NSW TAG

Transitioning Young People on Complex or High Cost Medicines from Paediatric to Adult Care Services: Guiding Principles and Supporting Resources

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NSW Therapeutic Advisory Group Inc.

Advancing quality use of medicines in NSW

New South Wales Therapeutic Advisory Group Inc. is an initiative of NSW clinical pharmacologists and pharmacists.

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Transitioning Young People on Complex or High Cost Medicines from Paediatric to Adult Care Services: Guiding Principles and Supporting Resources

Overview

Scope

These Guiding Principles and Resources[1] are designed to provide entities within NSW public hospitals responsible for medication management services including Drug and Therapeutic Committees (DTC) and pharmacy departments, as well as relevant clinicians[2] and consumers[3] a framework to facilitate:

- ongoing timely access to high cost and/or complex medicines and
- seamless transfer of relevant information regarding these medicines,

in order to ensure appropriate, effective and safe use of medicines as the young person transitions from paediatric care services to adult care services.

Purpose

1. To provide Guiding Principles and supporting resources to facilitate a consistent process of transitioning young people who are on complex and/or high cost medicines from paediatric specialist hospitals and networks to adult hospital care.
2. To provide a framework and methodology for appropriate notification and timely information provision when transitioning young people who require medications that are not funded through the Pharmaceutical Benefits Scheme (PBS) or private community pharmacy prescription or where there is unusual complexity around the provision and/or use of medications.
3. To transparently identify and address inequities where evidentially beneficial paediatric medicines are not funded due to PBS age restrictions.
4. To improve the transitioning experiences of the young person and their family/carer and the receiving hospital clinicians.

Background

Access to medicines in Australia may occur in a variety of ways. Most commonly, medicines are obtained via the Pharmaceutical Benefits Scheme (PBS), but significant difficulties can arise when medicines are not accessible via the PBS. Other potential ways to access medicines, particularly costly medicines, can be via the public hospital system, private health funding, sponsor-supported medicines access programs, participation in clinical trials and self-funding. Sometimes a patient may need to access medicines within their medication regimen from a variety of sources.

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[1] Some resources e.g. List of Common Relevant Medicines and DTC contacts may require regular review and updating.
[2] Relevant clinicians include prescribers of complex or high cost medicines, particularly those caring for paediatric patients and young adults.
[3] Relevant consumers include paediatric or young adult patients using complex or high cost medicines and their families and carers.

The ability to access medicines within the public hospital system also varies. Specialist paediatric hospitals often need to fund treatments available to adults but not to children due to PBS age restrictions. Such scenarios apply to therapies for inflammatory bowel disease, oncology, and rare genetic and metabolic diseases. Furthermore, with greater understanding of the pathogenesis of many conditions, more (often costly) treatments are becoming potentially appropriate and leading to better patient outcomes although they will usually not be funded by sources such as the PBS. For example, treatment of cystic fibrosis patients with allergic bronchopulmonary aspergillosis with omalizumab now means patients enter the adult care setting with improved respiratory function compared to the pre-omalizumab era. This has resulted in a reduced need for lung transplantation soon after transition.

Larger or metropolitan hospitals may also have bigger drug budgets than their smaller or non-metropolitan counterparts. Clarity regarding whether a treatment is funded via Activity Based Funding (ABF) and where that treatment is actioned can also impact on whether an adult hospital will accept the costs of treatment. (See Footnote 4 for NSW TAG's practical guidance regarding ABF)[4]. The various methods by which complex and high costs medicines may be obtained underscores the importance of having transparent and consistent decision-making and funding processes.

Considerations for making medicines accessible for patients include upholding quality use of medicine principles including the prescribing of cost-effective, evidence-based medicines in an equitable manner irrespective of age; considering short term and long term affordability issues; and, ensuring open, transparent and shared decision-making between patients, prescribers, and clinical governance and financial stakeholders. This is important for all patients but particularly so, for children and adolescents with conditions, where early intervention improves patient well-being and reduces or removes future disease burden and healthcare costs (e.g. Hepatitis C) or when lifelong patterns for self-care of chronic conditions are being established.

Conditions that frequently present medicine-related access and prescribing challenges during the transition of paediatric patients to adult care include respiratory conditions such as cystic fibrosis, seizure disorders, neuro- developmental or behavioral disorders and metabolic conditions. Certain medicines are also notoriously challenging. These include non-registered medicines that must be accessed by the Therapeutic Good Administration's Special Access Scheme (SAS), medicines that are not PBS-listed or do not have a relevant PBS indication, off-label medicines, costly over-the-counter therapies such as dietary supplements and some medicines that require extemporaneous preparation.

Affordability of medicines may also vary along the patient journey. For example, patients turning sixteen years of age lose their Health Care Card entitlements (which enable significant savings for PBS-listed medicines) unless they remain students. They must apply annually to keep their Health Care Card. In addition, medication costs are not covered under Australia's National Disability Insurance Scheme. This can be particularly challenging when there is a lack of hospital-based adult clinics for some conditions, such as neurodevelopmental disorders. In such cases, long term use of non-PBS or off-label medicines post transition to adult care may become unaffordable. Despite the patient being stabilized on the medicine(s), the medicine cost necessitates a change in (a likely less

[4] NSW Therapeutic Advisory Group. (2021) *Activity Based Funding of Medicines in Hospitals*. NSW TAG, Sydney.

effective) medication by the patient's General Practitioner. A longer term perspective for medicine decision-making may be warranted. For example, despite a medication remaining or becoming expensive when the patient transitions to adult care, it may be cost-saving overall to the health system if the expensive medication reduces future health resource use such as hospitalisations.

