

# Transition Models of Care

## ACI Transition Care Network

### Evidence check: Part 2

May 2022

### Summary of articles

Source	Summary
<p>Current practices and experience of transition of young people on long term home parenteral nutrition to adult services – a perspective from specialist centres</p> <p>Kyrana, et al (2016)<sup>1</sup> United Kingdom (UK)</p>	<ul style="list-style-type: none"> <li>• Questionnaire via Survey Monkey of 10 questions and sent via email to 170 gastroenterologist consultants in both paediatric and adult settings.</li> <li>• Paediatrics led transition.</li> <li>• Model was around transition clinic.</li> <li>• What worked well were joint clinics, orientation to the adult service. Checklist and competencies may assist in transition. Psychological support needed.</li> <li>• Outcome measures on feedback about clinic.</li> </ul>
<p>The Templestar Transitional Model of Care for epilepsy: the outcomes of a quality improvement project.</p> <p>Crowley, et al (2018)<sup>2</sup> Ireland</p>	<ul style="list-style-type: none"> <li>• Focus groups and questionnaire to survey 34 parents of young people with epilepsy on transitional and adolescent care.</li> <li>• Templestar Transitional Model of Care: three-tiered model of care (adolescent group, individual sessions outside of clinic, and a Saturday transition clinic).</li> <li>• Parents identify the need for transition to start at 12 years.</li> <li>• Paediatrics led transition.</li> <li>• Saturday clinic included patients and parents. The clinic was planned for a Saturday as the patients didn't want to miss out on anymore school, and parents didn't want to take any more days off work.</li> </ul>
<p>The genesis of systems of care for transition to adulthood services: emerging models in primary and specialist care.</p> <p>Wright et al (2018)<sup>3</sup> United States of America (USA)</p>	<ul style="list-style-type: none"> <li>• Effective Public Health Practice Project Quality Assessment Tool. Reviewed 200 peer-reviewed studies.</li> <li>• Provides a list of the emerging models of care for primary care and general care, transplant, diabetes, sickle cell, mental health.</li> <li>• Paediatrics led transition.</li> <li>• Primary health: six core elements, diabetes: tailored education sessions and one-on-one phone and web support over one year. Joint clinics in an adolescent and young adult space.</li> <li>• Transplant: multidisciplinary team (MDT) clinics, psychology led coordinators. European TRANSNephro Study.</li> </ul>

	<ul style="list-style-type: none"> <li>• Outcomes measured using the Delphi model: acceptability of quality of life, cost of resource, feasibility measure by attendance at medical appointments.</li> <li>• Identified that a navigator, nurse practitioner, social worker or program coordinator increases the effectiveness of the transition program due to difficulties in communication across multiple health care providers.</li> <li>• Encourages healthcare providers to start using emerging models of care that are currently being applied in the different specialties.</li> <li>• Transplants: less rejection of grafts compare to controls group.</li> </ul>
<p>From adolescents to adults with congenital heart disease: the role of transition.</p> <p>Moceri, et al (2014)<sup>4</sup> Germany</p>	<ul style="list-style-type: none"> <li>• Literature search using PubMed.</li> <li>• Identifies that transition should start in early adolescents (when they're starting to learn about their condition). Transfer at a higher range has better outcomes. The Transition Readiness Assessment Questionnaire (TRAQ) was used to gauge the transition readiness.</li> <li>• 76% of congenital heart disease patients were either lost to follow up or had a lapse in their care when leaving paediatricians. A structured education program (with a MDT) has assisted in a higher level of knowledge. Suggestion that a joint appointment with adult and paediatrician is also an option. Important to have a transition coordinator as they provide cohesion between paediatrician and adult physician. A detailed transfer letter from family and adult facility also required so that information is not lost. Congenital heart disease is different from other chronic diseases as the young person feels well and does not attend follow up.</li> <li>• Paediatrics led transition. Nurse-led transition interventions resulted in improvement in knowledge scores.</li> <li>• Transition process will help parents reduce their anxiety, prepare and adjust to this shift in responsibility.</li> </ul>
<p>Transition readiness in paediatric patients with inflammatory bowel disease: A patient survey of self-management skills.</p> <p>Whitfield, et al (2015)<sup>5</sup> USA</p>	<ul style="list-style-type: none"> <li>• This study was a cross-sectional survey involving a convenience sample of 69 patients aged 10–21 attending an outpatient paediatric gastroenterology appointment.</li> <li>• Use of a transition self-management checklist to determine readiness for transition.</li> <li>• The survey was created using Qualtrics (Provo, UT) survey software and administered via an iPad (Apple, Cupertino, CA) through a Qualtrics web link. The patient completed the survey on an iPad. The</li> </ul>

	<p>survey included questions on self-management of their medications, disease, etc.</p> <ul style="list-style-type: none"> <li>• Transition check used but they felt that it was the age of the young person, rather than the duration of the illness, that impacted readiness for transition. Majority were ready by 18 years of age.</li> <li>• Paediatric led transition.</li> </ul>
<p>Engagement and experience with cancer-related follow-up care among young adult survivors of childhood cancer after transfer to adult care.</p> <p>Szalda, et al (2015)<sup>6</sup> USA</p>	<ul style="list-style-type: none"> <li>• Young people were followed in a dedicated paediatric survivorship clinic and formally transferred to adult-focused, cancer-related follow-up care.</li> <li>• Outcome measures included follow-up appointment numbers in adult health after transition.</li> <li>• Half reported a cancer-related follow-up visit in the prior year, over one third of patients at risk of late effects and directed to continue cancer related follow-up are not receiving this care. Noted that the results showed a lack of understanding in the importance of follow-up care and that specific transition-readiness services weren't used. Formal transfer from a paediatric specialist to an adult provider may confer greater likelihood of engagement in the adult medical system.</li> <li>• Relied on patient report of healthcare utilisation. Self-report of healthcare utilisation in the past year may not be entirely accurate and biased.</li> <li>• Paediatric led transition.</li> </ul>
<p>An ecological approach to seeking and utilising the views of young people with intellectual disabilities in transition planning.</p> <p>Small, et al (2013)<sup>7</sup> UK</p>	<ul style="list-style-type: none"> <li>• Qualitative study with 43 young people with intellectual disabilities aged 14-22 years.</li> <li>• Individualised person-centred transition planning has not worked, and they offer an argument for using an ecological approach to seeking and using the views of young people with intellectual disabilities in transition planning as an alternative. Themes focused on relationships, family, support, educational and recreational activities, use of transportation and future wishes. The communication tool Talking Mats was adapted for this study.</li> <li>• Shows that the social networks of people with intellectual disability are limited. Transition planning appeared to be focused on shifts from school to college and then from college to day centres. Limited opportunities were considered and there was a sense that young people were placed according to what was available rather than according to their preferences. The lack of post-school option was a concern for many young people and their families. Young people with intellectual disabilities have limited social networks, limited involvement in mainstream activities and</li> </ul>

