



Government of **Western Australia**
Department of **Health**



The transition of adolescents and young adults with complex conditions from paediatric to adult health services

Clinical Senate of Western Australia

April 2019

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Joint statement

The Western Australian (WA) Clinical Senate joined senior paediatric and adult clinicians, consumers, the WA Child and Youth Health Network, researchers, government and non-government agencies to consider the transition of adolescents and young adults (AYAs) with complex conditions from paediatric to adult health services.

The debate considered available data and acknowledged the progress made through the development and implementation of strategies and policies, including *Paediatric Chronic Diseases Transition Framework 2009*, *2014 Position Statement on Youth Health*, from the Commissioner for Children and Young People WA, *WA Youth Health Policy 2018-2023 (the Policy)*, *the Policy Companion Resource – Understanding young people in WA and WA’s Young People Have a Say- Community Conversations Report*.

The purpose of the debate was to share *the Policy* with a broader clinical network. It was hoped attendees would learn how to better understand the complexities in the treatment of young people and the importance of realising the investment in the AYA Framework thus creating the platform to turn policy into practice.

The following definition of ‘transition’ from *the Policy* was used for the debate:

Transition – “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems.”

To address the issue of clinical relevance, the Clinical Senate focused on the following strategic priorities in the *WA Youth Health Policy 2018-2023 that related to improving health outcomes during transition*. Those being the following priority areas:

- Priority Area 2.3: Young people with complex and ongoing health and wellbeing needs are supported to optimise transition from paediatric to adult care
- Priority Area 3.1: Young people are supported by health systems that are committed to continuous improvement in youth health and wellbeing
- Priority Area 3.2: Young people are supported by a workforce that is equipped with the knowledge, skills and understanding to improve health outcomes

This issue is one that centres around models of care and clinical pathways and clinical buy in is critical to success. For safe transition clinicians need the knowledge and skills to treat young people (particularly on the adult side) and clinicians, their patients and families require support to navigate the services and access appropriate care.

Establishing systems for the training, mentoring, and participation of youth health advocates has the potential to transform traditional models of health-care delivery to create adolescent-responsive health systems.

The health system must adapt to increased consumer expectation and recognise the unique needs of young people. Services must be youth friendly, appropriate, and accessible.

The most powerful actions for adolescent health and wellbeing are intersectoral, multilevel, and multi-component: information and broadband technologies present an exceptional opportunity for building capacity within sectors and coordinating actions between them.

We must ensure that no adolescent drops out of our health system during this critical time in their life particularly when the young person is dealing with a rare or undiagnosed condition.

Investments in adolescent health and wellbeing bring a triple dividend of benefits now, into future adult life, and for the next generation of children.

“When a young person presents there should be no wrong door to entry and clinicians should be supportive throughout their pathway of care”.



Ms Tanya Basile
Chair
Clinical Senate of WA



Dr Aresh Anwar
Chief Executive
Child and Adolescent Health Service

July 2019



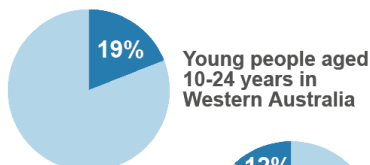
Plan for Transition in WA

Transition

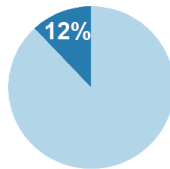
The purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems¹

Successful transition

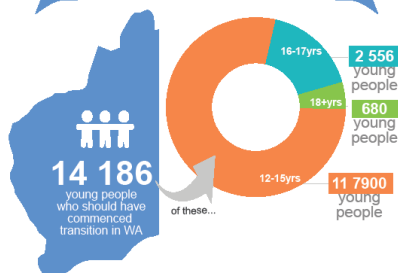
- ✓ Optimise the integration into adult services
- ✓ Ensure adherence to management
- ✓ Positive impact on the health and wellbeing of patient and family/carers



Adolescents living with a chronic condition globally²



Transition in WA



Current initiatives

- 2 Transition clinics established at SCGH and PCH for young people with complex and chronic conditions
- Many condition-specific programs e.g. Cystic Fibrosis, Diabetes supported by non-government organisations
- Undiagnosed Disease Program provides transition support and services
- PAPAYAS Planning and Promoting Adolescent to Young Adult Services Collaborative project between SCGH, PCH and the Child and Youth Health Network

05

April 2019

Clinical Senate Debate



Identify practical steps to turn the Policy into practice by:

- understanding the complexities of transition
- the impact of getting it wrong from the patients' perspective and
- the demand on the health system.

Purpose Improve the transition experience of adolescent and young adults with complex conditions to adult health services



Recommendations

Agency Responsible

- | | | | |
|----------------|---|----------|---|
| System | <ul style="list-style-type: none"> ➤ Development of systematic and formal transition processes ➤ Design and implement a mandatory training and development program (e-learning module) | CAHS | <ul style="list-style-type: none"> ➤ Child and Adolescent Health Service (CAHS) develop a "skills development clinical pathway" to be utilised by all HSPs, GPs and other specialists |
| System & HSP's | <ul style="list-style-type: none"> ➤ The Triple Aim Framework be used to measure and monitor the implementation of the Policy ➤ Fail-proof referral process which identifies priority populations using a standardised referral process, and ensures a controlled entry destination under the oversight of transition coordinators | Consumer | <ul style="list-style-type: none"> ➤ Young people (up to and including 24 years) must be involved in the planning, development and evaluation of services |
| HSP's | <ul style="list-style-type: none"> ➤ ...coordination with a focus on repurposing existing roles/responsibilities to align with the Trapeze model ➤ ...implementation of a consultation liaison model to support and guide teams around transition | All | <ul style="list-style-type: none"> ➤ Appointment of a youth health advocate |

Next steps

Plan for optimal transition of young people from Paediatric to adult health services across WA

