

## Special Issue on Health Care Transitions

## An Evidence Map for Interventions Addressing Transition from Pediatric to Adult Care: A Systematic Review of Systematic Reviews



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## ABSTRACT

**Problem:** Adolescents and young adults with chronic illnesses continue to face barriers as they transition from pediatric to adult care. An evidence map can help to identify gaps in the transition literature to determine targets for future research.

**Eligibility criteria:** We searched PubMed, CINAHL, PsycInfo, and Cochrane for systematic reviews published through February 2018. Eligible reviews included at least one comparative study testing a youth-focused intervention for improving transition with at least one quantitative health-related outcome reported.

**Sample:** We identified 431 unique reviews in our search, and 37 reviews (containing 71 eligible primary studies) met inclusion criteria.

**Results:** Most reviews (20 of 37) summarized some aspect of transition across diagnoses. Type 1 diabetes was the most common diagnosis studied (7 of 37 reviews and 24 of 71 primary studies). Only 14 of 71 primary studies focused on care after transfer to adult care.

**Conclusions:** The literature on interventions to improve transition to adult care has focused on a limited number of diagnoses, most commonly Type 1 diabetes. Common pediatric conditions, such as asthma, have not been studied with regard to transition. Efforts have been mainly targeted on transition preparation, with less focus on transition needs after transfer to adult care.

**Implications:** There is a need for transition research focused on common pediatric conditions and transition needs after transfer to adult care.

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## Background

The transition from pediatric to adult-oriented care can be difficult for adolescents and young adults with chronic illnesses. Adolescents, young adults, and their parents and providers have identified a multitude of barriers to the process (Doyle & Werner-Lin, 2015; Garvey et al., 2013; Gray et al., 2015; Hergenroeder, Wiemann, & Cohen, 2015; Kruszka, Lindell, Killion, & Criss, 2012; Okumura et al., 2010; Wright et al., 2014), and outcomes appear to worsen as adolescents

and young adults leave pediatric care and enter adult care (Mathias et al., 2014; Samuel et al., 2011; Sawicki et al., 2018; Watson, 2000). Guidelines to address the difficulties of transitional care continue to call for more evidence (Brown et al., 2016; White & Cooley, 2018), so that future guidelines can reflect best practices in this area.

An evidence map is a method of systematically collecting and organizing evidence to identify gaps in a particular field of research (Duan-Porter et al., 2016; Miake-Lye, Susanne, Roberta, & Shekelle, 2016). It has been used as one method to guide the future directions of a field and ensure research efforts are going towards areas of need. The methods to generate evidence maps and the data collection and presentation methods in evidence maps have varied (Miake-Lye et al., 2016). Systematic reviews of systematic reviews have been done to generate evidence maps (Singh et al., 2012). The aim of this paper is to conduct a systematic review of previously published systematic reviews that evaluated the transition from pediatric to adult care and contained interventions to improve that transition, with the goal of generating an

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evidence map to identify gaps in the transition literature and directions for future research.

## Methods

Following PRISMA reporting guidance (Moher, Liberati, Tetzlaff, Altman, & Group, 2009), we performed a systematic review looking specifically for systematic reviews related to transition from pediatric to adult care and then qualitatively synthesized the information from those reviews to generate an evidence map.

### Eligibility criteria

A full description of eligibility criteria can be found in Appendix A. Eligible populations included adolescents and young adults with any chronic illness. The included reviews did not have to be focused on transition interventions per se, but needed to have at least one study included in the review that evaluated an intervention that met all eligibility criteria. We chose a priori to focus on interventions based in clinical care to retain a focus on the health care transition, rather than other life transitions, like the move from high school to college. Any intervention focused on the transition from pediatric to adult care in the clinical setting was acceptable. Any quantitative health-related outcomes, including patient-reported outcomes, could be measured. These could include measures of disease control, changes in rate of patient follow-up, and patient knowledge and transition readiness. Any comparison was eligible, but simple program descriptions without comparisons were excluded. The studies could be of any duration.

### Search strategy

The databases searched for this systematic review were PubMed, Cochrane, CINAHL, and PsycInfo. Library staff were consulted to ensure searches were constructed properly for each database, including proper use of the systematic review or review filters as appropriate for each. Exact search terms and limits are provided in Appendix B. The initial PubMed, Cochrane, CINAHL, and PsycInfo searches were completed in November 2016 with an updated search in February of 2018. PROSPERO was searched in November of 2016 and in May of 2018.

The international prospective register of systematic reviews – PROSPERO (Booth et al., 2012) – was searched for registered systematic reviews relevant to the topic using a search for all reviews of any status with “transition” in the title and reviews that used the “transition to adult care” as a MeSH term.

To supplement our electronic searches, when an included systematic review cited other previously published systematic reviews, the included reviews were checked against search results and reviewed for eligibility. We also supplemented searches with a review of one of the author’s personal files (LCH). These additional searches led to one additional review that met final inclusion criteria.

### Study selection

Once the original search was complete, duplicates were removed. Two investigators (LCH, SVPN, or MGM) then independently reviewed titles and abstracts as an initial screen of search results. This was followed by dual review of full-text articles to determine eligibility using pre-specified criteria. Discrepancies were resolved either through consensus between authors or with consultation with another author (DEJ).

### Data extraction

Data abstraction occurred in two main phases. In the initial phase of data abstraction, each review was examined to determine which individual papers included in the review met the inclusion criteria. With

this complete, each review could then be examined with regard to the following information: aim of the review, type of synthesis used in the review (qualitative vs. quantitative), diagnoses of interest for the review (if any), number of papers included, number of included papers meeting our review’s inclusion criteria, number of included papers that were RCTs, number of included papers focused in adult-oriented care, and number of included papers from primary care. Each review and article were abstracted by one of the authors (LCH, SVPN or MGM), and this abstraction was reviewed for accuracy and completeness by a second author (LCH, SVPN, or MGM).

### Assessment of methodologic quality

Each article was scored utilizing the “assessment of multiple systematic reviews” (AMSTAR) criteria for assessing quality of systematic reviews, version 1 (Shea et al., 2009). Reviews were scored on 11 criteria, with each of the criteria being worth 0 or 1 point. An overall score was determined by adding up the points, where reviews with an AMSTAR score of 8 to 11 were considered high quality, reviews with a rating of 4 to 7 were considered to be of fair quality, and reviews with a score of 3 or less were considered to be of poor quality (CADTH, 2011; Marchi, Berg, Dencker, Olander, & Begley, 2015; Sharif, Janjua-Sharif, & Hesham, 2013).

### Data synthesis and evidence map development

Data was synthesized qualitatively, in tabular and narrative format, because of the clinical and methodological heterogeneity of the included reviews. To develop the evidence map, we summarized the reviews in the following ways. First, we tallied the number of reviews and trials published each year to describe the trend in numbers over time. We also tallied the number of reviews and trials that addressed specific diagnoses to identify health conditions with more or less focus. Reviews were also described based on the goal of the review, such as a general literature summary, a focus on transition interventions, or with a goal to generate a model of transition.

The papers focused on primary care and adult care were also described in further detail to understand gaps in these specific areas.

### Protocol and registration

The study protocol was registered on PROSPERO (<https://www.crd.york.ac.uk/prospéro/>) in September of 2016 (Protocol Number CRD42016046808). Because this was a systematic review of publicly available published literature, no IRB approval was required.

## Results

### Search results

A total of 431 unique citations were identified (Fig. 1). Thirty seven reviews met inclusion criteria (Betz, 2004; Betz, Nehring, & Lobo, 2015; Betz, O’Kane, Nehring, & Lobo, 2016; Bhawra, Toulany, Cohen, Moore Hepburn, & Guttmann, 2016; Bloom et al., 2012; Cairo et al., 2018; Campbell et al., 2016; Chu, Maslow, von Isenburg, & Chung, 2015; Clemente, Leon, Foster, Minden, & Carmona, 2016; Coyne, Hollowell, & Thompson, 2017; Coyne, Sheehan, Heery, & White, 2017; Crowley, Wolfe, Lock, & McKee, 2011; Davis, Brown, Julie, Epstein, & McPheeters, 2014; Doug et al., 2011; Embrett, Randall, Longo, Nguyen, & Mulvale, 2016; Farrell, Griffiths, & Fernandez, 2014; Forbes et al., 2002; Gabriel, McManus, Rogers, & White, 2017; Gray, Schaefer, Resmini-Rawlinson, & Wagoner, 2017; Hollowell, 2014; Hanna & Woodward, 2013; Hussen et al., 2014; Hynes et al., 2016; Kerr, Price, Nicholl, & O’Halloran, 2017; Lewis & Slobodov, 2015; Lugasi, Achille, & Stevenson, 2011; Nakhla, Daneman, Frank, & Guttmann, 2008; O’Hara et al., 2017; Paul, Street, Wheeler, & Singh, 2015; Prior, McManus,

