

# Transition Models of Care ACI Transition Care Network

## Evidence check: Part 1

May 2022

Rapid evidence checks are based on a simplified review method and may not be entirely exhaustive, but aim to provide a balanced assessment of what is already known about a specific problem or issue. This brief has not been peer-reviewed and should not be a substitute for individual clinical judgement, nor is it an endorsed position of NSW Health.

### Evidence check question

What organisational models of care have shown to improve the transition of care of adolescents from paediatric to adult health services?

### In brief

#### Key terms

The definitions of key terms used in this evidence check include:

- Transfer of care: when a person moves from one healthcare provider to another.
- Transition: “purposeful, planned movement of adolescents with chronic medical conditions from child-centred to adult-oriented health care.”<sup>1</sup>
- Transition intervention: an event, program or service to support transition from paediatric healthcare service to adult healthcare services.
- Successful transition: can’t define as yet.

#### Age for transition

- Starts at 12 years.<sup>2</sup>
- The duration of illness rather than age impacts transition readiness.<sup>3</sup>
- One systematic review suggests that transition readiness and transfer readiness have been conflated.<sup>4</sup>

#### Systematic reviews of transition of care for adolescents

- One systematic review, including 17 studies, reported that transfer of care was the most prominent intervention feature of healthcare transition service models.<sup>5</sup>
- One systematic review, including 10 studies, identified three broad categories of intervention, directed at: the patient (educational programs, skills training); staffing (transition coordinators, joint clinics run by paediatric and adult physicians); and service delivery (separate young adult clinics, out of hours phone support, enhanced follow-up). It reported that the most commonly-used strategies in successful programs were patient education and specific transition clinics.<sup>6</sup>

- Another systematic review, including 92 studies, highlighted that there was no standardised transition program and most guidelines used to develop transition services were not evidence-based in palliative care.<sup>7</sup>

## Models of care to support transition of care

Overall, a combination of strategies had been used in the studies to support transition. These included building specialist teams that cut across both paediatric and adult services (joint clinic), integrating the family into the transition care, dedicated navigators, peer groups, educational initiatives, and analyses of clients' pathways of care. These models are outlined in more detail below.

### Joint paediatric and adult clinics

These are jointly facilitated child and adult clinics with staged transition over many months or years and specific focus on psychosocial needs.<sup>8-10</sup>

- Shared-care models between paediatric and adult after-care clinics are superior to the transfer to adult after-care clinics.<sup>11</sup>
- Shared paediatric and adult clinics found guided transfers to be superior to traditional transfers from paediatric to adult care.<sup>12, 13</sup>
- This approach to transition enabled building a network of paediatric and adult healthcare providers, the young person, and their family.<sup>14</sup>
- Comments suggest that preparation and meeting the adult team made the transition process better.
- Young adults with rheumatic disease suggest the purpose of the clinic is to provide continuity in transition from paediatric to adult rheumatology care, while empowering the patient to become involved and responsible for their medical decisions and facilitation of optimum treatment.<sup>15</sup>
- In addition to illness management, the team helps patients deal with other life transitions.<sup>15</sup>

### Dedicated survivorship clinic

A clinic specifically set up for cancer survivors for their long-term care, regardless of age.<sup>16</sup>

- The results showed a lack of understanding in the importance of follow-up care among patients.
- Formal transfer from a paediatric specialist to an adult provider may confer greater likelihood of engagement in the adult medical system.

### Young adult and/or transition clinical teams

This is care managed by a young adult clinical team comprising a nephrologist, transplant nurse specialist, youth worker and pharmacist.<sup>17</sup>

- The pathway involved joint medical clinics at the paediatric centres including a paediatric nephrologist and paediatric renal transplant nurse specialist jointly working with an adult nephrologist and nurse specialist.<sup>17</sup>
- Clinicians suggest that the following factors support the transition: early joint clinics, multidisciplinary team meetings, promotion of self-managements with a long, planned process and a written plan.<sup>18</sup>
- Data suggest that tailored multidisciplinary youth-friendly service with open drop-in access may facilitate retention in care.<sup>19</sup>

- A wraparound team supporting the family and young person during their transition phase found that greater efforts need to be made to support the carers to reduce their strain and youth need to be given a voice.<sup>20</sup>
- One study conducted three meetings, first two with adolescent and family and a final meeting with patient independent of family. All psychology meetings were conducted with the patient alone. This study reported significant improvement in self-efficacy scores in all domains.<sup>21</sup>