	<p>limited interaction with non-disabled peers. A reliance on the micro system as the person with intellectual disabilities gets older is vulnerable to parental illness and death. Countering this with an augmented and accessible meso-system will require additional support and better utilisation of resources.</p> <ul style="list-style-type: none"> <li>• Paediatric led transition.</li> </ul>
<p>Systematic Review of Medical Home Models to Promote Transitions to Primary Adult Health Care for Adolescents Living With Autism Spectrum Disorder.</p> <p>Rogers, et al (2015)<sup>8</sup> USA</p>	<ul style="list-style-type: none"> <li>• Systematic review.</li> <li>• Adolescents, in general, are a group less likely to achieve medical home attainment compared to other age populations. The vulnerable populations included youth who were minority, from low-income households, uninsured, from non-English speaking households where the survey respondent did have some college, and those living with a mental health condition including autism spectrum disorder. Lack of published research regarding effective healthcare transition models specific to adolescents with autism spectrum disorder who need to maintain a medical home into early adulthood.</li> <li>• Medical home – a regular source of primary care that is accessible, family-centred, continuous, comprehensive, coordinated and compassionate.</li> <li>• Usual care not defined and no comparative or meta-analysis was used.</li> </ul>
<p>A multicenter prospective quasi-experimental study on the impact of a transition-oriented generic patient education program on health service participation and quality of life in adolescents and young adults.</p> <p>Schmidt, et al (2015)<sup>9</sup> Germany</p>	<ul style="list-style-type: none"> <li>• Qualitative study.324 adolescents with diabetes, chronic fatigue and/or inflammatory bowel disease (IBD). Mean age 16.8 years.</li> <li>• A specialised two-day workshop was developed.</li> <li>• Repeated measurement covariance analysis, using age as a covariate, showed that the transition workshop significantly affected transition competence, self-efficacy and satisfaction with school care six months post intervention.</li> <li>• According to an analysis of covariance, subjects of the intervention group showed a highly significant improvement.</li> <li>• The change of outcome measures in the intervention group across all three points of measurement, self-efficacy and transition competence directly post-intervention showed a substantial increase.</li> <li>• Outcome measures:             <ul style="list-style-type: none"> <li>○ transition competence (TC) scale – TC-a work-related preparedness, TC-b condition-related knowledge, TC-c, healthcare competence</li> <li>○ patient activation measure (PAM-13)</li> <li>○ child healthcare global – satisfaction, utility and needs.</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>• The authors felt that the concept of transition and age are confounded. Recruitment also showed some bias in terms of clinical centres. Outpatient centres and two inpatient rehabilitation centres were included. Due to organisational restrictions in these inpatient centres, it was not possible to randomly assign patients to treatment groups.</li> <li>• Paediatric led transition.</li> </ul>
<p>Systematic review: Health care transition practice service models</p> <p>Betz, et al (2015)<sup>10</sup></p> <p>USA</p>	<ul style="list-style-type: none"> <li>• Systematic review of literature between 2004-2013. Process resulted in 17 articles being reviewed.</li> <li>• Provides an extensive table summarising the articles and models used in the articles. More helpful than reading the whole article as it is very complex.</li> <li>• Lack of rigorous research designs. Use of tools with weak psychometric properties, samples that lacked sufficient size for analysis, and interventions with insufficient description for replication.</li> </ul>
<p>Looking through the patient lens - improving best practice for young people with juvenile idiopathic arthritis transitioning into adult care.</p> <p>Howland, et al (2015)<sup>11</sup></p> <p>UK</p>	<ul style="list-style-type: none"> <li>• Qualitative interviews, with interpretive phenomenological analysis.</li> <li>• Focused on juvenile idiopathic arthritis. N = 18: 7 medical and allied health practitioners; 6 young people; 5 parents.</li> <li>• Three models described, with increasing number of transition steps: direct transfer, transitional period and patient orientated.</li> <li>• The measure of success was determined subjectively.</li> </ul>
<p>Implementation of an academic adult primary care clinic for adolescents and young adults with complex, chronic childhood conditions.</p> <p>Berens, et al (2015)<sup>12</sup></p> <p>USA</p>	<ul style="list-style-type: none"> <li>• Retrospective medical record review of 332 records from people with cerebral palsy, spina bifida, down syndrome, genetic conditions or autism. Age range 14 to 54 years old.</li> <li>• Transition medicine clinic – providing a medical home in the adult healthcare system. Led by paediatric medical team.</li> <li>• Patient characteristics demonstrated the unique challenges faced by the clinic. Transition medicine clinic patients saw an average of 3.8 specialists (no timeframe provided).</li> <li>• Wide age range (14–54 years) confirms that many older patients with chronic disease were still receiving care from their paediatrician.</li> <li>• Due to the amount of time and effort spent on coordination, physicians spend a half-day in direct patient care and the remaining half-day managing ongoing patient care issues.</li> <li>• Indicators used include healthcare utilisation and patient characteristics (primary and secondary diagnoses).</li> </ul>

<p>An assessment of the experiences and needs of adolescents with chronic conditions in transitional care: a qualitative study to develop a patient education programme.</p> <p>Bomba, et al (2016)<sup>13</sup> Germany</p>	<ul style="list-style-type: none"> <li>• Provided some useful information about the types of things young people would like covered in transition information.</li> <li>• Twenty-nine cross-sectional qualitative interviews, with people with type 1 diabetes, chronic fatigue and/or chronic IBD. Age range 15–27 years.</li> <li>• Existing experience of transition in both paediatric and adult systems. No specific model discussed.</li> <li>• Themes identified: peer support, future and vocational issues, disease knowledge, transfer to adult medicine, changes in doctor-patient relationship, detachment from parents, own health management and the health system, implementation and methods of the transition training.</li> </ul>
<p>A comparison of five transition programmes for youth with chronic illness in Canada.</p> <p>Grant et al (2011)<sup>14</sup> Canada</p>	<ul style="list-style-type: none"> <li>• Review and contrast of five programs: On TRAC model, Good 2 Go Shared Management Model, The Maestro Project System Navigator Model, The Be Your Own Boss program – Edmonton, Young Adults with Rheumatic Diseases clinic – Calgary.</li> <li>• On TRAC and Good 2 Go appeared to be the models which covered all of the Canadian Paediatric Society and Society of Adolescent Health and Medicine principles, but neither of these have had a formal review.</li> <li>• The Maestro program expressed less difficulties and frustrations in establishing regular follow-up with their adult healthcare team after transition and it showed a lowering of adult care dropout, from 40% to 11%.</li> <li>• These programs also produced significant reduction in health distress.</li> <li>• Has a helpful table where it shows what principles are included in each program, but paper is very brief. No numbers of participants as it is an overview and comparison.</li> <li>• Indicators used include drop out in follow-up in adult care, satisfaction, self-management skills.</li> </ul>
<p>Effective process or dangerous precipice: qualitative comparative embedded case study with young people with epilepsy and their parents during transition from children's to adult services.</p> <p>Lewis, et al (2013)<sup>15</sup> England and Wales</p>	<ul style="list-style-type: none"> <li>• Qualitative comparative embedded case study.</li> <li>• Thirty young people; 28 parents. Included 19 child/parent pairs. Sex or gender not stated.</li> <li>• Case 1: single-visit handover clinic, in adult out-patients clinic. Case 2: teenager clinic with individualised follow-ups, in children's outpatient clinic.</li> <li>• Most promising model of transition care was "a jointly-facilitated child/adult epilepsy clinic with a staged transition over many months and years with specific focus on the real problems and social realities of living with epilepsy from the perspective</li> </ul>

	<p>of the young person. Importantly, this model still respected parents as partners in their child's care, if that is what young people wanted." Appropriate service model and appropriate communication "interdependent active synergistic ingredients" influencing young people's behaviour.</p>
<p>Descriptive analysis and profile of health care transition services provided to adolescents and emerging adults in the Movin' On Up health care transition program.</p> <p>Betz, et al (2018)<sup>16</sup> USA</p>	<ul style="list-style-type: none"> <li>• Very comprehensive description, albeit with some significant limitations in transferability of findings. Limited applicability of some specifics to the Australian context (e.g. some results specific to Hispanic population). However, a useful discussion about limits of medical origins of transition care, considering the interconnections of young peoples' health and life needs, and findings support the importance of holistic and long-term approaches to transition.</li> <li>• Retrospective analysis of 146 health records of spina bifida patients.</li> <li>• Interdisciplinary model with transition occurring from early adolescence to early adulthood (10–20 years).</li> <li>• Transition led by advanced practice nurse.</li> <li>• Movin' On Up program. Domains are individual, healthcare system, environmental, and family or social support. Healthcare transition (HCT) specialist oversees interdisciplinary transition plan, provides education to young people and parents, and coordinates services and referrals.</li> <li>• Outcomes included: 41-item Spina Bifida Extraction Tool, plus four intervention categories of Omaha System (teaching, guidance and counselling; treatment and procedures; case management; surveillance).</li> </ul>
<p>Resilience and transitioning to adulthood among emerging adults with disabilities.</p> <p>Mannino (2015)<sup>17</sup> USA</p>	<ul style="list-style-type: none"> <li>• Convergent parallel mixed methods: quantitative measures, focus groups, and individual interviews. Quantitative strand: n = 31; focus group: n = 5; individual interviews n = 5.</li> <li>• Speaks directly to transitioning into adulthood, and indirectly to transition between healthcare systems. Highlights the subjective and situational nature of individual experiences (of transition) and recommends a comprehensive approach to individual resilience when approaching transition.</li> <li>• "Examining strengths within the individual and their environment, building upon those strengths, and developing new strengths will make the individual better equipped to deal with challenges as they are transitioning."</li> <li>• Outcomes included resilience; disease burden on physical health; disease burden on mental health;</li> </ul>