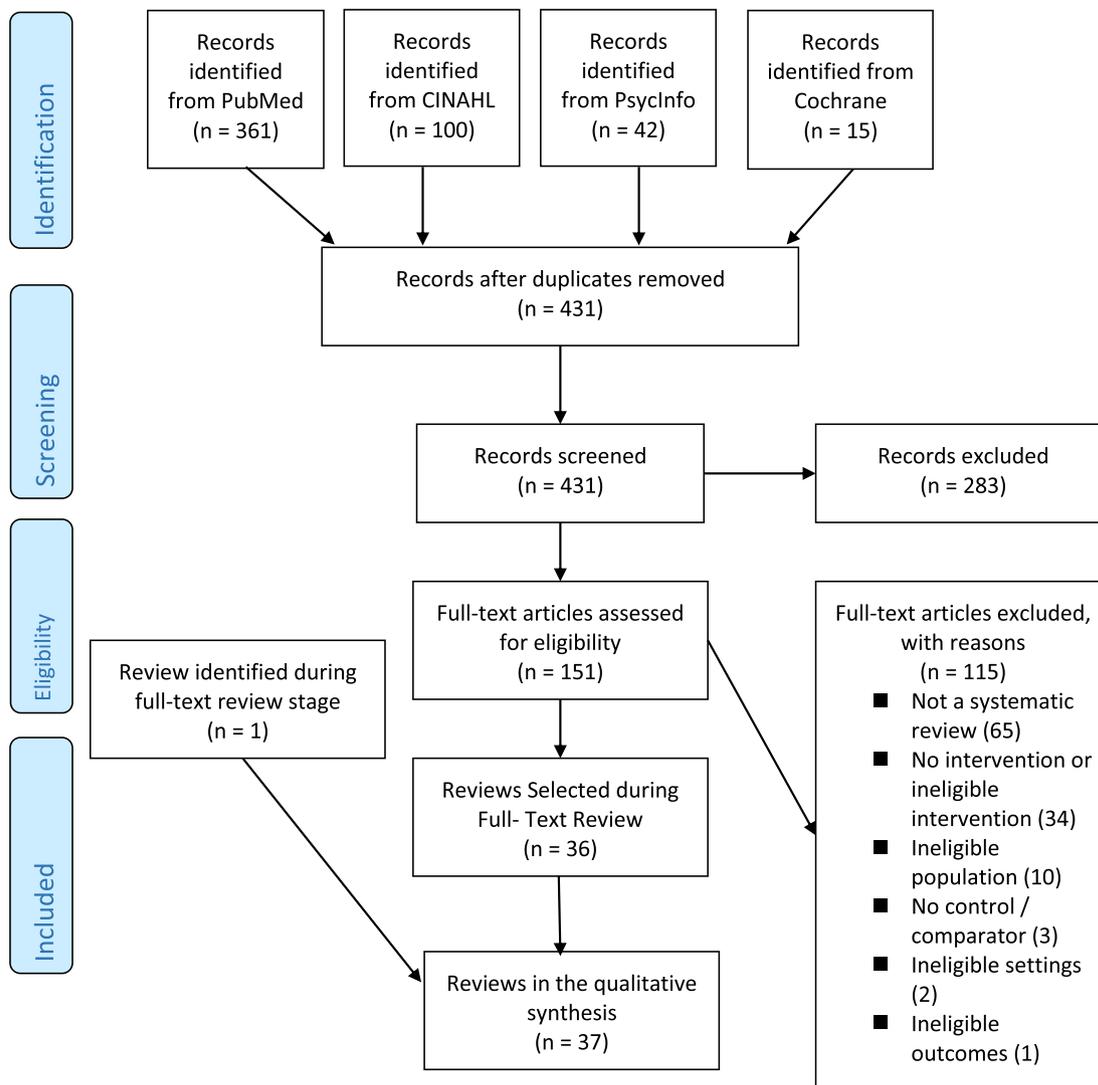


Fig. 1. PRISMA flow diagram.

White, & Davidson, 2014; Rachas et al., 2016; Raina, Wang, Krishnappa, & Ferris, 2018; Schultz & Smaldone, 2017; Sheehan, While, & Coyne, 2015; Wang, McGrath, & Watts, 2010; Watson, Parr, Joyce, May, & Le Couteur, 2011; While et al., 2004; Zhou, Roberts, Dhaliwal, & Della, 2016). Two of the papers used the same review results (Forbes et al., 2002; While et al., 2004) and so we describe them as a single review (the Forbes/While review) here. Of the 115 reviews that were excluded, 65 were excluded due to not being a systematic review (e.g. they did not include a systematic search or have a methods section). See Appendix C for list of excluded reviews.

#### Data synthesis

As shown in Table 1, all of the reviews used a qualitative data synthesis, though one review (Schultz & Smaldone, 2017) did have some quantitative synthesis as well. The number of primary studies each review included varied widely (range: 10–126, median: 19). The number of primary studies in each review that met our review inclusion criteria also varied (range: 1–38, median: 5). In only three of the reviews did all of the studies the authors included meet our eligibility criteria (Campbell et al., 2016; Chu et al., 2015; Schultz & Smaldone, 2017). AMSTAR scores varied across reviews, with a range of 3 to 11, and a median score of 7. Twelve of the 37 identified reviews were of high quality (Betz et al., 2015; Betz et al., 2016; Campbell et al., 2016; Clemente et al.,

2016; Doug et al., 2011; Farrell et al., 2014; Forbes et al., 2002; Gray et al., 2017; Hallowell, 2014; Kerr et al., 2017; O'Hara et al., 2017; Paul et al., 2015; While et al., 2004). Among those that were not high quality (n = 25), none assessed the likelihood of publication bias and none included a list of excluded studies. Other common methodologic concerns for the fair-to-poor quality reviews were not including the gray literature in their review, not assessing the quality of studies, and/or not using duplicate study selection and data abstraction at each step in the process of the review. Only one of the fair-to-poor quality reviews looked in the gray literature (Davis et al., 2014), and 12 of the fair-to-poor quality reviews assessed the quality of the included studies (Bhawra et al., 2016; Coyne, Hallowell, & Thompson, 2017; Coyne, Sheehan, et al., 2017; Embrett et al., 2016; Gabriel et al., 2017; Hanna & Woodward, 2013; Hynes et al., 2016; Nakhla et al., 2008; Rachas et al., 2016; Schultz & Smaldone, 2017; Sheehan et al., 2015; Zhou et al., 2016). A total of three of the fair-to-poor quality reviews had duplicate review and abstraction described for each step of the review (Chu et al., 2015; Embrett et al., 2016; Prior et al., 2014).

A total of 71 unique primary studies were identified as eligible from the 37 reviews (Appendix D) (Akchurin, Melamed, Hashim, Kaskel, & Del Rio, 2014; Annunziato et al., 2007; Annunziato et al., 2013; Annunziato et al., 2015; Bashore & Bender, 2016; Bauman, Kuhle, Bruce, Bolster, & Massicotte, 2016; Bent et al., 2002; Betz, Smith, & Macias, 2010; Brotzman, Blake, Myers, & Reece, 2001; Bundock et al.,

