

# Recognition for exemplar practice in implementing the NSQHS Standards

**Health service organisation:** Transition Support Service, The Royal Children's Hospital Melbourne

**Contact:** Evelyn Culnane, Manager, Transition Support Service

**Email:** [Evelyn.Culnane@rch.org.au](mailto:Evelyn.Culnane@rch.org.au)

## Background information about the exemplar practice

### The catalysts for change

*"I have increasing anxiety and paranoia about our imminent departure from the Royal Children's Hospital (RCH). I can see everything getting closer and as there are still so many unknowns and services that are ending without guarantees of equivalent services, my fear is eating into me!"*

Transition from paediatric to adult care if not well managed may result in adverse outcomes for patients, their families and the health system. Issues include fragmentation and prolonged gaps in care delivery, disengagement from adult health care and poorer health outcomes. For some chronic patient groups, the rate of loss-to-follow-up from paediatric to adult care is as high as 76% (1).

Transition is even more challenging for patients with complex chronic conditions who experience significantly higher hospitalisation rates, readmissions, more medication requirements and higher inpatient mortality rates, resulting in immense financial and organisational burden for the healthcare system (2-5). Therefore, a centralised and comprehensive transition service which assists in integrating health care systems and connections with the community including disability and primary care, is necessary.

Feedback obtained from RCH patients, their carers, paediatric and adult clinicians via the RCH Melbourne Adolescent Transition Pilot Study (2010-12), the RCH Adolescent Friendly Hospital Survey (2011) and the RCH Adult Services Gap Analysis Project (2012-13), indicated similar findings and gaps in care.

### Best practice in transition care recommendations

The RCH Transition Support Service embodies and delivers best practice in transition care.

The Royal Australasian College of Physicians' (RACP) position statement on transition recommends formal preparation of young people attending paediatric services, conjoint activities and comprehensive orientation to adult care. This includes the appointment of a central case

manager for the young person and carer throughout the transition process commencing during early adolescence with active engagement and involvement of the treating general practitioner and a planned 'handover' with the young person and carers (6).

Parents of young people with profound intellectual and multiple disabilities also recommend early transition planning, information provision and a joint consultation between paediatric and adult care (7).

Numerous other consensus statements and studies include recommendations which are core to the achievements of the RCH Transition Support Service (8-11).

## **Excellence in transition care at the RCH – Improvements in Safety and Quality of Care**

### **1. Transdisciplinary care for patients transitioning from the RCH to adult services:**

The RCH Transition Support Service provides tailored transdisciplinary care for over 1600 patients and their carers annually, an increase of 200% since 2015, supporting a greater population of vulnerable patients with complex chronic conditions, including those with neurocognitive and intellectual disabilities. Transition care commences early for patients from the age of 15 and are supported over several years enabling comprehensive patient-centred transition planning. As the Service actively fosters connected care across all units at the RCH and with external services, patients are transitioned to adult care safely and supportively.

### **2. Leading combined RCH and Adult Service Transition Clinics:**

The Transition Support Service leads/ co-leads more than 60 joint RCH and adult service transition clinics each year with over 30 subspecialties, ensuring that young people and their carers attending meet their new adult teams prior to transfer from the RCH and have the opportunity to contribute to shared discussions and planning for their long-term care. In 2013, only three joint RCH and adult service transition clinics occurred at the RCH. This significant increase is a result of through the Transition Support Service's active engagement with specialist services at the RCH and with equivalent adult services across Victoria, thereby improving patient and carer experience during the transition period and successfully bridging the gap between paediatric and adult services.

*"A key highlight from my transition was meeting with all the doctors from the Austin in a space that was familiar with my RCH doctor. This helped me to feel at ease."* (patient)

*"These transition clinics are a much-needed opportunity for clinicians to hand over often complicated patients effectively and safely"* (Neurologist, Royal Melbourne Hospital)

*"These joint clinics are great for us to know the patients before they graduate to our adult clinics and also for them to feel comfortable with us. Also the discussions about management options is very helpful and enjoyable"* (Neurologist, Alfred Hospital)

**1. Influencing the development of Young Adult Clinics across Victoria:**

The combined RCH and Adult Service Transition Clinics and collaborations have also provided impetus for the development of a greater number of Young Adult Clinic models at a number of adult hospital sites in recent years in Victoria, including the Royal Melbourne renal service, Monash Medical Centre's inflammatory bowel disease service, the Alfred Hospital's heart transplant service and the Young Adult Diabetes Services which exist at Western Health, the Austin, the Royal Melbourne and Monash Medical Centre. These clinics ensure that young people are managed in a developmentally appropriate clinical structure, encouraging engagement and attendance in adult health care.