### **Dedicated transition navigator or coordinator role**

- This model increased effectiveness of transition reducing difficulties associated with communicating with multiple providers.<sup>9</sup>
- Dedicated transition coordinator for diabetes clinic showed improvement in diabetes care for young adults with type 1 diabetes.<sup>22</sup>
- Twenty-three clinics with operational paediatric transitional navigator were assessed and yielded positive results. Involvement of the transitional navigator for one year post transition was found to be very important to support the young people.<sup>23</sup>
- Maestro Project System Navigator Model introduced a centralised, coordinated community-based navigation service for the care, education and support of diabetes for youths in Manitoba, Canada.<sup>15</sup> Youth mentors in this program served as a source for information for young people and provided them with guidance, encouragement and emotional support.<sup>15</sup>
- Movin' On Up healthcare transition program dedicated a position which oversees interdisciplinary transition plans, provides education and coordinates services and referrals.<sup>24</sup> This study highlights the subjective and situational nature of individual experiences (of transition) and recommends a comprehensive approach to individual resilience when approaching transition.

### **Transition to independence process model**

A model designed to guide processes for coordinating efforts of various specialties and community institutions within three interacting domains: living conditions, educational opportunities and employment and career.<sup>20</sup>

- In one study, an individualised transition approach is used to identify public services needed to support young adults between 14 and 25 years with emotional and/or behavioural conditions to become self-sufficient.<sup>25</sup>
- Focus on the system and on bringing together different services and stakeholders to guarantee successful transition not only to adult services but to adult life.<sup>26</sup>

### **Medical home model for transition**

A model to promote transition to primary care for young people with autism.<sup>27</sup> A medical home provided by paediatric team, often saw older patients that hadn't transferred care. Physicians spent half-day in direct patient care and remaining half-day managing ongoing patient care issues.<sup>28</sup>

- Medical home and transition service used for youth with autism found youth with higher severity of autism used transition service less.

### **Templestar Transition Model of Care**

This is a three-tiered model of care comprising of adolescent groups, individual sessions and Saturday transition clinic.<sup>2</sup>

- Parents identify the need for transition to start as early as 12 years of age as it's not just a logical process, but a lengthy process that requires detailed planning.
- Parents and young people felt that it was about preparation as well as the logical transfer to adult services.

### **On Your Own Feet Ahead!**

A quality improvement program that implemented local interventions to improve transitional care in the identified areas of concern reported by patients and clinicians as bottlenecks to successful transition.<sup>29</sup>

- This study found significant improvement in patients' experiences with transition care, such as the provision of opportunities for adolescents to visit the clinic alone and to decide who should be present during consultations.<sup>29</sup>

### **Social-ecological model of adolescent and young adult readiness to transition (SMART)**

The model outlines 11 domains that contribute to a young adult's readiness to transition to adult care; seven of these are considered modifiable variables, and the other four are considered less amenable to change.<sup>30</sup>

- Providers perceived healthcare utilisation, quality of life, and continuing on a stable disease trajectory were important indicators of success.
- Facilitators were maturity and motivation, a trusting and engaged relationship with provider, as well as continuing family and parental support.
- Challenges to success were identified in areas of psychological wellbeing, stroke with neurocognitive defect (disease specific), communication and health literacy.

### **Framework for Understanding Mental Health Service Utilisation (FUMHSU)**

This framework stratifies youth with mental health disorders into different categories: continuous user, single gap user, multiple gap user, and discontinuer. Focuses on the individual and their expectation and management of transition.<sup>26</sup>

### **Transition Service Integration Model (TSIM)**

This model describes how three primary systems (special education, rehabilitation and developmental disability) contribute to the process and outcome of transition to adulthood for youth with moderate to profound intellectual disabilities.<sup>26</sup>

### **On TRAC**

A youth-focused and family-centred model through implementing stages of transition care, on the basis of the developmental stages and capabilities of each individual.<sup>15</sup>

- All steps of the program were flexible to meet the unique physical and cognitive abilities of each individual and family.<sup>15</sup>
- Covers all nine Society of Adolescent Health and Medicine transition principles.<sup>15</sup>

### **Good 2 Go**

A planned, systematic approach for a gradual shift in adolescent responsibilities.<sup>15</sup> This model has incorporated many elements of the On TRAC program and the shared management model, meeting all aspects of the Canadian Paediatric Society recommendations.