**Table 1**  
Summary of characteristics of included systematic reviews.

Author (year)	Diagnosis targeted (if any)	Review focus	Synthesis method	AMSTAR rating (out of a possible 11)	Total papers in the review, n	Papers meeting inclusion criteria, n	Number of RCTs among included papers, n	Number of adult-care specific interventions among included papers, n	Number of primary care interventions among included papers, n
Betz (2004)	None	General literature summary	Qualitative	7	43	5	0	0	0
While et al./Forbes et al. (2002)	None	Transition Interventions	Qualitative	8	126	4	0	0	0
Nakhla et al. (2008)	Type 1 diabetes	General literature summary	Qualitative	6	16	6	2	0	0
Wang et al. (2010)	None	Generate a model of transition	Qualitative	5	46	1	0	0	0
Crowley et al. (2011)	None	Transition interventions	Qualitative	5	10	8	3	0	0
Doug et al. (2011)	None	General literature summary focused on palliative care	Qualitative	8	92	2	0	0	0
Lugasi et al. (2011)	None	Patient, family, and/or provider experience	Qualitative meta-summary	5	46	13	2	0	0
Watson et al. (2011)	Cerebral palsy, autism, and Type 1 diabetes	Transition interventions	Qualitative	5	19	9	0	3	0
Bloom et al. (2012)	None	Transition outcomes	Qualitative	5	15	5	0	0	0
Hanna and Woodward (2013)	Type 1 diabetes	Literature quality assessment	Qualitative	7	39	12	0	4	0
Davis et al. (2014)	None	Transition Interventions	Qualitative	7	30	25	2	4	0
Farrell et al. (2014)	Type 1 diabetes	Transition outcomes	Qualitative	10	13	9	0	2	0
Hallowell (2014)	Congenital Heart disease	General literature summary	Qualitative	8	13 <sup>a</sup>	3 <sup>a</sup>	0	0	0
Paul et al. (2015)	Mental health diagnoses	Multiple (interventions and barriers and/or facilitators)	Qualitative	8	19	3	0	2	0
Prior et al. (2014)	None	Transition outcomes	Qualitative	7	33	29	1	8	2
Betz et al. (2015)	None	General literature summary focused on parents	Qualitative	8	47	3	1	0	0
Chu et al. (2015)	None	Transition interventions	Qualitative	6	5	5	1	2	0
Hussen et al. (2014)	HIV	General literature summary	Qualitative	5	15	2	0	0	0
Lewis and Slobodov (2015) <sup>35</sup>	Spina bifida	General literature summary	Qualitative	4	15	2	1	0	0
Sheehan et al. (2015)	Type 1 diabetes	Patient, family, and/or provider experience	Qualitative	7	46	14	0	6	0
Betz et al. (2016)	None	Transition interventions	Qualitative	8	17	13	0	3	0
Bhawra et al. (2016)	None	Transition interventions in primary care	Qualitative	6	3	1	0	0	1
Campbell et al. (2016)	None	Transition interventions	Qualitative	11	4	4	4	1	0
Clemente et al. (2016)	Rheumatologic disorders	Transition interventions	Qualitative	8	27	5	0	0	0
Embrett et al. (2016)	Mental health disorders	Transition interventions	Qualitative	7	6	1	0	1	0
Hynes et al. (2016)	Type 1 diabetes	Barriers and/or facilitators	Qualitative	6	12	6	0	2	0
Rachas et al. (2016)	None	Transition outcomes	Qualitative	7	24	9	1	1	0
Zhou et al. (2016)	None	General literature summary for the years 2010–2014	Qualitative	6	61	2	1	0	0
Coyne, Hallowell, and Thompson (2017)	None	Transition outcomes	Qualitative	7	19	10	1	2	0
Coyne, Sheehan, et al. (2017)	Cystic fibrosis	Patient, family, and/or provider experiences	Qualitative	7	21	5	0	0	0
Gabriel et al. (2017)	None	Transition interventions	Qualitative	7	43	38	2	4	0
Gray et al. (2017)	None	Barriers and/or facilitators	Qualitative	8	56	5	0	0	0
Kerr et al. (2017)	None	Generate a model	Qualitative	8	78	6	1	0	0
O'Hara et al. (2017)	Type 1 diabetes	Transition interventions	Qualitative	8	18	5	0	5	0
Schultz and Smaldone (2017)	Type 1 diabetes	Transition interventions	Qualitative and quantitative	7	18	18	1	5	0
Cairo et al. (2018)	Obesity	General literature summary	Qualitative	3	53 <sup>b</sup>	**b	**b	**b	**b
Raina et al. (2018)	Renal transplant	Transition interventions	Qualitative	4	10	5	0	1	0

<sup>a</sup> The aim of the review was to focus on congenital heart disease originally. Due to little research focused on CHD at the time, included studies could cover any diagnosis, and in fact, none of the included papers focused on youth with CHD.

<sup>b</sup> No list of included studies provided in review manuscript, so cannot determine an exact number of eligible studies. Per the paper's PRISMA figure, 53 articles met the authors' inclusion criteria.

2011; Busse et al., 2007; Cadario et al., 2009; Chaturvedi, Jones, Walker, & Sawyer, 2009; Chaudhry, Keaton, & Nasr, 2013; Cole, Ashok, Razack, Azaz, & Sebastian, 2015; Cuttill, Hilton, & Drew, 2005; Dabadie et al., 2008; Dugueperoux et al., 2008; Dyrlov et al., 2000; Egan, Corrigan, & Shurpin, 2015; Fredericks et al., 2015; Gilmer, Ojeda, Fawley-King, Larson, & Garcia, 2012; Gimenez et al., 2013; Gleeson, Davis, Jones,

O'shea, & Clayton, 2013; Gravelle, Paone, Davidson, & Chilvers, 2015; Greveson, Morgan, Furman, & Murray, 2011; Haber, Karpur, Deschênes, & Clark, 2008; Hankins et al., 2012; Harden et al., 2012; Hilderson et al., 2016; Holmes-Walker, Llewellyn, & Farrell, 2007; Hommel, Birthe, Anne, & Jannet, 2012; Huang et al., 2014; Jensen et al., 2015; Johnston, Bell, Tennen, & Carson, 2006; Kipps et al., 2002;

Lane et al., 2007; Levy-Shraga et al., 2016; Logan et al., 2008; Mackie et al., 2014; Manteuffel, Stephens, Sondheimer, & Fisher, 2008; Markowitz & Laffel, 2012; Maslow et al., 2013; McDonagh, Shaw, & Southwood, 2006; McDonagh, Southwood, & Shaw, 2007; McQuillan, Toulany, Kaufman, & Schiff, 2015; Nakhla, Daneman, To, Paradis, & Guttman, 2009; Nieboer et al., 2014; Okumura et al., 2014; Orr, Fineberg, & Gray, 1996; Pape et al., 2013; Prestidge, Romann, Djurdjev, & Matsuda-Abdini, 2012; Rapley, Babel, Kaye, & Brown, 2013; Rapley, Hart, Babel, & Kaye, 2007; Remorino & Taylor, 2006; Rettig & Athreya, 1991; Sawyer et al., 1998; Schmidt, Herrmann-Garitz, Bomba, & Thyen, 2016; Sequeira et al., 2015; Shaw, Southwood, & McDonagh, 2007; Smith, Lewis, Whitworth, Gold, & Thornburg, 2011; Steinbeck et al., 2015; Steinkamp, Ullrich, Müller, Fabel, & Von Der Hardt, 2001; Styron et al., 2006; Van Wallegghem, MacDonald, & Dean, 2008, 2011, 2012; Vanelli et al., 2004; Vidal et al., 2004; Weitz, Heeringa, Neuhaus, Fehr, & Laube, 2015; Wiener, Battles, Ryder, & Zobel, 2007). Eligible primary studies contained a wide range of participants (range: 6 to 3613, median: 67). Outcomes of interest varied. Some studies focused on health outcomes like emergency visits, hospitalizations, clinic attendance, graft survival, and mortality, other focused on intermediate outcomes, like hemoglobin A1c (HbA1c) or tacrolimus levels. Many included patient-reported outcomes, like patient knowledge, self-reported transition readiness, or quality of life. Some also included patient satisfaction.

Papers were often cited in multiple reviews, with a median of 3 reviews citing a paper (range: 1 to 15). Among the eligible papers, there were four unique RCTs (Betz et al., 2010; Huang et al., 2014; Mackie et al., 2014; Steinbeck et al., 2015), 14 unique papers with a primary focus on adult-based care (Brotzman et al., 2001; Gilmer et al., 2012; Haber et al., 2008; Holmes-Walker et al., 2007; Johnston et al., 2006; Lane et al., 2007; Markowitz & Laffel, 2012; Pape et al., 2013; Rapley et al., 2013; Steinbeck et al., 2015; Styron et al., 2006; Van Wallegghem et al., 2008, 2011, 2012), and one with a focus on primary care (Brotzman et al., 2001). The paper focused in primary care was also focused on adult providers only (Brotzman et al., 2001). The papers not focused on adult care were either focused entirely on pediatric care ( $n = 20$ ) or had elements of pediatric and adult care involved ( $n = 38$ ). Nearly half of the primary studies (34) were published between 2012 and 2016 (Fig. 2).

### Evidence map

The overall number of systematic reviews included per year increased over time, with over half of the identified reviews having been published in 2014 or later (Fig. 2). Most of the reviews (20) did not focus on a specific diagnosis (Fig. 3). Among those that did, type 1 diabetes was most commonly the diagnosis of interest, with seven reviews focused on type 1 diabetes (Farrell et al., 2014; Hanna & Woodward, 2013; Hynes et al., 2016; Nakhla et al., 2008; O'Hara et al., 2017; Schultz & Smaldone, 2017; Sheehan et al., 2015), followed by two reviews focused on mental health problems (Embrett et al., 2016; Paul et al., 2015). Reviews most commonly sought to describe transition interventions (14 of the 37 reviews overall and 8 of the 20 reviews without a diagnosis of interest) (Fig. 4). The next most common focus was a review of the literature in general (9 of the 37 total reviews and 4 of the 20 reviews without a specific diagnosis of interest).

The diagnosis of interest in the primary studies varied (Fig. 5), with type 1 diabetes featuring most prominently (24 of the 71 primary studies) (Busse et al., 2007; Cadario et al., 2009; Cuttelli et al., 2005; Dyrlov et al., 2000; Egan et al., 2015; Gimenez et al., 2013; Holmes-Walker et al., 2007; Hommel et al., 2012; Johnston et al., 2006; Kipps et al., 2002; Lane et al., 2007; Levy-Shraga et al., 2016; Logan et al., 2008; Markowitz & Laffel, 2012; Nakhla et al., 2009; Orr et al., 1996; Rapley et al., 2007; Rapley et al., 2013; Sequeira et al., 2015; Steinbeck et al., 2015; Van Wallegghem et al., 2008, 2011; Vanelli et al., 2004; Vidal et al., 2004). A total of 6 studies included participants with multiple diagnoses (Bent et al., 2002; Bundock et al., 2011; Huang et al., 2014; Maslow et al., 2013; Nieboer et al., 2014; Schmidt et al., 2016), such as a study that included participants with a physical disability from a number of possible causes (cerebral palsy, spina bifida, neurodegenerative diseases) (Bent et al., 2002) and another that included participants with inflammatory bowel disease, cystic fibrosis, or type 1 diabetes (Huang et al., 2014). Some studies included participants with one of a group of similar diagnoses, such as the six studies that focused on rheumatologic disorders (Hilderson et al., 2016; Jensen et al., 2015; McDonagh et al., 2006; McDonagh et al., 2007; Rettig & Athreya, 1991; Shaw et al., 2007) and the four studies that focused on mental health diagnoses in general (Gilmer et al., 2012; Haber et al., 2008; Manteuffel et al., 2008; Styron et al., 2006).