- | | | | |
|---|--|---|--|
| 1 | Role: | HSP's will: | <ul style="list-style-type: none"> • Provide transition support at each hospital site • Encourage collaboration with PAPAYAS • Engage with education opportunities around youth health & transition |
| | <ul style="list-style-type: none"> ➤ Recognise the clinical challenge and the extent a poor transition process impacts on clinical outcomes | <ul style="list-style-type: none"> • Endorse a clinical pathway to improve transition • Identify a Transition Champion(s) within each HSP • Identify a Youth Advocate(s) within each HSP | |
| 2 | Role: | The Transition Care Working Group will: | |
| | <ul style="list-style-type: none"> ➤ Develop an annual work plan for the development of transition care services in WA & report against this | <ul style="list-style-type: none"> • Discuss transition issues • Inform practical work plans to improve transition • At minimum, include representatives from All HSP's and the Department of Health <ul style="list-style-type: none"> • Primary care • Young people, their parents/carers • Non-government organisations | |
| 3 | Role: | The PAPAYAS Steering Committee will: | |
| | <ul style="list-style-type: none"> ➤ Provide strategic advice & governance of PAPAYAS WA | <ul style="list-style-type: none"> • Comprise of executive representatives from each HSP • Meet 2 - 3 times/ year • Provide strategic advice to the Transition Care Working Group • Ensure evaluation & monitoring occurs | |
| 4 | Role: | PAPAYAS WA Program will: | |
| | <ul style="list-style-type: none"> ➤ Deliver state-wide transition care services | <ul style="list-style-type: none"> • Deliver education & resources to patients & families in collaboration with young people, their parents/carers • Develop a comprehensive transition website • Utilise technology for youth health screening, coordination of care & communication | |

Special Considerations

A **co-design approach** with young people, parents/carers should be taken

Project staff are required to coordinate & provide support to these initiatives

Evaluation & monitoring should be embedded into the planning of PAPAYAS WA

EXECUTIVE SUMMARY:

Plan for optimal transition of young people from Paediatric to adult health services across WA

Background:

The term 'transition' is best described as 'the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented health care systems'.

In Western Australia (WA), 19 % of the population are young people aged 10 to 24 years, with approximately 12 % of adolescents living with a chronic condition globally. Many of these young people will continue to require health services throughout life, and will need to transfer from a paediatric to adult service.

- During transition, young people are at risk of:
 - suboptimal or loss to medical follow up
 - reduced treatment adherence
 - poorer health outcomes resulting in Increased service costs
 - Increased psychological stress
- Transition is a priority for WA Health that should not be considered the sole responsibility of CAHS and other paediatric health service providers (HSPs).
- Transition has been included as a priority within:
 - *WA Health Clinical Services Framework 2014 – 2024;*
 - Enduring Strategy 4, Recommendation 13 of the *Sustainable Health Review Final Report*.
 - CAHS Operational Plan 2018 – 2020, Section 1.2.2.1.
 - *WA Youth Health Policy 2018 – 2023 (the Policy)*, Goals 2, Priority 2.3: Young people with complex and ongoing health and wellbeing needs are supported to optimise transition from paediatric to adult care.
- Transition has been recognised as an area of importance internationally and many world class paediatric sites have established transition programs. Examples include Trapeze at Sydney Children's Health Network, Transition Support Service at Melbourne Royal Children's Hospital, Well on Your Way: Youth in Transition in Alberta, Canada, GOT Transition in Washington and Cincinnati Children's Hospital Transition Medicine Service.

The Issue:

Adolescence is a time of significant physical, psychological, and social change for an individual, and is particularly challenging for young people with ongoing health condition/s. Health services often fail to meet the health and social needs of young people and their family/carers during this time of considerable change.

These young people may fall through the gaps which currently exist in services, ultimately leading to deterioration of their health status and compromising their quality of life. These young adults may re-present to adult services with preventable health conditions, leading to additional costs to health services as well as social costs to the patient and families/carers.

Successful transition is important to optimise integration into adult services and ensure adherence to management, positively impacting on the health and wellbeing of the patient and family/carers and resulting in reduced costs for the health service.

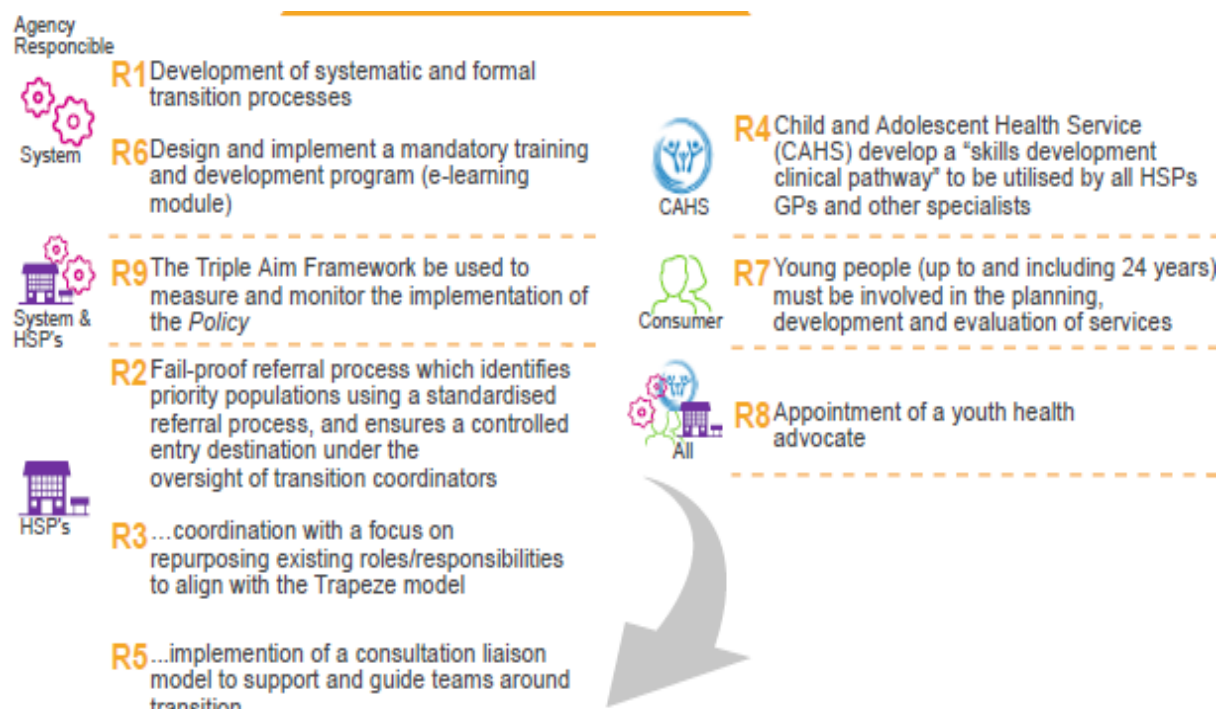
Current State:

