# 7 Transition of Care for Adolescents from Child to Adult Health Services: A Systematic Review

Fiona Campbell, Susie Aldiss, and Katie Biggs

## 7.1 Introduction

The transition from adolescence to adulthood is a challenging time of physical, psychological, and social change. Young people with any form of disability, long-term health condition or significant mental health problems can face even greater challenges, since they also have to deal with important changes in the care they need and the way it is provided. The role of the young person and their parents or guardians alters as the adolescent wants, and is expected to, exercise greater independence in the management of their care.

Health services that fail to adequately meet the needs of young people and their families at this time of considerable change may result in a deterioration in health status that can have negative long-term consequences (Busse et al. 2007; Kipps et al. 2002; Lotstein et al. 2013; Moons et al. 2009; Nakhla et al. 2009; Reid et al. 2004; Watson 2005; Yeung et al. 2008). Adolescence is also a time when adult behaviours become established and therefore, represents a window of opportunity to promote healthy behaviour and influence the public health burden of tomorrow's adults (Department of Health et al. 2006; Sawyer et al. 2012). Thus, the transfer of adolescents from child to adult services is a crucial time in the health of young people, who may potentially fall into a poorly managed 'care gap'.

F. Campbell (✉) · K. Biggs
School of Health and Related Research, University of Sheffield, Sheffield, UK
e-mail: f.campbell@sheffield.ac.uk; c.e.biggs@sheffield.ac.uk

S. Aldiss
School of Health Sciences, University of Surrey, Guildford, UK
e-mail: s.aldiss@surrey.ac.uk



C. L. Betz, I. T. Coyne (eds.), *Transition from Pediatric to Adult Healthcare Services for Adolescents and Young Adults with Long-term Conditions*,
https://doi.org/10.1007/978-3-030-23384-6_7

## 7.2 Background

'Transitional care' is the term used to describe services that seek to bridge this 'care gap'. It has been defined as 'the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented healthcare systems' (Blum et al. 1993). Until recently, the literature on transition had a fairly limited focus on conditions such as diabetes and arthritis, but transition is now emerging as a priority across all long-term conditions. This shift is partly due to advances in healthcare, resulting in more young people with conditions, such as cystic fibrosis, now surviving into adulthood (FitzSimmons 1993), but also to the growing realisation that services are failing to meet the needs of young people. Within the UK, it is argued that some of the issues around transition and the provision of developmentally appropriate care for young people, stem from lack of training for health professionals and the belief that adolescent health is not a distinct specialty, in contrast to many other European countries, Australia, New Zealand, Canada and the USA (Gleeson and Turner 2012; McDonagh et al. 2004; McDonagh and Viner 2006).

Preventing adolescents from becoming lost in the transfer between child and adult health services is a major challenge for healthcare providers (Gleeson and Turner 2012; Viner 1999). Providers must ensure open lines of communication are maintained between different service providers, professionals, young people themselves, and their families. Determining a young person's readiness to transfer to adult services, and tailoring services to the needs of adolescents rather than relying on physical age, also presents challenges. The diverse concerns of families and adolescents, whose abilities to take control are increasing, are complex; particularly for service providers within adult sectors where the majority of those receiving care are older people (for example, in the case of diabetes). The need to develop effective and efficient transitional care is supported by policy documents in the UK and the USA (Department of Health et al. 2006; Gleeson and Turner 2012; Viner 1999; American Academy of Family Physicians and American College of Physicians-American Society of Internal Medicine 2002; Canadian Paediatric Society 2006; Commission for Social Care Inspection 2007; Department for Children, Schools, Families, and Department of Health/Children's Mental Health Teams 2009; Department of Health and Department for Education and Skills 2004; Royal College of Nursing 2008; Royal College of Nursing Adolescent Health Forum 2004; Royal College of Paediatrics and Child Health 2003; Royal College of Physicians of Edinburgh Transition Steering Group 2008).

Patterns of health behaviour are established during adolescence that remain into adult life (for example, smoking, dietary habits, levels of physical activity) (Sawyer et al. 2007, 2012). For adolescents with existing long-term health needs, this period in their lives is often associated with a deterioration in their health status. As a

result, improving the healthcare of young people has become a national priority in the UK (Department for Children, Schools, Families, and Department of Health/ Children's Mental Health Teams 2009; Department of Health 2003, 2013,). However, there is a lack of evidence to guide the development of transitional care (Reid et al. 2004; Crowley et al. 2011; Kirk and Fraser 2014; Lugasi et al. 2011; Watson et al. 2011; While et al. 2004). The Care Quality Commission review of services for young people moving from child to adult health services found that funding arrangements were fragmented (Care Quality Commission 2014). A consequence of this was that some young people and their families were left without equipment, services, respite or other requirements during transition. Professionals with no former knowledge of, or connection with the young person and their family sometimes conducted the healthcare assessments to determine how to allocate funds, resulting in delayed funding.

As well as an historical neglect of adolescent healthcare, transitional care is hampered by existing professional practices and boundaries, service configuration, and a poor understanding of appropriate models of transitional care (McDonagh and Viner 2006; Viner 1999; While et al. 2004). In a survey of paediatric diabetic services in the UK, it was found that 21% of services still organised the transfer of adolescents to adult care by letter only (Gosden et al. 2010). In the USA, there has been only limited achievement of national health policy goals related to transition, despite consensus statements issued by the American Academy of Pediatrics, the American Academy of Family Physicians, the American College of Physicians, and other healthcare societies, stating the importance of supporting and facilitating the transition of adolescents with special healthcare needs into adulthood, and developing foundational guidance for healthcare processes to facilitate this (American Academy of Family Physicians and American College of Physicians-American Society of Internal Medicine 2002; Snow et al. 2009). A national survey revealed that most paediatric practices neither initiate transition planning early in adolescence nor offer transitional support services. The survey authors noted that some of the factors leading to gaps in transitional support are due to limited staff training, lack of an identified staff person responsible for transition, financial barriers, and anxiety on the part of paediatricians, adolescents, and their parents about planning for their future healthcare (McManus et al. 2008). The World Health Organisation (WHO) report 'Health for the world's adolescents: a second chance in the second decade', reports that health services for adolescents in both high and middle-low income countries are highly fragmented, poorly coordinated and uneven in quality (Dick and Ferguson 2015). Evidence suggests that adolescents experience many barriers to healthcare (WHO/UNAIDS 2015). This review addresses a critical aspect of adolescent healthcare, transition from child to adult services, and aims to identify the evidence to support the development of effective transitional care services.

## 7.3 Objectives

To evaluate the effectiveness of interventions designed to improve the transition of care for adolescents from child to adult health services and explore what factors might contribute to their effectiveness.

## 7.4 Methods

### 7.4.1 Criteria for Considering Studies for This Review

#### 7.4.1.1 Types of Studies

We considered randomised controlled trials (RCTs), controlled before- and after-studies (CBAs), and interrupted time-series studies (ITSs) evaluating the effectiveness of interventions that aimed to improve the transition of care for adolescents from child to adult health services. We included CBAs only if they had at least two intervention and two control sites. We included ITSs if they had a clearly defined point in time when the intervention occurred and three data collection points before and after the intervention.