**2. Creating a State-wide Network through connection and capacity building, to optimise the long term care of vulnerable and complex patients:**

The transition care of medically and developmentally complex patients is a challenge for all health services. In addition to the multiple partnerships the RCH Transition Support Service has established with adult health services, it has actively sought to address this issue through the creation of a network of adult General Medicine services in Victoria and the initiation of cross-collaborative learning and communication systems with relevant medical units at the RCH. The Transition Support Service has now established strong partnerships and integrated transition care pathways with General Medicine services at Melbourne Health, Western Health, Monash Health, Alfred Health, Northern Health, Austin Health, St Vincent's Health and regional centres in Barwon and Bendigo Health. The establishment of this network of General Medicine services in Victoria enables safe, coordinated care of complex patients as they transition from the RCH to adult services.

**3. Safe preventative care in adult emergency departments:**

The Transition Support Service has led the development of collaborative pathways with adult hospital emergency departments in Victoria to develop shared management plans for patients with high care needs transferring from the RCH. Partnerships with emergency department teams at the Northern, the Royal Melbourne, the Austin, the Western, St Vincent's Melbourne, Bendigo Health and Barwon Health have been established. This consultative process brings together input from the family, emergency department physicians, RCH specialists and relevant care providers in adult health, mental health (if relevant) and community services, assisting in the safe pre-emptive transfer of the most complex and vulnerable patients.

**4. Ensuring safe and appropriate transfer of care from the RCH to adult services:**

The Transition Support Service ensures patients are transferred successfully to appropriate services in a coordinated, safe and consultative manner. As transition planning occurs early in consultation with patients, carers and clinicians, adult and community services are identified and negotiations with these services are initiated by the Transition Support Service to ensure entry into the new service/s and that transfer of care is managed well. This system also ensures that patients who may be 'lost' in adult services are reconnected with care through the Service's direct communication with the patient and family and appropriate adult health services.

**5. Transition care for patients with an intellectual disability (ID) and/or autism spectrum disorder (ASD) with mental health or behavioural comorbidities:**

The care of patients with an ID and/or ASD within acute health settings is complex as it requires considered and systemic integration of multiple sectors including health and mental health, disability and community care. This is further complicated when change in service provision occurs during the period of transition to adult care; a period which is often associated with escalated behavioural concerns and developmental issues. This issue has been a particular focus of the Transition Support Service.

A key innovation led by the Transition Support Service was the development and implementation of *Fearless Tearless Transition*, a new clinical management model in 2019 for patients with ID and/or ASD with mental health or behavioural comorbidities (please see Appendix 1), bringing together several RCH medical teams, the North Western Melbourne Primary Health Network, the Centre for Developmental Disability Health, dual disability services in Victoria, mental health services and consumers.

Carer feedback informed the *Fearless Tearless Transition* model of care from 2016-17, revealing that 40% families did not have a regular or trusted GP, over 50% families did not have adequate respite nor links with community providers and 64% carers expressed moderate to high levels of anxiety regarding transfer to adult care (this data is yet to be published). This provided the impetus for the implementation of a shared care approach for patients 15 years and over, between RCH and relevant community paediatricians with over 240 GPs in Victoria in 2018-19.

*Fearless Tearless Transition* has achieved the following key objectives:

- The consistent management of adolescent patients with ID and/or ASD at the RCH, including dedicated transition support to assist families in navigating and engaging with appropriate adult and community care
- More defined transition and transfer pathways for patients with ID and/or ASD, where previously there were none
- The development and use of consistent clinical assessment tools by RCH paediatricians, to measure severity of mental health issues and patient/family needs
- Increased engagement and communication with service providers in the community to share in the care of these patients. The RCH now partners with over 240 GPs and other external mental health and care providers in Victoria, thereby increasing knowledge and capacity in general practice
- Dedicated resources for GPs
- Dedicated transition resources for families
- Dedicated resources for RCH clinicians to assist in the management of patients with ID and/or ASD, including the development of a training video in the use of the aforementioned clinical assessment tools
- The publication of a GP Health Pathway for care of patients with ID and/or ASD

*"This document, 'Fearless Tearless Transition', reads beautifully and will be incredibly helpful for GPs. I am so impressed with this project." (GP Clinical Editor, North Western Melbourne Primary Health Network)*

*"The work that you and the team are doing with the transition of patients with severe Autism and intellectual disability is so amazing and necessary. Working with you has had a profound impact on me." (Emergency Department physician, Dandenong Hospital)*

