ Sedation ✗ General anaesthetic ✗ Multidisciplinary team assessment		Accessibility and amenities ✓ Wheelchair accessible ✗ Hoist available ✓ Disabled toilet ✗ Changing table with hoist ✓ Disabled parking	

Mid North Coast LHD

Barringa Private Hospital Mackays Rd, Coffs Harbour NSW 2450 Phone: (02) 6659 4469 Phone: (02) 6659 4480 Fax: (02) 6659 4499 Email: raked@ramsayhealth.com.au www.baringaprivate.com		Services ✕ Public ✓ Private ✓ Inpatient ✓ Outpatient	
Billing and referrals Minimum age: None ✓ Bulk billing ? Non-PBS funding ✓ Referrals outside LHD	Sedation and anaesthetic ? Sedation ✓ General anaesthetic ✓ Multidisciplinary team assessment	Accessibility and amenities ✓ Wheelchair accessible ✓ Hoist available ✓ Disabled toilet ✕ Changing table with hoist ✓ Disabled parking	

Newstart Rehabilitation Suite 2, 10B Highfields Cct, Macquarie Specialist Centre, Port Macquarie NSW 2444 Phone: (02) 6581 5505 Fax: (02) 6581 5505 Email: office@newstartrehab.com.au www.portmacquarieprivate.com.au/Specialists/Specialists/port-macquarie-private-hospital/general-medicine/101052/dr-rosllyn-avery		Services ✕ Public ✓ Private ✕ Inpatient ✓ Outpatient	
Billing and referrals Minimum age: 10 ✓ Bulk billing ✕ Non-PBS funding ✓ Referrals outside LHD	Sedation and anaesthetic ✕ Sedation ✕ General anaesthetic ✕ Multidisciplinary team assessment	Accessibility and amenities ✓ Wheelchair accessible ✕ Hoist available ✓ Disabled toilet ✕ Changing table with hoist ✓ Disabled parking	

Murrumbidgee LHD

Rehab Department, Wagga Wagga Base Hospital Edward St, Wagga Wagga NSW 2650 Phone: (02) 5943 1400		Services ✓ Public ✕ Private ✓ Inpatient ✓ Outpatient	
Billing and referrals Minimum age: 16 ? Non-PBS funding ✓ Referrals outside LHD	Sedation and anaesthetic ✕ Sedation ✕ General anaesthetic ✕ Multidisciplinary team assessment	Accessibility and amenities ✓ Wheelchair accessible ✓ Hoist available ✓ Disabled toilet ✕ Changing table with hoist ✓ Disabled parking	

Northern NSW LHD

Rehab Balance 186 Broken Head Rd, Newrybar NSW 2479 Phone: (04) 3946 9191 Fax: (02) 5631 8000 Email: info@rehabbalance.com.au www.rehabbalance.com.au		Services ✗ Public ✓ Private ✓ Inpatient ✓ Outpatient	
Billing and referrals Minimum age: 16 ~ Bulk billing ✓ Non-PBS funding ✓ Referrals outside LHD	Sedation and anaesthetic ✗ Sedation ✗ General anaesthetic ✓ Multidisciplinary team assessment	Accessibility and amenities ✓ Wheelchair accessible ✗ Hoist available ✓ Disabled toilet ✗ Changing table with hoist ✓ Disabled parking	

Northern Sydney LHD

Rehab and Aged Care Service, Bernard Curran Rehabilitation Unit, Hornsby Ku-ring-gai Hospital Palmerston Rd, Hornsby NSW 2077 Phone: (02) 9477 9514 Fax: (02) 9477 5684		Services ✓ Public ✗ Private ✓ Inpatient ✓ Outpatient	
Billing and referrals Minimum age: 17 ✓ Non-PBS funding ✓ Referrals outside LHD	Sedation and anaesthetic ✓ Sedation ✗ General anaesthetic ✓ Multidisciplinary team assessment	Accessibility and amenities ✓ Wheelchair accessible ✓ Hoist available ✓ Disabled toilet ✓ Changing table with hoist ✓ Disabled parking	