There is a need for a comprehensive transition care program for young people moving from paediatric to adult health services in WA.

- There is currently no:
 - cohesive, co-ordinated approach to transition
 - consensus over appropriate age of transfer to adult services
 - streamlined or centralised referral pathway or co-ordination of referrals
 - website or online resource for WA transition information
 - current process for identifying youth health advocates or health care professionals who will champion and support transition processes within each WA Health service or specialist department
 - forum for collaboration and discussion between paediatric and adults sites (e.g. A Transition Care Network)
 - use of technology for facilitating transition , as requested by Young People in WA Youth Health policy
 - database for capturing transition data

In May 2019 a Clinical Senate was held to discuss transition in WA. Nine Clinical Senate Recommendations outlining the need for improved transition services in WA are proposed for consideration by HEC.

Clinical Recommendations by Senate to support better transition of adolescents



What is needed:

A dynamic, holistic approach to transition should be applied for each young person as part of their long term management plan.

Young people should be given the opportunity to be involved in their individualised transition plan, and encouraged to participate in decisions, empowering the individual. Commencement of transition planning should occur from onset of the patient's chronic health condition/disability, with active preparation commencing at different ages depending on the developmental capacity of the patient. The medical and psychosocial needs of the young person should be considered, along with the changing roles of the family/carers and various health professionals.

The identification phase of transition at 12-13 years of age is the time for clinicians to introduce the concept of transition to the patient/family/carers and instigate positive and open communication on the impending transfer to adult services to encourage a sense of normality and realistic expectation setting of the adult services. Identifying a case manager/transition care coordinator/navigator within the young person's paediatric and adult treating teams and/or GPs would significantly aid the transition process and support the patient, family/carers and treating team(s) to facilitate a successful transition to adult services. GP engagement and correspondence should be regular and ongoing.

What helps transition care work well?

Successful approaches to transition are characterised by a holistic and collaborative approach supported by adult and paediatric HSPs, with the consistent involvement of GPs, community and school health care professionals, and most importantly patients and their families/carers.

Features of effective transition programs include the following components:

1. “Transition Care” roles including:
 - Clinic Leads
 - Transition Coordinators
 - Youth mentors
2. Accessible and practical information:
 - Websites with detailed information on transition
 - Clinician, parent and patient “Checklists”
3. Ownership of transition by the young adult when possible by:
 - Preparation and support to allow self-management of their condition
 - Empowering the young person to progress safely to autonomy

Planning a transition program in WA should also consider:

- patient empowerment and self-management
- the roles of parents and families
- primary care
- community services
- Education.

Enablers

- Clear, structured transition process
- Patient advocacy – patient, parent/carer, clinician, General Practitioner (GP), private sector (case manager/coordinator/navigator)
- Individualised transition plans
- Communication - regular, open and positive dialogue from/between health services
- Extensive and early preparation at PCH –early introduction to transition at approx. 12 years, annual reviews, one-on-one appointments, expectation setting for adult hospital
- Availability of resources/education information
- GP/private sector engagement
- Collaboration between/within paediatric and adult hospital(s) – case meetings, transition clinic, verbal handover, continuity of care
- Detailed handover – medical records transferred including medical and psychosocial state
- Involvement of community organisation/s - mentorship program
- Orientation service
- Use of technology - social media group for peer support
- Flexibility with appointments/cancelations, email/text for cancel/book
- Environment - Youth-friendly physical environment, location of services
- Treating team – supportive, clinicians working across various hospitals, professional networks

Barriers

- Lack of formal transition process
- Case complexity – number of specialties, specialties across various locations/hospitals/private services
- No case manager/coordinator/navigator
- No communication from health services providers to patient/parent/carers, as well as between health services and between specialties
- Lack of interest from adult clinicians in public/private health services and GPs
- Lack of collaborative approach across/within hospital/s, lack of continuity between specialties
- Lack of formal handover process – transfer of medical records, discharge summaries
- Complexity of referral process, referrals not received at adult hospital
- Lack of confidence in adult system
- Intimidating physical environment of adult hospital
- Lack of GP engagement
- Lack of resources - information on available services, transition checklist, map/floor plan, staffing
- No monitoring/tracking patients
- Delayed access to adult services
- Capacity of clinicians/GP – training opportunities, professional development

Currently Available Resource

Planning and Promoting Adolescent and Young Adult Services (PAPAYAS)

PAPAYAS (Planning and Promoting Adolescent and Young Adult Services) a collaboration that began in 2018 between a group of health professionals from SCGH and PCH committed to improving health services for adolescents and young adults. PAPAYAS includes:

- SCGH Executive members
- CAHS Executive members
- Adolescent Medicine Specialist
- Adult and Paediatric physicians
- WA Youth Health Network Representatives

The work of this program can build upon current transition care initiatives in WA which include:

- A number of long standing condition-specific transition programs e.g. for Cystic Fibrosis and Diabetes.
- Two new (Feb 2019) comprehensive transition clinics; one each at PCH and SCGH.
- A transition Undiagnosed Diseases Program which has been underway since 2017 and despite a focus on finding diagnoses for patients is also supporting their transition.
- A range of WA health system policies promoting transition care.