### **Other Patient-centred Initiatives led by the RCH Transition Support Service**

The Transition Support Service leads a number of other patient-centred initiatives to ensure positive experience in transition, including:

1. The creation of a Parent Support Network for families with young people with an ID and/or ASD with mental health or behavioural concerns.
2. Healthcare transition plans and transfer passports for patients and carers. These resources are also made available within the RCH Patient Portal electronic medical record and provides assistance for clinicians with transition planning ([Transition Support Service - http://www.rch.org.au/transition](http://www.rch.org.au/transition)).
3. Provision of medical information on a USB and disc for patients and carers prior to transfer from the RCH.
4. Patient education resources on a range of adolescent topics ([Transition Support Service - http://www.rch.org.au/transition](http://www.rch.org.au/transition)). All resources have been developed in collaboration with relevant consumer organisations and individual patients and carers.
5. An annual Graduation Ceremony at the RCH for patients and families leaving the care of the RCH.
6. An annual Educational Support Seminar at the RCH to support the educational and vocational aspirations of RCH and Monash Children's Hospital patients; a collaboration with Capital City Local Learning Employment Network, the Ronald McDonald Learning Program, the Victorian Curriculum and Assessment Authority, the Victorian Tertiary Admissions Centre and universities and TAFEs.

## **Details on implementation**

Include information on how the improvement has been implemented in all relevant areas of the organisation; how the practices have been communicated to all relevant parties e.g. the workforce or, where relevant, the community; how the improvement is built into day-to-day operations; and how the improvement is or can be sustained.

Excellence in transition care is now routine practice at the RCH across all areas, and is now operationally funded through the RCH.

The Transition Support Service ensures best practice through the delivery of patient-centred, clinically relevant and responsive care. This is achieved through the provision of direct clinical care and leadership in systems development, advocacy, education and research.

This has been achieved through the Transition Support Service's leadership in:



1. Establishing strong partnerships with all specialist teams at the RCH and with adult services in Victoria and Australia and numerous collaborative initiatives.
2. Delivering a whole-hospital sustainable transition of care system which is supported by several medical, nursing and allied health team members who champion transition care across the RCH and is not reliant on single clinicians. The Transition Support Service provides a central point of contact for families and clinicians across Victoria and further afield.
3. Clear referral processes are in place from all RCH departments to the Transition Support Service. Patients may also self-refer via their treating clinicians or through direct contact with the Service.
4. Ensuring governance and shared accountability for excellence in transition care at the RCH through the RCH Adolescent Transition Procedure and RCH Access Policy (please find documents attached). These systems ensure that improvements can be sustained and continue to be responsive to changing needs as the population of complex patients requiring adult care transition increases.
5. Caring for the most complex patients at the RCH through innovations such as the Fearless, Tearless Transition model of care led by the Transition Support Service for all RCH patients with an ID and/or ASD. This has been widely adopted by clinicians at the RCH and with over 240 GPs across metropolitan and regional Victoria.
6. Informing the development of an RCH-wide clinical management and preventative care strategy for all patients with behaviours of concern.
7. Regular capacity building and knowledge provided to RCH clinicians and external providers.
8. Numerous collaborations with other health services. For example, the Transition Support Service is leading a partnership with Evelina Children's Hospital in London to trial the *Fearless Tearless Transition* model of care at this site.
9. Building knowledge and capacity in General Practice through the shared care transition process and the publication of GP Health Pathways in collaboration with the North Western Melbourne Primary Health Network for patients with ID and/or ASD and for patients with Neurofibromatosis (NF1). The NF1 GP Health Pathway was established in partnership with the RCH neurology department and Royal Melbourne Hospital's neuro-oncology service to assist GPs with understanding the monitoring needs of patients with NF1 and referral pathways in Victoria.
10. Building knowledge and capacity within other health services across Australasia and internationally. The Transition Support Service is the Chair of the Transition special interest group for Children's Healthcare Australasia and delivers regular presentations at numerous conferences and forums.
11. Advocacy and systems development initiatives, including the Transition Support Service's contribution at the Royal Commission into Victoria's Mental Health System
12. Collaborative research initiatives including a National Medical Health and Research Council (NHMRC) project to improve transition care for patients with congenital heart disease, an NHMRC project to inform the care of adolescents and young adults with cerebral palsy and a 3-year International Interdisciplinary Study of Healthcare Transition of Adolescents to Adult Care from the RCH and Helsinki University Central Children's Hospital Finland.