Rehabilitation Department and Spasticity Clinic, Royal North Shore Hospital Reserve Rd, St Leonards NSW 2065 Phone: (02) 9463 1833 Fax: (02) 9463 1017 Email: NSLHD-accreferrals@health.nsw.gov		Services ✓ Public ✗ Private ✓ Inpatient ✓ Outpatient	
Billing and referrals Minimum age: 18 ~ Non-PBS funding ~ Referrals outside LHD	Sedation and anaesthetic ✗ Sedation ✗ General anaesthetic ✗ Multidisciplinary team assessment	Accessibility and amenities ✓ Wheelchair accessible ✓ Hoist available ✓ Disabled toilet ✓ Changing table with hoist ✓ Disabled parking	

South Eastern Sydney LHD

Rehab Department, Prince of Wales Hospital 320-346 Barker St and High St, Randwick NSW 2031 Phone: (02) 9382 2222 www.princeofwalesprivatehospital.com.au		Services ✓ Public ✗ Private ✓ Inpatient ✓ Outpatient	
Billing and referrals Minimum age: 18 ✓ Non-PBS funding ~ Referrals outside LHD	Sedation and anaesthetic ✗ Sedation ~ General anaesthetic ✓ Multidisciplinary team assessment	Accessibility and amenities ✓ Wheelchair accessible ✓ Hoist available ✓ Disabled toilet ✓ Changing table with hoist ~ Disabled parking	

Rehab Department, St George Hospital Ground Floor, Prince William Wing, Belgrave St, Kogarah NSW 2217 Phone: (02) 9113 2267		Services ✓ Public ✗ Private ✗ Inpatient ✓ Outpatient	
Billing and referrals Minimum age: 12 ? Non-PBS funding ~ Referrals outside LHD	Sedation and anaesthetic ✓ Sedation ✓ General anaesthetic ✓ Multidisciplinary team assessment	Accessibility and amenities ✓ Wheelchair accessible ✓ Hoist available ✓ Disabled toilet ✗ Changing table with hoist ✓ Disabled parking	

South Western Sydney LHD

Rehabilitation Department, Liverpool Hospital Brain Injury Unit, Entrance K Elizabeth and Goulburn Sts, Liverpool NSW 2170 Phone: (02) 8738 5495 Fax: (02) 8738 5495 Email: SWLHD-SpasticityManagementService@health.nsw.gov.au www.swslhd.health.nsw.gov.au/Liverpool/BIRU/SMS.html		Services ✓ Public ✗ Private ✗ Inpatient ✓ Outpatient	
Billing and referrals Minimum age: 12 ~ Non-PBS funding ✓ Referrals outside LHD	Sedation and anaesthetic ✓ Sedation ✗ General anaesthetic ✓ Multidisciplinary team assessment	Accessibility and amenities ✓ Wheelchair accessible ✓ Hoist available ✓ Disabled toilet ✓ Changing table with hoist ✓ Disabled parking	

St Vincent's Health Network

Rehabilitation Department, St Vincent's Hospital 170 Darlinghurst Rd, Darlinghurst NSW 2207 Phone: (02) 8382 9571 Fax: (02) 8382 9431 Email: svhs.dayrehab@svha.org.au		Services	
		✓ Public ✗ Private	✓ Inpatient ✓ Outpatient
Billing and referrals	Sedation and anaesthetic	Accessibility and amenities	
Minimum age: 18 ✓ Non-PBS funding ~ Referrals outside LHD	✗ Sedation ✗ General anaesthetic ✓ Multidisciplinary team assessment	✓ Wheelchair accessible ✗ Hoist available ✓ Disabled toilet ✗ Changing table with hoist ~ Disabled parking	

Sydney LHD

Neurology Department, Concord Repatriation General Hospital Hospital Rd, Concord NSW 2139 Phone: (02) 9767 6416 Fax: (02) 9767 7807		Services	
		✓ Public ✗ Private	✗ Inpatient ✓ Outpatient
Billing and referrals	Sedation and anaesthetic	Accessibility and amenities	
Minimum age: 18 ✗ Non-PBS funding ✓ Referrals outside LHD	✗ Sedation ✗ General anaesthetic ✗ Multidisciplinary team assessment	✓ Wheelchair accessible ✗ Hoist available ✓ Disabled toilet ✗ Changing table with hoist ✓ Disabled parking	