A collaborative and transparent partnership-based model whereby all relevant stakeholder's skills, experience and knowledge are recognised and actively maintained will achieve the best outcomes for the young person and their supporting carers and clinicians. Given the challenges faced by paediatric patients transitioning to the adult health care system, it is critical that this transition is as seamless as possible and supported well with timely and comprehensive communication occurring between the patients, their family/carers and health care professionals within and across relevant primary, secondary and tertiary care settings.

Considerations for Seamless Transition

These Guiding Principles should be read in conjunction with the resource, Key Principles for Transition of Young People from Paediatric to Adult Health Care.[5]

These Guiding Principles presume that an adult physician has been linked with the transitioning young adult (via referral from the treating paediatric physician or general practitioner). Unfortunately, this linking process is often delayed and poses a major barrier to transitioning patients. Transitioning patients often require multiple teams, which further complicates transition, as not all services may be available in the local hospital or local health district (LHD). Some services are only available as statewide service, e.g. genetic metabolic and comprehensive epilepsy services. There are often long wait times for many appointments, so this delay needs to be factored in and flagged so that medications can still be provided in the time between the last paediatric appointment and first adult appointment. Sometimes there is no publicly funded health care option in the person's residential region and this can make communication between health care providers in various settings challenging.

The age of the young person transitioning may vary considerably. Age thresholds for transitioning and accepting young adults can vary between services. Sometimes, in order to account for long wait times, the patient can be quite young but not meet the adult health care service's age criteria of 18 years of age for acceptance. At other times, they can be older because, for example, they may have lost a year of schooling due to their chronic condition and transition is planned for the final year of school. Notably these transitions accompany many other transitions the young adult patient may be experiencing such as taking up educational opportunities or joining the workforce in other cities, regions or jurisdictions.

These challenges underscore the importance of early planning for transitioning, particularly when the therapeutic care is complex, costly and/or involves multiple healthcare providers. Paediatric hospitals require an early identification system such as routine review of outpatient dispensing reports on patients before/when they turn 16 years of age to proactively identify patients that should have started the transition process.

[5] Agency for Clinical Innovation and Trapeze, The Sydney Children's Hospitals Network. (2014) *Key Principles for Transition of Young People from paediatric to Adult Health Care*. ACI, Sydney.

It is possible that patients may be transitioned to multiple hospitals/health districts or to unfamiliar hospitals/health districts, private physicians or statewide services. There can be a lack of clarity about a LHD's responsibility to care for a patient living in their catchment when it provides a service that a patient requires. For example, there may be a lack of available specialist care or a lack of vacancies to take on new patients. Transitioning challenges are generally less likely when adult and paediatric hospitals are co-located and care is transferred between these co-located services although the patient may not live within the catchment of that adult hospital. These issues can complicate and delay decisions regarding care transition.

There is sometimes a lack of clarity regarding which NSW hospital/LHD may be responsible for the funding of prescription medicines that are not subsidized by the PBS, especially when the patient is not a resident of the LHD where the prescriber practices. This poses risks to the wellbeing of the young person but also the institution. In the current context of transition of paediatric patient transition to adult care, this will require discussion between the DTCs and Pharmacy Departments of the transferring and receiving hospitals and underscores the importance of early communication especially when it involves the use of high cost medicines. Nevertheless, reliance on advocacy by parents or clinicians or relationships between healthcare entities is an unsatisfactory method for funding determination as it may reinforce existing inequities for the marginalised groups.

The NSQHS Standards: Comprehensive Care, Clinical Governance, Partnering with Consumers, Medication Safety and Communicating for Safety support successful transition of patients on complex/costly medicines from paediatric to adult care. See Box 1 for applicable action items of the Standards.

BOX 1: Applicable Action Items from Relevant NSQHS Standards

Comprehensive Care

- Action 5.03 states: Clinicians use organisational processes from the Partnering with Consumers Standard when providing comprehensive care to:
  - Actively involve patients in their own care
  - Meet the patient's information needs
  - Share decision making
- Action 5.06 states Clinicians work collaboratively to plan and deliver comprehensive care

Clinical Governance

- Action 1.15 states: The health service organisation:
  - Identifies the diversity of the patients, carers and families using its services
  - Identifies groups of patients using its services who are at higher risk of harm
  - Incorporates information on the diversity of its patients, carers and families and higher-risk groups into the planning and delivery of care
- Action 1.05 states: The health service organisation considers the safety and quality of health care for patients in its business decision-making

Partnering with Consumers

- Action 2.06 states: The health service organisation has processes for clinicians to partner with patients and/or their substitute decision maker to plan, communicate, set goals and make decisions about their current and future care
- Action 2.07 states: The health service organisation supports the workforce to form partnerships with patients and carers so that patients can be actively involved in their own care