The Transition Support Service also provides regular consultation and partners with numerous consumer organisations, including HeartKids Australia in the publication of the National Strategic Action Plan for Congenital Heart Disease, Kidney Health Australia in the implementation of its Commonwealth-funded Young Adults Program, the Oesophageal Atresia Research Auxiliary and the International Network on Esophageal Atresia in the development of international transition guidelines and the recently published Management of People with a Fontan Circulation: a Cardiac Society of Australia and New Zealand Position Statement, a partnership with the ANZ Fontan Advocacy Committee and paediatric and adult cardiology services in Australia and New Zealand (8).

## Details on evaluation

Include information on the measures used to evaluate the improvement and evaluation data that shows the positive change in safe and quality care, and/or in patient outcomes.

Continuous evaluation and improvement of the Transition Support Service occurs through regular feedback provided by patients and their carers, RCH and adult service clinicians, GPs and other health care providers in the community. The Service's immense scope of practice in the field of transition and associated innovations, enables direct and immediate translation of research into clinical care.

## Hospital benchmarking data

The Transition Support Service utilises comparative Australian paediatric hospital data for benchmarking. Data obtained from Children's Healthcare Australasia demonstrates that the RCH has maintained the lowest overage outpatient rate in Australia, despite the total patient load increasing from 66,195 to 71,510 (see Table 1). 'Overage patients' is defined as the proportion of patients aged 20 and over, as the upper access age at RCH is 19. This has been achieved, in part, through timely, safe and coordinated transfer of RCH patients to adult care, thereby improving long term health outcomes and access to the RCH for younger patients.

**Table 1: Overage outpatient data from paediatric hospitals in Australia in 2015 and 2018.**

Hospital	Proportion of overage outpatients	
	2015 (%)	2018 (%)
Royal Children's Hospital	0.3	0.3
Randwick Children's Hospital, NSW	1.9	1.6
Westmead Children's Hospital, NSW	3.0	3.0
Perth Children's Hospital, WA	0.5	Not available
SA - WCHN	Not available	Not available
Queensland Children's Health, QLD	0.4	0.6

## **International Interdisciplinary Transition Research Study 2018-2021**

The Transition Support Service is measuring patient outcomes and quality of transition care through its current 3-year International Interdisciplinary Study of Healthcare Transition of Adolescents to Adult Care from the RCH and Helsinki University Central Children's Hospital Finland. This will evaluate the impact of the RCH Transition Support Service and transition more broadly, from the perspective of patients and their carers as they transition from the RCH to adult services over the 3-year study period. These outcomes will be compared and benchmarked against international hospital data obtained from the research partners in Helsinki.

Preliminary results from 132 young people and 132 carers indicate that 78% of young people and 67% of carers receiving transition support either strongly agree or agree that they are satisfied with the Transition Support Program; 70% of young people either agree or strongly agree that transition clinics helped them to develop their skills and knowledge to self-manage their medical condition; and 89% of young people reported feeling confident and prepared about transferring to adult health services. Over half (59%) of the carers and 43% of young people surveyed indicated that they felt anxious about transferring from the RCH to an adult service. Similarly, only 37% of carers and 43% of young people reported that they were looking forward to transferring from the RCH to an adult service.

A key element of this study will to measure healthcare usage of patients following transfer from the RCH to adult services and contribute to better understanding the financial impact and 'burden' of care, particularly for patients with complex chronic medical needs with multiple comorbidities and disabilities and their families.

The initial stage of this project in early 2018 sought feedback from RCH and adult service clinicians. 128 RCH clinicians rated how well supported their patients are with transition from the RCH now in contrast to five years prior. More than 60% of RCH clinicians believe we now support patients Quite Well or Very Well with their transition, compared to just over 20% in 2013. Furthermore, when we compared the response of RCH and adult service clinicians in Victoria to determine their perception of how well the transition processes are working currently, 92% adult clinicians and 86% RCH clinicians responded with the belief that we are now managing transition Somewhat Well to Very Well (see Figure 1).



