Approved AS 27/07/2021

9 WA Clinical Senate 2019 Recommendations

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 Indictors (KPIs) that ensure compliance against the Policy via HSP Action Plans developed within the next 12 months.***

Progress made by CAHS Transition Service within CAHS:

- The CAHS Transition Policy is in place as of August 2020 to standardise transition to adult services across CAHS.
- A database has been developed which identifies all PCH patients at 13 years and allows updates at four key stages of transition:
  - 13 years: initiation of transition discussion
  - 14-16 years: formalisation and progression of a transition plan, ongoing transition discussions with families. Identifying appropriate adult services. Engagement with local community services and ongoing engagement with GP. Consideration of financial and legal implications of transfer to adult services. Gathering of relevant clinical information in preparation for transfer.
  - 16-17 years: all referrals made to appropriate adult services (tertiary, local, community and GP).
  - 18 years: last review at PCH and discharge from paediatric services.
  - At each of these stages patients are flagged so that information regarding their progress through transition can be documented in the database.
  - PCH HoDs will receive a quarterly update informing them of which patients they have in their service who are >13 years, their progress through transition and which clinicians/clinics/services they attend.
- This will promote accountability, reporting to PCH Operations Committee and allow us to provide support for patients who have barriers to transition and help to work around these barriers to ensure that they can engage with appropriate services after 18 years.

Within WA Health:

- CAHS Transition Service has had engagement from some of the adult HSPs. The WA Health Adolescent and Young Adult Transition Network (WAHAYATN) has been established and the work plan is currently under development in collaboration with the Child and Youth Health Network. This will be finalised in August. Progress of WAHAYATN and the work plan has been disrupted by COVID.
- Collaborations with adult services have included:
  - Joint meetings with the Child and Youth Health Network with the clinical service planners of each HSP to discuss training opportunities and promote the service
  - GP education sessions
  - Development of a new AMA Dr YES Youth Health and Transition Training module to be taught to high school students by medical students in collaboration with CAHS Transition Service.

- Meeting with Executive Director of Clinical Service Strategy and Population Health at EMHS.
- Further collaboration with EMHS and the Child Development Service (CDS) around transition of patients with Autism Spectrum Disorders and Intellectual Disability. Including development of a pathway for minimising crisis admissions for this group of young people.
- Dr Rachel Collins and Karen Clarke (CAHS Transition Coordinator) are leading the implementation at PCH of the winning design from the EMHS "Innovative Design Thinking: Youth Think Tank" with a focus on Transition. This lead to the development of the QRious Youth Health Hub and QR code which is currently being developed for launch at EMHS and PCH in 2021.
- Collaboration with Executive Director of the Neurological Council of WA (NCWA) to implement a new pilot utilising the skills of NCWA nurses and upskilling them in Adolescent Neurology and Youth Health to support patients in the community as they transition from paediatric to adult neurology services.
- Dr Rachel Collins has become the General Paediatric representative on the Adult and Young Adult Medicine Committee of the RACP to collaborate with Adult Physician training through the RACP to address transition nationally through college education and training. Currently working on a College position paper on Transition in Australia.
- Dr Rachel Collins has become a member of the National Clinical Research Collaborative K2A (Kids to Adults) and is collaborating in national research around how to improve transition throughout Australia.

Key elements for HSPs to consider are (ongoing issues in red):

- Individualised age of transitions (12-25yrs) based on negotiation between the patient and clinician
  - Addressed by CAHS Transition policy and education
- Managing paediatric attachment to patients through highlighting clear transition pathways
  - Good progress has been in made in this area throughout CAHS through clinician education around the importance of early transition planning.
- Multidisciplinary team meetings to include families/carers
  - We have managed to increase awareness of the benefit of this approach.
  - Being made increasingly accessible through telehealth.
  - Looking at clarification around funding for these types of MDT meetings via telehealth.
- A shared care period between paediatric and adult services is critical
  - Paediatric and adult specialists want to be able to do joint transition clinics but funding /sessions continues to be a problem and this needs to be addressed.
  - All specialist departments at PCH have raised this as a concern.
  - We have discussed this with EMHS as well who are considering solutions.
- Record management and access to services is patient centred (not service centred)
  - This is and will continue to be an ongoing problem while we do not have electronic medical records.
  - Currently we are educating patients that their CAHS medical records won't transfer to adult HSPs with them. We have created a CAHS Transition Summary

document for families to self-populate and have educated families around the use of My Health Record.
  - No definitive solution has been found for this problem. Anecdotally this is a major area of concern and dissatisfaction for patients, families and clinicians.

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.***

Progress made by CAHS Transition Service:

- CAHS Transition Service is consultative service with a Medical lead (0.2 FTE) and a Transition Coordinator (0.5 FTE) that supports departments within CAHS when barriers to transition occur by identifying referral pathways, following up referrals and facilitating collaboration across HSPs.
- This process is very complicated and system wide mapping would be incredibly beneficial. This would require appropriate time and resources from the systems manager.