Medication Safety

- Action 4.03 states: Clinicians use organisational processes from the Partnering with Consumers Standard in medication management to:
  - Actively involve patients in their own care
  - Meet the patient's information needs
  - Share decision-making
- Action 4.11 states: The health service organisation has processes to support clinicians to provide patients with information about their individual medicines needs and risks

Communicating for Safety

- Action 6.01 states: Clinicians use the safety and quality systems from the Clinical Governance Standard when:
  - Implementing policies and procedures to support effective clinical communication
  - Managing risks associated with clinical communication
  - Identifying training requirements for effective and coordinated clinical communication
- Action 6.03 states: Clinicians use organisational processes from the Partnering with Consumers Standard to effectively communicate with patients, carers and families during high-risk situations to:
  - Actively involve patients in their own care
  - Meet the patient's information needs
  - Share decision-making
- Action 6.04 states: The health service organisation has clinical communications processes to support effective communication when:
  - Identification and procedure matching should occur
  - All or part of a patient's care is transferred within the organisation, between multidisciplinary teams, between clinicians or between organisations; and on discharge
  - Critical information about a patient's care, including information on risks, emerges or changes
- Action 6.01 states: Clinicians use the safety and quality systems from the Clinical Governance Standard when:
  - Implementing policies and procedures to support effective clinical communication
  - Managing risks associated with clinical communication
  - Identifying training requirements for effective and coordinated clinical communication
- Action 6.01 states: Clinicians use the safety and quality systems from the Clinical Governance Standard when:
  - Implementing policies and procedures to support effective clinical communication
  - Managing risks associated with clinical communication
  - Identifying training requirements for effective and coordinated clinical communication

Guiding Principles

GP = Guiding Principle

GP 1: A consistent process for medicines management that informs the roles and responsibilities of the relevant stakeholders and communication between them should be established for all transitioning patients on complex/high cost medicines within the NSW public healthcare system.

(See Figure 1)

The process requires:

- appointment of an accountable paediatric working group responsible for the hospital's transition process, the members of which include a paediatric Pharmacy/DTC representative, to ensure comprehensive communication of identified medication management issues and their solutions.
- collation of actual/potential medication-related issues by the paediatric Pharmacy Department/DTC to assist clinician(s), patient and family discussion and counselling and communication with the receiving adult Pharmacy Department and DTC. (See Guiding Principle 2)
- communication of the actual and/or potential medication-related issues and details of the new adult care physician(s) taking over care to the adult DTC and Pharmacy Department. Contact details of Pharmacy Departments/DTCs are provided under Supporting Resource 4.
- use of a standardised form to communicate medication transitioning issues between clinicians, DTCs and Pharmacy Departments of paediatric and adult services. (See Supporting Resource 2).

This transition process of medication-related issues is reliant upon and will be assisted by:

- early identification of all transitioning young adults (from 16 years of age) by the paediatric health care service including the Pharmacy Department.
- early identification and acceptance by the new adult care physician(s)
- early joint review of the transitioning patient by the clinicians in the children's hospital and the adult hospital(s) that includes joint assessment of actual and potential medication–related issues at least 12 months prior to transitioning. Whenever relevant, non-hospital based clinicians who may be taking over some of the patient's care should be included in the joint review or failing that receive relevant communication regarding transition and potential issues.

The joint review by the children's hospital team and the adult health care team/service is critical as it cannot be assumed that the same medications will be continued by the accepting doctor or service.

GP 2: The children’s hospital should adhere to a pre-determined and agreed timeframe of information provision to the receiving facility and relevant clinician(s) undertaking adult care (once care has been accepted).

Delays in notification processes may result in an interruption in therapy and not be in the interests of the patient. The notification process should:

- include clinicians and/or services that will be taking over medication approvals, provision and/or advice including the relevant DTC and pharmacy departments.
- make use of defined categories of transitioning patients’ medication-related issues (patients may have more than one issue) to assist timely and seamless transition.
- consider a minimum notification time prior to adult transition. Greater notification time is required for more complex medications with 12 months often optimal.

Supporting Resource 1 displays categories of medication-related issues and provides suggested minimum notification times according to medication-related issue.

Notification of clinicians or services taking over medication approvals, provision and/or advice including the relevant DTC and pharmacy departments can be assisted by using Supporting Resource 2.

GP 3: The children’s hospital should be transparent and provide full disclosure to the adult hospital regarding the decision-making process for medicines approval, details regarding the provision of medications (and related services) and the source of funding for medications, while the patient has been under their care.

Disclosure may be assisted with the use of existing documentation and underscores the importance of having adequate DTC resourcing for DTC approval and monitoring processes and communications. The duration of medicine approval should be communicated if the paediatric hospital has only approved a therapy for a certain period of time.

Disclosure may be actioned by providing the original DTC Individual Patient Use (IPU) forms, the DTC decisions and outcome monitoring reports, if available, to the adult hospital DTC/Pharmacy Department. Supplying letters regarding provision under the Categories B of the Special Access Scheme (SAS) and copies of SAS Category C forms is recommended. Communications between the DTC secretaries can assist supporting evidence and information transfer. (See Supporting Resource 4 for contact lists of Pharmacy Departments and DTCs.)

GP 4: The children's hospital should have documentation of the shared decision making undertaken with the patient (and carers) when accessing medication(s) via Medicine Access Programs.