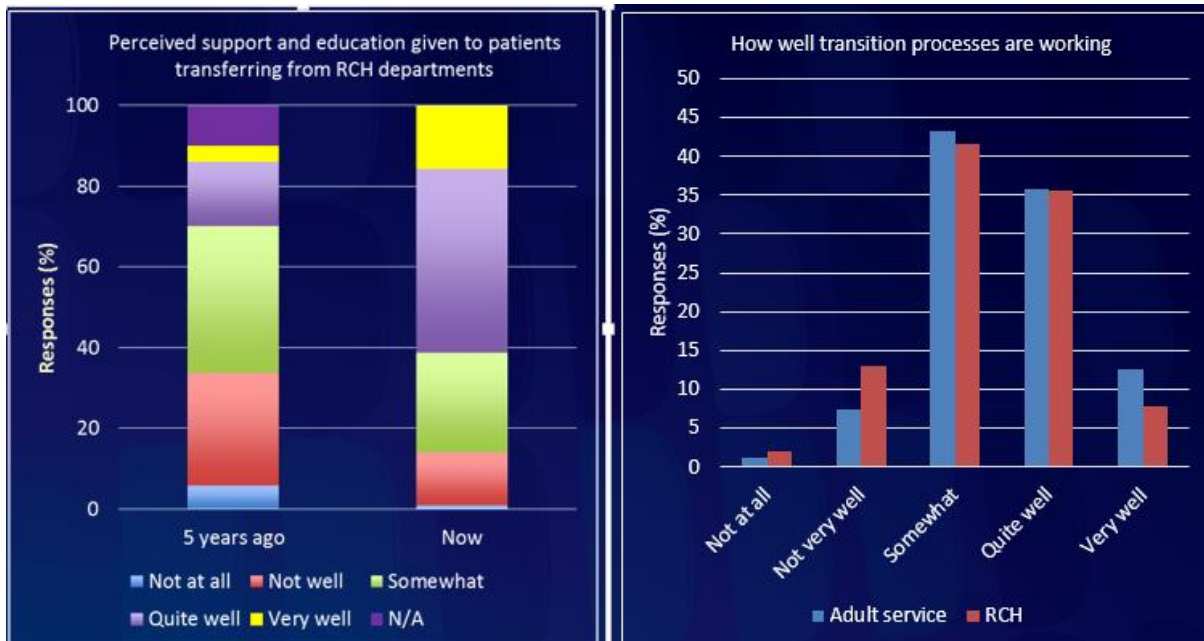


Figure 1: Survey of 128 RCH and 107 Adult Service clinicians involved in the transition care of patients in Victoria from the Royal Melbourne, Alfred, St Vincent's Melbourne, Austin Hospital, Monash Medical Centre and regional centres

## Testimonials from patients, families, clinicians and other key stakeholders

Please find below additional testimonials from:

### 1. Patients and carers:

- "We are very grateful for your assistance through this emotional journey as we leave the safe haven of the RCH and make the first tentative steps into adult services. We would have been lost without this level of expertise and care."
- "You make the impossible possible and brought a smile to my family."
- "Each meeting with you brings us into a more confident stage in managing our son's future."
- "Transition into the adult health system has gone smoothly because of you."
- "Without your assistance, I would not have been able to get the care that I needed."
- "The Transition team have done all they can to set me up with the tools and skills I need to take control of my health."
- "Your incredible support with transition the whole way through was invaluable."
- "Thank you so much for all these contacts and information, for the chat yesterday and your advice and encouragement. Very much appreciated."
- "Thank you so much for your help this morning. Because of you, this is the first time we had a great experience in the emergency department for the 5.5 hours we were there."
- "Transition into the adult health system has gone smoothly thanks to all your care, coordination and support."

2. Clinicians and other key stakeholders:

- *"99% cardiology patients are now transferring successfully to the Royal Melbourne because of the great transition process we've now established together." (Cardiologist, Royal Melbourne)*
- *"We believe our transition model is improving outcomes for young people moving from the RCH to RMH." (Nephrologist, Royal Melbourne)*
- *"I am in awe of the integrity of your work and your team. Our families are impressed with your service and always comment on the practical support you provide with all issues which affect daily life." (Nephrologist, RCH)*
- *"Together we have made more progress towards better transition for complex patients in a few weeks than over several years before!" (Neurodevelopment and Disability Consultant, RCH)*
- *"A number of significant presentations at national oncology network meetings have all promoted your team's work as the gold standard in relation to a model of transition care." (Clinical Coordinator, Victorian Comprehensive Cancer Centre)*
- *"It is very clear that you have significant expertise and a strong passion in the area of adolescent transition." (Emergency Department Physician, St Vincent's Hospital Melbourne)*
- *"I am delighted that there is a dedicated Transition Support Service at RCH checking on the welfare of these complex surgical patients. I've been pushing for something similar here for years...." (Surgeon, Royal Hobart Hospital)*
- *"The work that you have undertaken and achieved in transition is exemplary. We were inspired by your thought-provoking presentation. I hope that we will keep in touch and learn from your service's excellent transition practice." (Chief of Medicine, Evelina Children's, London, UK)*
- *"The service you provide at the RCH is second to none and I am looking forward to sharing your model of care with my team back home." (Nephrologist, University of Southampton Hospital, UK)*
- *"You have done a ton of work in transition with significant success." (Cardiologist, Royal Prince Alfred, NSW)*
- *"Your pioneer work in transition will be a major inspiration for our service going forward." (Endocrinologist, Aarhus University Hospital, Denmark)*
- *"I am forever amazed at the quality of the work of your service on such little FTE." (Networking Coordinator, Children's Healthcare Australasia)*