	<p>satisfaction with life; future orientation; quantity of social support resources.</p>
<p>Urologic provider experiences in transitioning spina bifida patients from paediatric to adult care. Agrawal, et al (2019)<sup>18</sup> USA</p>	<ul style="list-style-type: none"> <li>• Electronic survey of 79 urologists.</li> <li>• Demonstrated diversity in clinicians' views and practices. Supported need for continuity of multidisciplinary care, and closer partnerships between generalist and specialist clinicians, but without outcome measures to base this on.</li> <li>• The article considered urologists' perceptions of transition, not evaluation of an intervention model. Participants may not be representative. Patients' and others' perspectives not sought.</li> </ul>
<p>Transition care for adolescents from paediatric services to adult health services (Review). Campbell, et al (2016)<sup>19</sup> International</p>	<ul style="list-style-type: none"> <li>• Systematic literature review of four studies (N = 238 participants).</li> <li>• Four studies: two-day workshop, nurse-led 1:1 teaching session, web/SMS educational intervention and structured program with transition coordinator.</li> <li>• All four studies were randomised controlled trials. Control groups received usual care or other modified transitional-care model.</li> <li>• Note that study had very tight exclusion criteria and review is only of four heterogenous studies. Note also that the interventions of all four studies focused on young people, not on providers – interesting to ask Bacchi's question "What's the problem represented to be?" The finding that the four transition programs showed little difference between control and test groups should be interpreted in this light. There seemed to be some ambiguity about whether transition readiness referred to readiness to enter or complete the process of transition. The discussion of readiness on page seven suggests that transition readiness and transfer readiness have been conflated.</li> <li>• Page eight states primary outcome measure was disease-specific measurable or patient-reported outcomes. Page nine lists outcomes identified as secondary: transitional readiness, self-efficacy, disease-specific outcomes, wellbeing measures, knowledge of disease and treatment, use of health services, transfer from paediatric to adult services, use of healthcare resources.</li> <li>• No firm conclusions due to study limitations. Three studies indicated slight improvements in transition readiness. Possible slight improvement in young person's knowledge of their condition and use of health resources. No evidence of difference in health status, quality of life or wellbeing, transfer rates from paediatric to adult services.</li> </ul>



<p>Acute diabetes complications across transition from paediatric to adult care in Ontario and New Foundland and Labrador: A population-based cohort study.</p> <p>Shulman, et al (2020)<sup>20</sup> Canada</p>	<ul style="list-style-type: none"> <li>• Population-based cohort study, 2,618 young people with diabetes.</li> <li>• Useful information about the different cohorts, some of which may be relevant to Australian context. For example, one cohort had much lower rates of socioeconomic disadvantage, more rural population, less specialised transition and adult care model. Limited findings about transition models themselves.</li> <li>• Ontario: multiple specialist multidisciplinary centres. Paediatric clinicians transfer care by age 18. Diverse clinic-specific transition services. Newfoundland and Labrador: single tertiary care paediatric diabetes centre. Young adult clinic run by nurse practitioner, overseen by internist for young people in St John. No transition protocol for young people outside St John.</li> <li>• Outcomes included occurrence of diabetes complications.</li> </ul>
<p>Measuring the "Triple Aim" in transition care: A systematic review.</p> <p>Prior, et al (2014)<sup>21</sup> USA</p>	<ul style="list-style-type: none"> <li>• Systematic literature review of 33 articles.</li> <li>• Investigating the measures used to review models, not the models themselves. Very few studies addressed all three outcome measures: experience of care, population health and cost of care.</li> <li>• Very limited. It investigated measures used, rather than outcomes. However, tables 1 and 2 are comprehensive lists of the reviewed papers and might identify papers relevant to the study that have not previously been picked up in the search.</li> </ul>
<p>The medical home and health care transition for youth with autism spectrum disorder.</p> <p>Rast, et al (2018)<sup>22</sup> USA</p>	<ul style="list-style-type: none"> <li>• Retrospective analysis of survey results – 1,119 surveys with completed data on youth aged 12 to 17 years.</li> <li>• Medical home and HCT service: Discussing switch to doctor who treats adults; discussing changing healthcare needs as an adult; planning how to get or keep insurance cover as an adult; encouragement by doctor for child to take age-appropriate responsibility for own healthcare.</li> <li>• Greater receipt of HCT service for youth with a medical home. Youth with autism spectrum disorder did not receive HCT service at the same rate as peers with other special health care needs but likely to have greater need for these services. Youth whose parents reported lower levels of severity of autism spectrum disorder had higher receipt of HCT service, and youth with higher severity had lower rates of receipt of HCT service.</li> </ul>
<p>Transitioning adolescents and young adults with sickle cell disease from</p>	<ul style="list-style-type: none"> <li>• Provider opinion – semi-structured interview on sickle cell anaemia. Paediatric and adult providers. Only 13 recruited from 30 invited.</li> </ul>

<p>paediatric to adult healthcare: Provider perspectives.</p> <p>Stollon (2015)<sup>23</sup> USA</p>	<ul style="list-style-type: none"> <li>• Social-ecological Model of Adolescent and Young Adult Readiness to Transition. 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.</li> <li>• Interview. Healthcare utilisation, quality of life, and continuing on a stable disease trajectory were considered important indicators of success. Threats: socioeconomic status, psychological wellbeing, stroke with neurocognitive defect (disease specific); emergency department skills, communication and health literacy. Facilitators were maturity and motivation; a trusting and engaged relationship with provider; continuing family and parental support.</li> </ul>
<p>Gathering expert opinion to inform benchmarks to support transitional care.</p> <p>Aldiss (2019)<sup>24</sup> UK</p>	<ul style="list-style-type: none"> <li>• Qualitative study to identify a clinical practice benchmark 'tool'. Three groups involved: researchers and policy makers, healthcare providers involved in transition and youth. This only reports on the first group. 21 'diverse' experts – no further details.</li> <li>• This was a brainstorming approach in a workshop followed by focus groups to distil results as per stated aim.</li> <li>• Nothing particularly novel from brainstorming but table 1 is a very comprehensive list of possible benchmarking and practice areas. Overall view that low levels of funding and professional interest were real life barriers.</li> </ul>
<p>Bridging the gap: an integrated paediatric to adult clinical service for young adults with kidney failure.</p> <p>Harden, et al (2012)<sup>25</sup> UK</p>	<ul style="list-style-type: none"> <li>• Comparison between two models of care. 21 participants (11 female) ages 16 to 18.</li> <li>• Good, clear evidence for improvements when patients undergo supported transition.</li> <li>• Managed by a young adult clinical team comprising a nephrologist, transplant nurse specialist, youth worker, and pharmacist. The pathway involves joint medical clinics at the paediatric centres, including a paediatric nephrologist and paediatric renal transplant nurse specialist jointly working with an adult nephrologist and adult renal transplant nurse specialist.</li> <li>• 67% of the transplants were lost for those transitioning unsupported, versus 0% lost when patients underwent integrated transition.</li> <li>• The methodology was appropriate, but the historic control doesn't account for advancements in medicine that could account for some of the transplant losses.</li> </ul>

<p>A systematic review of the literature on ethical aspects of transitional care between child- and adult-orientated health services.</p> <p>Paul, et al (2014)<sup>26</sup> UK</p>	<ul style="list-style-type: none"> <li>• Systematic review on young people with mental health concerns.</li> <li>• Two models noted as potentially effective, the Partnerships for Youth Transition model and the Young Adult Service.</li> <li>• Informative in that it illustrates a lack of evidence and no standard evidence-based model.</li> </ul>
<p>Centre-Based Quality Initiative Targets Youth Preparedness for Medical Independence: HEMO-Milestones Tool in a Comprehensive Haemophilia Clinic Setting.</p> <p>Croteau, et al (2016)<sup>27</sup> USA</p>	<ul style="list-style-type: none"> <li>• Quality improvement study.</li> <li>• Transition process and HEMO-milestones tool implemented by MDT. Implement HEMO-milestones tool to assess transition readiness and areas to address for patient.</li> <li>• Facilitated by the development of the HEMO-milestones tool, this project succeeded in creating an environment where all providers were more diligent about discussing transition issues and providing both targeted education when needed and anticipatory guidance. The HEMO-milestones tool contains transition goals and milestones specific to patients with bleeding disorders, as well as other goals and milestones necessary to achieve. This feature enabled the researchers to cover essential transition topics for the patient population with one concise tool and improve clinician awareness of the need for specific educational materials during the comprehensive visit.</li> <li>• Determining the right age for initiating the transition discussion can be difficult, each patient and family progress at different rates in each area of competency. The team designed a transition approach to incorporate all ages in their care, from birth through transfer to adult care. In this way, they were able to recognise and help parents adapt not only to the adult care transition but also to early life transitions, such as starting school.</li> </ul>
<p>Transitional care of a childhood cancer survivor to adult services: facilitating the process of individual access to different models.</p> <p>Frey, et al (2016)<sup>28</sup> Europe</p>	<ul style="list-style-type: none"> <li>• Literature review.</li> <li>• Reviewed PubMed and Cochrane to look at publications of the last year's focus.</li> <li>• Discussion of some papers focused on: facilitating the process of transition for childhood cancer survivors, addressing some of the issues concerning the evaluation of transition processes and the possible criteria for these.</li> <li>• Shared care models between paediatric and adult after-care clinics are superior to the transferral to adult after-care clinics. The evaluation of the individual factors influencing a successful transition is important. There are still very few criteria established that address what a successful transition includes.</li> </ul>