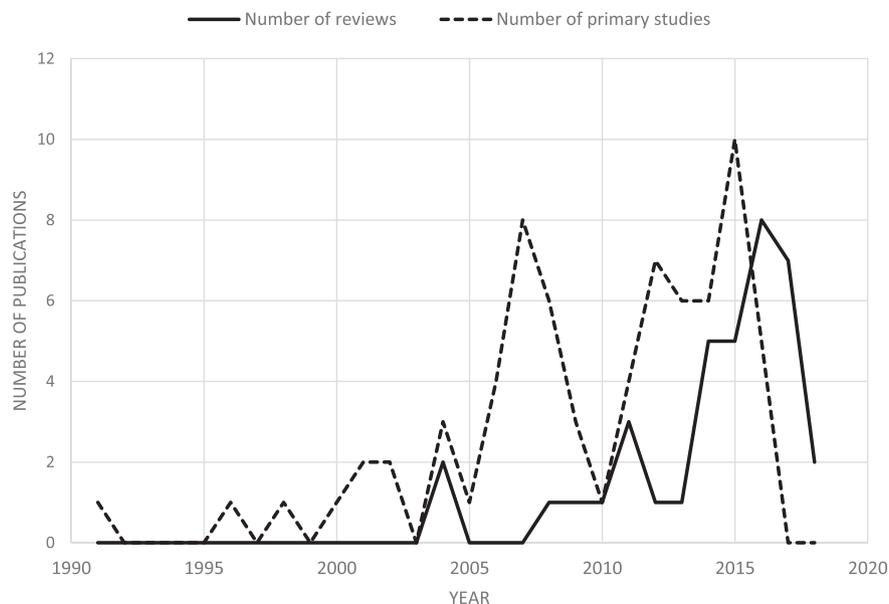


Fig. 2. Number of reviews and primary studies included by year.

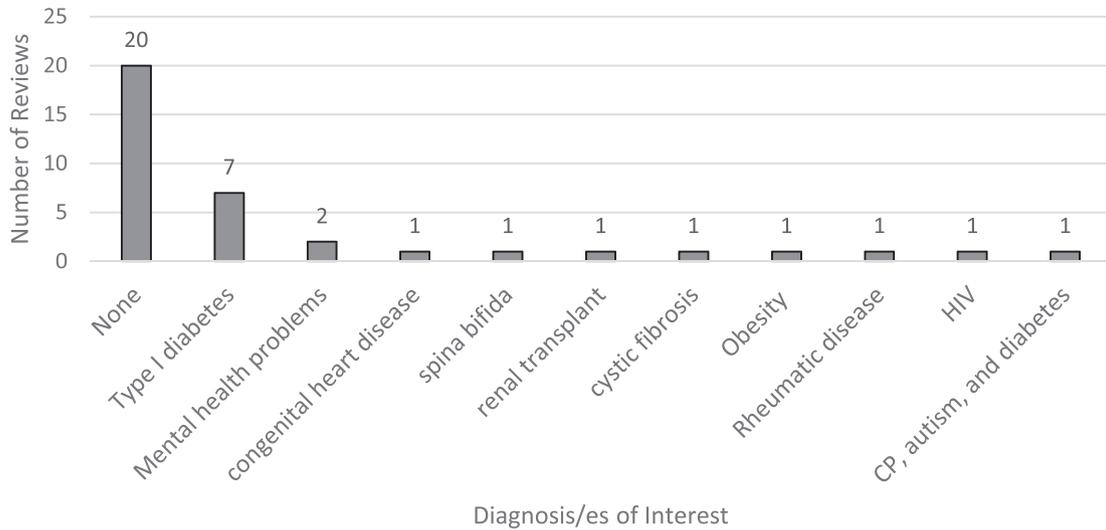


Fig. 3. Number of reviews by diagnosis of interest.

We identified four RCTs in the included reviews (Betz et al., 2010; Huang et al., 2014; Mackie et al., 2014; Steinbeck et al., 2015). Three of these assessed educational interventions (Betz et al., 2010; Huang et al., 2014; Mackie et al., 2014), with two (Betz et al., 2010; Mackie et al., 2014) providing in-person disease education and one (Huang et al., 2014) delivering educational material via a web-based platform and text messaging. The fourth RCT provided standardized telephone support at regular intervals for a year after transfer to adult care and was based in adult care (Steinbeck et al., 2015).

Among the 14 primary studies focused on improving transitional care exclusively on the adult side of the transition, seven were either specifically testing a young-adults-only clinic/service or had a young-adults-only clinic

as a major piece of the intervention (Gilmer et al., 2012; Haber et al., 2008; Holmes-Walker et al., 2007; Johnston et al., 2006; Lane et al., 2007; Rapley et al., 2013; Styron et al., 2006). Care navigation, case management, and transition coordination also feature prominently, with 7 of the 14 primary studies on adult transition support including this type of service (Brotzman et al., 2001; Holmes-Walker et al., 2007; Rapley et al., 2013; Styron et al., 2006; Van Wallegghem et al., 2008, 2011, 2012).

A single paper focused on primary care after transfer to adult care evaluated a primary care home for young adults with sickle cell disease. It found non-significant reductions in emergency department use and a non-significant increase in the number of patients on hydroxyurea (Brotzman et al., 2001).

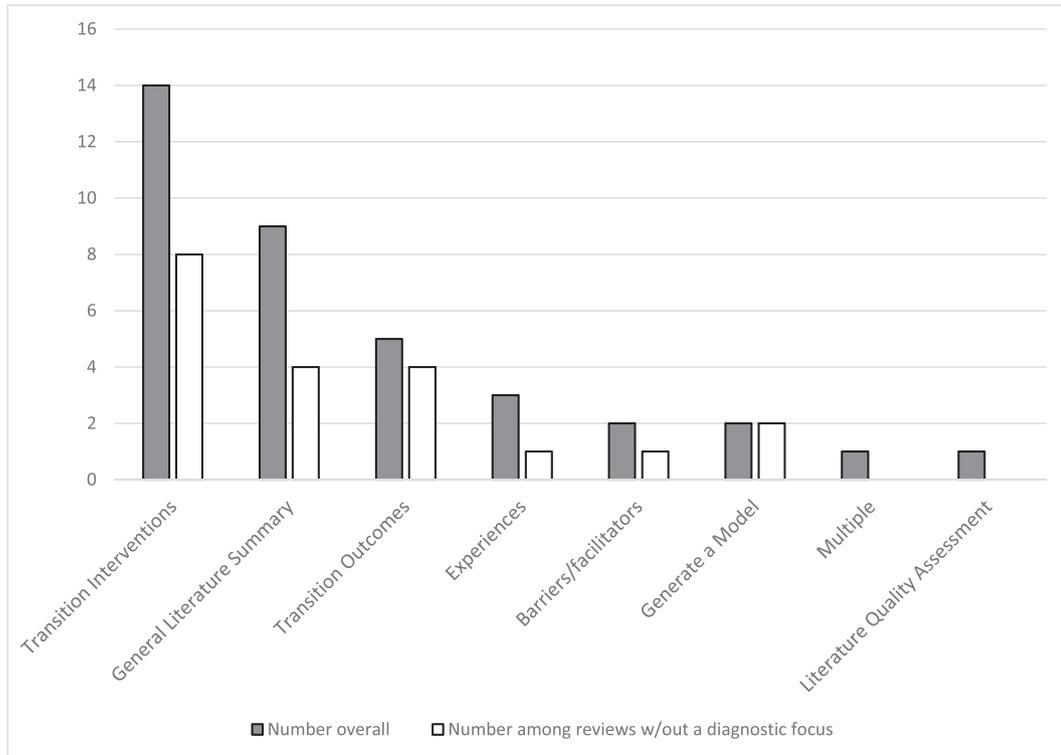
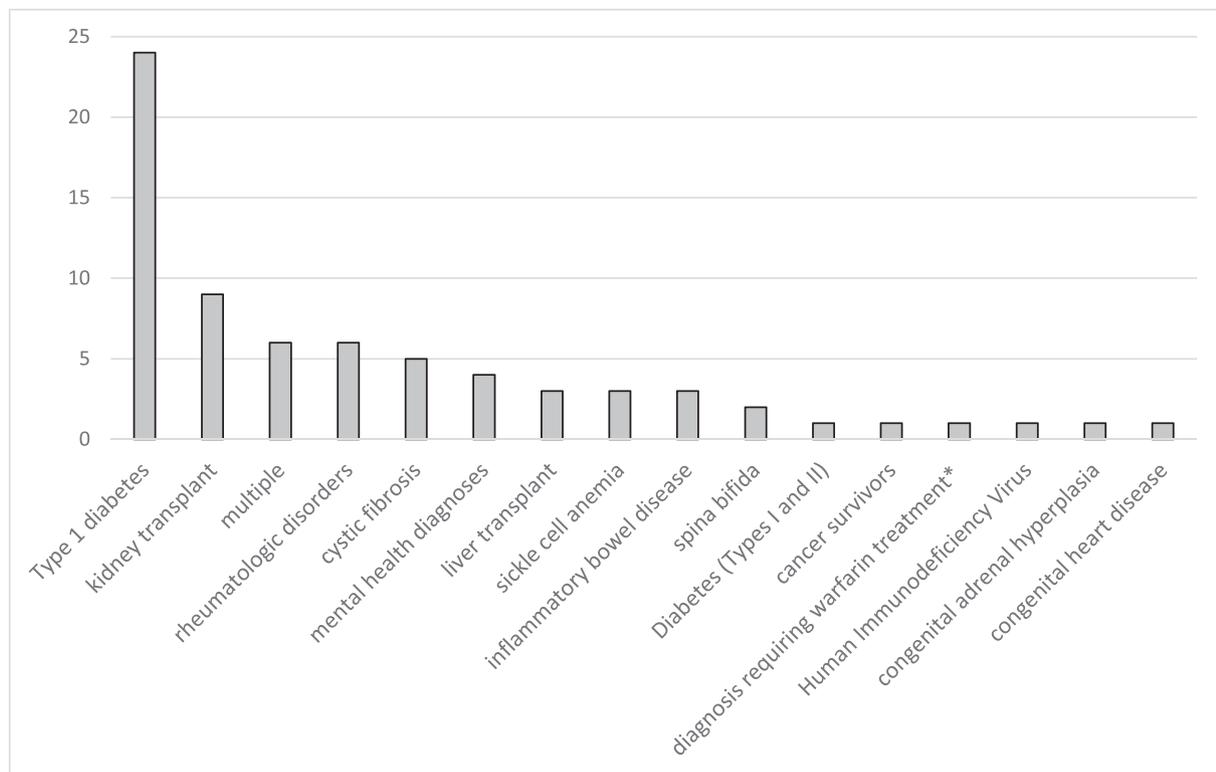