## Education programs

This model of care included workshops or education programs that are targeted at patients.<sup>31, 32</sup>

- One study showed significant improvement in self-efficacy and transition competence.<sup>32</sup>
- One study identified aspects patients would like included in education programs (peer support, vocational issues, disease knowledge, transfer to adult medicine, changes in patient-doctor relationship, detachment from parents, methods of transition).<sup>32</sup>

## Measures noted for transition outcomes include:

- Quality of life<sup>9, 30, 33</sup>
- Costs<sup>9</sup>
- Attendance at appointments<sup>9,34</sup>
- Follow up attendance at adult clinics<sup>16,15,12, 33</sup>
- Healthcare utilisation<sup>35, 30</sup>
- Patient characteristics<sup>35</sup>
- Patient satisfaction<sup>15</sup>
- Self-management skills<sup>15, 34</sup>
- Resilience<sup>36</sup>
- Disease burden on physical health<sup>36</sup>
- Disease burden on mental health<sup>36</sup>
- Satisfaction with life<sup>36</sup>
- Quantity of social support resources<sup>36</sup>
- Stable disease trajectory<sup>30</sup>
- Future orientation<sup>36</sup>
- Preparedness<sup>37</sup>
- Knowledge of illness and medications<sup>37</sup>
- Adverse effects of medications<sup>37</sup>
- University of North Carolina TRxANSITION Scale<sup>TM38</sup>
- Disease activity and status, primarily markers of disease control<sup>34,33</sup>
- Adherence to treatment<sup>33</sup>
- Patient and family experience.<sup>33</sup>

## The facilitators to successful transition of care

- Coordinated and tailored transitional care, delivered in partnership with healthcare professionals, young people and their families.<sup>13</sup>
- Direct communication between key participants (young person, family and carer, paediatric team, adult team).<sup>13</sup>
- Careful documentation in medical record.<sup>13, 15</sup>
- Regularly updated transition policies.<sup>13</sup>
- Clear description of multidisciplinary team members.<sup>13</sup>
- Appropriate training for healthcare workers in adolescent care.<sup>13</sup>
- An increased evidence base.<sup>13</sup>
- Involving young people in person-centred quality of planning and preparing them for the process of transition and changes in the environment.<sup>14, 29</sup> For vulnerable populations, such as people with intellectual disability, the presence of the young person in the planning meeting.<sup>39</sup>
- Supporting and preparing family of the young people for the transition.<sup>14</sup>
- Having a known, clear transition process.<sup>31</sup>
- Adolescent and adult clinic involvement in transition.<sup>40</sup>

## The challenges to successful transition of care

- Lack of the voice of young people: it is highly likely that their views will differ from the hard-quantitative data missing from the studies reviewed and that clinicians will value.
- Interactions that do not take into account a young person's needs or view can be frustrating for patient and families.
- There are still very few criteria established that address what a successful transition includes.<sup>11</sup>
- Continuity of multidisciplinary care, closer relationships between generalists and specialists, but without outcome measure to base this on.<sup>41</sup>

## Tools to aid the transition process

A variety of different tools were used throughout the literature to aid the transition process. They are:

- Transition Readiness Assessment Questionnaire (TRAQ)<sup>31, 42</sup>
- Irritable bowel disease (IBD) checklist<sup>3</sup>
- Talking mats<sup>43</sup>
- The HEMO-milestones tool<sup>44</sup>.
- The Self-Management and Transition to Adulthood with Rx= Treatment (STARx)<sup>42</sup>
- IBD Self-Efficacy Scale for Adolescents and Young Adults (IBDSES-A)<sup>21, 42</sup>
- Starin Questionnaire<sup>20</sup>
- Family Life questionnaire<sup>20</sup>
- Participant's rating form<sup>20</sup>

- Individualised transition plan with a focus on five goals: maximising education, bowel continence, and goals set by the spina bifida clinic coordinator, parent and carer, and patient<sup>45</sup>
- A structured form to be used during visits to ensure that all topics have been covered<sup>46</sup>
- Online healthcare transition planning tool that could be integrated onto electronic medical record. The resulting Transition Planning Tool is an assessment and education tool designed to facilitate healthcare transition over the course of clinic visits. The tool appeared to be useful and was adapted to maximise satisfaction among practitioners<sup>47</sup>
- Mind the Gap survey instrument and On Your Feet questionnaire.<sup>29</sup>

## Limitations

There is lack of high-quality studies such as randomised trials. Most of the studies were descriptive and not outcome focused. There are a variety of models and local jurisdictions and contexts that need to be considered in interpreting the results.