	<ul style="list-style-type: none"> <li>• Apart from the extensive evidence in the literature, describing different guidelines and models, there is still uncertainty about the transition process itself including, what a successful transition looks like and what the criteria for evaluation are.</li> </ul>
<p>A transition care programme which improves diabetes control and reduces hospital admission rates in young adults with Type 1 diabetes aged 15-25 years.</p> <p>Holmes-Walker, et al (2007)<sup>29</sup> Australia</p>	<ul style="list-style-type: none"> <li>• Quality assurance activity.</li> <li>• Between July 2001 and March 2006, 191 young adults with diabetes aged 15–25 years had registered with the program and had attended at least one appointment at the young adult clinic.</li> <li>• Led by a single transition coordinator and qualified diabetes educator. The program consisted of a reminder system for appointments, rebooking of missed appointments and an after-hours phone support service for sick day management.</li> <li>• The aims of the program were to improve specialist clinic attendance after leaving paediatric services, improve glycaemic control and reduce admissions to hospital with diabetic ketoacidosis.</li> <li>• The transition support program has resulted in improvement in diabetes care for young adults with type 1 diabetes. Clinic attendance rates show 82% have attended a specialist appointment in the last 6 months and a further 12% have been seen in the last 12 months. Glycaemic control has improved with a fall in HbA1c of 0.13% per visit for the first four visits. There was a significant reduction in admissions with diabetic ketoacidosis during the program.</li> </ul>
<p>Improving the transition between paediatric and adult healthcare: a systematic review.</p> <p>Crowley, et al (2011)<sup>30</sup> UK</p>	<ul style="list-style-type: none"> <li>• A systematic literature review in July 2010 of studies which consistently evaluated health outcomes following transition programs, either by comparison with a control group or by measurement pre-intervention and post-intervention.</li> <li>• Focused on medical outcomes rather than transition-based outcomes. All six interventions that resulted in significant improvements were in studies of patients with diabetes mellitus, with glycosylated haemoglobin level, acute and chronic complications, and rates of follow-up and screening used as outcome measures.</li> <li>• Ten studies met the inclusion criteria, six of which showed statistically significant improvements in outcomes. Descriptive analysis identified three broad categories of intervention, directed at: the patient (educational programs, skills training); staffing (named 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). The conditions</li> </ul>

	<p>involved varied (e.g cystic fibrosis, diabetes mellitus), and outcome measures varied accordingly. The most commonly used strategies in successful programs were patient education and specific transition clinics (either jointly staffed by paediatric and adult physicians or dedicated young adult clinics within adult services).</p>
<p>We suffer from being lost: Formulating policies to reclaim youth in mental health transitions. Vloet, et al (2011)<sup>31</sup> Canada</p>	<ul style="list-style-type: none"> <li>• Thematic analysis: evidence and policy review on youth mental health.</li> <li>• Three approaches were considered and thematic analysis applied. Prospective recommendations for developing a shared care model to then test.</li> <li>• No youth were consulted on the model.</li> </ul>
<p>Transition to adult services for children and young people with palliative care needs: a systematic review. Doug, et al (2009)<sup>32</sup> UK</p>	<ul style="list-style-type: none"> <li>• Ninety-two studies included. Papers on transition, no standardised transition program identified and most guidelines used to develop transition services were not evidence-based. Most studies on transition programs were condition specific.</li> <li>• Identified was evidence of poor continuity between child and adult providers, with most originating from within child settings.</li> <li>• Supports the addition of support workers for transition. Recommends use of validated outcome measures to facilitate research and service development.</li> </ul>
<p>Can a transition clinic bridge the gap between paediatric and adult inflammatory bowel disease care models? Nardonne, et al (2020)<sup>33</sup> Canada</p>	<ul style="list-style-type: none"> <li>• Systematic review – reviews multiple models and risk assessment for transition.</li> <li>• Timing of transfer cannot be predefined as it is not a question of chronological age and it depends on the achievement of maturity of each individual.</li> <li>• Recommends transition during remission for conditions specific cohort.</li> <li>• The Transition Readiness Assessment Questionnaire (TRAQ) widely used but not validated at the time of review (2020), summarises The Self-Management and Transition to Adulthood with Rx= Treatment (STARx) and IBD Self-Efficacy Scale for Adolescents and Young Adults (IBDSES-A).</li> </ul>
<p>The Guided Transfer of care improves adult clinic show rate. Lal, et al (2019)<sup>34</sup> USA</p>	<ul style="list-style-type: none"> <li>• Prospective non-randomised cohort study. Thirty-six patients aged 16-26 years.</li> <li>• Combined paediatric and adult led. Combined clinic with an endocrinologist who is able to see both paediatrics (late teens) and adults to assist with continuum of care.</li> <li>• Traditional transfers from paediatric to adult care were unsuccessful compared to guided transfers.</li> </ul>

	<ul style="list-style-type: none"> <li>• Outcome measured on the number of patients attending their first two adult endocrinology appointments.</li> <li>• Limitation included only having one paediatric or adult endocrinologist available. Subjects were not randomised. Gender, ethnicity and insurance type weren't ruled out. Guided transfer only available to those who stayed in the same healthcare system.</li> </ul>
<p>Perceptions of family environment and wrapped processed: associations with age and implications for serving transitioning youth in systems of care.</p> <p>Haber, et al (2012)<sup>35</sup> USA</p>	<ul style="list-style-type: none"> <li>• Archival research based on two evaluations: Family Environmental Study and Wraparound Processes Study. 256: 10–12 years, 13–14 years, 15 years and 16–17 years.</li> <li>• The wraparound team support the family and young person during their transition phase. Did not mention a control group.</li> <li>• Greater efforts need to be made to support the carers to reduce their strain as this could reduce the motivation for carers to participate in teams, enhance youth relationships with other team members (e.g. support networks). Youth need to be given a voice.</li> <li>• Outcomes based on scores provided from the carer: Starin Questionnaire, Family Life questionnaire and Participant's rating form.</li> <li>• Limited number of participants over 17 years available. Wraparound would not work in families where there are relationship strains or disengaged.</li> </ul>
<p>Transition from paediatric to adult diabetes care: smooth or slippery.</p> <p>Beaufort, et al (2009)<sup>36</sup> Poland</p>	<ul style="list-style-type: none"> <li>• Questionnaires (21 items) sent to diabetes healthcare professionals in 36 countries via email. A follow up email was sent four months later. The questionnaire included some transition questions. 578 members of International Society of Paediatrics and Adolescent Diabetes. 2/3 were physicians and the rest were other health care professionals. 16% (92) of those responded to the survey.</li> <li>• Comparison between structured transition programs compared to informal programs.</li> <li>• Half of those who responded said they already had a structured transition program in place. A review of the results showed that most paediatric centres lacked a structured program. If they do exist, they occur at the local level and are limited to informal, personal contact between centres. Adolescent and young adults require a specific approach to support their transition. Early joint clinics, MDT, promotion of self-management with a long, planned process would be accompanied by a written plan. Also wise for paediatric team to collaborate with adult teams who understand and enjoy this population.</li> </ul>

	<ul style="list-style-type: none"> <li>Limited sample and sample size, with some not responding to the questionnaire.</li> </ul>
<p>Impact of a transition program with navigator on loss to followup, medication adherence, and appointment attendance in haemoglobinopathies.</p> <p>Allemang, et al (2019)<sup>37</sup> Canada</p>	<ul style="list-style-type: none"> <li>Retrospective observational study. One year prior to transition (18 years) and one year post transition.</li> <li>Model of Improvement Framework. Cross-appointed transitional coordinator led who was with joint paediatric and adult clinics. A dedicated transition clinic was held monthly on the paediatric campus for those aged 18 years.</li> <li>Transition-readiness assessment used to gauge, but transition started at 12 years.</li> <li>Clinics (23 in total) with operational paediatric transitional navigator were assessed and yielded positive results. Improved adult clinic attendance, improved medication adherence, reduced loss in follow up, reduced wait time between paediatric and adult appointment, improved patient satisfaction. Involvement of the transitional navigator for one year post transition was very important to support the young person.</li> <li>Control – pre-transitional navigator transition patients. These patients had a structured program.</li> <li>Transition with a transitional navigator decreased the level of loss to follow up from 29% to 7%. No difference between admission between the groups noted.</li> </ul>
<p>Transition of management of patients with IBD.</p> <p>Ziesler, et al (2014)<sup>38</sup> USA</p>	<ul style="list-style-type: none"> <li>Summary document and literature review of transition for IBD patients, start at 10 to 12 years with final stages at 18 to 23 years. To advocate for transition programs to shift the responsibility from the parent to patient.</li> <li>79% of UK gastroenterologists felt that their patients were not ready for transition. A number of studies demonstrate that there are gaps in knowledge for transitioned patients live medical treatment and illness. USA gastroenterologists also found that there was a lack of preparedness of newly-transitioned patients.</li> <li>Outcomes – preparedness, knowledge of illness and medications, adverse effects of medication.</li> </ul>
<p>Parent-perceived Facilitators in the Transition of Care for Young Adult Survivors of Childhood Cancer.</p> <p>DiNofia, et al (2017)<sup>39</sup> USA</p>	<ul style="list-style-type: none"> <li>Exploratory study: descriptive cross-sectional survey study – 41 responses to 123 surveys.</li> <li>Study examined young people and family wants around transition in oncology.</li> <li>A notable difference between survivor and parent responses was the importance of “including parents as a central role in survivorship care.” Only 43% of survivors reported parental inclusion as “very</li> </ul>