#### 7.4.1.2 Types of Participants

We included adolescents with conditions that required ongoing clinical care (for example, diabetes mellitus, cystic fibrosis, muscular dystrophy, congenital heart disease, cerebral palsy, autism, juvenile idiopathic arthritis, solid organ transplantation, and epilepsy), who would be leaving child services and would require ongoing services in adult healthcare units, or had already transferred to adult services, and their families, parents, or guardians,

There was no restriction on the age of the participants to avoid excluding studies that may involve children younger than 12 years, as transition interventions may begin in advance of the actual transfer. Thus, we also considered transition interventions that had begun before children reached adolescence. However, for the purpose of this review, the term ‘adolescence’ refers to young people aged between 12 and 19 years.

#### 7.4.1.3 Types of Interventions

We considered any care (or clinical pathway) model aimed at improving the transition of care for adolescents from child to adult health services (for example, dedicated adolescent units, joint clinics, the use of specialised key workers). We included transitional care models independent of the duration of the interventions or the time points of the intervention (some start at an early stage, when a child is 12–14 years old; others may start when the child is 15 or 16 years old).

Comparator interventions included current practice, usual care, or a modified version of the intervention. We also considered trials that compared different transitional care models.

#### 7.4.1.4 Types of Outcome Measures

We were interested in a wide range of outcomes including:

Disease-specific patient outcomes or status, using validated measures, for example, glycated haemoglobin (HbA1c), lung function, disease-specific patient-reported outcomes (PROMs), transitional readiness, patient satisfaction, treatment adherence, health-related quality of life, disease-related knowledge and self-advocacy skills.

#### 7.4.1.5 Search Methods for Identification of Studies

We searched electronic databases and reference lists of relevant papers to identify studies matching the inclusion criteria. A comprehensive search of electronic databases including MEDLINE, EMBASE, CINAHL, PsycINFOR, HMIC and Web of Science (from inception to June 2018) was undertaken, with search strategies designed by an information specialist using a range of key words and MESH (Medical Subject Headings) terms. We did not restrict the searches by language or publication status.

### 7.4.2 Data Collection and Analysis

#### 7.4.2.1 Selection of Studies

We downloaded all titles and abstracts identified by the electronic searches into the reference management database Endnote (version x9) and removed duplicates. Titles and abstracts were screened independently by the review authors. We excluded studies that did not meet the inclusion criteria, and retrieved the full text of citations that appeared relevant, or where relevance was unclear. We used a PRISMA study flow chart to summarise the number of papers included and excluded at each stage (Moher et al. 2009)—see Fig. 7.1.

### 7.4.3 Data Extraction and Management

Three review authors (FC, SA, KB) independently extracted data onto piloted data extraction form. Differences in data extracted were explored and resolved by discussion among the reviewer authors. Data extracted from the included studies included: setting (country, location, provider, site of provision), methods (study design, methods of measuring outcomes, assessment of confounders), intervention (focus, funding, context, attributes, duration, service configuration), and outcomes (including harmful effects).

### 7.4.4 Assessment of Risk of Bias in Included Studies

Risk of bias was assessed independently by the review authors using the Cochrane tool for assessing risk of bias on seven criteria; (1) adequate sequence generation; (2) concealment of allocation; (3) blinded or objective assessment of primary outcomes; (4) adequately addressed incomplete outcome data; (5) free from selective reporting;

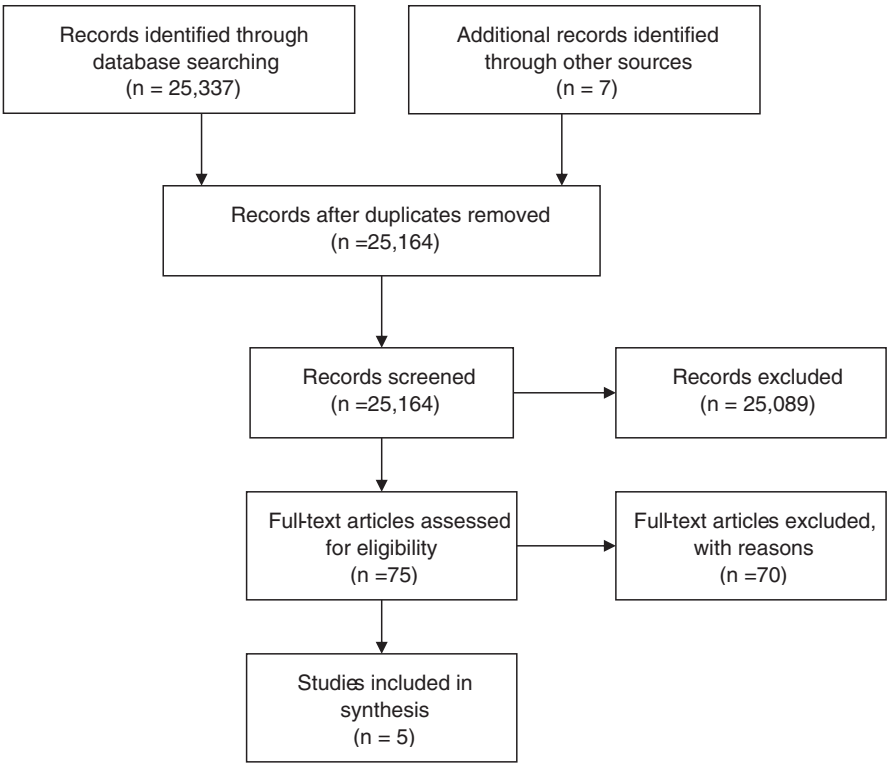


**Fig. 7.1** Study flow diagram

(6) free of other risk of bias, including generalisability of participants and length of follow-up; (7) similar baseline characteristics (Higgins and Altman 2008). We categorised the risk of bias for these criteria as low, unclear, or high. We considered studies to be at an overall low risk of bias if all risk of bias criteria were judged as 'adequate' methodology. We judged the risk of bias to be high when there were one of the following: inadequate methods of randomisation and allocation concealment, a lack of blinding of the outcome assessment, the use of subjective patient-reported outcome measures, and the absence of similarity between groups at baseline.

### 7.4.5 Measures of Treatment Effect

We did not pool the data due to the heterogeneity of the interventions and the different methods of measuring and reporting the outcome variables. We reported the data in natural units, reporting pre-intervention and post-intervention means for both study and control groups, and we calculated the unadjusted absolute change from baseline with 95% confidence intervals (CI).

## 7.5 Results

### 7.5.1 Description of Studies

#### 7.5.1.1 Results of the Search

The electronic database searches and other sources yielded 25,164 citations after duplicates were removed. From our review of these abstracts, 75 studies appeared to meet the eligibility criteria and were retrieved for further assessment, 70 of which were excluded with reasons (see Campbell et al. 2016 for list of excluded studies).

Five studies, recruiting a total of 358 participants, met the inclusion criteria and were included in the review. All of the papers were published in English.

### 7.5.2 Included Studies

#### 7.5.2.1 Study Design

Five randomised controlled studies met the inclusion criteria (Betz et al. 2010; Huang et al. 2014; Mackie et al. 2014; Steinbeck et al. 2014; White et al. 2017). One of these was a cluster randomised design trial, which the authors reported taking into account in the analyses of the data (Mackie et al. 2014).