Continued access to medication(s) by the young patient following involvement in a clinical trial is usually organised using a Medicine Access Program with ongoing access to a medicine available until it is listed on the PBS. (N.B. This can be problematic if it is not ultimately listed on the PBS or there is a delay in PBS listing.) Although the Medicine Access Program should be applicable to the patient wherever they may be receiving care, there can be limitations to access arrangements within an adult public hospital context including access to compassionate Medicine Access Programs. Further details regarding Medicine Access Programs can be found in the CATAG Managing Medicine Access Programs: Guiding Principles for the governance of Medicine Access Programs in Australian hospitals, Version 2, June 2018. The accompanying CATAG forms support recording of shared decision making.

GP 5: The children's hospital should follow the same recommended transitioning processes

For patients transitioning to:

- **more than one adult hospital and/or**
- **more than one specialist and/or**
- **a LHD whether the patient resides in that LHD or not.**

The same standardized Paediatric to Adult Transition of Complex or High Cost Medication (PATCH-Me) Communication Form can be used for multiple DTCs and Pharmacy Departments of paediatric and adult services and serves to ensure all stakeholders have all relevant information. (See Supporting Resource 2)

GP 6: The children's hospital should at the earliest opportunity make a referral to the relevant transition support service*

***Trapeze for Sydney Children's Hospital Network (SCHN) or the ACI Transition Coordinator for John Hunter Children's Hospital and other paediatric health services whenever:**

- **any medication-related issues are identified in the early joint assessment (GP 2),**
- **any of the patient's medications meet the categories shown in Supporting Resource 1 and/ or**
- **the patient is eligible to enter the Trapeze program**.

The Trapeze service and ACI transition care service are invaluable for transitioning young adults with complex chronic illnesses treated at paediatric hospitals. Trapeze works closely with the Agency for Clinical Innovation (ACI) Transition Care service to provide comprehensive services to young people with chronic conditions in New South Wales, Australia. Trapeze is located within The Sydney Children's Hospitals Network (SCHN) and the ACI Transition Care Service provides a statewide service. The Trapeze referral form can be found here and the ACI Transition Care Service referral form can be found here. Other useful resources for transitioning clinicians and patients may be found here. Attaching the Trapeze/ACI Transition Care referral forms to the Paediatric to Adult Transition of Complex or High Cost Medication (PATCH-Me) Communication form (Supporting Resource 2) will assist notification and communications between relevant stakeholders.

When patients are on complex/costly medicines, the referral to the Trapeze or ACI Transition Care Service should occur at least 12-24 months before the age of 18 years depending on the complexity involved. See Supporting Resource 5.

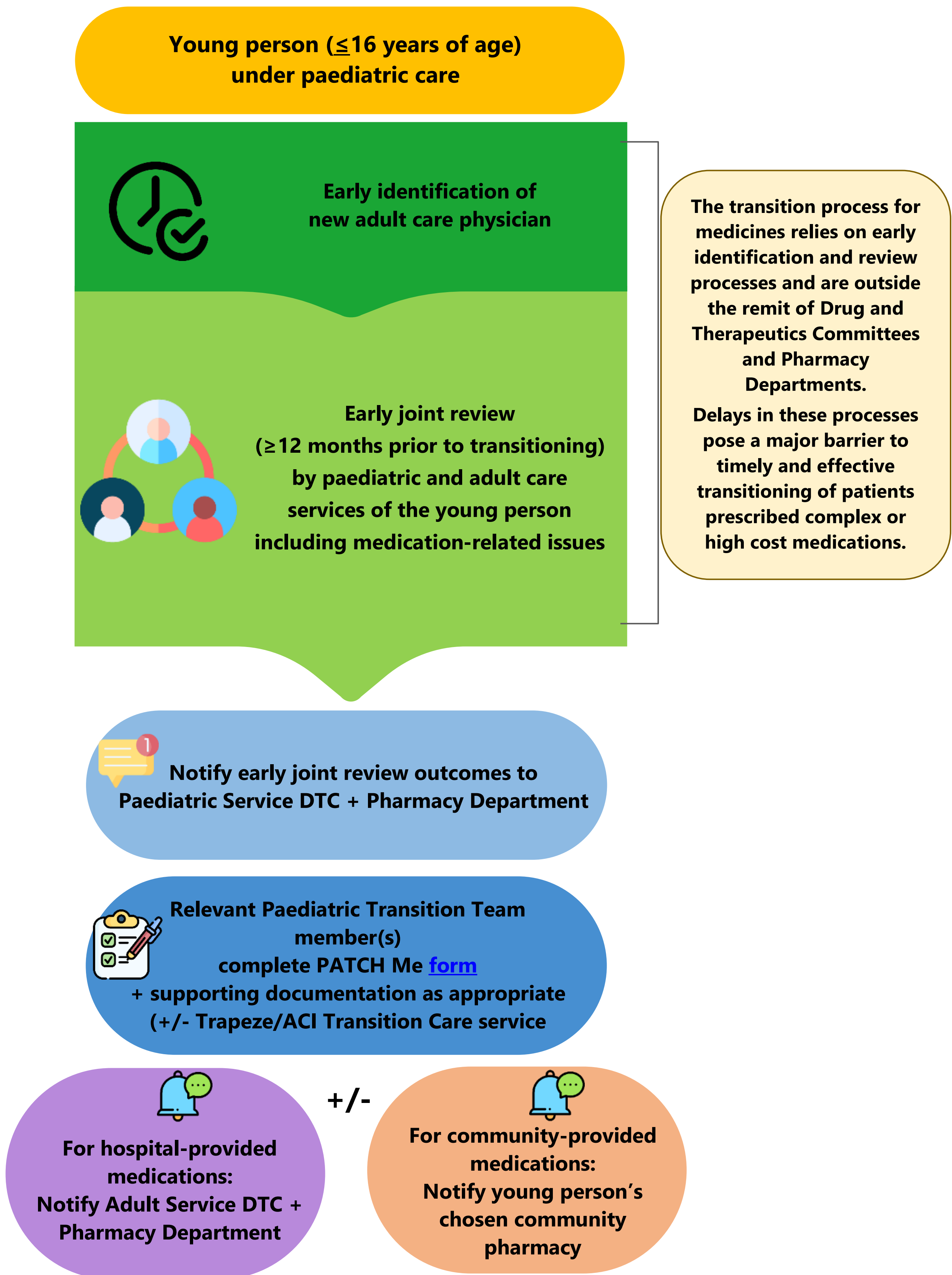
GP 7: An accountable process that tracks the successful transition of access, prescribing and use of identified medications for an individual patient including patient involvement in shared decision-making should be established.