Planning

Determining and designing the elements needed for optimal transition care in WA will need a system wide, co-design approach¹ which will be undertaken over a period of time.²

Next Steps: Proposed Actions

Plan for optimal transition of young people from paediatric to adult health services across WA

Based on the WA Youth Health policy and the two Clinical Senate Debates the following three practical steps are recommended:



1: HSPs to recognise the clinical challenge and the extent to which it impacts on clinical outcomes and to endorse a clinical pathway to improve transition.



2: Each HSP to identify a transition champion(s) who can represent their organisation as a representative on a system wide **Transition Care Working Group** which will discuss transition issues and inform practical plans to improve transition.

To help ensure that the Transition Care Working Group can meet its goals all HSPs are asked to consider committing to:

- Ensuring appropriate representation on the Transition Care Working Group.
- Identifying an executive sponsor.
- Providing transition support at each hospital site (from existing resources)

¹ Note: this approach, consistent with Sustainable Health Review, is currently underway in Canada with McMaster University's Child-Bright program transition to adult care. They are in year 3 of 5 years of co-creating an intervention.

² Note: A potential 5 year aim is full integration with current hospital clinical and supportive services as per Canada's Good to Go transition clinic <http://www.sickkids.ca/patient-family-resources/resource-navigation-service/transitioning-to-adult-care/index.html>

- Encouraging collaboration with PAPANAS and engagement with educational opportunities around youth health and transition.



3: Support the need for standardisation of transition care and support PAPANAS to implement change through clinician feedback and engagement of transition champions.

Commit to a developing comprehensive state-wide transition care program leveraging the **PAPANAS** name and networks including:

- Delivery of education and resources to patients and families in collaboration with consumer representatives.
- Development of a comprehensive transition website.
- Introduction and development use of technology for youth health screening, co-ordination of care (e.g. the new Manage My Care app) and communication between health care providers.

Background

The World Health Organisation (WHO) has identified youth health as an international priority. It is also a key priority of the Commissioner for Children and Young People WA.

For this to occur we need to ensure there are well resourced networks of appropriately trained clinicians, supported by well-resourced transition coordinators to facilitate linkages between adolescent and young people and health and psychological support. Successful transition requires more than a referral letter. Young people living with a rare chronic disease also have the right to access appropriate health care in an age appropriate setting³.

The opening of the Perth Children's Hospital (PCH) in May 2018 highlighted the gaps in the interface between child and adolescent and adult health services. Now co-located on the same site as Sir Charles Gairdner Hospital (SCGH), both health services recognised the need to ensure better coordination of care where AYA patients are transitioning.

The Clinical Senate of WA has held several debates on youth health between 2009 and 2012 and had previously identified the need for a youth health policy. Since then the Child and Youth Health Network (CYHN) collaborated broadly to ensure development of a state wide policy that would provide the foundation for change. The *Policy* was released in April 2018.

Regardless of which chronic and complex disease they have, young people face similar problems with the transition to adult care. These are reported to be: inadequate preparation; difficulty finding appointments on the adult side; inadequately coordinated specialist adult services; unwillingness of GPs to take on complex cases; inadequate resources to coordinate the transition process; and lack of psychological support.³

The catalyst for this debate was to identify "why". Why was there a need for a framework to support change? Once endorsed why was *the Policy* not being implemented? Why despite examples of successful transition in some disease groups do we continue to have failures in other disease or undiagnosed conditions? Why the transition of a young person with cancer is supported yet other equally challenging health issues not? Why are there care and service biases for transitioning patients? Why are people in early middle-age still receiving care in a paediatric setting?

The challenges with regard to our current inability to successfully transition young people from child to adult health services are extensive. There are also barriers in our ability to implement policies and they include factors related to human behaviour, knowledge, ability, motivation and system barriers. As we work in a complex system there is a need to regularly assess the requirements for our workforce and our patients.

Where gaps in care or the identification of inappropriate care is known, we must work across our health services and extensive networks to ensure improvement.

The system manager and health services should facilitate our government and non-government partnerships and broaden our networks and through regulation and the development of indicators on transition so we can measure and track progress. We must learn from programs of success and create transferable systems.

³ Zurynski, Yvonne & Elliott, Elizabeth. (2013). Challenges of transition to adult health services for patients with rare diseases. The Medical journal of Australia. 198. 575-6. 10.5694/mja13.10424.

We have known for a decade what is required – we have consulted widely and have the foundation for change in *the Policy*. WA Health must now lead the change, invest for the long term and importantly, keep their promise to action the recommendations clearly outlined in the endorsed policy.



Recommendations

The recommendations below were informed by the presentations from key note speakers, a plenary debate and workshop themes. In accordance with Senate processes, the recommendations from the debate will be shared with both the System Manager and the Health Service Boards for consideration and implementation.

The recommendations are:

1. The WA Clinical Senate recommends that the System Manager prioritises the development of systematic and formal transition processes between Health Service Providers (HSPs) for young people with complex and ongoing healthcare. This priority should be driven through HSP Key Performance Indicators (KPIs) that ensure compliance against *the Policy* via HSP Action Plans developed within the next 12 months.

Key elements for HSPs to consider are

- Individualised age of transitions (12-25yrs) based on negotiation between the patient and clinician
 - Managing paediatric attachment to patients through highlighting clear transition pathways
 - Multidisciplinary team meetings to include families/carers
 - A shared care period between paediatric and adult services is critical
 - Record management and access to services is patient centred (not service centred)
2. Establish a fail-proof referral process for the transfer of patients from paediatric to adult care which identifies priority populations using a standardised referral process, and ensures a controlled entry destination under the oversight of transition coordinators.
 3. The WA Clinical Senate recommends that all HSPs improve transition care coordination with a focus on repurposing existing roles/responsibilities to align with the Trapeze model which is implemented through an enhanced Complex Needs Coordination Team (CoNeCT) program within the next 12 months.
 4. The WA Clinical Senate recommends the Child and Adolescent Health Service (CAHS) develop a “skills development clinical pathway” to be utilised by all HSPs GPs and other specialists.