	<p>important” in their decision to transition care compared with 83% of parents.</p> <ul style="list-style-type: none"> <li>• An overwhelming majority of participants (93%) reported having an understanding of the need for long-term follow-up care.</li> <li>• Seventy-five percent reported being aware of their child’s specific risks for long-term complications, whereas 95% reported having at least “some awareness”.</li> <li>• When participants were asked if they were willing to transition their child’s survivorship care from paediatric to adult care settings, 74% of parents responded affirmatively, 18% said “it does not matter,” and 8% responded negatively.</li> </ul>
<p>Epilepsy in transition from child care to adult service: a missing link in sub-Saharan Africa.</p> <p>Adebiyi, et al (2016)<sup>40</sup> Africa</p>	<ul style="list-style-type: none"> <li>• Literature searches and interviews with adolescent patients attending the adult neurology clinic at the University College Hospital, Ibadan.</li> <li>• Two-pronged approach to transition of care for epileptic patients is suggested. The first is the well-known hospital-based care involving child and adult neurologists, with the other one being a community based one where workers support and visit families at home.</li> <li>• Identified that most referrals made when patient are aged 15-18 years.</li> <li>• Transition of care articles in epilepsy were only available from South Africa.</li> <li>• Two-pronged approach to transition of care for epileptic patients is suggested but the use of community health extension workers is recommended.</li> <li>• Patients interviewed were concerned that insufficient information was provided by healthcare provided on epilepsy and on stigmatisation by peers.</li> <li>• Significant limitations in study. Method not adequately described for either review or interviews. Only one database was searched. Results not described in sufficient detail. Number of interviews not provided, nor participant characteristics. Nil inclusion or exclusion criteria stated for either literature search or interviews.</li> </ul>
<p>A chronic care model for spina bifida transition.</p> <p>Fremiona, et al (2017)<sup>41</sup> USA</p>	<ul style="list-style-type: none"> <li>• Commentary.</li> <li>• Transition needs for adolescents and young adults with spina bifida:             <ul style="list-style-type: none"> <li>○ designated transition program</li> <li>○ beginning transition plans between 12 to 14 years</li> </ul> </li> </ul>



	<ul style="list-style-type: none"> <li>○ including up-to-date medical summary, insurance coverage plan and care provider list in transition plan</li> <li>○ incorporating adolescent views and preferences</li> <li>○ interviewing adolescent alone for portion of visit</li> <li>○ identifying adult providers</li> <li>○ self-management and healthcare navigation coaching</li> <li>○ flexible transfer timing based on patient situation</li> <li>○ preventative care throughout transition.</li> <li>● A spina bifida-specific transition clinic based on the chronic care management model facilitates the complex chronic care management and transition planning for adolescents and young adults with spina bifida.</li> <li>● Very low-quality study design. Large potential for bias.</li> </ul>
<p>Clinical outcomes post transition to adult services in young adults with perinatally acquired HIV infection: mortality, retention in care and viral suppression.</p> <p>Foster, et al (2020)<sup>42</sup> UK</p>	<ul style="list-style-type: none"> <li>● Retrospective database and electronic record review of all young adults living with perinatal HIV who ever attended the service between January 2006 and December 2017.</li> <li>● 180 young adults living with perinatal HIV registered between 1 January 2006 and 31 December 2017 contributed 921 person-years of follow-up post transition to adult services.</li> <li>● Youth Friendly Service with multidisciplinary care and walk-in access. Of 180 youth registered, four (2.2%) died, 14 (7.8%) transferred care and four (2.2%) were lost to follow up. For the 158 retained in care:             <ul style="list-style-type: none"> <li>○ The median age was 22.9 years [interquartile ranges (IQR) 20.3–25.4]</li> <li>○ 56% were female</li> <li>○ 85% Black African</li> <li>○ A median length of follow-up in adult care of 5.5 years (IQR 2.9-7.3).</li> <li>○ 57 (99.4%) ever received an antiretroviral therapy prescription 127/157 (81%) with a latest HIV-viral load less than 200 copies RNA/ml, median CD4p cell count of 626 cells/ml (IQR 441–820).</li> <li>○ The all cause mortality was 4.3/1000 person-years [95% confidence interval (CI) 1.2–11.1], 10 fold the aged-matched UK HIV-negative population [0.43/1000 person-years (95% CI 0.41–0.44)].</li> <li>○ Post transition, 17/180 (9.4%) developed a new AIDS diagnosis; crude incidence rates 18.5/1000 person-years (95% CI 10.8–29.6).</li> </ul> </li> </ul>

	<ul style="list-style-type: none"> <li>Data suggest that tailored multidisciplinary youth friendly service with open drop-in access may facilitate retention in care.</li> </ul>
<p>EULAR/PReS standards and recommendations for the standards of transitional care of young people with juvenile onset rheumatic diseases.</p> <p>Foster, et al (2016)<sup>43</sup> Europe</p>	<ul style="list-style-type: none"> <li>Five-step consensus process, to develop standards. Systematic literature review published elsewhere (Clement, Leon, Foster et al, ref #42 in article's reference list).</li> <li>195 adult and paediatric rheumatology clinicians received e-survey. Survey comprised statements requiring responses on a 10-point Likert scale. Statements were derived from two meetings of an expert panel made up of clinicians and patient representatives (young people).</li> <li>Network approach to transition, comprising paediatric and adult healthcare providers, young person, and their family.</li> <li>Ideal age for transition – recommends 11 years (ideal) by 14 years (essential) or at time of diagnosis if older.</li> <li>A table of 12 recommendations, standards and quality indicators, including “essential/minimal” and “idea/optimal” components.</li> </ul>
<p>Transition to adult care in young people with neuromuscular disease on non-invasive ventilation.</p> <p>Onofri, et al (2019)<sup>44</sup> UK &amp; Italy</p>	<ul style="list-style-type: none"> <li>Retrospective comparative study – 30 records (15 Italy, 15 UK).</li> <li>Transition model                         <ul style="list-style-type: none"> <li>Italy: ongoing care by paediatrician.</li> <li>UK: paediatric to adult services within same heart and lung hospital, plus external neuromuscular specialist.</li> </ul> </li> <li>Of some interest, but limited. Descriptive of differences and similarities between two very different approaches in two different populations, thus limited ability to extrapolate findings. Conclusion is general: transition is complex and multidisciplinary and needs more research.</li> </ul>
<p>Perceived burden and neuropsychiatric morbidities in adults with 22q11.2 deletion syndrome.</p> <p>Karas, et al (2014)<sup>45</sup> Canada</p>	<ul style="list-style-type: none"> <li>Mail survey with quantitative and qualitative analysis with 53 carers; 20 adults with 22q11.2DS.</li> <li>Results mostly not directly relevant to transition. No data on transition. However, one section focuses on “transition services” (pp.8-9): finding of widespread dissatisfaction with transition services.</li> <li>Recommends syndrome-specific transition services but does not provide data to support this. This section of the paper focuses on reporting other literature on this topic.</li> </ul>
<p>Transition of patients with childhood onset epilepsy: Perspectives from paediatric and adult neurologists.</p>	<ul style="list-style-type: none"> <li>Survey of paediatric and adult neurologists if they had experience of transition care.</li> </ul>