#### 7.5.2.2 Participants

The participant population (N = 358) in all five trials were adolescents, with the mean age ranging from 16 to 18 years. The transition programmes that were evaluated differed in the types of chronic condition upon which they focused. Huang et al. (2014) recruited patients with a range of chronic conditions that included cystic fibrosis, inflammatory bowel disease, and type 1 diabetes. The other trials focused on patients with specific chronic conditions including; heart disease (Mackie et al. 2014), type 1 diabetes (Steinbeck et al. 2014; White et al. 2017) and spina bifida (Betz et al. 2010). All five trials excluded patients who had developmental delay or cognitive impairment. These were small trials, including between 26 and 120 participants each. See Table 7.1 for a summary of the participant's characteristics, the study settings and interventions.

#### 7.5.2.3 Setting

In four studies (Huang et al. 2014; Mackie et al. 2014; Steinbeck et al. 2014; White et al. 2017), the patients were recruited from tertiary care hospital units and outpatient clinics; Betz et al. (2010) recruited from hospitals and support groups. In all studies, the interventions were delivered while participants were in the community and receiving outpatient care. Two trials were undertaken in the USA (Betz et al. 2010; Huang et al. 2014), one in Canada (Mackie et al. 2014), and two in Australia (Steinbeck et al. 2014; White et al. 2017).

**Table 7.1** Participant characteristics and interventions

| Study | Population | Transition programme | Components of intervention |
|---|---|---|---|
| Betz et al. (2010) | *USA*. N = 80 (65) randomised (analysis)<br>*Age*: 14–18 years, mean 16 years (SD 1.4)<br>*Female*: 39/65 (60%)<br>*Clinical condition*: Spina bifida | *Name*: Transition preparation training<br>*Setting of intervention*: *Professionals delivering intervention*: 'Trainer'<br>*Frequency/duration of intervention*: 3 modules with 8 sessions, 2 days<br>*Method of delivery*: Face-to face workshop<br>*Control*: Usual care | *Module 1* (2 sessions): Assessment of goals and dreams related to health, school work, community living, housing, recreation and leisure;<br>*Module 2* (2 sessions): Creating comprehensive transition plan—including identification of service needs, service referrals and contact information;<br>*Module 3* (4 sessions): Learning opportunities to practice strategies for obtaining services: Role-playing, one-to-one, coaching, reinforced learning, audio-visual aids, Internet and mentored learning |
| Huang et al. (2014) | *USA*. N = 81 (75) randomised (analysis)<br>*Age*: 12–22 years, median 17 years (range 12–20)<br>*Female*: 44/81 (54%)<br>*Clinical conditions*: Cystic fibrosis, inflammatory bowel disease and type 1 diabetes | *Name*: MD2Me web-based and text-delivered disease management and skill-based intervention<br>*Setting of intervention*: Based in a tertiary care paediatric academic setting<br>*Professional delivering the intervention*: Not described<br>*Frequency/duration of intervention*: 8 months<br>*Method of delivery*: Intervention delivered on the Internet but details of how it was developed were not provided.- Short message service (SMS) algorithm linked to clinical team<br>*Control*: Monthly messages via mail or email addressing general health issues. Usual health services communication was available | An 8-month technology-based disease management intervention based on Bandura's social cognitive theory<br>2-month intensive web-based and text-delivered disease management and skill-based intervention followed by a 6-month review period<br>Recipients also had access to a texting algorithm for disease assessment and healthcare team contact. Tailored text messages and queries were delivered (three to five messages/week) to ensure that participants received and understood intervention messages. After 2 months, website access was provided as a disease management and information<br>Weekly reminder SMS messages were also delivered to reinforced previously introduced concepts and skills |

**Table 7.1** (continued)

| Study | Population | Transition programme | Components of intervention |
|---|---|---|---|
| Mackie et al. (2014) | *Canada.* N = 66. randomised (analysis). Adolescents attending a tertiary care cardiology clinic at a children's hospital<br>*Age*: 15–17 years (mean 16.5, SD 1) | *Name*: Nurse-led transition intervention<br>*Intervention setting*: Private room near outpatients, alongside usual clinic appointment<br>*Professionals delivering intervention*: Experienced cardiology nurses<br>*Frequency/duration of intervention*: One session: 1 h—mean duration 68 min (SD = 18)<br>*Method of delivery*: Face-to-face meeting<br>*Control*: Usual care, not standardised | Structured meeting with nurse, including introduction to transition and its importance, discussion of confidentiality, disease knowledge which was participant specific discussion of potential future cardiac complications, health contacts information, adolescent issues discussion, written material introducing youth oriented issues given and links to relevant websites. A 'MyHealth' passport was created including name of cardiac condition, previous cardiac interventions, name and purpose of medications and the need for endocarditis prophylaxis. This was provided to the participants in a plastic wallet and a copy emailed to the participant |
| Steinbeck et al. (2014) | *Australia.* N = 26. Two university teaching hospitals<br>*Age*: ≥16 years of age, range 17.3–18.8 years Identified by their diabetologist as ready to transition<br>*Female*: 14/26 (53.8%)<br>*Clinical condition*: Type 1 diabetes mellitus (T1DM) | *Name*: Comprehensive transition programme (CTP)<br>*Intervention setting*: Participants were being cared for by adult specialist diabetes services as outpatients<br>*Professionals delivering intervention*: Transition co-ordinator<br>*Frequency/duration of intervention*: Week 1: ≤6-min telephone conversation, Month 3 and 6, mean duration 8.5 min (range 2–20 min)<br>*Method of delivery*: Telephone<br>*Control*: Standard care, the transition co-ordinator made the first adult diabetes service appointment for participants in both arms | Structured transition protocol where the transition co-ordinator provided the young person with a hard and soft copy of their contact details, the adult services details, websites of useful services and information, personal diabetes healthcare information using a standardised template (with input from the young person) and a formal referral letter. The 'transition co-ordinator' provided standardised telephone communication support at week 1 (duration ≤6 min), 3 and 6 months (mean duration 8.5 min) and 12 months<br>Week 1: Aim was to ensure participants understood the transition process<br>Months 3 and 6: Communication support concerned participants general well-being, life events, transition difficulties and contact with their adult diabetes service. The transition co-ordinator did not provide specific diabetes management advice |

(continued)

**Table 7.1** (continued)

| Study | Population | Transition programme | Components of intervention |
|---|---|---|---|
| White et al. (2017) | *Australia.* N = 120 (104 primary outcome, 69 secondary outcomes) randomised (analysis) | *Name*: Appointment management<br>*Intervention setting*: Transitioning from a tertiary paediatric diabetes service at a Children's hospital to on adult services at one of eight centres in Melbourne<br>*Professionals delivering intervention*: Appointment manager<br>*Frequency/duration of intervention*: 12 months<br>*Method of delivery*: Telephone and text reminders, telephone and email contact<br>*Control group*: Usual care | Personalised transition schedule detailing information of the relevant adult clinic<br>USB memory stick containing their personal medical data<br>Information pack containing diabetes-related targets and advice<br>Appointment manager acted as the point of contact between intervention group participants and the relevant adult clinics, undertaking telephone reminders and sending text message reminders within 48 working hours of each scheduled clinic visit. Participants encouraged to initiate contact with the appointment manager with any questions or concerns. Automatic rebooking for missed adult appointments, contact attempted by phone, text, email or letter after two missed appointments |

#### 7.5.2.4 Description of Interventions

The five included RCTs evaluated interventions that focused on the patient, rather than targeting health professionals or systems. Betz et al. (2010) evaluated a cognitive-behavioural programme delivered via a workshop to adolescents Huang et al. (2014) evaluated a web-based and SMS delivered skill-based intervention; Mackie et al. (2014) evaluated an education/skills training intervention delivered by an experienced cardiology nurse; Steinbeck et al. (2014) evaluated the use of three standardised telephone communications (over 6 months) from a transition co-ordinator following discharge from paediatric care, and paper and electronic copies of information on services and healthcare for diabetes and White et al. (2017) evaluated the effect of an appointment management intervention.