This pathway will:

1. Ensure all young people with complex chronic medical conditions, identified on WebPAS at 13 years of age, have commenced on a transition pathway.
2. Be monitored by HSP's for completion rates.
3. Better utilise the existing CAHS checklist that:

- a. provides the child and parent with decision making resources
 - b. facilitates enrolment with a GP that the young person chooses and ensures regular communication with that GP.
 - c. seeks the young person's feedback at multiple points during the transition
 - d. recognises that discharge from the transition process would need flexibility based on maturity/developmental stages and attainment of skills
 - e. includes skills development for staff, patients, parents and carers.
5. Each Health Service Provider (HSP) implements a consultation liaison model to support and guide teams around transition (but not to take ownership. Through this shared care model professional development and service gaps are identified and actioned at the point of clinical care.
 6. The WA Clinical Senate recommends that a mandatory training and development program (e-learning module) on adolescents and young adults health for all staff is developed. This should be considered as a high priority and urgency is recommended for implementation within the next 12 months.
 7. Young people (up to and including 24 years) must be involved in the planning, development and evaluation of services by:
 - Two or more young people being appointed to the onsite Health Service Advisory Body (i.e. CAC)
 - This should be included within the Health Service Advisory Body Terms of Reference
 8. The WA Department of Health requires Health Service Providers to appoint a youth health advocate. This should be considered as a high priority and urgency is recommended for implementation
 9. The WA Clinical Senate recommends that the Triple Aim Framework be used to measure and monitor the implementation of *the Policy*.
 - Population health
 - CAHS provides transparent data reflective of the impending demand to each adult health care service
 - disease specific outcomes - continuous monitoring health service level, mortality and quality of life
 - self-care skills - during the transition process, a measure of self-care skills is documented and gaps addressed
 - Health Service Providers (HSPs) implement a standardised experience of care toolkit which measures feedback from patients, parents/carers, and clinicians and identifies barriers of care via continuous survey e.g. Mind the Gap.
 - Cost utilisation will be measured by specific clinic profiles and waitlists, Do Not Attend (DNA) rates, Emergency Department (ED) attendances and hospital readmission rates.

Vision

The aims of the debate were to:

Identify practical steps to turn *the Policy* into practice by understanding the complexities of transition, the impact of getting it wrong from the patients' perspective (fragmented or interrupted care) and the demand on the health system.

Improve the transition experience of adolescent and young adults with complex conditions to adult health services.

Approach

The sponsor for the debate was Dr Aresh Anwar, Chief Executive, CAHS

The debate included several keynote addresses including consumers who shared their lived experiences. These speakers set the context for debate and informed the discussion. In the plenary session, additional expert witnesses shared their knowledge, experience and stories, providing insight into what is happening locally, nationally and internationally as well as considering the impact at the community level.

Key questions posed during the plenary session related to the key enablers required, what is missing and importantly, the responsibility of individuals and health services to ensure there is a smooth transition for all young people transitioning to adult health services.

The Senators were split into working groups to identify and recommend practical strategies for change around key outcomes from three specific priority areas from *the Policy*.

The groups developed recommendations for both the Director General as System Manager and Health Service Boards. The areas of focus were:

Readiness for transition- 8 outcomes considered with 4 chosen for development of recommendations

Priority Area 2.3 Young people with complex and ongoing health and wellbeing needs are supported to optimise transition from paediatric to adult care

The following outcomes were considered from this priority area

2.3.1 Health Service Providers develop an agreed systematic and formal transition process for all young people living with complex and ongoing health and wellbeing needs, starting in early adolescence

2.3.2 Agreed standardisation of transition ages across health services

2.3.3 Health services working with young people living with complex and ongoing health and wellbeing needs commit to the development and implementation of transition programs

2.3.4 Health Service Providers assign transition coordination responsibilities to a position based in a paediatric and an adult health service

2.3.6 A transition readiness checklist is completed at regular intervals from early adolescence

2.3.7 Health services provide resources covering transition and associated services available to young people and their families or carer

2.3.8 Health Service Providers monitor and evaluate transition processes to inform future planning, policy and services

2.3.9 Young people living with complex and ongoing health and wellbeing needs are supported to develop skills to manage their health as early as possible to aid transition

System Response – 8 outcomes were identified as priorities with 5 chosen for development of recommendations

Priority Area 3.1: Young people are supported by health systems that are committed to continuous improvement in youth health and wellbeing

3.1.1 Young people participate in planning, development, delivery and evaluation of youth specific services, resources and campaigns

3.1.2 Priority youth populations are identified and considered in service and program development, evaluation and improvement

3.1.3 Data collection, sharing and analysis informs improvements in service delivery

3.1.5 A youth health advocate is identified within each organisation

Priority Area 3.2: Young people are supported by a workforce that is equipped with the knowledge, skills and understanding to improve health outcomes

Presentations from the day can be found on the Clinical Senate website:

<http://ww2.health.wa.gov.au/Improving-WA-Health/Clinical-Senate-of-Western-Australia>

Key data

The following statistics were provided by Dr Aresh Anwar, Executive Sponsor of the debate.

- By 2013, mortality in 1 to 4 year olds had fallen to a quarter of the levels identified in 1980.
- By contrast, deaths in 20-24 year olds had fallen to around 60% of the 1980 levels.
- Deaths in many high-income and middle-income countries are now higher in older male adolescents than in 1 to 4 year olds.

WA data

There are 58,900 children and young adults in WA

- 0-8 yr olds = 309,363 (52.5%)
- 9-14 yr olds = 187,200 (31.8%)
- 15-17 yr olds = 92,405 (15.7%)
- 152,00 live in regional and remote WA
- 38,900 of all children in WA are Aboriginal

Welcome to Country

Ms Ingrid Cumming, a Whadjuk Balardong Nyungar custodian and traditional owner performed the Welcome to Country.