Fig. 4. Topical focus of the systematic reviews, both overall and among reviews without a diagnosis of interest.



\* ex. Artificial heart valve, history of deep vein thrombosis, etc.

Fig. 5. Counts of primary studies by their diagnosis of interest. \* ex. Artificial heart valve, history of deep vein thrombosis, etc.

## Discussion

In this review of systematic reviews, we were able to provide an evidence map showing the focus of the transitional care intervention literature and to identify gaps in that literature. Notably, there was significant emphasis on type 1 diabetes, both among the reviews and the trials included in those reviews. More common childhood-onset conditions, like asthma, ADHD, autism, and depression have not been reviewed specifically, though interventions for mental health transition generally have been assessed. Research regarding transition for patients with these more common conditions is needed.

The lack of papers focused on transition in primary care settings is another gap to address in future transition research. Research in this realm should be done thoughtfully, and with full knowledge of the available transition research done to date. Some of the interventions in specialty settings can be resource intensive, such as a social worker who is specifically focused on transitioning patients or “dual visits” where both the pediatric and adult provider see the patient at the same time, but only one physician can be paid. These have been well-received by patients and families, but are difficult to translate directly to primary care. The “Got Transition” tools ([GotTransition](#)) provide an excellent set of supports and guides for both primary care and specialty care practices to initiate transitional care quality improvement (QI) in their practices and have been associated with clinic process improvements when initiated in primary care offices ([McManus et al., 2015](#); [White, McManus, McAllister, & Cooley, 2012](#)). When considering research in primary care transition, investigators are encouraged to test novel interventions that would augment or adapt the previous transition work that has been done. They might also consider tailoring the general guidance on best transition practices to the unique needs of particular populations.

We suggest that research in transition consider a wider breadth of interventions in the adult realm. While several papers covered young-

adult specific clinics and care navigation, either alone or in combination, there may be other tools that support transition in the adult care realm that could be tested (e.g., provider education, efforts by adult clinics to re-schedule missed appointments, meetings with a social worker at the first visit). Again, the “Got Transition” tools offer some good guidance for QI for adult-focused care, but as the recent AAP clinical report noted, and this review reinforced, integration into adult care and measurement of longer-term outcomes for young adults with childhood-onset conditions after their transfer to adult care are key needs ([White & Cooley, 2018](#)).

We were unable to find reviews focused on individual mental health diagnoses, such as depression or anxiety, distinct from reviews focused on all mental health diagnoses. The transition needs of those with depression or anxiety may be different from those with more severe mental illness, such as bipolar disorder or schizophrenia. A more nuanced review or set of reviews looking at mental health diagnoses individually may allow for greater understanding of the similar and unique transition needs of these populations.

There was significant variability in the quality of the reviews, with many reviews not assessing the gray literature, the quality of the included studies, or the risk of publication bias. In fact, none of the reviews rated as being of fair-to-poor quality assessed for risk of publication bias. While the AMSTAR criteria have been updated, all of these elements continue to be important, with assessment of the quality of the included studies and assessment for risk of publication bias considered critical elements of the systematic review ([Shea et al., 2017](#)). Future reviews, therefore, should include these elements.

As far as we can tell, none of the reviews were registered in PROSPERO, a systematic review tracking system, similar to [clinicaltrials.gov](#) for clinical trials ([Booth et al., 2012](#)). We recommend that future systematic reviews on transition consider this for two reasons. First, protocol registration is now considered a critical element of a systematic review in the AMSTAR 2 criteria ([Shea et al., 2017](#)). Second,

this may help reviewers avoid duplication of work. As our results noted (Table 1), the Shultz and O'Hara reviews were both focused on transition interventions for those with Type 1 diabetes and were both published in 2017, suggesting that these two groups were doing very similar work at the same time (O'Hara et al., 2017; Schultz & Smaldone, 2017). Protocol registration in PROSPERO may have prevented this duplication of effort. Similarly, consistent registration of protocols in PROSPERO will also allow those seeking to do new reviews to be aware of past work, which seems to have been lacking in the reviews we found. Notably, both the Paul and Embrett reviews were focused on mental health transition. The Embrett review, which was published later, had only one eligible study for our review, whereas the Paul review had three (Embrett et al., 2016; Paul et al., 2015). Embrett et al. did their search in August 2013, before the Paul review was published. Had the protocol been registered, they may have been able to incorporate the Paul review findings into their review.

There are limitations to this review. We limited to English-language studies. We used the original AMSTAR criteria, rather than AMSTAR 2. The AMSTAR 2 criteria were not available at the time of our initial data abstraction. Because we identified trials based on what previously identified reviews found, we may have missed some primary trials in this review. Since our primary aim was to generate an evidence map by systematically reviewing previous reviews, this was a natural consequence of our methodology. A future systematic review could consider focusing additional searches of all primary studies.

As another limitation, our review did not identify primary studies focused on conditions like asthma, ADHD, and autism, suggesting that there may not be much in the transition literature on these diagnoses. That being said, the reviews specifically targeting mental health transition (Embrett et al., 2016; Paul et al., 2015) found primary studies that the reviews targeting interventions or transition in general did not. So it is possible that a targeted review on the more common pediatric-onset diagnoses, like asthma or ADHD, may find trials not previously identified in existing reviews, which our review missed.

In conclusion, through use of a systematic review of systematic reviews methodology, we were able to generate an evidence map to guide future research in transition. Notable gaps are a lack of transition interventions focused on patients with disorders commonly seen in children and adolescents, like asthma and ADHD, as well as a lack of interventions focused on the adult care portion of transition and a lack of interventions focused on primary care settings. Future work should consider addressing the gaps noted.

### Authorship statement

Dr. Laura Hart contributed to conceptualization of the review, data acquisition and analysis, writing of the original draft, and review and editing of the manuscript.

Dr. Sonya Patel-Nguyen contributed to refining of the methodology, data acquisition and analysis and editing of the manuscript.

Dr. Meredith Merkle contributed to data acquisition and analysis and editing of the manuscript.

Dr. Daniel Jonas contributed to conceptualization of the review, data adjudication and analysis, study supervision, and review and editing of the manuscript.

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### Declaration of Competing Interest

The authors have no conflicts of interest to report.