Three interventions sought to improve knowledge and self-management skills in preparation for transition to adult care (Betz et al. 2010; Huang et al. 2014; Mackie et al. 2014). The intervention by Steinbeck et al. (2014) was implemented post-discharge from paediatric care and sought to promote better use of adult diabetic services. The appointment management intervention evaluated by White et al. (2017) aimed to promote clinic attendance at adult health clinics and prevent disengagement after transition. The components of the interventions, and the number and duration of the sessions varied. None of the studies provided details of how the time

of transfer to adult services for individual patients was decided. A description of each intervention follows.

**Transition Preparation Training (Betz et al. 2010)**
The cognitive-behavioural programme, called the Transition Preparation Training, was delivered via a 2 day weekend workshop and consisted of three modules (Day 1 was 5 h long and contained modules 1 and 2, Day 2 was 4.5 h long and covered module 3). The workshop assessed goals and dreams related to health, school work, community living, housing, recreation and leisure. It also facilitated the creation of a comprehensive transition plan, with the identification of service needs, service referrals, and contact information. The information was reinforced with learning opportunities to practice strategies for obtaining services, and included role-playing, one-on-one interactions, coaching, audio-visual aids, Internet and reinforced and mentored learning. The treatment group had Transition Preparation Training alongside usual spina bifida care management; the control group received only usual care, though the details of 'usual spina bifida care management' were not described. The authors did not report who delivered the intervention.

**MD2Me Intervention (Mora et al. 2017)**
The web and SMS delivered technology programme (Mora et al. 2017) involved an 8-month management programme based on Bandura's Social Cognitive Theory. The intervention targeted the self-management constructs of monitoring disease symptoms, responding to monitoring with appropriate treatments, and actively working with healthcare providers to manage care. For 2 months, young people logged into a secure website weekly to receive theme-based materials outlining common disease management and communication skills, and lifestyle tips. Case studies were provided to increase usability. Tailored text messages and queries were delivered (three to five messages per week) to ensure that participants received and understood the intervention messages. After 2 months, website access was provided as a disease management and information resource. Weekly reminder text messages were also delivered to reinforce previously introduced concepts and skills. To facilitate patient-initiated communication, intervention group patients were given access to an automated SMS algorithm that provided disease management decision support and a healthcare team communications portal. Participants could activate the SMS to report health concerns. Controls received monthly messages via mail or email (participant preference) addressing general health issues. Disease-specific information was provided as appropriate (for example, in the healthy nutrition module). Usual healthcare communication portals were available to patients in the control group. It was not clear who had designed or delivered the program.

**Skills Training/Education for Young People (Sattoe et al. 2016)**
The intervention evaluated by Mackie et al. (2014) was one structured meeting with an experienced cardiology nurse, the duration of which was not described. The elements of the structured meeting included: discussion about transition and

its importance, issues of confidentiality, issues related to their cardiac condition, complications, medication, details of important contact names, and an introduction to relevant websites. Case studies were used to address health behaviour and written materials were supplied. A 'MyHealth' passport was also created, including the name of their cardiac condition, previous cardiac interventions, name and purpose of medications, and if there was a need for endocarditis prophylaxis. Participants in the usual care group were variably provided verbal or written information, or both, by their cardiologist or cardiology clinic nurse, at the discretion of these providers.

**Comprehensive Transition Programme** (Steinbeck et al. 2014)
The intervention evaluated by Steinbeck et al. (2014) included the transition coordinator making the first adult diabetes service appointment and providing their contact details (this was also done for the participants in the usual care group). The intervention group received adult diabetic services, directions and transport, useful websites, information relevant to personal diabetic healthcare, and a formal referral letter. This was followed by four standardised telephone communications at week 1, and at 3 and 6 months to provide support, establish an understanding of the transition process, and discuss the participant's general well-being, life events, transition difficulties, and contact with their adult diabetic services. The duration of the calls varied, but their mean duration at months 3 and 6 was 8.5 min. At 12 months, a follow-up phone call was made to confirm transfer status (Steinbeck et al. 2014).

**Appointment-Management Intervention (White et al. 2017)**
The appointment management intervention incorporated a personalised transition schedule detailing information of the relevant adult clinic location, contact telephone numbers to confirm or reschedule clinic appointments, and diabetes team contact details. USB memory sticks containing a young person's personal medical data (transition referral letter, previous diabetes clinic letters, recent laboratory or complication screening results and other relevant clinical details) and an information pack containing diabetes-related targets and advice. The appointment manager acted as the point of contact between intervention group participants and the relevant adult clinics, undertaking telephone reminders within 1 week and sending short message service (SMS) reminders within 48 working hours of each scheduled clinic visit. Interventions group participants were encouraged to initiate contact with the appointment manager with any questions or concerns relating to the transition process or appointment scheduling and were provided with relevant contact details in the form of a business card. Automatic rebooking was requested for any missed adult appointments. If participants did not attend multiple appointments, contact was attempted by telephone, text messages, email or letter. The appointment manager did not provide medical advice or support, and participants were adviced to contact their relevant treating team where necessary.

#### 7.5.2.5 Outcomes Measured
The outcomes measured and tools used are summarised in Table 7.2. There were a wide range of tools used, limiting comparison in study outcomes.

**Table 7.2** Summary of the findings

| Author (year) Follow-up | Outcome measure | Results: Intervention and comparator | Reported between-group difference | Summary |
|---|---|---|---|---|
| *Health status* | | | | |
| Huang et al. (2014) Follow-up: 8 months | Karnofsky performance scale | I: Data not reported C: Data not reported | Data not reported | No statistical difference between groups |
| *Disease status* | | | | |
| Huang et al. (2014) Follow-up: 8 months | Various tests[a] | I: Data not reported C: Data not reported | Data not reported | No statistical difference between groups |
| Steinbeck et al. (2014) Follow-up: 12 months | HbA1c % | I: Median 10.2% (IQR 8.8 to 13.2) N = 14 C: Median 8.3% (IQR7.7 to 9.7) N = 12 | p = 0.01 | Favours comparator (statistically significant) |
| White et al. (2017) Follow-up: 12 and 24 months | HbA1c % | 0–12 m follow-up I: 8.4% (SD 1.9) N = 49 C: 8.6% (SD 1.5) N = 55 | 12 m follow-up MD −0.20 (95% CI −0.86 to 0.46) | 12 m follow-up Favours intervention but not statistically significant |
| | | 12–24 m follow-up I: 8.2% (SD 1.9) N = 32 C: 8.5% (SD1.3) N = 37 | 24 m follow-up MD −0.30 (95% CI −1.08 to 0.48) | 24 m follow-up Favours intervention but not statistically significant |
| *Transition achieved and time taken* | | | | |
| Steinbeck et al. (2014) Follow-up: 12 months | Transition achieved | I: 11/14 (79%) C: 12/12 (100%) | RD: −0.21 (95% CI −0.45 to 0.02) | Favours control but not statistically significant |
| | Time taken to transfer (weeks) | I: Median 15 (IQR 8 to 19) N = 14 C: Median 14 (IQR 11 to 20) N = 12 | p = 0.7 | No statistical difference between groups |
| *Transition readiness and self-efficacy* | | | | |
| Huang et al. (2014) Follow-up: 8 months | [b]TRAQ (full questionnaire) | I: Mean 4 (0.8) N = 38 C: Mean 3.8 (0.8) N = 37 | MD 0.20; (95% CI −0.16 to 0.56) | Favours intervention but not statistically significant |
| Mackie et al. (2014) Follow-up 6 months | TRAQ (self-management) | I: Mean 3.59 (0.83) N = 24 C: Mean 3.16 (1.05) N = 25 | MD 0.43 (95% CI −0.09 to 0.95) | Favours intervention but not statistically significant |