Rehab Department, Royal Prince Alfred Hospital Department of Rehabilitation Medicine Spasticity Clinic QE2 Building, Missenden Rd, Camperdown NSW 2050 Phone: (02) 9515 9839		Services	
		✓ Public ✗ Private	✓ Inpatient ✓ Outpatient
Billing and referrals	Sedation and anaesthetic	Accessibility and amenities	
Minimum age: 18 ✗ Non-PBS funding ✓ Referrals outside LHD	✗ Sedation ✗ General anaesthetic ✓ Multidisciplinary team assessment	✓ Wheelchair accessible ✗ Hoist available ✓ Disabled toilet ✗ Changing table with hoist ✓ Disabled parking	

Neurology Department, St Vincent's Private Suite 702, St Vincent's Clinic, 438 Victoria St, Darlinghurst NSW 2010 Phone: (02) 8382 6739 Fax: (02) 8382 6739 Email: recp702@stvincents.com.au		Services ✓ Public ✓ Private ✗ Inpatient ✓ Outpatient
Billing and referrals Minimum age: 16 ✗ Bulk billing ✗ Non-PBS funding ✓ Referrals outside LHD	Sedation and anaesthetic ✓ Sedation ✗ General anaesthetic ✓ Multidisciplinary team assessment	Accessibility and amenities ✓ Wheelchair accessible ✗ Hoist available ✓ Disabled toilet ✗ Changing table with hoist ✓ Disabled parking

Sydney Neurology 94 Mallett St, Camperdown NSW 2050 Phone: (02) 9351 0730 Fax: (02) 9351 0653 Email: info@sydneyneurology.com.au sydneyneurology.com.au		Services ✗ Public ✓ Private ✗ Inpatient ✓ Outpatient
Billing and referrals Minimum age: 18 ? Bulk billing ✗ Non-PBS funding ✓ Referrals outside LHD	Sedation and anaesthetic ✗ Sedation ✗ General anaesthetic ✗ Multidisciplinary team assessment	Accessibility and amenities ✓ Wheelchair accessible ✗ Hoist available ✓ Disabled toilet ✗ Changing table with hoist ~ Disabled parking

Western NSW LHD

Rehabilitation Department, Bathurst Base Hospital Howick St, Bathurst NSW 2795 Phone: (02) 6330 5758 Fax: (02) 6330 5758 Email: WNSWLHD-bathurstsmc@health.nsw.gov.au		Services ✓ Public ✗ Private ✗ Inpatient ✓ Outpatient
Billing and referrals Minimum age: 18 ✗ Non-PBS funding ✓ Referrals outside LHD	Sedation and anaesthetic ✗ Sedation ✓ General anaesthetic ✗ Multidisciplinary team assessment	Accessibility and amenities ✓ Wheelchair accessible ✗ Hoist available ✓ Disabled toilet ✗ Changing table with hoist ✓ Disabled parking

Rehab Department, Orange Health Service 1502 Forest Rd, Orange NSW 2800 Phone: (02) 6369 3129 Fax: (02) 6360 1382 Email: tracey.davis@health.nsw.gov.au		Services	
		✓ Public ✗ Private	✗ Inpatient ✓ Outpatient
Billing and referrals	Sedation and anaesthetic	Accessibility and amenities	
Minimum age: 18 ✗ Non-PBS funding ✓ Referrals outside LHD	✓ Sedation ✓ General anaesthetic ✓ Multidisciplinary team assessment	✓ Wheelchair accessible ✓ Hoist available ✓ Disabled toilet ✓ Changing table with hoist ✓ Disabled parking	