## Appendix A. Systematic review eligibility criteria<sup>a</sup>

	Inclusion	Exclusion
Population	Adolescents and young adults (defined as ages 13 to 24) with a chronic physical or mental illness or physical, intellectual, or developmental disability	Parents/caregivers, of these patients. <b>Notes:</b> Studies with some participants older or younger than the target age range were eligible, as long as they included participants in the target age range as well.
Intervention	Any intervention related to the healthcare transition from pediatric to adult-oriented care (examples include: transition education/training, self-management training, care coordination, shared care, introduction to adult team prior to transfer)	Studies that did not have an intervention and were only observational. Studies focused on education or vocational transition interventions were also excluded.
Comparator	Usual care, transfer letter alone, scheduling an adult visit. Pre-post testing also acceptable.	Studies that did not have a comparator or included a comparison unrelated to the intervention.
Outcomes	Any quantitative health-related outcome (examples: time to transfer, measures of disease control (such as HbA1C), proportion of patients transferred, mortality, patient reported outcomes, ER utilization).	No specific quantitative outcome excluded. Studies with no outcomes reported excluded. Qualitative outcomes excluded.
Timing (of outcome)	Any timing acceptable	
Time range of literature review	From 1990 through March 2016	<b>Notes:</b> Systematic reviews must be published in the review time range. Included systematic reviews need to have some, but not all included studies in the time range.
Settings	Primary care or subspecialty clinic	Healthcare systems. Public health interventions were also excluded.
Study designs allowed <sup>b</sup>	Systematic Reviews written in English covering the topic of transition. The practice guidelines and consensus statements that include the elements of a systematic review. <sup>c</sup>	RCTs, case-control, cohort studies; narrative reviews. Articles written in languages other than English. The practice guidelines and consensus statements that include the elements of a systematic review. <sup>c</sup>

<sup>a</sup> Reviews had to meet all criteria for inclusion. That is, if the focus of the intervention was the parent, but the outcome was focused on the adolescent/young adult, the review would be excluded due to interventions not being targeted to the population of interest.

<sup>b</sup> If a particular systematic review includes some articles that meet inclusion criteria and some articles that do not, the review will be included.

<sup>c</sup> These types are articles are addressed in the inclusion and exclusion criteria as they are captured as part of the PubMed filter for systematic reviews.

## Appendix B. Search strategies

Database	Search strategy
PubMed	Search string: (adolescenc*[tw] OR young adult*[tw] OR teen*[tw]) AND (transition*[tw] OR transfer*[tw] OR continuity[tw]) AND (pediatric*[tw] OR paediatric*[tw] OR health service*[tw]). Limits: Systematic Review Filter
Cochrane	Search string: (transition* OR transfer* OR continuity OR continuum) AND (pediatric* OR paediatric* OR child OR adolescen*) AND adult AND (Health Services OR health service* OR medical care OR health care OR healthcare). Limits: Cochrane reviews and other reviews
CINAHL	Search string: (transition* OR transfer* OR continuity OR continuum) AND (pediatric* OR paediatric* OR child OR adolescen*) AND adult) AND ((MH "Health Services+") OR health service* OR medical care OR health care OR healthcare). Limits: Systematic Reviews publication type.
PsycInfo	Search string: (transition* OR transfer* OR continuity OR continuum) AND (pediatric* OR paediatric* OR child OR adolescen*) AND adult) AND ((DE "Health Care Services" OR DE "Continuum of Care" OR DE "Long Term Care" OR DE "Mental Health Services" OR DE "Palliative Care" OR DE "Primary Health Care") OR health service* OR medical care OR health care OR healthcare). Limits: Systematic review methodology

## Appendix C. List of excluded reviews

Reference	Reason for exclusion
Standards of medical care for patients with diabetes mellitus. <i>Diabetes care</i> . 1989;12(5):365–368.	Not a systematic review
Standards of medical care for patients with diabetes mellitus. American Diabetes Association. <i>Diabetes care</i> . 1994;17(6):616–623.	Not a systematic review
Transition of care provided for adolescents with special health care needs. American Academy of Pediatrics Committee on Children with Disabilities and Committee on Adolescence. <i>Pediatrics</i> . 1996;98(6 Pt 1):1203–1206.	Not a systematic review
Abraham J, Kannampallil T, Caskey RN, Kitsiou S. Emergency Department-Based Care Transitions for Pediatric Patients: A Systematic Review. <i>Pediatrics</i> . 2016;138(2).	Ineligible population
Acuna Mora M, Moons P, Sparud-Lundin C, Bratt EL, Goossens E. Assessing the level of evidence on transfer and transition in young people with chronic conditions: protocol of a scoping review. <i>Systematic reviews</i> . 2016;5(1):166.	Not a systematic review
Alvarez-Escola C, Fernandez-Rodriguez E, Recio-Cordova JM, Bernabeu-Moron I, Fajardo-Montanana C. Consensus document of the Neuroendocrinology area of the Spanish Society of Endocrinology and Nutrition on management of hypopituitarism during transition. <i>Endocrinologia y nutricion: organo de la Sociedad Espanola de Endocrinologia y Nutricion</i> . 2014;61(2):68.e61–68.e11.	Not a systematic review
Andrade DM, Bassett AS, Bercovici E, et al. Epilepsy: Transition from pediatric to adult care. Recommendations of the Ontario epilepsy implementation task force. <i>Epilepsia</i> . 2017;58(9):1502–1517.	Not a systematic review
Barr NG, Longo CJ, Embrett MG, Mulvale GM, Nguyen T, Randall GE. The transition from youth to adult mental health services and the economic impact on youth and their families. <i>Healthcare management forum</i> . 2017;30(6):283–288.	No/ineligible intervention
Beresford B. On the road to nowhere? Young disabled people and transition. <i>Child: care, health and development</i> . 2004;30(6):581–587.	No/ineligible intervention
Betz CL. Health care transitions of youth with special health care needs: the never ending journey. <i>Communicating nursing research</i> . 2008;41:13–29.	Not a systematic review
Betz CL, Lobo ML, Nehring WM, Bui K. Voices not heard: a systematic review of adolescents' and emerging adults' perspectives of health care transition. <i>Nurs Outlook</i> . 2013;61(5):311–336.	No comparator
Binks JA, Barden WS, Burke TA, Young NL. What do we really know about the transition to adult-centered health care? A focus on cerebral palsy and spina bifida. <i>Archives of physical medicine and rehabilitation</i> . 2007;88(8):1064–1073.	No/ineligible intervention
Blum RW. Introduction. Improving transition for adolescents with special health care needs from pediatric to adult-centered health care. <i>Pediatrics</i> . 2002;110(6 Pt 2):1301–1303.	Not a systematic review
Bogetz JF, Rassbach CE, Berecknyei S, Mendoza FS, Sanders LM, Braddock CH, III. Training health care professionals for 21st-century practice: A systematic review of educational interventions on chronic care. <i>Academic Medicine</i> . 2015;90(11):1561–1572.	Ineligible population
Brier MJ, Schwartz LA, Kazak AE. Psychosocial, health-promotion, and neurocognitive interventions for survivors of childhood cancer: a systematic review. <i>Health psychology: official journal of the Division of Health Psychology, American Psychological Association</i> . 2015;34(2):130–148.	No/ineligible intervention
Broad KL, Sandhu VK, Sunderji N, Charach A. Youth experiences of transition from child mental health services to adult mental health services: a qualitative thematic synthesis. <i>BMC psychiatry</i> . 2017;17(1):380.	No/ineligible intervention
Brooks AJ, Smith PJ, Cohen R, et al. UK guideline on transition of adolescent and young persons with chronic digestive diseases from paediatric to adult care. <i>Gut</i> . 2017;66(6):988–1000.	Not a systematic review
Bryant R, Porter JS, Sobota A, Association of Pediatric Hematology/Oncology N, American Society of Pediatric Hematology O. APHON/ASPHO Policy Statement for the Transition of Patients With Sickle Cell Disease From Pediatric to Adult Health Care. <i>Journal of pediatric oncology nursing: official journal of the Association of Pediatric Oncology Nurses</i> . 2015;32(6):355–359.	Not systematic review
Bryant R, Walsh T. Transition of the chronically ill youth with hemoglobinopathy to adult health care: an integrative review of the literature. <i>Journal of pediatric health care: official publication of National Association of Pediatric Nurse Associates &amp; Practitioners</i> . 2009;23(1):37–48.	No/ineligible intervention
Bucknall TK, Hutchinson AM, Botti M, et al. Engaging patients and families in communication across transitions of care: an integrative review protocol. <i>Journal of Advanced Nursing</i> . 2016;72(7):1689–1700.	Not a systematic review
Calvo I, Anton J, Bustabad S, et al. Consensus of the Spanish society of pediatric rheumatology for transition management from pediatric to adult care in rheumatic patients with childhood onset. <i>Rheumatology international</i> . 2015;35(10):1615–1624.	Not a systematic review
Cameron FJ, Amin R, de Beaufort C, Codner E, Acerini CL. ISPAD Clinical Practice Consensus Guidelines 2014. <i>Diabetes in adolescence. Pediatric diabetes</i> . 2014;15 Suppl 20:245–256.	Not a systematic review
Cavenaugh B, Giesen JM. A Systematic Review of Transition Interventions Affecting the Employability of Youths with Visual Impairments. <i>Journal of Visual Impairment &amp; Blindness</i> . 2012;106(7):400–413.	Ineligible setting
Clarke T, Lusher J. Transitioning patients with inflammatory bowel disease (IBD) from adolescent to adult services: a systematic review. <i>Frontline gastroenterology</i> . 2016;7(4):264–270.	No/ineligible intervention
Clayton PE, Cuneo RC, Juul A, Monson JP, Shalet SM, Tauber M. Consensus statement on the management of the GH-treated adolescent in the transition to adult care. <i>European journal of endocrinology</i> . 2005;152(2):165–170.	Not a systematic review
Cleverley K, Bennett K, Jeffs L. Identifying process and outcome indicators of successful transitions from child to adult mental health services: protocol for a scoping review. <i>BMJ open</i> . 2016;6(7):e012376.	Not a systematic review
Collins JL. Integrative Review: Delivery of Healthcare Services to Adolescents and Young Adults During and After Foster Care. <i>J Pediatr Nurs</i> . 2016.	Ineligible population
Cooke E. Transitional care for young people with diabetes: policy and practice. <i>Paediatric nursing</i> . 2007;19(6):19–22.	Not a systematic review