(continued)

**Table 7.2** (continued)

| Author (year) Follow-up | Outcome measure | Results: Intervention and comparator | Reported between-group difference | Summary |
|---|---|---|---|---|
| | TRAQ (self-advocacy) | I: Mean 4.28 (0.56) n = 24<br>C: Mean 4.01 (0.95) n = 25 | MD 0.37 (95% CI −0.06 to 0.80) | Favours intervention but not statistically significant |
| Huang et al. (2014)<br>Follow-up: 8 months | Patient Activation Measure (PAM) | I: Data not reported<br>C: Data not reported | Data not reported | All outcomes improved compared to control group (reported in publication) |
| Betz et al. (2010)<br>Follow-up: 4 months | Community Life Skills (CLSS) | I: Mean 19.12 (SD 4.25) N = 31<br>C: Mean 18.35 (SD 3.42) N = 34 | MD: 0.77 (95% CI −1.12 to 2.66) | Favours intervention but not statistically significant |
| Betz et al. (2010)<br>Follow-up: 4 months | Self-Care Practice (DSCPI) | I: Mean 63.29 (SD 13.73) N = 31<br>C: Mean 66.99 (17.61) N = 34 | MD: −3.70 (95% CI −11.34 to 3.94) | Favours usual care but not statistically significant |
| *Disease knowledge/health literacy* | | | | |
| Mackie et al. (2014)<br>Follow-up: 6 months | MyHeart | I: Mean 75 (SD 15) N = 24<br>C: Mean 61 (SD 25) N = 26 | MD: 14.00 (95% CI 2.67 to 25.33) | Favours intervention (statistically significant) |
| *Wellbeing* | | | | |
| Betz et al. (2010)<br>Follow-up: 4 months | PARS III | I: Mean 85.7 (SD 11.98) N = 31<br>C: Mean 84.41 (SD 11.77) N = 34 | MD: 1.29 (95% CI −4.49 to 7.07) | Favours intervention but not statistically significant |
| Steinbeck et al. (2014)<br>Follow-up: 12 months | [c]Change in global self-worth | I: Median = 0 (IQR −0.8 to 0.1) (N = 9)<br>C: Median −0.3 (IQR −0.9 to 0.1) (N = 5) | p = 0.9 | Favours intervention but not statistically significant |
| *Use of health services* | | | | |
| Huang et al. (2014)<br>Follow-up: 8 months | Patient initiated healthcare communication | I: 2/38<br>C: 0/37 | RD: 0.05 (95% CI −0.03 to 0.14) | Favours intervention but not statistically significant |
| Steinbeck et al. (2014)<br>Follow-up: 12 months | Patient initiated healthcare communication | I: 3/9<br>C: 2/9 | RD: 0.11 (95% CI −0.30 to 0.52) | Favours intervention but not statistically significant |

**Table 7.2** (continued)

| Author (year) Follow-up | Outcome measure | Results: Intervention and comparator | Reported between-group difference | Summary |
|---|---|---|---|---|
| Steinbeck et al. (2014) Follow-up: 12 months | Patients with a diabetes-related hospitalisations in past 12 months | I: 1/14<br>C: 3/12 | RD: −0.18 (−0.46 to 0.10) | Favours intervention but not statistically significant |
| White et al. (2017) Follow-up: 12 and 24 months | Mean number of adult clinics attended | 0–12 months<br>I: 2.3 (SD 1.1) N = 49<br>C: 2.3 (SD 1.4) N = 55 | MD: 0.00 (95% CI −0.48 to 0.48) | Favours intervention but not statistically significant |
| | | 12–24 months<br>I: 2.5 (SD 1.3) N = 32<br>C: 1.4 (SD 1.8) N = 37 | MD: 1.10 [95% CI 0.37 to 1.83] | Greater attendance of adult clinics for those receiving intervention (statistically significant) |
| | Failed to attend adult health services | 0–12 months<br>I: 3/49 (6%)<br>C: 6/55 (11%) | RD: −0.05 [95% CI −0.15 to 0.06] | Favours intervention but not statistically significant |
| | | 12–24 months<br>I: 2/32 (6%)<br>C: 18/37 (49%) | RD: −0.42 [95% CI −0.61 to −0.24] | More young adults without the intervention failed to attend adult health services (statistically significant) |

HbA1c %: Haemoglobin A1c or glycated haemoglobin test—a blood test that gives a good indication of how well diabetes is being controlled

MyHeart: The MyHeart scale was developed for this study and consists of seven short questions. It is reported as a percentage correct score. It was developed for this study, was piloted to confirm face and content validity

CLSS (Community Life Skills): 33 item tool using a binary scale (yes/no) contains 6 areas of foci measuring various types of community skills

DSCPI (Self-Care Practice): 18 item self-report questionnaire measuring both general health behaviours and specific self-care behaviours. Respondent's record responses to items using a ratio scale from 0 (none at all) to 100 (all the time). Higher scores reflect a higher level of self-care abilities

Karnofsky Performance Scale: A functional status assessment scale used in chronic disease populations (0–100) where 100 represents perfect health and 0 represents death

PARS III: measures subjective well-being. Contains 28 items measuring six areas of functioning associated with maladjustment, peer relations, dependency, hostility, productivity, anxiety-depression and withdrawal

*MD* mean difference, *CI* confidence interval, *SD* standard deviation, *RD* risk difference, *IQR* Interquartile range

[a]Peadiatric Ulcerative Colitis Activity Index, Paediatric Crohn's Disease Activity Index, Cystic Fibrosis Clinical Score, Diabetes Quality of Life Brief

[b]TRAQ (Transition Readiness Assessment Questionnaire) is a measure of readiness for transition and assesses performance of chronic disease self-management skills. It is scored by using a 6 point scale where 0 points were given for subjects who felt that the skill was not necessary for their care, and 5 was given for performing the skill consistently when needed

[c]Change in global self-worth Score 1 = low self-worth; Score 4 = high self-worth

Disease-specific patient outcomes and status were our primary outcome and were measured in three studies (Huang et al. 2014; Steinbeck et al. 2014; White et al. 2017). Huang et al. (2014) used validated scales developed for each disease experienced by the participants, including: the Paediatric Ulcerative Colitis Activity Index, Paediatric Crohn's Disease Activity index, Cystic Fibrosis Clinical Score, and the Diabetes Quality of Life Brief Clinical Inventory. None of the results from these measurement tools was reported. Steinbeck et al. (2014) and White et al. (2017) reported HbA1c %, IFCC mmol/mol.