Western Sydney LHD

Specialist Services, Norwest Private Suite G22, 9 Norbrik Dr, Bella Vista NSW 2153 Phone: (02) 8850 8100 Fax: (02) 8814 5785 Email: ashleigh.akle@specialistservices.com.au www.norwestprivatehospital.com.au		Services	
		✗ Public ✓ Private	✗ Inpatient ✓ Outpatient
Billing and referrals	Sedation and anaesthetic	Accessibility and amenities	
Minimum age: 14 ✓ Bulk billing ✗ Non-PBS funding ✓ Referrals outside LHD	✗ Sedation ✗ General anaesthetic ✗ Multidisciplinary team assessment	✓ Wheelchair accessible ✗ Hoist available ✓ Disabled toilet ✗ Changing table with hoist ✓ Disabled parking	

Neurophysiology Department, Westmead Hospital 151 Hawkesbury Rd, Westmead NSW 2154 Phone: 8890 6097 Fax: 9633 3272 Email: jewel.horwood@health.nsw.gov.au		Services	
		✓ Public ✗ Private	✗ Inpatient ✓ Outpatient
Billing and referrals	Sedation and anaesthetic	Accessibility and amenities	
Minimum age: 16 ✗ Non-PBS funding ~ Referrals outside LHD	✗ Sedation ✓ General anaesthetic ✗ Multidisciplinary team assessment	✓ Wheelchair accessible ✓ Hoist available ✓ Disabled toilet ✓ Changing table with hoist ✓ Disabled parking	

Rehabilitation, Westmead Rehabilitation Private Hospital 7 Coleman St, South Wentworthville NSW 2145 Phone: 8833 3555 Fax: (02) 8833 3533 Email: westmead@healthcare.com.au westmeadrehab.net.au		Services	
		✗ Public ✓ Private	✓ Inpatient ✓ Outpatient
Billing and referrals	Sedation and anaesthetic	Accessibility and amenities	
Minimum age: 18 ✓ Bulk billing ✗ Non-PBS funding ✓ Referrals outside LHD	✗ Sedation ✗ General anaesthetic ✗ Multidisciplinary team assessment	✓ Wheelchair accessible ✓ Hoist available ✓ Disabled toilet ✗ Changing table with hoist ✓ Disabled parking	

ACT Health

Rehab Department, Canberra Hospital Yamba Dr, Garran ACT 2605 Phone: (02) 5124 0000 www.health.act.gov.au/hospitals-and-health-centres/canberra-hospital		Services	
		✓ Public ✗ Private	✗ Inpatient ✓ Outpatient
Billing and referrals	Sedation and anaesthetic	Accessibility and amenities	
Minimum age: 17 ✓ Non-PBS funding ~ Referrals outside LHD	✗ Sedation ✓ General anaesthetic ✓ Multidisciplinary team assessment	✓ Wheelchair accessible ? Hoist available ✓ Disabled toilet ? Changing table with hoist ✓ Disabled parking	

Specialist Centre for Rehabilitation, Recovery and Research, University of Canberra Hospital Brindabella Rehabilitation Centre, Lvl 1, 20 Guraguma St, Bruce ACT 2617 www.health.act.gov.au/hospitals-and-health-centres/canberra-hospital		Services	
		✓ Public ✗ Private	✗ Inpatient ✓ Outpatient
Billing and referrals	Sedation and anaesthetic	Accessibility and amenities	
Minimum age: 17 ✓ Non-PBS funding ~ Referrals outside LHD	✓ Sedation ✗ General anaesthetic ✓ Multidisciplinary team assessment	✓ Wheelchair accessible ✓ Hoist available ✓ Disabled toilet ✓ Changing table with hoist ✓ Disabled parking	

Albury Wodonga Health

Rehab Department, Wodonga Hospital Vermont St, Wodonga VIC 3690 Phone: 6051 7111 awh.org.au		Services	
		✓ Public ✗ Private	✗ Inpatient ✓ Outpatient
Billing and referrals	Sedation and anaesthetic	Accessibility and amenities	
Minimum age: None ✓ Non-PBS funding ✗ Referrals outside LHD	✗ Sedation ✓ General anaesthetic ✓ Multidisciplinary team assessment	✓ Wheelchair accessible ✓ Hoist available ✓ Disabled toilet ✗ Changing table with hoist ✓ Disabled parking	