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Reference	Reason for exclusion
Dashiff C, Hardeman T, McLain R. Parent-adolescent communication and diabetes: an integrative review. <i>J Adv Nurs</i> . 2008;62(2):140–162.	No/ineligible intervention
DeBaun MR, Telfair J. Transition and sickle cell disease. <i>Pediatrics</i> . 2012;130(5):926–935.	Not a systematic review
Di Rezze B, Nguyen T, Mulvale G, Barr NG, Longo CJ, Randall GE. A scoping review of evaluated interventions addressing developmental transitions for youth with mental health disorders. <i>Child: care, health and development</i> . 2016;42(2):176–187.	No/ineligible intervention
Donkoh C, Underhill K, Montgomery P. Independent living programmes for improving outcomes for young people leaving the care system. <i>The Cochrane database of systematic reviews</i> . 2006(3):Cd005558.	Ineligible population
Edwards D, Noyes J, Lowes L, Haf Spencer L, Gregory JW. An ongoing struggle: a mixed-method systematic review of interventions, barriers and facilitators to achieving optimal self-care by children and young people with type 1 diabetes in educational settings. <i>BMC pediatrics</i> . 2014;14:228.	No/ineligible intervention
Everson-Hock ES, Jones R, Guillaume L, et al. Supporting the transition of looked-after young people to independent living: A systematic review of interventions and adult outcomes. <i>Child: care, health and development</i> . 2011;37(6):767–779.	Ineligible population
Fegran L, Ludvigsen MS, Aagaard H, Uhrenfeldt L, Westergren T, Hall EO. Experiences of health care providers in the transfer of adolescent or young adults with a chronic condition from pediatric to adult hospital care: a systematic review protocol. <i>JBI database of systematic reviews and implementation reports</i> . 2016;14(2):38–48.	Not a systematic review
Fink-Samnick E, Muller LS. Case management across the life continuum: ethical obligations versus best practice. <i>Professional case management</i> . 2010;15(3):153–156.	Not a systematic review
Foster HE, Minden K, Clemente D, et al. EULAR/PRES standards and recommendations for the transitional care of young people with juvenile-onset rheumatic diseases. <i>Annals of the rheumatic diseases</i> . 2016.	Not a systematic review
Friesen EL, Slattery P, Walker L. Assistive technology in transition readiness assessment instruments for adolescents with physical disabilities: A scoping review. <i>International Journal of Child &amp; Adolescent Health</i> . 2017;10(3):263–274.	No/ineligible intervention
Freyer DR. Transition of care for young adult survivors of childhood and adolescent cancer: rationale and approaches. <i>Journal of clinical oncology: official journal of the American Society of Clinical Oncology</i> . 2010;28(32):4810–4818.	Not a systematic review
Freyer DR, Kibrick-Lazeur R. In sickness and in health: transition of cancer-related care for older adolescents and young adults. <i>Cancer</i> . 2006;107(7 Suppl):1702–1709.	Not a systematic review
Gawlik A, Malecka-Tendera E. Transitions in endocrinology: treatment of Turner's syndrome during transition. <i>European journal of endocrinology</i> . 2014;170(2):R57–74.	No/ineligible intervention
Ginsberg Y, Beusterien KM, Amos K, Jousselin C, Asherson P. The unmet needs of all adults with ADHD are not the same: A focus on Europe. <i>Expert Review of Neurotherapeutics</i> . 2014;14(7):799–812.	No/ineligible intervention
Goossens E, Bovijn L, Gewillig M, Budts W, Moons P. Predictors of Care Gaps in Adolescents With Complex Chronic Condition Transitioning to Adulthood. <i>Pediatrics</i> . 2016;137(4).	No/ineligible intervention
Gravholt CH, Andersen NH, Conway GS, et al. Clinical practice guidelines for the care of girls and women with Turner syndrome: proceedings from the 2016 Cincinnati International Turner Syndrome Meeting. <i>European journal of endocrinology</i> . 2017;177(3):G1–g70.	Not a systematic review
Gray ME, Nieburg P, Dillingham R. Pediatric Human Immunodeficiency Virus Continuum of Care: A Concise Review of Evidence-Based Practice. <i>Pediatric clinics of North America</i> . 2017;64(4):879–891.	Not a systematic review
Hall BJ, Sou KL, Beanland R, et al. Barriers and Facilitators to Interventions Improving Retention in HIV Care: A Qualitative Evidence Meta-Synthesis. <i>AIDS and behavior</i> . 2017;21(6):1755–1767.	Not a systematic review
Hamdani Y, Mistry B, Gibson BE. Transitioning to adulthood with a progressive condition: best practice assumptions and individual experiences of young men with Duchenne muscular dystrophy. <i>Disability and rehabilitation</i> . 2015;37(13):1144–1151.	Not a systematic review
Hardaker L, Halcomb EJ, Griffiths R, Bolzan N, Arblaster K. The role of the occupational therapist in adolescent mental health: a critical review of the literature. <i>Australian e-Journal for the Advancement of Mental Health</i> . 2007;6(3):10p–10p.	No/ineligible intervention
Heath G, Farre A, Shaw K. Parenting a child with chronic illness as they transition into adulthood: A systematic review and thematic synthesis of parents' experiences. <i>Patient education and counseling</i> . 2016.	Ineligible population
Heerde JA, Hemphill SA, Scholes-Balog KE. The impact of transitional programmes on post-transition outcomes for youth leaving out-of-home care: a meta-analysis. <i>Health &amp; social care in the community</i> . 2018;26(1):e15–e30.	Ineligible outcomes
Heery E, Sheehan AM, While AE, Coyne I. Experiences and Outcomes of Transition from Pediatric to Adult Health Care Services for Young People with Congenital Heart Disease: A Systematic Review. <i>Congenital heart disease</i> . 2015;10(5):413–427.	No/eligible intervention
Herbert L, Owen V, Pascarella L, Streisand R. Text message interventions for children and adolescents with type 1 diabetes: a systematic review. <i>Diabetes Technol Ther</i> . 2013;15(5):362–370.	No/ineligible intervention
Heuschkel R, Salvestrini C, Beattie RM, Hildebrand H, Walters T, Griffiths A. Guidelines for the management of growth failure in childhood inflammatory bowel disease. <i>Inflammatory bowel diseases</i> . 2008;14(6):839–849.	Not a systematic review
Hughes GC, O'Hanrahan S, Kavanagh G, McNicholas F. Review of international clinical guidelines for adolescents on transition to Adult Mental Health Services and adults with attention-deficit hyperactivity disorder and their application to an Irish context. <i>Irish Journal of Psychological Medicine</i> . 2017;34(1):59–73.	Not a systematic review
Jalkut MK, Allen PJ. Transition from pediatric to adult health care for adolescents with congenital heart disease: a review of the literature and clinical implications. <i>Pediatric Nursing</i> . 2009;35(6):381–387.	No control/comparator intervention
Joly E. Transition to Adulthood for Young People with Medical Complexity: An Integrative Literature Review. <i>Journal of Pediatric Nursing</i> . 2015;30(5):e91–e103.	No/ineligible intervention
Joly E. Integrating transition theory and bioecological theory: a theoretical perspective for nurses supporting the transition to adulthood for young people with medical complexity. <i>Journal of Advanced Nursing</i> . 2016;72(6):1251–1262.	Not a systematic review
Jonikas JA, Laris A, Cook JA. The passage to adulthood: psychiatric rehabilitation service and transition-related needs of young adult women with emotional and psychiatric disorders. <i>Psychiatr Rehabil J</i> . 2003;27(2):114–121.	Not a systematic review
Jordan A, McDonagh JE. Transition: getting it right for young people. <i>Clinical medicine (London, England)</i> . 2006;6(5):497–500.	Not a systematic review
Jordan L, Swerdlow P, Coates TD. Systematic review of transition from adolescent to adult care in patients with sickle cell disease. <i>Journal of pediatric hematology/oncology</i> . 2013;35(3):165–169.	No/ineligible intervention
Kennedy A, Sawyer S. Transition from pediatric to adult services: are we getting it right? <i>Current opinion in pediatrics</i> . 2008;20(4):403–409.	Not a systematic review
Knoll S, Focker M, Hebebrand J. Clinical problems encountered in the treatment of adolescents with anorexia nervosa. <i>Zeitschrift fur Kinder- und Jugendpsychiatrie und Psychotherapie</i> . 2013;41(6):433–446.	Not a systematic review
Lall P, Lim SH, Khairuddin N, Kamarulzaman A. Review: an urgent need for research on factors impacting adherence to and retention in care among HIV-positive youth and adolescents from key populations. <i>Journal of the International AIDS Society</i> . 2015;18(2 Suppl 1):19393.	No/ineligible intervention
Laska MN, Pelletier JE, Larson NI, Story M. Interventions for weight gain prevention during the transition to young adulthood: A review of the literature. <i>Journal of Adolescent Health</i> . 2012;50(4):324–333.	Ineligible population
Lebensburger JD, Bemrich-Stolz CJ, Howard TH. Barriers in transition from pediatrics to adult medicine in sickle cell anemia. <i>Journal of blood medicine</i> .	Not a systematic