Three studies (Betz et al. 2010; Huang et al. 2014; Mackie et al. 2014) reported on readiness for transition using different tools. Tools used included the Transition Readiness Assessment Questionnaire (TRAQ) scale (Huang et al. 2014; Mackie et al. 2014), the Patient Activation Measure (PAM) scale, the Community Life Skills Scale (CLSS) and the Denyes Self-Care Practice (DSCPI-90) (Betz et al. 2010).

Two studies (Huang et al. 2014; Mackie et al. 2014) reported on disease knowledge. Mackie et al. (2014) used the MyHeart scale; Huang et al. (2014) used the Test of Functional Health Literacy in Adults.

Two studies (Betz et al. 2010; Huang et al. 2014) reported on well-being and quality of life one using the Personal Adjustment and Role Skills Scale (PARS) III (Betz et al. 2010) and another used the Pedatric Quality of Life Scale (PedsQL) (Huang et al. 2014).

Health Resource use was evaluated in three studies including; patient-initiated healthcare communications (Huang et al. 2014), costs and reported the number of diabetes-related hospitalisations in the previous 12 months (Steinbeck et al. 2014) and number of clinic appointments attended 0–12 and 12–24 months after transition (White et al. 2017). White et al. (2017) also measured disengagement from specialist services if they had not attended any adult outpatient clinic appointments.

## 7.6 Summary of the Findings

We included five RCTs (N = 358 participants) in this review. Data were reported for the following outcomes: disease-specific outcomes, readiness for transition, adherence and acceptability, health-related quality of life and well-being, knowledge of condition, healthcare use (see Table 7.2 for a summary of findings). There were no data reported on patient satisfaction, self-advocacy, transitional issues or unanticipated or adverse outcomes.

The certainty of the body of evidence from these studies is low. The five studies explored different types of transitional care interventions: transition-preparation training, delivered in a 2-day workshop for adolescents with spina bifida; a web and SMS-based educational intervention for adolescents with a range of different conditions; a one-hour, nurse-led, one-on-one teaching session with the additional support of a 'health passport' for youth with heart disease; a structured, comprehensive transition programme with a transition co-ordinator for adolescents with type 1 diabetes and an appointment management intervention (Betz et al. 2010; Huang et al. 2014; Mackie et al. 2014; Steinbeck et al. 2014; White et al. 2017). This review

highlights the lack of robust evaluation for other models of transitional care. There are also groups of young people, such as those with mental illness, whose health conditions need specific interventions and have not yet been evaluated using RCTs or rigorous comparative designs.

Disease-specific outcome measures were reported in two studies; the transition interventions in these studies led to no little or no difference in outcomes. Huang et al. (2014) reported little or no difference in health status between treatment and control groups, however, the data were not reported or provided by the author. Steinbeck et al. (2014) found that the clinical outcomes measured, including measures of diabetes control, were better in the control group. However, this difference may be due to differences in baseline values in which the HbA1c % was higher in the control group. They found little or no difference in the use of adult services between the intervention and control groups or any difference in the numbers achieving the recommended number of clinic attendances annually. The study was limited in its power to identify differences due to the small number of participants (N = 26). Steinbeck et al. (2014), found that follow-up HbA1c in young people with type 1 diabetes mellitus increased by 1.2% for each percentage increase in baseline HbA1c, independent of treatment group (1.2%, 95% CI 0.4 to 1.9, P = 0.01). White et al. (2017) found that appointment management had no independent effect on glycated haemoglobin after transition.

Transition interventions may lead to slight improvements in disease management and self-efficacy (transition readiness). Transition readiness is a term that refers to the process of building the capacity of adolescents and those involved in their care to prepare for, enter, continue, and complete transition. It involves multiple components, is measurable and potentially modifiable. Transition readiness measures have a range of clinical purposes, but in research, they allow the assessment of outcomes of an intervention and comparisons between groups. Disease management and self-efficacy were measured using various tools. Two studies evaluating the one-on-one nurse-led intervention (Mackie et al. 2014), and the technology-based intervention (Huang et al. 2014), suggest that these transition interventions may lead to slight improvements in readiness for transition, and chronic disease self-management measured at 6- to 8-month follow-ups. Results using the TRAQ tool were: MD 0.20; 95% CI −0.16 to 0.56 (Huang et al. 2014), MD 0.43; 95% CI −0.09 to 0.95 (TRAQ Self-management; Mackie et al. 2014), MD 0.37; 95% CI −0.06 to 0.80 (TRAQ Self-advocacy; Mackie et al. 2014). Results using the PAM tool were: MD 10; 95% CI 2.96 to 17.04 (Huang et al. 2014). In contrast, transition-preparation training delivered via a 2-day workshop for patients with spina bifida did not lead to any difference in measures of self-care practice regarding general health behaviours, when measured using DSCPI-90© (Betz et al. 2010).

One study evaluating a technology-based intervention (Huang et al. 2014), and another evaluating a comprehensive transition programme (Steinbeck et al. 2014), found that these interventions may lead to slightly more young people taking positive steps to initiate contact with health professionals themselves (relative risk: 4.87; 95% CI 0.24 to 98.12 and 1.50; 95% CI 0.32 to 6.94 respectively).

Young people's knowledge of their disease was slightly improved with a nurse-led, one-on-one intervention to prepare young people for transition to an adult congenital heart programme (MD 14; 95% CI 2.67 to 25.33; Mackie et al. 2014).

Transition interventions may not lead to any difference in well-being or quality of life. Two studies measured well-being and quality of life using PARS III (Betz et al. 2010), or the PedsQL tool (Huang et al. 2014). Both the technology-based intervention (Huang et al. 2014), and the 2-day workshop for young people with spina bifida found little or no difference between intervention and control groups (MD 1.29; 95% CI −4.49 to 7.07) (Betz et al. 2010). Huang et al. (2014) did not report the data.

Little or no differences in rates of transfer from paediatric to adult diabetes services were found at 12-month follow-up in one small study (N = 26) that compared a comprehensive transition process with standard practice (Steinbeck et al. 2014).

There was also a higher drop-out rate of participants in the workshop-based intervention (Betz et al. 2010), with scheduling being cited by five of those withdrawing as a barrier to participation. This may be an important factor to consider in the design of further transitional care services. Participation and uptake was the same in both intervention and control groups for the one-on-one, single session with a cardiology nurse (Mackie et al. 2014), and the web and SMS text-based technology programme (Huang et al. 2014).

One study reported the number of diabetes-related hospitalisations in the previous 12 months. Participation in a comprehensive transition programme may lead to slightly fewer disease-related hospital admissions (relative risk: 0.29; 95% CI 0.03 to 2.40) (Steinbeck et al. 2014).

## 7.7 Quality of the Evidence

All five included studies were randomised controlled trials, and although the method of randomisation was described and judged to be adequate, the process of allocation concealment was not described in three of the studies. Only one study attempted blinding at outcome assessment. These limitations introduce a risk of selection and performance bias. As we were unable to pool data, we could not explore the presence of statistical heterogeneity. Assessing consistency among trials was not possible, as the five included studies were small (recruited only 358 participants in total), recruited different study populations, and evaluated different interventions. The short follow-up periods (ranging from 4 to 12 months) also limited the quality of the evidence, providing inadequate data to determine either the full impact of the interventions or the sustainability of the outcomes.