An approach that incorporates patient's outcomes and experiences is most likely to ensure ongoing and effective involvement by the patient in their future care. Hospitals should ensure that the needs of patients or groups of patients that are unlikely to self-advocate are met.

GP 8: The medication-related transition process should be routinely evaluated at the paediatric hospital and receiving adult hospital(s).

Barriers to the process should be routinely identified so they can be resolved and documents updated as required. Barriers may include limited workforce, changes in medicine access criteria, delays in seeing the new treating team, lack of consensus regarding recommended therapy and issues related to documentation, transfer of information and engagement of stakeholders. Regular meetings with key stakeholders may be required.

Figure 1: Transition process flow chart



Supporting Resources

SR = Supporting Resource

SR 1. Patient categories where notification is required

Notification should ideally occur at least 12 months before transition with minimum notification times shown below. Transition will not be able to occur if a receiving physician(s) for adult care has not agreed to take over care so this process must occur earlier than the minimum times listed. Please note: this list is not exhaustive. The minimum time is listed, however, in many circumstances clinical complexity will require greater time for comprehensive transition of medicine-related processes. In addition, consider referral to TRAPEZE or ACI Transition Services noting that referrals to transition services are not automatic. Consider referral whenever transition barriers/complexity are present.

Category of Medicine Issue	**Minimum notification time** prior to adult care transition
1. The patient is receiving a medication where **special prescribing rights** are required (e.g. cannabinoids).	12 months
2. The patient is enrolled in a **clinical trial** where the trial is to continue after transition of care.	9 months
3. The patient is enrolled in a **pharmaceutical company Medicines Access Program** (includes Compassionate Access Programs and Product Familiarisation Programs where the program is to continue after transition of care).	9 months
4. The patient is receiving medicine(s) being **funded through a charitable organisation** where the medication is expected to continue after transition of care.	9 months
5. The patient is receiving medication(s) expected to be **ineligible for PBS funding or unaffordable with private prescription**.	9 months when yearly cost ≥ $5,000, 3 months < $5,000
6. The patient is receiving medication(s) through **the TGA Special Access Scheme.**	9 months when yearly cost ≥ $5,000, 3 months < $5,000
7. The patient is receiving **locally compounded medications** to be supplied by the receiving hospital.	9 months when yearly cost ≥ $5,000, 3 months < $5,000
8. The patient **is not covered by Medicare.**	6 months
9. The patient is **unable to access PBS** for high cost drugs **due to age-related criteria** (e.g. Infliximab). (Note: such a circumstance may delay transition).	6 months
10. The patient has physical or developmental issues, which may require **special medication considerations** such as requirement for liquid preparations if NG/PEG is the only route of administration and crushing a solid dosage form is not appropriate.	3 months
11. The patient is receiving medication where the copayments are likely to represent an **unsustainable financial burden.**	3 months
12. The patient is being transferred **from Justice Health**.	6 - 9 months
13. The patients has **complex medication issues** not covered by the above categories.	3 months

SR 2. Paediatric to Adult Transition of Complex or High Cost Medicines (PATCH-Me) Form

[to be completed by member(s) of Paediatric Transition Team]

Patient's full name	*Complete all details or affix patient label here*				
Sex	☐ male ☐ female	Carer name		Relationship of carer	
D.O.B.	__/__/__	Carer phone		Carer email	
Address		General Practitioner name			
Phone number		General Practitioner phone			
Email contact		General Practitioner email			