## Any additional information

- Appendix 1: Fearless Transition Model of Care for Patients with Intellectual Disability and/or Autism Spectrum Disorder with mental health or behavioural comorbidities at the RCH
- Royal Children's Hospital Melbourne's Transition to Adult Care Procedure

## References

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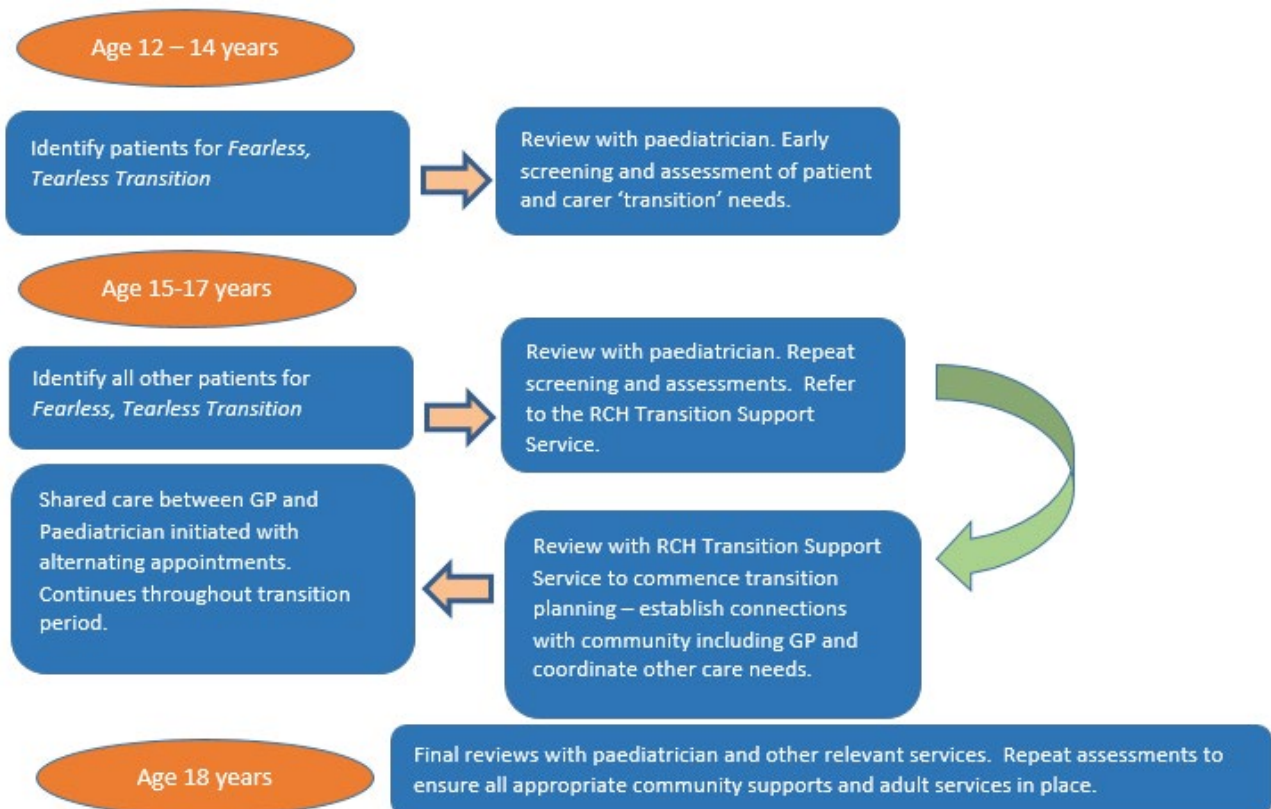
## Appendix 1:

### ***Fearless Tearless Transition* RCH model of care for patients with an intellectual disability (ID) and/or autism spectrum disorder (ASD) with mental health or behavioural comorbidities**

In 2019, 157 young people with dual disabilities and their carers engaged in *Fearless, Tearless Transition*, a new model of care at the RCH designed to foster better long-term care outcomes.