## 7.8 Conclusions

The evidence to support the development of transitional care services is at present, limited by the absence of rigorously evaluated interventions. We were only able to include five studies, that had recruited a total of 358 participants and

looked at different types of interventions. All targeted the individual adolescent; none targeted the healthcare professionals or the organisation of care. Thus, a limited range of potential models of transitional care have been evaluated. There are many other models of transitional care that need to be evaluated and included in a systematic review before one can gain a complete understanding about the evidence in this area.

The evidence is very limited in terms of exploring the long-term effects of the interventions, as the follow-up of the included studies was relatively short (4–24 months). Transitional care plays a crucial role in preventing the deterioration that can occur in young peoples' health status once they transfer to adult health services. However, as only one study included clinical outcome data and the follow-up period was limited to 24 months, there is no evidence on the effectiveness of the interventions in preventing this deterioration in health status in the long-term.

The evidence presented in this review is also limited in its applicability. The available evidence is drawn from a limited number of settings, it is unclear to what extent the results are relevant to other healthcare delivery settings. Whilst one of the studies targeted patients with a range of conditions, the other four studies focused on one condition only (Huang et al. 2014). Therefore, the scope of the evidence, in terms of representing the many types of long-term health conditions that adolescents may experience is also limited. We did not identify any studies that assessed the transfer of young people into primary care. The included studies did not address how the interventions might impact differentially on disadvantaged groups.

More robust research evidence of transitional care interventions is needed. However, using designs such as RCTs to evaluate a complex intervention that crosses medical, social, and educational disciplines, as well as child and adult services is challenging (McDonagh and Viner 2006; McDonagh and Kelly 2010). Transitional care is complex and difficult to evaluate, there are not always clear measurable outcomes (Suris and Akre 2015). Furthermore, prospective research that extends from early adolescence (as current guidance advocates) through to the post-transfer period in adult care is confounded by today's financial climate. The risk of relying on the current evidence base, is that interventions that are more readily evaluated and perhaps less complex, have a greater body of research evidence than more complex interventions that are potentially much more difficult to evaluate in an RCT design, but which might provide more significant outcomes. Further research is underway (Colver et al. 2013; Kreuzer et al. 2014; Mora et al. 2017; Sattoe et al. 2016) and the evidence base to support the development of transitional care will be further informed by these results when they are published.

## 7.9 Key Points

- Nurses who are interested in conducting systematic reviews are advised to include an information specialist and someone with expertise in systematic reviewing as a member of the research team.

- The Prospero database of systematic reviews should be accessed and reviewed to avoid duplication of projects.
- Many journals now publish the protocols of systematic and scoping reviews enabling early dissemination of proposed projects.
- The EQUATOR database provides valuable information to author on the reporting requirements of review and research papers.
- Online review platforms enable more highly efficient process for conducting different types of systematic literature reviews.

## 7.10 Useful Resources

- Cochrane Database of Systematic Reviews.
- This database contains systematic reviews conducted by researchers and professionals on a variety of topics pertaining to healthcare. https://www.cochranelibrary.com/cdsr/about-cdsr.
- Covidence. https://www.covidence.org.
- This is a production platform to enable users to conduct systematic reviews, scoping reviews. This platform enables citations to be imported to be assessed according to the eligibility criteria online. Enables automated screening of abstracts and full texts by reviewers for inclusion and exclusion that results in flow sheet detailing the process.
- EQUATOR Guidelines. http://www.equator-network.org/.
- This website contains a vast number of guidelines for publication of manuscripts pertaining to research and literature reviews. High impact journals will expect authors to construct their manuscripts based upon these reporting guidelines that have become the publication standards.
- PROSPERO. https://www.crd.york.ac.uk/prospero/.
- This international database houses the listing of systematic reviews that are currently being conducted. Researchers are encouraged to register and update the progress of their systematic reviews to avoid duplication and foster communication among scholars. https://joannabriggs.org/critical_appraisal_tools; https://casp-uk.net/.

**Acknowledgements** The authors would like to thank Philip O'Neill for his assistance with the screening of evidence.

## References

American Academy of Family Physicians, American College of Physicians-American Society of Internal Medicine. A consensus statement on health care transitions for young adults with special health care needs. Pediatrics. 2002;110:1304–6.

Betz CL, Smith K, Macias K. Testing the transition preparation training program: a randomized controlled trial. Int J Child Adolesc Health. 2010;3(4):595–607.

Blum RW, Garell D, Hodgman CH, Jorissen TW, Okinow NA, Orr DP, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. J Adolesc Health. 1993;14(7):570–6.

Busse FP, Hiermann P, Galler A, Stumvoll M, Wiessner T, Kiess W, et al. Evaluation of patients' opinion and metabolic control after transfer of young adults with type 1 diabetes from a paediatric diabetes clinic to adult care. Horm Res Paediatr. 2007;67(3):132–8.

Campbell F, Biggs K, Aldiss SK, O'Neill PM, Clowes M, McDonagh J, et al. Transition of care for adolescents from paediatric services to adult health services. Cochrane Database Syst Rev. 2016;4:CD009794. https://doi.org/10.1002/14651858.CD009794.pub2.

Canadian Paediatric Society. Care of adolescents with chronic conditions. Paediatr Child Health. 2006;11(1):43–8.

Care Quality Commission. From the pond into the sea (children's transition to adult health services). 2014. https://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report_Summary_lores.pdf.

Colver AF, Merrick H, Deverill M, Le Couteur A, Parr J, Pearce MS, et al. Study protocol: longitudinal study of the transition of young people with complex health needs from child to adult health services. BMC Public Health. 2013;13(1):675.

Commission for Social Care Inspection. Growing up matters: better transition planning for young people with complex needs. London: Commission for Social Care Inspection; 2007. http://www.yorkshirefutures.com/what_works/growing-matters-better-transition-planning-young-people-complex-needs.

Crowley R, Wolfe I, Lock K, McKee M. Improving the transition between paediatric and adult healthcare: a systematic review. Arch Dis Child. 2011;96(6):548–53.

Department for Children, Schools, Families, Department of Health/Children's Mental Health Teams. Keeping children and young people in mind - the government's full response to the independent review of CAMHS. 2009. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_1107852010.

Department of Health. Getting the right start: national service framework for children. Standard for hospital services. 2003. www.doh.gov.uk/nsf/children/gettingtherightstart2003.

Department of Health. Improving children and young people's health outcomes: a system wide response. 2013. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/214928/9328-TSO-2900598-DH-SystemWideResponse.pdf.

Department of Health, Department for Education and Skills. National service framework for children, young people and maternity services. Department of Health; 2004. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4089101.

Department of Health, Child H, Maternity Services. Transition: getting it right for young people. Improving the transition of young people with long-term conditions from children's to adult health services. London: Department of Health Publications; 2006. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4132145.

Dick B, Ferguson BJ. Health for the world's adolescents: a second chance in the second decade. J Adolesc Health. 2015;56(1):3–6.

FitzSimmons SC. The changing epidemiology of cystic fibrosis. J Pediatr. 1993;122(1):1–9.

Gleeson H, Turner G. Transition to adult services. Arch Dis Child. 2012;97(3):86–92.