This evidence check was completed as a collaboration with ACI and partners. Title and abstract screening and full text data extraction were divided amongst team members with differing expertise in evidence synthesis. No quality checking of these processes was undertaken.

## Background

The Transition Indicators Project aims to improve service delivery for transition processes by providing data and information to inform evidence-based decision making and reporting and data capabilities. Key outputs for the project include an evidence review on models of transition and developing a suite of indicators to measure successful transition outcomes.

## Methods (Appendix)

PubMed was searched on the 17 March 2020. Search terms and inclusion criteria are included in the Appendix. 366 abstracts were found.

Six members from the Transition Indicators Working Group volunteered to participate in the evidence review. Their details are in Appendix 2. Each abstract was screened in the software Covidence independently by two of the six reviewers and either included or excluded against the inclusion criteria. Conflicts were resolved in consultation with a third independent reviewer. 144 articles were then left for full text review, of which 73 articles met the inclusion criteria and were included in the review. Another three articles were identified through reading reference lists. A total of 76 full text articles were included and data was extracted by the eight reviewers (approx. 11 per reviewer).

A summary of each of the full text articles is available in part 2 of this report.

## Appendix

### PubMed search terms

((("adult health care"[Title/Abstract] OR "adult care"[Title/Abstract] OR "adult service\*\*"[Title/Abstract])

AND (transition\*[Title]) OR (transfer\*[Title])) OR ("Transition to Adult Care"[Mesh]))

AND (Models, Organizational[MeSH] OR organizational innovation[MeSH] OR "Patient-Centered Care/organization and administration"[Mesh] OR Delivery of Health Care, Integrated[MeSH] OR "model of care"[tiab] OR "models of care"[tiab] OR "care model\*\*"[tiab] OR "care delivery model\*\*" [tiab] OR



“organisation of”[tiab] OR “organisational model\*”[tiab] OR “organisation model\*”[tiab] OR “organization of”[tiab] OR “organizational model\*”[tiab] OR “organization model\*”[tiab] OR “healthcare delivery model\*”[tiab] OR “integrated care”[tiab] OR “integrated model\*”[tiab] OR “multidisciplinary care”[tiab] OR “multidisciplinary management”[tiab])

**Filters:** English, from 2010 – 2020

366 results on 17 March 2020

### Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> <li>• Organisation models of care (the way care is delivered)</li> <li>• Any health indication or condition</li> <li>• 2010 onwards</li> <li>• Young people aged between 14 and 25 years</li> <li>• Models to transition from paediatric to adult health (the way care is delivered)</li> <li>• Both inter and intra transfer</li> </ul>	<ul style="list-style-type: none"> <li>• Non-systematic reviews, comments, editorials</li> <li>• Non-English language</li> <li>• No full text available</li> </ul>

### Reviewers

Reviewer	Role	Organisation
Abigail Alsop (for last reviews)	Project Manager, Priority Populations	Sydney Children’s Hospitals Network
Dani Feuerlicht	Youth and Diversity Manager	Sydney Children’s Hospitals Network
Rachael Havrlant	A / Network Manager, Transition Care	Agency for Clinical Innovation
Pamela Joseph	Lecturer	University of Sydney
Antonio Mendoza Diaz	Senior Research Officer, ICAMHS   Conjoint Lecturer, School of Psychiatry	South Western Sydney Local Health District   University of NSW
Samantha Mihailovich (for last reviews)	Project Officer, Trapeze	Sydney Children’s Hospitals Network
Kate Steinbeck	Medical Foundation Chair in Adolescent Medicine	Sydney Children’s Hospitals Network   University of Sydney
Nerida Walker	Project Officer Patient Report Measures	Agency for Clinical Innovation



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