#### **Preliminary outcomes**

- Increased network of psychiatrists identified in Victoria with expertise in managing adults with dual disability - from 10 to 59
- Increased network of general practitioners (GPs) identified as having an interest and/or expertise in the management of people with dual disabilities - from 60 to 248
- Shared care process between paediatricians and GPs commenced with 118 young people with dual disabilities from ages 15 to 18
- Strengthened connections between the RCH and community care providers for people with dual disabilities
- Early screening and needs assessments conducted from the age of 12, including supports required for carers
- Active engagement and capacity building of GPs
- Active engagement of adult psychiatrists and other mental health care providers for people with dual disabilities



# Transition to Adult Care Procedure

## Transition to Adult Care Procedure

### 1. Overview / Procedure Description

Every adolescent with a chronic health condition and/or disability at the Royal Children's Hospital will have a well-managed transition process from paediatric to adult health and community care.

### 2. Related Policy

[Access \(www.rch.org.au/policy/policies/Access\\_-\\_RCH\)](http://www.rch.org.au/policy/policies/Access_-_RCH)

### 3. Definition of Terms

Transition is "a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-orientated health care systems." (2)

#### Note:

1. Transition is NOT synonymous with transfer. It is an active process, while transfer is a single event that is part of the transition process.
2. Transition is a process which results in a safe, coordinated and supportive transfer to adult and community care.

### 4. Procedure details

Effective adolescent transition is based on an understanding that transition in health care is just one aspect of the wider transitions that take place at this time due to the completion of secondary education, changing relationships with parents and families, and for some adolescents, greater capacity for independence in health care.

Transition is best begun early, in a planned and collaborative manner, that is age and developmentally appropriate, accounting for school and social considerations.

[Aims and key elements of adolescent transition \(www.rch.org.au/transition/for\\_health\\_professionals/Aims\\_of\\_Adolescent\\_Transition/\)](http://www.rch.org.au/transition/for_health_professionals/Aims_of_Adolescent_Transition/)

### Age of RCH patients

"Although it may be useful to set a target age, there is no "right" time for transition. A flexible approach is called for that takes developmental readiness into account and links to other social transitions such as leaving school" (4)

The RCH [Access \(http://www.rch.org.au/policy/policies/Access\\_-\\_RCH\)](http://www.rch.org.au/policy/policies/Access_-_RCH) Policy outlines age considerations for RCH patients.

### Process of adolescent transition

Every adolescent at the RCH with a chronic health condition and/or disability should have an identified transition lead who ensures that the transition plan (which includes the transition passport) is initiated, coordinated, regularly reviewed and implemented. For some patients, more than one transition lead may be required.

The transition lead provides a holistic overview and integration of the various transition treatment and ongoing management needs, and communicates this plan across all paediatric and adult/community care teams and with the patient and their parent/carer.

The transition lead can be any member of the young person's clinical team and/or a member of the RCH Transition Support Service. The transition passport should be in the patient's electronic medical record with transition planning to commence from the age of 15. This ensures transition care is coordinated, centralised (where possible) and well communicated.

[http://www2.rch.org.au/transition/parents.cfm?doc\\_id=13819](http://www2.rch.org.au/transition/parents.cfm?doc_id=13819)

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Was this document useful? <a href="http://www.rch.org.au/Templates/intranet/RchPbTwoCollIntranetFPageid=52628">Please give us your feedback. (www.rch.org.au/Templates/intranet/RchPbTwoCollIntranetFPageid=52628)</a>	



## Considerations

- **Developmental Disabilities (including physical and intellectual)** - For patients who may not achieve independence and where there may be additional transitions to consider (e.g. community supports), it is crucial that transition planning in consultation with the parents/carers start as early as possible (5), including:
  - Assignment of transition lead/s well in advance of transfer
  - Coordination of transition plans from various specialties
  - Early engagement with local general practitioners and community providers
  - Advance notification (along with transfer of patient information) to receiving adult services if appropriate, taking into consideration waitlist times and service eligibility criteria.
  - Consideration of disability supports, including therapies in transition planning.
  - Multidisciplinary transition planning meetings which could include adult services and other relevant community services.
  - Use of Victorian Young Adult Complex Disability Clinics for patients with congenital physical disabilities or other services specific to adults with developmental needs to assist with social, emotional, behavioural or therapy needs. This may include consideration of the National Disability Insurance Scheme and its role in providing adequate services for adolescents with disabilities, particularly during transition from paediatric to adult care.
  - Other Health Services - strong partnerships are essential to ensure the RCH delivers comprehensive and coordinated transition to adult care for every adolescent with a chronic condition and/or disability.