Presenter highlights

The lived experiences

Two guest speakers shared their lived experiences and offered suggestions for how to improve transition.

Ms Alysha Loffler

Ms Alysha Loffler shared her journey as an adolescent with a rare and undiagnosed condition. At 16, she left PMH with no referrals and was faced with the challenge of navigating the adult health system which included the need to see more than one specialist across both sides.

This lack of a pathway and system support between 16-18 years of age had a negative impact on her health. When her condition started to flare she attended the ED at PMH however, when they realised she was 16, staff tried to send her home. If not for one clinician who offered to help, she would not have been seen.

After leaving PMH, Ms Loffler went two full years without seeing any clinicians or receiving treatment and during this period her secondary illnesses flared.

At 18 she found herself a new GP from Bunbury in WA who offered great assistance and continuity of care. The GP however, was unable to gain access to historical medical information. The GP was reliant on Alysha to provide information based on recall and letters from various clinics.

Ms Loffler was finally able to see a private specialist, but that was only possible because her parents were able to pay for it – ‘not everyone has that type of support’.

Alysha’s messages to improve transition:

- Referrals must be in place before an AYA leaves the child health service.
- No young person should drop out of the health system. They must be supported and given a pathway or they will continue to fall through the cracks.
- Care and access to care is critical during transition or it will greatly impact your health.
- There is a need to adjust the extensive wait times in the public system for appointments. This is something that must change!
- Scheduling of appointments needs to be easier, particularly when you have to see several specialists.
- Information must be accessible and shared with GPs and specialists. Clinicians must not be reliant upon the recall of the patient for information.
- There is the need for better communication between health services and GPs.
- There are good pathways for some patients but not so, for patients with complex or undiagnosed conditions.

Ms Loffler concluded:

My health issues may not have progressed as far if my health had been managed appropriately.

Ms Loffler contributed throughout the day further assisting clinicians to better understand the issues and importantly, working with them towards solutions.

Ms Tegan Rossiter

Ms Rossiter was born with a cleft palate. She provided an overview of the challenges of transition as well as reflecting on what aspects worked well in her care.

Positives of my transition

- I was able to remain with the same practitioners throughout my care. This helped with the fluidity of the transition and build personal relationships.
- I was able to access a high level of care, and am very grateful.
- I was fortunate enough to live proximal to PMH/PCH which helped with all the appointments.

Negatives

- Poor coordination of the appointments meant that sometimes I would have to go to several appointments a week, during school/work hours. This stunted a lot of my education and my work options.
- A lack of psychiatric assistance throughout my treatment impacted my life heavily.
- It is expensive to pay for parking, food etc. in hospital, and little compensation for what could be up to a 4 hour appointment.
- A lack of information during my transition, making it a very confusing time.

What would I change?

- Better psychological help for patients during transition.
- More accessible information on what transition entails, including a rough timeline or series of events that will be occurring throughout transition.
- Better coordination of appointments which would reduce the amount of time taken off during school and work.

The catalyst for change

Dr Aresh Anwar, Chief Executive, Child and Adolescent Health Service

Dr Anwar was the Executive Sponsor for the debate and provided his key points around the catalyst for change. He shared this definition of transition described in the Perth Children's Hospital Transition and Transfer Framework:

“the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult health care systems”

- He outlined the disease profile of youth to demonstrate the changes e.g. Type 2 Diabetes which has risen from 5% to 1:5.
- Medical advances and better care mean that more children with serious illnesses and disabilities are surviving into adulthood. There is a powerful argument to make sure that now, more than ever, care for these young people is integrated and coordinated around their needs and the needs of their families.
- Disease patterns are changing and aggressive intervention from the start of life has lifelong implications.
- 8-12% of children have a disability, 8-12% of children live with a chronic disease.
- Medical intervention has enabled people to live longer with >90% survivorship.

- Mortality has fallen sharply in younger children in high-income and middle-income countries compared with older adolescents and young adults.¹⁵ By 2013, mortality in 1 to 4 year olds had fallen to around a quarter of 1980 levels (appendix figure 1). By contrast, deaths in 20 to 24 year olds had only fallen to around 60% of 1980 levels. Deaths in many high-income and middle income countries are now higher in older male adolescents and young male adults than in 1 to 4 year olds. (Lancet Published online May 9, 2016 [http://dx.doi.org/10.1016/S0140-6736\(16\)00579-1](http://dx.doi.org/10.1016/S0140-6736(16)00579-1))
- At PCH 11,000 children who should be entering transition; 3000 were imminent requiring transition with over 100 of the patients being over 18 years of age.
- Patients are not just seeing single specialities as they have complex health needs and therefore are on average seeing three or more specialties.
- There have been guidelines around transition since 2009 however, these guidelines and our behaviours have not changed.
- Policy and practice do not match up and this created confusion and there is a significant shortfall between the policy and practice.
- For young people, their families and sometimes the staff caring for them, there is often confusion and frustration.
- Failed transition leads to poor engagement with health services and adverse health outcomes.
- Young people can find themselves without essential care or equipment because of the different ways services are provided, or while funding arrangements are resolved.
- There is solid evidence that morbidity and mortality increase for young people following the move from paediatric to adult services.

He challenged our thinking around the timing of transition according to developmental stage and maturity, and not age.

He queried: Are we using the right specialties - should we be asking Geriatricians to be looking after younger patients?

Dr Anwar concluded:

We must learn from existing exemplars of transition; be generous in sharing knowledge; acknowledge, respect and build on the considerable body of work and partnerships in this space (in WA); and most importantly do so that it is more than talking shop!

Transition – just one aspect of adolescent health care

Dr Donald Payne, Consultant Paediatrician, Sir Charles Gairdner Hospital, Headspace and WA Youth Cancer Service

Dr Payne reminded participants that this was not the first time transition had been discussed from a system-wide perspective. It is the fourth session in the last ten years (journey) since the development of the 2009 Paediatric Chronic Diseases Transition Framework.