Trapeze/ ACI Transition Service referral	*(Circle)* Yes / No / not applicable (because________________________________) If Yes, • provide date of referral ________________ • attach Trapeze referral form / ACI Transition Service referral form and/or provide contact name, email and phone number: ____			
Consent:	☐ I have discussed this referral with the young person and their carer/guardian and they agree their information may be provided to the adult hospital, their general practitioner and other relevant care providers as discussed as part of the transitioning process			
Form completed by *Paediatric Transition Team Member*	Name	Position	**Contact details** *Phone*	*Email*
Date form sent to adult hospital(s)		**Date form sent to General Practitioner**		

PAEDIATRIC hospital service details					
Hospital name		**Pharmacy department**	**Contact name**	**Email**	**Phone**
		DTC	**Contact name**	**Email**	**Phone**
		Complete this column if more than one specialist caring for patient		*Complete this column if more than one specialist caring for patient*	
Specialist name	1.	2.		3.	
For treatment of					
Date of last paediatric appointment					
Email					
Phone					

ADULT hospital service details *(if more than one adult hospital providing ongoing care, complete another form or add another table).*

Hospital name		Pharmacy department	Contact Name	Email	Phone
		DTC	Contact Name	Email	Phone
Date of expected transfer of services		*Complete this column if more than one specialist caring for patient*		*Complete this column if more than one specialist caring for patient*	
Specialist name	1.	2.		3.	
For treatment of					
Date of appointment					
Email					
Phone					

Medication List (add more rows as required)

Medication	Form	Dose	Indication	Proposed supply~	Further information^	Comments/Checklist

~Proposed supply may include: adult hospital, paediatric hospital, community pharmacy, sponsor.
^Further information may include: PBS, non-PBS; SAS medicine; off-label use; via Medicine Access program (MAP); requires special prescribing rights; requires DTC approval; private script; over the counter; compounded.

SR 3. List of commonly encountered and/or complex or high cost medicines requiring specific strategies to access

MEDICATION	Common BRAND NAMES	INDICATION(S)	SPECIAL APPROVALS[i]	Registered indication(s)	PBS/Non-PBS	AVAILABLE FROM
Antipsychotics-weight neutral: aripirazole or lurasidone		Challenging behaviours in neurodevelopmental population	-	Aripiprazole: adult use in schizophrenia/non-bipolar I disorder. Lurasidone: schizophrenia in adults and adolescents	Non-PBS (PBS for schizophrenia only)	**Hospital Pharmacy** **or** **Community pharmacy**
Atropine ampoules for injections	Atropine sulfate injection Pfizer®	Secretions (off label for non-pre-anaesthetic use to reduce salivary secretions and bronchial secretions		Various	Listed on PBS general schedule: limited quantity supplied	**Hospital Pharmacy** **or** **Community pharmacy**
Azithromycin	Various incl. Zithromax®	Immunomodulation	-	Depends on type of infection	Listed on PBS general schedule: limited quantity supplied	**Hospital Pharmacy** **or** **Community pharmacy**
Cannabidiol	Epidyolex®	Various	SAS Cat B for non-Dravet Syndrome and prescriber needs to be authorised cannabidiol prescribing	Seizures associated with Dravet and Lennox-Gestaut syndromes	PBS Auth for Dravet Syndrome; Non-PBS for L-G Syndrome	**Hospital Pharmacy** **or** **Community pharmacy**
Medicinal cannabis products (excl. cannabidiol Epidyolex®)	Various brands & strengths	Various	SAS Cat B may be needed approval depending on specific product & its scheduling. Prescriber needs to be authorised cannabidiol prescribing	NIL with exception of nabiximols Sativex® in adults for spasticity due to multiple sclerosis.	Non-PBS	Depends on product **Hospital Pharmacy** **or** **Community pharmacy**

MEDICATION	Common BRAND NAMES	INDICATION(S)	SPECIAL APPROVALS[i]	Registered indication(s)	PBS/Non-PBS	AVAILABLE FROM
Clobazam	Various incl Frisium®	Seizures (use may be off-label)	-	- Short term use (<=1 month) in adults for the symptomatic management of acute anxiety and sleep disturbances associated with anxiety. - Adjunctive therapy in patients (4 years of age and over) with partial refractory and Lennox-Gastaut epilepsy types not adequately stabilized with current anticonvulsant therapy	Non-PBS	Use tablets to compound liquid if required **Hospital Pharmacy** **or** **Community pharmacy**
Clonidine	Various incl. Catapres®	Various Off label use	-	Essential hypertension. Renal hypertension.	Listed on PBS general schedule	**Community pharmacy**
Diazepam liquid	Diazepam Elixir® Orion Perrigo	Various	-	Various: anxiety, muscle spasm, cerebral spasticity, acute alcohol withdrawal.	Tablets: Listed on PBS general schedule Liquid: Non-PBS	**Community pharmacy**
Erythromycin	Eryc®	Gastroparesis (given up to 3 times a day)	-	Various infections incl URTI, LRTI, chlamydial, Camphylobacter enteritis, acne, rosacea and rheumatic fever prophylaxis	Listed on PBS general schedule. Limited quantity supplied	**Hospital pharmacy** **or** **Community pharmacy**
Esomeprazole sachets	Various incl Nexium®	Patients with PEGs or feeding tubes	-	Dyspepsia, reflux and peptic ulcers	Sachets not available PBS.	**Hospital Pharmacy** **or** **Community pharmacy**
Fenfluramine	Fintepla®	Dravet Syndrome in those patients who do not respond to cannabidiol	SAS B application required. Requires additional registration with sponsor.	NIL	Non-PBS	**Hospital pharmacy**
Glycopyrronium Bromide tablets (Glycopyrrolate)	Various	Secretions	SAS Category C form required	Peri-operative indications only	Non-PBS	**Hospital pharmacy**
Hyoscine Bromide Patch	Scopoderm®	Secretions	SAS Category C form required	NIL	Non-PBS	**Hospital pharmacy**