## 5. Responsibility

### Chief Executive Officer

- To support comprehensive adolescent transition processes for every young person in our care with a chronic condition and/or disability who requires transfer to an adult health service.
- To support joint transition initiatives between the RCH and adult clinicians, including relevant service providers in the community. To monitor accountability and ensure reporting of transition performance from divisions and departments.

### Executive Directors

- To support a comprehensive adolescent transition process for every young person in our care with a chronic condition and/or disability who requires transfer to an adult health.
- Involve adult health care providers and relevant services in the community, including the GP, in transition planning.
- To monitor accountability and ensure reporting of transition performance from their departments as outlined by their divisional scorecards.

### Heads of Department.

- To ensure that all adolescents 15 years and over have at least one transition lead assigned and a written transition plan located in the Electronic Medical Record.
- To monitor and report their department's transition performance
- To develop and implement an optimal transition model of care for all adolescents 15 years and over who receive care in their department, including consideration of joint transition processes with adult health services.
- To develop and maintain updated records of current, prospective and retrospective patient transfers.

### Departments

- To monitor and report their transition performance.
- To ensure that all adolescents 15 years and over have an assigned transition lead and a transition plan documented in the EMR.
- To support the holistic transition of adolescents receiving care in their department.
- To contribute to the department's records of current, prospective and retrospective patient transfers.

### Staff

- All RCH staff that are responsible for the care of young adults with a chronic condition and/or disability should proactively identify those who require a transition process and ensure that this process is followed and recorded in the department's transition records.
- To ensure that all adolescents 15 years and over have a documented transition plan in the EMR.

### Transition Lead

- To coordinate and implement the transition plan for adolescents 15 years or older who are referred to the Transition Support Service, in communication with the patient and their parent/carer, treating clinicians, adult health providers and other services in the community where

relevant

- To act as the primary transition contact for that young person, as well as for parents/carers, RCH clinicians and multidisciplinary staff, adult health services and primary care.
- To initiate, implement and refine transition processes within their department.
- To embed transition practice into the care of all adolescent patients and parents/carers within their department.

## Transition Support Service

- To manage all aspects of the Transition Support Service including the delivery of optimal transition care across the RCH; set strategic direction and deliver performance targets, lead the Transition Support Service team, provide consultation to internal and external services as required, lead transition research and other related initiatives in partnership with relevant providers, deliver education and develop transition resources and systems with clinical and surgical units at the RCH, equivalent adult health services, primary care and primary health networks, the Department of Health and Human Services and relevant providers in the community.
- Report to Directors and Executive on transition performance across the organisation.
- The Transition Support Service Manager reports to the Head of the Department of Adolescent Medicine..

## Transition Support Service Tools & Services

- RCH Transition (<http://www.rch.org.au/transition>) Website
- ([http://www2.rch.org.au/transition/intranet/MR\\_Transition\\_Form.pdf](http://www2.rch.org.au/transition/intranet/MR_Transition_Form.pdf)) Transition Fact Sheets ([http://www.rch.org.au/transition/factsheets\\_and\\_tools/transition\\_checklists](http://www.rch.org.au/transition/factsheets_and_tools/transition_checklists))
- Self - Management & Transfer Readiness Checklists ( <http://www.rch.org.au/transition>)
- Transfer to Adult Services Passport ([http://www.rch.org.au/transition/factsheets\\_and\\_tools/transition\\_checklists](http://www.rch.org.au/transition/factsheets_and_tools/transition_checklists)) (also located in EMR)

## 6. References

Health 2040 Discussion Paper, Future of Health Care in Victoria, State Government of Victoria, 2015

Position Paper for the Society for Adolescent Medicine, Transition to Adult Health Care for Adolescents and Young Adults with Chronic Conditions, 2003

Suris et al., Key Elements for, and Indicators of, a Successful Transition: An International Delphi Study, Journal of Adolescent Health, 2015

Transition: Moving on well, Department of Health UK, 2008

Bindels-de Heus, K. et al., Transferring Young People with Profound Intellectual and Multiple Disabilities From Pediatric to Adult Medical Care: Parents' Experiences and Recommendations, Intellectual and Developmental Disabilities, 2013

## 7. Contacts

RCH Transition Support Service ([http://www.rch.org.au/transition/about\\_us/What\\_is\\_Adolescent\\_Transition/](http://www.rch.org.au/transition/about_us/What_is_Adolescent_Transition/))