- The evidence has shown that health outcomes in young people are poorer than expected. For example the mortality rates in 20-24 year olds is higher than in the under five year olds.
- In WA, a gap can be identified for children aged 15-17 years of age. Our system is letting this group down. We must fix this issue through redesign.
- The implications for young people not receiving the care they need at this age can result in significant complications at a later stage, which could have been avoided.

For example: If young people with cystic fibrosis are not provided with adequate and ongoing care, it can have irreversible impact on their lungs and if a young person has sugar issues that are not addressed it can lead to diabetes. If these issues are not managed, treated or followed up the impact on the health system is enormous and for the patient can lead to early death.

- Areas of significant costs to the patient and the health care system for young people include diabetes, renal transplant, eating disorders and neuromuscular disorder. There is additional significant cost when these young people drop out of the system and then present later, often with completely avoidable conditions. We must invest now for longer term savings.
- Some specialty areas are good examples of best practice in transitional care. For example Oncology through the AYA Oncology youth cancer services (30 years).
- *The Policy* provides valuable information to inform and guide change.
- There is great opportunity to build on the momentum of change happening at PCH.
- Transition is not hard, it just requires a commitment to act!

Dr Donald Payne concluded:

The Policy, recommendations and companion documents all arose out of consultation with health professionals, young people and their families. There are specific responsibilities and requirements to ensure accountability of HSPs.

I ask you to consider transition as one important component of young people's health and it must be viewed in the context of the broader system of care for youth health. A system that embraces youth health will include transition.

The Policy clearly defines the way forward. The time for action is now.

Plenary

The plenary session was facilitated by Professor David Forbes and was structured in two parts. The first session was a Panel of leading clinicians currently working across both adolescent and adult health services, who highlighted the current state of play. The second part consisted of several scenarios from experts aimed at addressing the key questions for debate.

1. Panel

Network Perspective – Dr Helen Wright

- The development of *the Policy* involved broad consultation with both young people and clinicians. *The Policy* outlines a number of high value and low cost recommendations for change across the system.
- Nationally there are gold standard practices that can be adapted for the WA setting.
- Health Services need to adapt to the unique needs of young people.
- To improve youth health services requires leadership and collaboration.
- There are economic benefits to investing in youth health and managing transition well!
- There is a lack of quality evidence regarding youth health and there is the opportunity for WA to lead the way.

Paediatrics Perspective - Dr Rachel Collins

- Transitioning patients often experience multiple planned and unplanned hospital presentations.
- It is important to consider the accompanying social, financial and economic complexities of these patients when planning for their care.
- There are issues related to funding consumables and access to services.
- AYAs are vulnerable and interruptions to life and disruptions to education are stressful. Retaining close therapeutic connections across hospital and school services is essential.
- Non-medical support is also required in relation to school services, with consideration of potential learning difficulties and side effects of treatments impinging of education.
- AYAs find it very hard to access appropriate specialists.
- With an unclear referral pathway it is our responsibility as clinicians to reduce the stress and provide continuity of care.
- GPs and primary care professionals want to be involved in transition (early) and can assist. This is also important with regard to clinical handover and can have an impact on patient safety and quality of care.

Adult Perspective - Dr Matthew Skinner

- Dr Skinner became interested in transition after hearing two young people share their stories at a grand rounds presentation on the Planning and Promoting Adolescent & Young Adult Services (PAPAYAS) project.
- He applied the learnings in the establishment of the HIV clinic with improvements in care coordination and empowering patients to achieve their goals and improve their health outcomes.
- It is important to be coordinators of services and educators for patients about their illness.
- As clinicians, we must facilitate the patient to be empowered so they can achieve goals – to improve the health outcomes of the individuals.
- We must also consider how to use scarce resources more wisely.

Rare Diseases Perspective - Dr Gareth Baynam

- “Rare diseases are rare and everywhere” as there are 6-8,000 individual rare diseases.
- There are approximately 60,000 children in WA living with a rare disease in WA with a majority experiencing genetic rare diseases- enough to fill Optus Stadium!
- The rare diseases patient community, and multiple other stakeholders, identify that improved transition pathways are required for children and adolescents with rare diseases.
- Improving rare diseases diagnosis is an opportunity to assist with increasing the efficiency of transition, and health system efficiency more generally.
- A diagnosis gives these patients a clearer transition pathway. Diagnosis is the portal to best medical care.
- Undiagnosed rare diseases patients are a cohort that have many commonalities and will also benefit from tailored and enhanced transition.
- Critical success factor to transition is having transition coordinators (‘high touch’) and interdisciplinary teams that empower the family, patient and medical professionals for enhanced transition; and clinical access to ‘high tech’ approaches to improve diagnosis, such as genomic sequencing.

Mental Health Perspective - Donald Payne

- We must consider the complexities of treatment for AYAs with mental health issues.
- Challenges include finding services that will continue to provide treatment as children get older. For example community services like Headspace Midland can only see patients up to 25 years of age.
- General practitioners and community services can play an important role in continuity of care.
- As patients get older it’s harder to find a GP who will treat them as an adult without private psychology.
- Partnerships are important – there is the need to take the discussion to the non-government organisations that provide a broader range of support in this area.

2. Expert input to address key questions

Professor David Forbes reiterated some of the key points highlighted as a disconnect between policy and practice; there has only been incremental changes over the past ten years; and that the proximity of PCH to SCGH has not improved transition despite many expecting it would just happen.

The facilitated debate resulted in the following outputs.

Enablers:

- Ensuring referrals are in place when the patient is leaving the child health services (continuity of care).
- Ensuring common access (adult and paediatric) to the health record.
- Increasing Genetic services (access and diagnosis).
- An increased focus on providing multidisciplinary care supported by a transition coordinator for all transitional patients.
- Ensuring well defined pathways of care for both clinicians and their patients.
- Recognising the importance of providing mental health/psychosocial support for AYAs who are transitioning.
- Discussion on the pathway for transition must start early in the patient journey and include liaison with their patient and their family.
- Empowering and educating the patient to be able to direct their own care.
- Consider the role of outpatient care as part of transition.
- Early involvement (not at age 12) of GPs as care coordinators with experience in dealing with the family unit and psychosocial issues.