Gosden C, Edge JA, Holt RI, James J, Turner B, Winocour P, et al. The fifth UK paediatric diabetes services survey: meeting guidelines and recommendations? Arch Dis Child. 2010;95(10):837–40.

Higgins JPT, Altman DG. Assessing risk of bias in included studies. In: Higgins JPT, Green S, editors. Cochrane handbook for systematic reviews of interventions version 5.0.1 [updated September 2008]: The Cochrane Collaboration; 2008. www.cochrane-handbook.org.

Huang JS, Terrones L, Tompane T, Dillon L, Pain M, Gottschalk M, et al. Preparing adolescents with chronic disease for transition to adult care: a technology program. Pediatrics. 2014;133:e1639–e46.

Kipps S, Bahu T, Ong K, Ackland FM, Brown RS, Fox CT, et al. Current methods of transfer of young people with type 1 diabetes to adult services. Diabet Med. 2002;19(8):649–54.

Kirk S, Fraser C. Hospice support and the transition to adult services and adulthood for young people with life-limiting conditions and their families: a qualitative study. Palliat Med. 2014;28(4):342–52.
Kreuzer M, Prüfe J, Bethe D, Vogel C, Großhennig A, Koch A, et al. The TRANSNephro-study examining a new transition model for post-kidney transplant adolescents and an analysis of the present health care: study protocol for a randomized controlled. Trial. 2014;15(1):505.
Lotstein DS, Seid M, Klingensmith G, Case D, Lawrence JM, Pihoker C, et al. Transition from pediatric to adult care for youth diagnosed with type 1 diabetes in adolescence. Pediatrics. 2013;131(4):e1062–e70.
Lugasi T, Achille M, Stevenson M. Patients' perspective on factors that facilitate transition from child-centered to adult-centered health care: a theory integrated metasummary of quantitative and qualitative studies. J Adolesc Health. 2011;48(5):429–40.
Mackie AS, Islam S, Magill-Evans J, Rankin KN, Robert C, Schuh M, et al. Healthcare transition for youth with heart disease: a clinical trial. Heart. 2014;100:1113–8.
McDonagh JE, Kelly DA. The challenges and opportunities for transitional care research. Pediatr Transplant. 2010;14(6):688–700.
McDonagh JE, Viner RM. Lost in transition? Between paediatric and adult services. BMJ. 2006;332(7539):435–6.
McDonagh JE, Southwood TR, Shaw KL. Unmet education and training needs of rheumatology health professionals in adolescent health and transitional care. Rheumatology (Oxford). 2004;43:737–43.
McManus MA, Fox H, O'Connor K, Chapman T, MacKinnon J. Pediatric perspectives and practices on transitioning adolescents with special needs to adult health care. National Alliance to Advance Adolescent Health. Factsheet. 2008;6:1–6.
Moher D, Liberati A, Tetzlaff J, Altman DG, The Prisma Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. PLoS Med. 2009;6(6):e1000097-e.
Moons P, Hilderson D, Van Deyk K. Congenital cardiovascular nursing: preparing for the next decade. Cardiol Young. 2009;19(Suppl 2):106–11.
Mora MA, Sparud-Lundin C, Bratt E-L, Moons P. Person-centred transition programme to empower adolescents with congenital heart disease in the transition to adulthood: a study protocol for a hybrid randomised controlled trial (STEPSTONES project). BMJ Open. 2017;7(4):e014593.
Nakhla M, Daneman D, To T, Paradis G, Guttmann A. Transition to adult care for youths with diabetes mellitus: findings from a Universal Health Care System. Pediatrics. 2009;124(6):e1134–e41.
Reid GJ, Irvine MJ, McCrindle BW, Sananes R, Ritvo PG, Siu SC, et al. Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex congenital heart defects. Pediatrics. 2004;113(3):197–205.
Royal College of Nursing. Lost in transition: moving young people between child and adult health services. Royal College of Nursing; 2008. http://www.rcn.org.uk/__data/assets/pdf_file/0010/157879/003227.pdf.
Royal College of Nursing Adolescent Health Forum. Adolescent transition care. Royal College of Nursing; 2004. http://www.rcn.org.uk/__data/assets/pdf_file/0011/78617/002313.pdf.
Royal College of Paediatrics and Child Health. Bridging the gaps: health care for adolescents. London: RCPCH; 2003. http://www.rcpch.ac.uk/sites/default/files/bridging_the_gaps.pdf.
Royal College of Physicians of Edinburgh Transition Steering Group. Think Transition: developing the essential link between paediatric and adult care. Edinburgh: Royal College of Phsicians of Edinburgh; 2008. http://www.rcpe.ac.uk/clinical-standards/documents/transition.pdf.
Sattoe JN, Peeters MA, Hilberink SR, Ista E, van Staa A. Evaluating outpatient transition clinics: a mixed-methods study protocol. BMJ Open. 2016;6(8):e011926.
Sawyer SM, Drew S, Yeo MS, Britto MT. Adolescents with a chronic condition: challenges living, challenges treating. Lancet. 2007;369(9571):1481–9.
Sawyer SM, Afifi RA, Bearinger LH, Blakemore SJ, Dick B, Ezeh AC, et al. Adolescence: a foundation for future health. Lancet. 2012;379(9826):1630–40.
Snow V, Beck D, Budnitz T, Miller DC, Potter J, Wears RL, et al. Transitions of care consensus policy statement: American College of Physicians, Society of General Internal Medicine,

Society of Hospital Medicine, American Geriatrics Society, American College of Emergency Physicians, and Society for Academic Emergency Medicine. J Hosp Med. 2009;4(6):364–70.
Steinbeck KS, Shrewsbury VA, Harvey V, Mikler K, Donaghue KC, Craig ME, et al. A pilot randomized controlled trial of a post-discharge program to support emerging adults with type 1 diabetes mellitus transition from pediatric to adult care. Pediatr Diabetes. 2014;16(8):1–6.
Suris J-C, Akre C. Key elements for, and indicators of, a successful transition: an international Delphi study. J Adolesc Health. 2015;56(6):612–8.
Viner R. Transition from paediatric to adult care. Bridging the gaps or passing the buck? Arch Dis Child. 1999;81(3):271–5.
Watson AR. Problems and pitfalls of transition from paediatric to adult renal care. Pediatr Nephrol. 2005;20(2):113–7.
Watson R, Parr JR, Joyce C, May C, Le Couteur AS. Models of transitional care for young people with complex health needs: a scoping review. Child Care Health Dev. 2011;37(6):780–91.
While A, Forbes A, Ullman R, Lewis S, Mathes L, Griffiths P. Good practices that address continuity during transition from child to adult care: synthesis of the evidence. Child Care Health Dev. 2004;30(5):439–52.
White M, O'Connell MA, Cameron F. Clinic attendance and disengagement of young adults with type 1 diabetes after transition of care from paediatric to adult services (TrACeD): a randomised, open-label, controlled trial. Lancet Child Adolesc Health. 2017;1(4):274–283.
WHO/UNAIDS. Global standards for quality health-care services for adolescents: a guide to implement a standards-driven approach to improve the quality of health-care services for adolescents. Geneva: World Health Organization; 2015.
Yeung E, Kay J, Roosevelt GE, Brandon M, Yetman AT. Lapse of care as a predictor for morbidity in adults with congenital heart disease. Int J Cardiol. 2008;125(1):62–5.