MEDICATION	Common BRAND NAMES	INDICATION(S)	SPECIAL APPROVALS[!]	Registered indication(s)	PBS/Non-PBS	AVAILABLE FROM
Intravenous Immunoglobulin (IVIg)	Intragam, Privigen, Flebogamma, Gamunex, Octagam	For indications not supported by BloodStar		See Bloodstar	N/A	**Hospital**
Macrogol	Movicol®	Constipation	-	ARTG LIsted	Non-PBS	**Hospital pharmacy** **or** **Community pharmacy**
Melatonin	Various formulations and strengths incl. Life Extension®, Circadin® Slenyto®	Disturbed sleep	SAS Category C form may be required for some formulations/ products	-Short-term monotherapy in primary insomnia in >55 yoa (Circadin®) - Insomnia in autism spectrum disorder or Smith-Magenis syndrome, where sleep hygiene measures are insufficient (Slenyto®)	Non-PBS	**Hospital pharmacy** **or** **Community pharmacy** Some products may be available online e.g. iherb.com
Mexilitine	Mexitil®	Ventricular arrhythmias; Myotonic disorders; Function- limiting-dystrophic and non-dystrophic myotonia	SAS Category B form required	NIL	Non-PBS	**Hospital Pharmacy** **or** **Community pharmacy**
Naltrexone	Naltrexone®	Cholestatic pruritis refractory to other treatments e.g. cholestyramine		-Adjunct in treatment of alcohol dependence -Adjunct in maintenance of abstinence from opioids after opioid detoxification	PBS Authority for treatment of alcohol dependence only	**Hospital Pharmacy**
Ondansetron	Various incl. Zofran®	Nausea & vomiting outside that induced by cytotoxic therapy/radiotherapy/surgery	-	Prevention and treatment of: - nausea and vomiting induced by cytotoxic therapy and radiotherapy; and, - post-operative nausea and vomiting (injection form only)	PBS for nausea & vomiting associated with cytotoxic therapy or radiotherapy	**Hospital pharmacy**
Piracetam	Nootropil®	Seizures	SAS Category B form required	NIL	Non-PBS	**Hospital pharmacy**
Potassium Citrate (oral liquid)	Uricosal®	Hypokalaemia/ urinary alkalinisation	-	ARTG Listed - Urinary alkalizer. - Potassium replacement.	Non-PBS	**Hospital pharmacy** **or** **Community pharmacy**

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MEDICATION	Common BRAND NAMES	INDICATION(S)	SPECIAL APPROVALS[!]	Registered indication(s)	PBS/Non-PBS	AVAILABLE FROM
Hypertonic Sodium Chloride Nebulising Solution	Hypersal 6%® Mucoclear 3% & 6%®	Secretions	SAS Category B	NIL	Non-PBS	**Hospital pharmacy**
Psychostimulant medicines e.g. (dexamfetamine lisdexamfetamine methylphenidate)	Various	Registered indications not on PBS	Written authority from NSW Ministry of Health required.	-Narcolepsy and hyperkinetic behaviour disorders in children (Aspen Dexamfetamine) - ADHD; Binge Eating Disorder in adults (Lisdexamfetamine VyVanse®) - Narcolepsy and ADHD (methylphenidate, various brands & formulations)	PBS for ADHD only (Authority Required)	**Community pharmacy**
Tacrolimus suspension	Various	Patients unable to take capsules		No registered liquid formulation (Capsules/injection are registered for Prevention of transplant rejection	PBS Streamlined Authority for management of rejection in patients following organ or tissue transplantation only	**Hospital pharmacy** Suspension requires extemporaneous preparation
Thalidomide	Thalomid®	Autoinflammatory syndrome with no genetic target and refractory to other therapy e.g. erythema nodosum leprosum. Behcet's syndrome	National distribution systems for lenalidomide, pomalidomide & thalidomide require registration of medical practitioners, pharmacists & patients.	-Multiple Myeloma -Erythema Nodosum Leprosum	PBS Streamlined Authority for multiple myeloma only	**Hospital Pharmacy**
Tramenitib	Mekinist®	Neurofibromatosis Conditions with target identified through PRISM		Melanoma, anaplastic thyroid cancer, non-small cell lung cancer	Non-PBS	**Hospital Pharmacy and/or Sponsor**