<p>Nabbout, et al (2020)<sup>46</sup> France</p>	<ul style="list-style-type: none"> <li>• Not a single model provided; opinion and experience.</li> <li>• Eighty-one percent of child neurologists and 55% of neurologists worked together through an identified paediatric–adult network within their institutions (<math>p = 0.027</math>). Five had worked within a transition program and 20% and 12% of paediatric and adult neurologists respectively had read transition guidelines.</li> <li>• Not relevant in this evidence check under the criteria as it is not describing a transition model or indicators.</li> </ul>
<p>Adolescents with Chronic Kidney Disease: Transition to Adult Care Program Development; English speaking participants ages 15-23 with a diagnosis of CKD stage <math>\geq 3</math> or status post renal transplant. Hill, Tamara (Dissertation) (2017)<sup>47</sup> USA</p>	<ul style="list-style-type: none"> <li>• Program development – Thesis. HCT supported by middle range transition theory.</li> <li>• <math>N = 19</math> 16–27 years. Average age of the participant was 20 years old. 54% females, 47% males.</li> <li>• Nurse led transition in paediatrics. Three stages: recruitment, establishing a personal plan and education, meeting new nephrologist, skill acquisition. Needed to score over 85% on transition-readiness tool.</li> <li>• The sub-scales that had the highest correlation coefficients with the total score were found to be statistically significant with strong positive relationships to their domains:             <ul style="list-style-type: none"> <li>○ Self-management (<math>N = 19, r = 0.914, p(N = 19, r = 0.914, p &lt; 0.01, \text{two-tailed})</math>)</li> <li>○ Insurance (<math>N = 19, r = 0.830, p &lt; 0.01, \text{two-tailed})</math>)</li> <li>○ School (<math>N = 19, r = 0.818, p &lt; 0.01, \text{two-tailed})</math>).</li> </ul> </li> <li>• Four participants transitioned with a passport and having achieved 85% score.</li> <li>• Outcomes used: Renal function; University of North Carolina TRxANSITION Scale™. This scale has ten comprehensive areas (sub-scales): 1) type of illness, 2) Rx=medications, 3) adherence, 4) nutrition, 5) self-management, 6) informed-reproduction, 7) trade/school, 8) insurance, 9) ongoing support and 10) new healthcare provider. Disease neutral.</li> <li>• Pre and just prior tests were done but not all participants were transitioned (4 of 19) which limits conclusion.</li> </ul>
<p>Improving the Transition from Paediatric to Adult Diabetes Healthcare: A Literature Review. Wafa (2015)<sup>48</sup></p>	<ul style="list-style-type: none"> <li>• Variable study design. Included if transition care models were evaluated but accepted any evaluation rather than defining success. Type 1 diabetes mellitus was the focus of 12 studies.</li> <li>• Multiple majority retrospective studies.</li> <li>• Outcomes used: Primarily markers of disease control, self-management procedures, clinic visit.</li> </ul>

	<ul style="list-style-type: none"> <li>• In study order:             <ol style="list-style-type: none"> <li>1. Patients in the structured transfer program had a shorter gap between the last paediatric and first adult visit, better clinic attendance, lower A1C levels and reported better transition experience compared to the unstructured transfer patients.</li> <li>2. 7% of patients were lost to follow up versus 24% in a historical comparison group.</li> <li>3. Among patients who attended the young person’s clinic, there was lower clinic nonattendance (12% versus 24%), lower mean A1C (8.4% versus 9.5%), higher rates of blood pressure monitoring (100% versus 88%), higher rates of screening for nephropathy and lower rates of nephropathy.</li> <li>4. 82% of program participants attended clinics in the last six months. A1C decreased by 0.13% per visit; over 1st 4 visits diabetic ketoacidosis admission rates decreased by 1/3 (incidence density ratio 0.62, p&lt;0.05).</li> <li>5. Attendance in Saturday clinics twice as likely to be better compared to weekday clinics.</li> <li>6. Falling attendance varied between health districts.</li> <li>7. Young adult clinic patients within the highest tertile of HbA1c had the largest decrease.</li> <li>8. Patients with lower A1C levels, those using an insulin pump or multiplexity injections, patients with greater paediatric physician visits and those who asked questions during the diabetes transition clinic visit were more likely to attend clinic visits in adult care.</li> <li>9. Patients transferred to a new physician were four times more likely to be hospitalised after transfer compared to those with no change in physician.</li> </ol> </li> </ul>
<p>“It’s Just Going to a New Hospital I That’s It.” Or Is It? An Experiential Perspective on Moving From Paediatric to Adult Cancer Services.</p> <p>McCann (2013)<sup>49</sup> Scotland</p>	<ul style="list-style-type: none"> <li>• Qualitative case control; pre-transition and post transition groups. 12 (plus parent or carer who was interviewed separately); 17-25 years; pre female /male 3:3; post 4:2.</li> <li>• Comments suggesting that preparation and meeting the adult team made the process better.</li> </ul>
<p>Linking user and staff perspectives in the evaluation of innovative transition projects for youth with disabilities.</p> <p>McAnaney (2016)<sup>50</sup> Ireland</p>	<ul style="list-style-type: none"> <li>• Program evaluation. 39 in the program mean age 24.5 Male:Female 25:14; 19 not mean age.</li> <li>• Intervention not primarily related to health, more readiness for life.</li> <li>• Physical health no difference, quality of life improved p=0.05.</li> </ul>

	<ul style="list-style-type: none"> <li>The relevance of this study is questionable in this context.</li> </ul>
<p>Uncharted Territory: Systematic Review of Providers' Roles, Understanding, and Views Pertaining to Health Care Transition.</p> <p>Nehring (2015)<sup>51</sup> USA and other countries</p>	<ul style="list-style-type: none"> <li>Not informative – other than to point to future research directions.</li> <li>Systematic review of articles on providers published between 2005–2015. "This systematic review is designed to answer the following questions pertaining to HCT of adolescents, emerging adults - special health care needs: 1) What is the state of the HCT science pertaining to the role of providers involved in this specialty area of practice? 2) What research problems or questions have been investigated pertaining to providers involved with HCT? 3) What evidence has been generated that can be applied to improve the HCT training or service competencies of paediatric and adult health care professionals? and 4) What evidence can be applied to the provision of CT services for AEA-SHCN?"</li> <li>Research question 1-3 not applicable.</li> <li>Q4 evidence or lack thereof: Need longitudinal studies post transfer; scales based upon providers' assessments of functional and clinical outcomes are needed that can be used to triangulate with other measurements used, such as biophysiological metrics (i.e. HbA1c), clinical data (i.e. avoidable hospitalisations) and self-reports.</li> </ul>
<p>Patients with juvenile idiopathic arthritis become adults: the role of transitional care.</p> <p>Conti (2018)<sup>52</sup> International</p>	<ul style="list-style-type: none"> <li>Non-systematic review which considers transition to adult care as just one aspect (much devoted to change in the disease process). From Table 2, which describes various models, there are statements which record the preferred transfer time (end of high school), when all parties agree the individual is developmentally mature, and indicators of success (seen adult provider twice) and then this statement: "Among the potential indicators of a 'successful' transition, clinical parameters (disease activity and status), adherence to treatment and attendance of adult healthcare as well as patient and family experience, work achievements and quality-of-life measures should be included. Some authors indicate that the 'patient not lost to follow-up' is the most important indicator of a positive outcome". Overall quality of data was considered poor by the authors.</li> </ul>
<p>What Care Models Have Generalists Implemented to Address Transition from Paediatric to Adult Care?: a Qualitative Study.</p>	<ul style="list-style-type: none"> <li>Qualitative study of generalist physicians in the American context. This appears to be more primary care. Nineteen providers – 25 invited and 17 completed – selected by first authorship.</li> </ul>

<p>Hart (2019)<sup>53</sup> USA</p>	<ul style="list-style-type: none"> <li>• Four models described: 1. primary care for adults with childhood-onset conditions, within adult-oriented primary care practices, 2. mix of transition support and primary care in paediatric settings, 3. bridge program consisting of paediatric and adult-oriented components, 4. consultative transition support service based in an adult oriented health care setting.</li> <li>• Two suggestions were peer involvement in the process and ensuring that they book a follow-up appointment to check that the transition-relevant appointments had been kept.</li> </ul>
<p>Identifying metrics of success for transitional care practices in childhood cancer survivorship: A qualitative study of survivorship providers. Sadak, et al (2017)<sup>54</sup> USA</p>	<ul style="list-style-type: none"> <li>• Qualitative study to identify transition indicators using phone interviews. Twenty-nine purposively sampled health providers (all invited accepted) who work with an established transition care model.</li> <li>• Assumption that the providers were familiar with general transition procedures.</li> <li>• There were two main themes identified:             <ul style="list-style-type: none"> <li>○ RIm</li> <li>○ Model of care must include well-established provider partners throughout the healthcare system.</li> </ul> </li> <li>• The bias that runs through many of these studies is speaking to the converted, if you only talk to experts. Little consideration of the youth voice. Difficulty in translating themes into measurable outcomes.</li> </ul>
<p>Adolescents with HIV and transition to adult care in the Caribbean, Central America and South America, Eastern Europe and Asia and Pacific regions. Bailey (2017)<sup>55</sup> International</p>	<ul style="list-style-type: none"> <li>• Review (not systematic), only used PubMed from health databases but did consider grey literature.</li> <li>• Basically, this study focuses on very medical issues but does not have the data to report how these might relate to predicting transition outcomes. These outcomes more likely reflect service capacity and lack of defined pathways.</li> <li>• "We focused on studies exploring outcomes following transition to adult care (including clinical or immunological /virological outcomes, anti-retro-viral resistance, loss to follow up, death). Due to the paucity of data on post-transition outcomes, we also describe published data on characteristics and health status of young people as they approach age of transition, as a key determinant of health in early adulthood, and information available on current transition processes, to give insight into future research priorities."</li> <li>• This is a snapshot study making the most of what literature is available rather than using quality studies. Despite its title it is a scoping study.</li> </ul>