Important factors to improve transition

- Advocating for the development of standardised referral and care pathways across the services.
- A state-wide transition approach with standardised processes.
- Managing expectations that financial commitments will no longer be fully covered when using adult tertiary care.
- The provision of training for clinicians to manage complex cases while encouraging a multidisciplinary approach and the use of transition coordinators.
- *“The challenge for adult physicians is how they take over the care of a disease they may know nothing about”.*
- The need for clinical leadership and champions to advocate for change.

Considering the specific needs of rural and remote patients in state-wide services. •
Recognising that Adolescent medicine is a specialty field.

- Training for clinical staff must include adolescent development to understand the complexities.
- Recognition that the adolescent brain is developing through to the age of 25.

- In the presence of complex disease the capacity of this development is not fully understood.
- Normal adolescent behaviour will impact on the ranges of care compliance.
- In knowing this, should there be separate adolescent units within hospitals or liaison teams prepared to work with specialty units who care for adolescents?
- Coordination is best placed in tertiary centres using a hub and spoke model.
- Stronger links must be developed with non-government organisations to help patients navigate the system.
- Improved communication between hospitals and general practice is necessary to facilitate communication with families and long term follow-up care.
- We must facilitate sharing of paediatric records.
- Adolescent health units must be part of our clinical design and infrastructure and must be youth friendly in order to meet the needs of young people.
- There must be better communication between hospitals and GPs and GPs to specialists who play a critical role in keeping patients and their families informed.

Recognising the relationship between mental health and physical health

- Our physical and mental health is profoundly interlinked.
- The siloing of physical and mental health services is a huge issue.

Important messages from consumers on the day:

“We must treat patients while understanding the broader context of their lives”

“Transitioning with no diagnosis is extremely problematic and much harder”

“Parents often feel confused, isolated and abandoned”

Key message: “It’s not going to be one thing, multiple things working together to make it successful”.

A graphic depiction containing some of the key messages emerging from the full morning session is provided as Appendix 2.

Appendices

Appendix 1: Presenters, expert witnesses and invited guests

- Ms Ingrid Cumming, Whadjuk Balardong Nyungar custodian and traditional owner
- Ms Tanya Basile, Chair, Clinical Senate of WA
- Dr David Russell-Weisz, Director General, Department of Health WA
- Dr Aresh Anwar, Chief Executive, Child and Adolescent Health Service
- Dr Donald Payne, Consultant Paediatrician, Headspace Midland and WA Youth Cancer Services
- Ms Alysha Loffler, Member, Telethon Kids Youth Advisory Council
- Ms Tegan Rossiter, Support Officer, Ability Centre
- Professor David Forbes, Deputy Chair, North Metropolitan Health Service Board
- Dr Helen Wright, Paediatrician, Perth Children's Hospital and Co-lead, Child and Youth Health Network
- Dr Gareth Baynam, Clinical Geneticist, Perth Children's Hospital
- Dr Matthew Skinner, General/Infectious Diseases Physician, Sir Charles Gairdner Hospital
- Dr Rachel Collins, General Paediatrician, Perth Children's Hospital
- Dr Ali Buckland, Medical Registrar, Sir Charles Gairdner Hospital
- Dr Siobhain Mulrennan, Respiratory Consultant and Adult Cystic Fibrosis Director, Sir Charles Gairdner Hospital
- Ms Anne McKenzie, Manager, Community Engagement, Telethon Kids Institute
- Dr John Wray, Developmental Paediatrician, State Child Development Centre
- Professor David Joske, Clinical Haematologist and Medical Co-Director, Medical Specialties Division, Sir Charles Gairdner Hospital
- Mr Caleb Jones, Principal, School of Special Educational Needs: Medical and Mental Health, Department of Education
- Dr Lisa Miller, Consultant Liaison Psychiatrist, Sir Charles Gairdner Hospital
- Dr Janine Spencer, Head of Paediatrics, Fiona Stanley Hospital
- Dr Tony Ryan, General Physician, Fiona Stanley Hospital
- Mr Mason Rothwell, Senior Policy and Advocacy Officer, Youth Affairs Council of Western Australia
- Ms Rebecca Evans, Deputy Chair, Executive Committee, Youth Disability Advocacy Network
- Mr Alexander McNeilly, Nursing Student, University of Notre Dame
- Ms Marie Deverell, Senior Development Officer, Health Networks, Department of Health WA
- Dr Lisa Cuddeford, Clinical Lead, WA Paediatric Palliative Care Service

- Professor Sharon Parker, Director, Centre for Transformative Work Design, Future of Work Institute, Curtin University
- Ms Nikki Peapell, Operations Manager, Headspace Midland
- Ms Karen Clarke, Discharge and Transition Coordinator, Perth Children's Hospital
- Dr Andre Schultz, Director, Cystic Fibrosis Services, Perth Children's Hospital
- Ms Jackie Tang, Assistant Director General, Service Delivery, Metropolitan Communities, Department of Communities WA
- Mr Stephen Cohen, Chief Psychologist Department of Communities WA
- Dr Thomas Walwyn, Senior Paediatric Oncologist, Perth Children's Hospital
- Ms Trish Heath, Director Policy and Research, Commissioner for Children and Young People
- Ms Deborah Karasinski, Board Chair, Child and Adolescent Health Service Board
- Professor Mark Khangure, Board Member, South Metropolitan Health Service Board
- Dr Robyn Lawrence, Chief Executive, North Metropolitan Health Service
- Ms Liz MacLeod, Chief Executive, East Metropolitan Health Service
- Dr Hilary Fine, Board Member, North Metropolitan Health Service Board
- Ms Kate Gatti, Executive Director, Clinical Services, South Metropolitan Health Service

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