Within WA Health:

- A system wide solution to these issues is yet to be found.
- Having a Transition Coordinator within CAHS has been invaluable in terms of clinician and family support, system navigation and overcoming barriers. Having Transition Coordinators in the adult HSPs would also be incredibly beneficial for similar reasons; we have been given this feedback numerous times by clinicians and managers from adult and paediatric services as well as executives and health networks.
- Referral pathways to public adult HSPs have been streamlined by the introduction of e-referral throughout WA. However identifying services to refer to for some conditions can be challenging.
- Referral pathways to private services are complex and lack visibility or accountability. This is a source of frustration to clinicians and families and a potential risk.
- It has been identified that patients transferring from paediatric to adult care often do not get prioritised and go 'to the back of the list' meaning that there are long wait times for their follow up appointments leading to long breaks in care, a letter has been sent to Assistant Director General (Clinical Excellence Division) to requesting that consideration is given to prioritise the transfer of patients to adult outpatient services in a similar way to that of WA Health Elective Surgery Access and Waiting List Management policy.

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.**

Progress made by CAHS Transition Service within CAHS:

- We have successfully established the CAHS Transition service which is a consultation liaison model and complex care clinic which provides education, family and clinician support, as well as governance and accountability regarding transition. We are working on collaborative research, project design and evaluation.
- Trapeze is a useful resource but is not the 'gold standard. We are working with TKI and other research partners to evaluate the CAHS Transition Service and look at how to develop the program and develop a "Gold standard" program for transition in WA.

Within WA Health:

- We have not been made aware of Adult services repurposing existing roles to support transition and would be keen to hear of any developments in this area.

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:**
   a. **Ensure all young people with complex chronic medical conditions, identified on WebPAS at 13 years of age, have commenced on a transition pathway.**
   b. **Be monitored by HSP's for completion rates.**
   c. **Better utilise the existing CAHS checklist that:**
      i. **provides the child and parent with decision making resources**
      ii. **facilitates enrolment with a GP that the young person chooses and ensures regular communication with that GP**
      iii. **seeks the young person's feedback at multiple points during the transition**
      iv. **recognises that discharge from the transition process would need flexibility based on maturity/developmental stages and attainment of skills**
      v. **includes skills development for staff, patients, parents and carers**

Progress made by CAHS Transition Service within CAHS:

- Identification of patients requiring commencement of transition planning is enabled by the creation of the CAHS Transition Policy and CAHS Transition Database.
- Reports of transition progress will be accessed through the Transition Database and presented quarterly at PCH Operations Committee as well as being accessible to Executive by BIU upon request
- We have completed an audit, which was presented at the 2020 WA Child Health Symposium.
- We have commenced a pilot of electronic HEADS (Youth Health) screening. The Sydney Children's Hospital Network is collaborating on this with us as they have just published a similar study.
- We run a monthly complex Transition clinic and have created resources including a webpage, accessible via Health point and the CAHS Internet.
- We have developed online resources, TAKE 5 education resources and a "Transition Starts at 13" logo (below) to promote conversations around transition.

- Promotion of the co-designed *My Health in My Hands* resource supporting young people to become more independent with their health

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.**

- This has been successfully implemented at CAHS but not in the adults HSPs as far as we are aware. We would be keen to strongly advocate for this model (including a transition coordinator) being implemented at other HSPs and this view is supported by the Child Youth Health Network

6. **The WA Clinical Senate recommends that a mandatory training and development program (e-learning module) on adolescent and young adult 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.**

- We feel that staff are unlikely to engage with mandatory training. However we have provided face to face education, Take 5s and online resources. This education is ongoing. We are collaborating with Adolescent Medicine to promote and deliver Youth Health Education and Transition Education. This has been very successful to date.

7. **Young people (up to and including 24 years) must be involved in the planning, development and evaluation of services by:**
   a. **Two or more young people being appointed to the onsite Health Service Advisory Body (i.e. CAC)**
   b. **This should be included within the Health Service Advisory Body Terms of Reference**

- CAHS have been compliant with this. We have no visibility of the adult health services; however do not think there are any youth representatives on the adult HSP CACs currently. If there are this is AdHoc and not part of the TORs

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**

- This has not happened. The WA Child and Youth Health Network and WAHAYATN are keen for this to happen. The Network (WAHYAYTN) needs support from the adult HSPs to establish and support these roles.

9. **The WA Clinical Senate recommends that the Triple Aim Framework be used to measure and monitor the implementation of *the Policy*.**

   a. **Population health - CAHS provides transparent data reflective of the impending demand to each adult health care service**

- The PCH Transition database can provide this information in real time

   b. **Disease specific outcomes - continuous monitoring at health service level, mortality and quality of life and ongoing research will be needed in these areas.**

- Dr Rachel Collins is currently working with TKI and national research partners eg K2A to facilitate this. Much of this will need to be department specific and collaborations with departments is being supported.

   c. **Self-care skills - during the transition process, a measure of self-care skills is documented and gaps addressed**

- Utilisation of Health Literacy questionnaires and hopefully the Flinders' Chronic Disease self-management tool will be useful in developing this area. This will be included in family and clinician education. We are developing ongoing research in this area.

   d. **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.**

- We are working on this from a CAHS perspective and have not heard anything regarding the evaluation processes in the adult services.

   e. **Cost utilisation will be measured by specific clinic profiles and waitlists, Do Not Attend (DNA) rates, Emergency Department (ED) attendances and hospital readmission rates.**