<p>The journey for adolescents and young adults with chronic conditions transitioning to adult care with successful warfarin management</p> <p>Bauman, et al (2016)<sup>56</sup> Canada</p>	<ul style="list-style-type: none"> <li>• Pre and post- comparison of adolescents and young adults requiring indefinite warfarin therapy within a structured self-management program.</li> <li>• Model is KIDCLOT (transition policy including warfarin self-management); based on client learning.</li> <li>• No difference in median knowledge scores. Significant difference in the number of international normalised ratio tests performed. All 19 patients continued to attend appointments with adult providers.</li> </ul>
<p>Movin' On Up: An Innovative Nurse-Led Interdisciplinary Health Care Transition Program.</p> <p>Betz, et al (2015)<sup>57</sup> USA</p>	<ul style="list-style-type: none"> <li>• Descriptive study – Movin' Up: integrated HCT program.</li> <li>• Movin' Up: (a) HCT nursing specialist, (b) interdisciplinary HCT plans, (c) interdisciplinary HCT team, (d) direct HCT services, (e) telephone follow ups.</li> <li>• Outcomes were not captured as part of this descriptive study. However, they talk about the complexities of measuring transition and discuss capturing outcomes such as bowel and/or bladder continence, avoidable hospitalisation, and emergency department visits. Acknowledges the need for outcomes that capture biopsychosocial dimensions, not just physiology.</li> </ul>
<p>The epilepsy transition care gap in young adults with childhood onset epilepsy.</p> <p>Baca et al (2018)<sup>58</sup> USA</p>	<ul style="list-style-type: none"> <li>• Descriptive within a longitudinal cohort. 308 (mean 24; SD = 4) 51.3% male (158).</li> <li>• A specific model was not tested, rather they assessed whether this sample had experienced transition-change discussions.</li> <li>• Of the cases 15% reported having a transition discussion prior to leaving paediatric care. Those with "active" epilepsy were more likely to have had transition discussions (31%), with those who had completed college education or those with neurodevelopmental spectrum disorders most likely not to have had these discussions. Not having transition discussions was associated with different care pathways afterwards.</li> </ul>
<p>Transition of paediatric to adult care in inflammatory bowel disease: Is it as easy as 1, 2, 3?</p> <p>Afalzi, et al (2018)<sup>59</sup> USA</p>	<ul style="list-style-type: none"> <li>• Described the development of a program, did not evaluate it. Doesn't advocate for a specific model, but discusses two frameworks: Escher JC and the SMART Model (Schwartz and colleagues).</li> <li>• Didn't use these questionnaires, but they mentioned: Transition Readiness Assessment Questionnaire; the Morisky Adherence Scale; Seattle Children's Hospital readiness to transition tool; Patient Health Questionnaire-9 for depression.</li> <li>• No results were presented. Descriptive paper only.</li> </ul>

<p>Development of an evidence-based individualized transition plan for spina bifida.</p> <p>Hopson, et al (2019)<sup>60</sup> USA</p>	<ul style="list-style-type: none"> <li>• Retrospective analysis of individualised transition plans – 32 participants (50% female), mean age of 16.4 years.</li> <li>• Individualised transition plan focuses on five goals: maximising education, bowel continence, and goals set by the spina bifida clinic coordinator, parent and/or carer, and patient.</li> <li>• The article focused on whether patients had progressed in achieving the five goals they had set out to achieve, and it seems like they had.</li> <li>• It was unclear whether baseline measures had been collected. The study did not report on standardised outcome measures.</li> </ul>
<p>Implementation of a transition model to adult care may not be enough to improve results: National study of kidney transplant recipients.</p> <p>Kosola, et al (2018)<sup>61</sup> Finland</p>	<ul style="list-style-type: none"> <li>• Compared outcomes in a longitudinal study before and after a transition model was implemented.</li> <li>• Referrals to adult care – 132 (54 before, 78 after). Cohort 1: 74% male, cohort 2: 65% male.</li> <li>• Patients attended an outpatient transition clinic, preparing to take responsibility for their transition. The goals are that at transfer, adolescents: are familiar with their condition and course of illness; know the effects and possible side effects of their medications; understand the importance of control visits; have some knowledge of their future outcome. Also issues relevant to all adolescents such as substance use, sexual health, and fertility are discussed. A structured form is used during visits to ensure that all topics have been covered. A paediatrician meets patients alone for part of the appointment to support self-management from an early age. Family members are also prepared for transition. An adolescent psychiatrist and a social worker are an integral part of the transition team.</li> <li>• Overall patient and graft survival were similar before and after the implementation of the transition model.</li> </ul>
<p>Preventing Youth from Falling Through the Cracks Between Child/Adolescent and Adult Mental Health Services: A Systematic Review of Models of Care.</p> <p>Nguyen, et al (2017)<sup>62</sup> Canada</p>	<ul style="list-style-type: none"> <li>• Systematic review of youth with mental health concerns.</li> <li>• Three models were identified: Framework for Understanding Mental Health Service Utilization (FUMHSU); the Transition to Independence Process model (TIP) and the Transition Service Integration Model (TSIM) .             <ul style="list-style-type: none"> <li>○ FUMHSU model stratifies youth with mental health disorders into different categories: continuous user, single gap user, multiple gap users, and discontinuers.</li> <li>○ The TIP model was designed to guide processes for coordinating efforts of various specialties and community institutions within three interacting domains: living conditions,</li> </ul> </li> </ul>



	<p>educational opportunities, and employment and career. 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.</p> <ul style="list-style-type: none"> <li>○ TSIM 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.</li> <li>● FUMHSU focuses on the individual and their expectation and management of transition, whereas TIP and TSIM 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.</li> </ul>
<p>The Role of Paediatric Psychologists in the Transition of Youth to Adult Health Care: A Descriptive Qualitative Study of Their Practice and Recommendations.</p> <p>Bonanno, et al. (2018)<sup>63</sup> Canada</p>	<ul style="list-style-type: none"> <li>● Qualitative analysis of the role of psychologists in transition.</li> <li>● Ten psychologists talk about their role in transition teams, which focuses on assessment, support interventions, education and information, and interprofessional collaboration and liaison.</li> <li>● Psychologists commented on four areas to improve transition: the adult healthcare setting, a cooperation between the paediatric and adult healthcare settings, the paediatric healthcare setting and psychologist practice.</li> <li>● Recruitment limits experiences to a handful of transition models.</li> </ul>
<p>“Getting ready for the adult world”: how adults with spinal muscular atrophy perceive and experience healthcare, transition and well-being.</p> <p>Wan, et al. (2019)<sup>64</sup> Australia</p>	<ul style="list-style-type: none"> <li>● Qualitative study. Adults with spinal muscular atrophy, 25 participants (ages 16–48 for people with spinal muscular atrophy (19), 49–66 for parents (5), and 42 for partners (1).</li> <li>● Six out of 17 interviewed found the transition scary and challenging. There were ill-defined processes, and when it worked it was often due to structured well-supported transitions or continuity of healthcare providers.</li> <li>● Sample was oddly distributed, with uneven group sizes.</li> </ul>
<p>Integrating an EMR-based Transition Planning Tool for CYSHCN at a Children’s Hospital: A Quality Improvement Project to Increase Provider Use and Satisfaction.</p>	<ul style="list-style-type: none"> <li>● Quality improvement study with 25 providers and 109 consumers (aged 16–25 years)</li> <li>● Online healthcare transition planning tool that could be integrated onto the electronic medical record. The resulting transition planning tool is an assessment and education tool designed to facilitate HCT over the course of clinic visits.</li> </ul>