MEDICATION	Common BRAND NAMES	INDICATION(S)	SPECIAL APPROVALS[!]	Registered indication(s)	PBS/Non-PBS	AVAILABLE FROM
Various MABs e.g. infliximab, vedolizumab, ustekinumab		Various auto-immune conditions e.g. Inflammatory Bowel Diseases (Crohn's disease, ulcerative colitis), rheumatoid arthritis, ankylosing spondylitis, psoriatic arthritis, psoriasis		Rheumatoid arthritis/ankylosing spondylitis in adults (infliximab); Inflammatory Bowel Disease in adults (vedolizumab, ustekinumab) or in those aged => 6 yoa (infliximab), psoriatic arthritis (infliximab/ustekinumab in adults); plaque psoriasis (infliximab in adults/ ustekinumab in those aged =>6 yoa)	PBS Authority for various auto-immune conditions with strict clinical criteria including dosing regimens and age limits	**Hospital pharmacy and/or Sponsor**
Omalizumab	Xolair®	Non-cystic fibrosis bronchiectasis		Allergic Asthma or Chronic Spontaneous Urticaria in in those => 12 yoa; Chronic rhinosinusitis with nasal polyps in adults	PBS Authority in severe uncontrolled asthma in those > 12 yoa (+ various clinical criteria)	**Hospital Pharmacy and/or Sponsor**
Various JAK inhibitors e.g. ruxolitinib; tofacitinib	Jakavi®; Xeljanz®	Various autoimmune conditions responsive to JAK inhibition Graft vs host disease (second-line therapy)		Ruxolitinib: myelofibrosis (primary or secondary to polycythaemia vera or essential thrombocythaemia), polycythaemia vera or graft-versus-host disease. Tofacitinib: rheumatoid arthritis, psoriatic arthritis, ulcerative colitis.	Ruxolitinib: PBS Authority for myelofibrosis only. Tofacitinib: PBS Authority for various auto-immune conditions in those >=18 yoa	**Hospital Pharmacy and/or Sponsor**

[!] N.B. SAS Category B approval letters and completed Category C forms can be supplied to adult hospitals by the relevant paediatric hospital.

SR 4. First Contact Points for Pharmacy/ Medications Communications regarding a Young Person Transitioning from Paediatric Care to Adult Care

Please refer to the NSW TAG Practical Guidance webpage for the most current *SR 4. First Contact Points for Pharmacy/ Medications Communications regarding a Young Person Transitioning from Paediatric Care to Adult Care.*
N.B. This contact list is subject to change and if no response is received, the hospital pharmacy department should be phoned by contacting the hospital switchboard.

SR 5. Other useful resources and tools regarding paediatric to adult transition

Trapeze

Trapeze provides comprehensive transition support services to young people with chronic conditions in New South Wales, Australia. Trapeze is located within The Sydney Children's Hospitals Network (SCHN).
Visit this webpage for the referral form: http://www.trapeze.org.au/content/referral-pathway

Dr Jane Ho, Staff Specialist, Children's Hospital Westmead, Westmead NSW
Phone: 02 9382 5457 OR Fax: 02 9382 5680
Email: trapeze.schn@health.nsw.gov.au;
Postal Address: Trapeze, Sydney Children's Hospital, Randwick. Centre for Adolescent and Young Adult Health, Level 7, The Bright Alliance, Corner of High and Avoca Street, Randwick, NSW 2031.

Agency for Clinical Innovation (ACI) Transition Care Service

ACI Transition Care Services is a state-wide service and accepts referrals for young people known and not known to SCHN. Please see website for service and referral criteria details. There are three ACI Transition Care Coordinators (TCCs) based in NSW. The Service accepts referrals for young people with chronic conditions 14-25 years.

Transition Care Co-ordinators:
Angie Myles, Northern Area Transition Care Coordinator
Phone: 02 4925 7866
Mobile: 0434 361 202

Paula Carroll, Western Area Transition Care Coordinator
Mobile: 0436 323 321

Silvana Techera, South Eastern Area Transition Care Coordinator
Mobile: 0425 232 128

Other ACI Transition Resources

- Transition Readiness Checklist
- Ideas for parents and carers to support young people with chronic conditions with their transition: link
- Key Principles for Transition of Young People from Paediatric to Adult Health Care: link

Other Information and Resources

The Kids to Adults: Chronic Illness Alliance (K2A Alliance) is an Australian network of researchers, clinicians and advocates with a shared vision: to improve the clinical care and quality of life of children, adolescents and young adults living with a chronic illness or disability.

Victoria

- The Royal Children's Hospital Melbourne – Readiness to transfer checklist - link

South Australia

- Women's & Children's Hospital. *Transition to adult services: Transition medication checklist* - link

Western Australia

- Government of Western Australian Child and Adolescent Health Service and Perth's Children Hospital. *Transition to adult healthcare* web page - link

Acknowledgments

How these guiding principles and supporting resources were developed

Professor Christopher Liddle (Chair of NSW TAG, 2011-2019) recommended the development of guidance for transitioning paediatric patients on complex and/or high cost medicines from paediatric to adult services. Professor Liddle identified this as a challenging issue for NSW Drug and Therapeutic Committees (DTCs) during his tenure as Western Sydney LHD DTC Chair. Professor Liddle developed the first draft that identified problematic transitioning categories and recommended notification times. NSW TAG convened the PATCH-Me Expert Advisory Group (a multidisciplinary group of hospital-based health professionals with recognised expertise in governance of high cost medicines, paediatric clinical pharmacy and transitioning of paediatric patients to adult services) to further develop this document. Following input and review from the Expert Advisory Group, key external stakeholders were consulted prior to publication on the NSW TAG website.

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