<p>Wiemann, et al. (2015)<sup>65</sup> USA</p>	<ul style="list-style-type: none"> <li>• The tool appeared to be useful and was adapted to maximise satisfaction among practitioners.</li> <li>• Outcome measures including satisfaction with the tool and change of practitioner behaviour in response to using the tool.</li> </ul>
<p>Young adults with ADHD: an analysis of their service needs on transfer to adult services. Taylor, et al (2010)<sup>66</sup> UK</p>	<ul style="list-style-type: none"> <li>• Case note review of 139 young people aged 14 years and over with attention deficit hyperactivity disorder (ADHD).</li> <li>• To identify the ongoing service needs of young people with ADHD.</li> <li>• The need for services for adults with ADHD was recognised. Young people with mental health problems in addition to their ADHD will need support from adult mental health services. However, a significant group of young adults are likely to be managed well by specialist nurses working with general practitioners in a primary care setting or adult mental health.</li> </ul>
<p>Transition From Paediatric to Adult Care: Internists' Perspectives. Peter, et al (2009)<sup>67</sup> USA</p>	<ul style="list-style-type: none"> <li>• Surveys sent to 134 clinicians to understand the concerns of adult healthcare providers regarding transition for young adult patients with childhood-onset conditions.</li> <li>• Internists clearly stated the need for better training in congenital and childhood-onset conditions, training of more adult subspecialists, and continued family involvement. They also identified concerns about patients' psychosocial issues and maturity, as well as financial support to care for patients with complex conditions. One of the greatest difficulties is finding a knowledgeable, willing adult care provider.</li> </ul>
<p>Adolescent transition clinic in inflammatory bowel disease: quantitative assessment of self-efficacy skills. Yerushalmy-Feler, et al (2017)<sup>68</sup> Israel</p>	<ul style="list-style-type: none"> <li>• Pre and post efficacy of intervention, not blind.</li> <li>• Intervention was transition team conducted three meetings, the first two with adolescent and family, final meeting is patient independent of family. All psychology with patient alone. No control group.</li> <li>• Significant improvement in self-efficacy scores in all domains. These findings suggest that an organised and planned transition program is a valuable tool for providing successful transition of adolescents with IBD to adult-oriented care.</li> <li>• Validated 'IBD-yourself' self-efficacy questionnaires were filled in twice, once before starting and again after completing the transition process, and the two scores were compared.</li> </ul>
<p>Adult Care Transitioning for Adolescents with Special Health Care</p>	<ul style="list-style-type: none"> <li>• Statistical comparison of cohort enablers.</li> <li>• Completed 750 interviews with families receiving family-centred care.</li> </ul>

<p>Needs: A Pivotal Role for Family Centred Care. Duke, et al (2009)<sup>69</sup> USA</p>	<ul style="list-style-type: none"> <li>• Positive correlations between family-centred care and access to seeking transition counselling.</li> <li>• No inferential assumptions. No interventions evaluated.</li> </ul>
<p>Multidisciplinary Support for Healthcare Transitioning Across an Urban Healthcare Network. Davidson, et al (2015)<sup>70</sup> USA</p>	<ul style="list-style-type: none"> <li>• Analysis of compliance to factors by 84 providers who are involved in care of children over 12.</li> <li>• Survey to assess clinician compliance to the elements of MDT medical home care and specialty care and access to planned transition conversations.</li> <li>• Low response rate. This study assessed data collected from a large urban academic healthcare network, reflecting current protocols and population served, and therefore may not be relevant to all healthcare settings. Also, only the clinician or academic view was measured.</li> </ul>
<p>Implementing a transition pathway in diabetes: a qualitative study of the experiences and suggestions of young people with diabetes. Price, et al (2011)<sup>71</sup> UK</p>	<ul style="list-style-type: none"> <li>• Qualitative analysis on interviews with 11 participants aged 16–18 years.</li> <li>• Assess the four-step clinic process of quarterly MDT clinic appointments in final year of paediatric clinic.</li> <li>• Results theme: Interactions that do not take into account a young person’s needs or view can be frustrating. Opportunity for capacity building in clinical workforce for transition needs was identified.</li> </ul>
<p>Reducing bottlenecks: professionals’ and adolescents’ experiences with transitional care delivery. Nieboer, et al. (2014)<sup>72</sup> Netherlands</p>	<ul style="list-style-type: none"> <li>• Pre and post longitudinal study of clinicians and patients – 390 respondents, 54% female average age 16=+2.3 years.</li> <li>• ‘On Your Own Feet Ahead!’ quality improvement program: teams implemented local interventions to improve transitional care in the identified areas of concern reported by patients and clinicians as bottlenecks to successful transition.</li> <li>• Significant improvement in patients’ care experiences with transition program, such as the provision of opportunities for adolescents to visit the clinic alone and to decide who should be present during consultations.</li> <li>• Mind The Gap survey instrument and On Your Feet questionnaire from quality improvement program.</li> <li>• No insight into which interventions had the greatest impact on (which) care experiences. Interventions that were studied were implemented within the usual consultation approach. Did not evaluate additional possibilities for counselling, such as specific psychosocial treatments for children and youth.</li> </ul>

<p>Person-centred reviews as a mechanism for planning the post-school transition of young people with intellectual disability.</p> <p>Kaehne, et al (2014)<sup>73</sup> UK</p>	<ul style="list-style-type: none"> <li>• Documentation analysis study of school transition – education outcomes for 44 clients with intellectual disability who also receive healthcare.</li> <li>• Documentation review of content and level of stakeholder involvement in transition planning meetings.</li> <li>• Involving young people is important to increase the chances of person-centred quality of planning. For vulnerable population such as people with intellectual disability, the presence of the young person in the planning meeting is recommended.</li> <li>• Interviews limited to documented reviews that have already taken place, not pre and post planning sessions.</li> </ul>
<p>Ambulatory Care Utilization Among Patients with Spina Bifida: Change in Care from Childhood to Adulthood</p> <p>Shepard, et al (2018)<sup>74</sup> USA</p>	<ul style="list-style-type: none"> <li>• Analysis of service utilisation as an indicator of transition success – 763 patients aged 18–25, no gender reported.</li> <li>• No intervention identified, standard transition, service utilisation reviewed.</li> <li>• Patients who do not transition well to adult care and remain engaged in paediatric model have significantly higher utilisation of all care compared to those who successfully transition.</li> <li>• Study recommended a urology specialist leadership in a patient-centred model.</li> </ul>
<p>The transition of paediatric Marfan patients to adult care: a challenge and its risks.</p> <p>Stark, et al (2018)<sup>75</sup> Germany</p>	<ul style="list-style-type: none"> <li>• Retrospective analysis of transition of 149 Marfan’s patients.</li> <li>• Intensive clinical review and testing and recruitment to adult interventions for improved outcomes and risk reduction.</li> <li>• No education program or transition model were tested. Recommended health education and self-management with aid of MDT but not tested in this article. "Age-based disease education and understanding of disease in the family and of the patient are relevant."</li> <li>• No patient reported measures, surveys or evaluation of transition, anecdotal and adherence to clinical recommendations.</li> </ul>
<p>Transitioning HIV-Positive Adolescents to Adult Care: Lessons Learned From Twelve Adolescent Medicine Clinics.</p> <p>Tanner, et al (2016)<sup>76</sup> USA</p>	<ul style="list-style-type: none"> <li>• Interview data on transition from 174 clinicians at 12 sites, comparing protocol and guidelines used for transition.</li> <li>• Adolescent and adult clinic involvement in transition is essential to reduce service fragmentation, provide coordinated and continuous care, and support individual and community level health.</li> <li>• The study design also relied on a purposive sample of adolescent program and clinical staff perspective, without speaking to all adolescent staff or to adult</li> </ul>

	clinic staff (with the exception of clinics serving adolescent and adult patients), families or guardians or youth.
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## Study designs

Type	Article numbers from above table (not reference list)
Literature review	4, 28, 38, 55
Systematic review	8, 10, 19, 21, 26, 30, 32, 33, 51, 62
Qualitative survey or assessment	1, 3, 5, 6, 7, 9, 11, 13, 14, 18, 22, 23, 24, 25, 36, 40, 45, 46, 49, 52, 53, 54, 63, 64, 67, 71
Survey and focus group	2
Patient database or record review	12, 42, 66
Case study	15
Descriptive analysis	16, 57, 58, 59
Mixed methods	17
Cohort study	20, 34
Quality improvement	27, 29, 65
Thematic analysis	31
Archival research	35
Retrospective observation study	37
Exploratory study	39
Consensus process	43
Comparative study	44
Thesis	47
Variable	48
Program evaluation	50
Other	56, 69, 70, 73
Retrospective analysis	60, 75
Longitudinal study	61, 72
Quantitative assessment	68

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