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Reference	Reason for exclusion
2012;3:105–112.	review
Lee A, Bailey B, Cullen-Dean G, Aiello S, Morin J, Oechslin E. Transition of Care in Congenital Heart Disease: Ensuring the Proper Handoff. <i>Current cardiology reports</i> . 2017;19(6):55.	Not a systematic review
Leung Y, Heyman MB, Mahadevan U. Transitioning the adolescent inflammatory bowel disease patient: guidelines for the adult and pediatric gastroenterologist. <i>Inflammatory bowel diseases</i> . 2011;17(10):2169–2173.	Not a systematic review
Lewis SA, Noyes J, Mackereth S. Knowledge and information needs of young people with epilepsy and their parents: Mixed-method systematic review. <i>BMC pediatrics</i> . 2010;10:103.	No/ineligible intervention
Ludvigsson JF, Agreus L, Ciacci C, et al. Transition from childhood to adulthood in coeliac disease: the Prague consensus report. <i>Gut</i> . 2016;65(8):1242–1251.	Not a systematic review
March S. Parents' perceptions during the transition to home for their child with a congenital heart defect: How can we support families of children with hypoplastic left heart syndrome? <i>Journal for Specialists in Pediatric Nursing</i> . 2017;22(3):n/a-n/a.	Ineligible population
Martin S, Sutcliffe P, Griffiths F, et al. Effectiveness and impact of networked communication interventions in young people with mental health conditions: A systematic review. <i>Patient education and counseling</i> . 2011;85(2):e108–e119.	No/ineligible intervention
Masterton KJ, Tariman JD. Effective Transitional Therapy for Adolescent and Young Adult Patients With Cancer: An Integrative Literature Review. <i>Clinical Journal of Oncology Nursing</i> . 2016;20(4):391–397.	Ineligible population
McCallum C. Supporting young people's transition from children's to adult services in the community. <i>British journal of community nursing</i> . 2017;22(1):668–674.	Not a systematic review
McDonagh JE, Shaw KL. Adolescent rheumatology transition care in the UK. <i>Pediatric annals</i> . 2012;41(5):e8–15.	Not a systematic review
Mencin AA, Loomba R, Lavine JE. Caring for children with NAFLD and navigating their care into adulthood. <i>Nature reviews Gastroenterology &amp; hepatology</i> . 2015;12(11):617–628.	Not a systematic review
Micklos L. Transition and Interprofessional Collaboration In Moving from Pediatric to Adult Renal Care. <i>Nephrology Nursing Journal</i> . 2014;41(3):311–317.	Not a systematic review
Minden K, Schalm S. Transition from pediatric to adult rheumatological care. <i>Zeitschrift fur Rheumatologie</i> . 2016;75(6):635–645.	Not a systematic review
Molter BL, Abrahamson K. Self-Efficacy, Transition, and Patient Outcomes in the Sickle Cell Disease Population. <i>Pain Management Nursing</i> . 2015;16(3):418–424.	No/ineligible intervention
Mulvale GM, Nguyen TD, Miatello AM, Embrett MG, Wakefield PA, Randall GE. Lost in transition or translation? Care philosophies and transitions between child and adult mental health services: a systematic review. <i>Journal of mental health (Abingdon, England)</i> . 2016:1–10.	No/ineligible intervention
Murcott W. A scoping review of care received by young people aged 16–25 when admitted to adult mental health hospital wards. <i>Journal of Public Mental Health</i> . 2016;15(4):216–228.	Not a systematic review
Nguyen T, Embrett MG, Barr NG, et al. Preventing youth from falling through the cracks between child/adolescent and adult mental health services: A systematic review of models of care. <i>Community mental health journal</i> . 2017;53(4):375–382.	Ineligible setting
Nguyen T, Stewart D, Gorter JW. Looking back to move forward: Reflections and lessons learned about transitions to adulthood for youth with disabilities. <i>Child: care, health and development</i> . 2018;44(1):83–88.	Not a systematic review
Nutt DJ, Fone K, Asherson P, et al. Evidence-based guidelines for management of attention-deficit/hyperactivity disorder in adolescents in transition to adult services and in adults: recommendations from the British Association for Psychopharmacology. <i>Journal of psychopharmacology (Oxford, England)</i> . 2007;21(1):10–41.	Not a systematic review
Pacaud D, Yale JF, Stephure D, Trussell R, Davies HD. Problems in transition from pediatric care to adult care for individuals with diabetes. <i>Canadian Journal of Diabetes</i> . 2005;29(1):13–18.	Not a systematic review
Peters A, Laffel L. Diabetes care for emerging adults: recommendations for transition from pediatric to adult diabetes care systems: a position statement of the American Diabetes Association, with representation by the American College of Osteopathic Family Physicians, the American Academy of Pediatrics, the American Association of Clinical Endocrinologists, the American Osteopathic Association, the Centers for Disease Control and Prevention, Children with Diabetes, The Endocrine Society, the International Society for Pediatric and Adolescent Diabetes, Juvenile Diabetes Research Foundation International, the National Diabetes Education Program, and the Pediatric Endocrine Society (formerly Lawson Wilkins Pediatric Endocrine Society). <i>Diabetes care</i> . 2011;34(11):2477–2485.	Not a systematic review
Pihoker C, Forsander G, Fantahun B, et al. ISPAD Clinical Practice Consensus Guidelines 2014. The delivery of ambulatory diabetes care to children and adolescents with diabetes. <i>Pediatric diabetes</i> . 2014;15 Suppl 20:86–101.	Not a systematic review
Pipe SW, Valentino LA. Optimizing outcomes for patients with severe haemophilia A. <i>Haemophilia: the official journal of the World Federation of Hemophilia</i> . 2007;13 Suppl 4:1–16; quiz 13 p following 16.	Not a systematic review
Rapley P, Davidson P. Enough of the problem: a review of time for health care transition solutions for young adults with a chronic illness. <i>Journal of Clinical Nursing</i> . 2010;19(3/4):313–323.	Not a systematic review
Rogers K, Zeni MB. Systematic review of medical home models to promote transitions to primary adult health care for adolescents living with autism spectrum disorder. <i>Worldviews Evid Based Nurs</i> . 2015;12(2):98–107.	No/ineligible intervention
Rosen DS, Blum RW, Britto M, Sawyer SM, Siegel DM. Transition to adult health care for adolescents and young adults with chronic conditions: position paper of the Society for Adolescent Medicine. <i>The Journal of adolescent health: official publication of the Society for Adolescent Medicine</i> . 2003;33(4):309–311.	Not a systematic review
Sable C, Foster E, Uzark K, et al. Best practices in managing transition to adulthood for adolescents with congenital heart disease: the transition process and medical and psychosocial issues: a scientific statement from the American Heart Association. <i>Circulation</i> . 2011;123(13):1454–1485.	Not a systematic review
Sayal K, Prasad V, Daley D, Ford T, Coghill D. ADHD in children and young people: Prevalence, care pathways, and service provision. <i>The Lancet Psychiatry</i> . 2018;5(2):175–186.	Not a systematic review
Shrewsbury VA, Baur LA, Nguyen B, Steinbeck KS. Transition to adult care in adolescent obesity: a systematic review and why it is a neglected topic. <i>International Journal of Obesity</i> . 2014;38(4):475–479.	No/ineligible intervention
Smith MB. Pros and cons. <i>Evidence-based child health: a Cochrane review journal</i> . 2014;9(4):749–750.	Not a systematic review
Smith C, Gettings S. Reshaping policy to deliver holistic care for adolescents with Crohn's disease. <i>Nursing children and young people</i> . 2016;28(10):19–24.	Not a systematic review
Stewart D, Stavness C, King G, Antle B, Law M. A critical appraisal of literature reviews about the transition to adulthood for youth with disabilities. <i>Physical &amp; Occupational Therapy in Pediatrics</i> . 2006;26(4):5–24.	No/ineligible intervention
Stinson J, Kohut SA, Spiegel L, et al. A systematic review of transition readiness and transfer satisfaction measures for adolescents with chronic illness. <i>International journal of adolescent medicine and health</i> . 2014;26(2):159–174.	No/ineligible intervention
Stokes D. Empowering Children with Autism Spectrum Disorder and Their Families within the Healthcare Environment. <i>Pediatr Nurs</i> . 2016;42(5):254–255.	Not a systematic review
Swift KD, Sayal K, Hollis C. ADHD and transitions to adult mental health services: a scoping review. <i>Child: Care, Health &amp; Development</i> . 2014;40(6):775–786.	No control/comparator
Thomson L, Fayed N, Sedarous F, Ronen GM. Life quality and health in adolescents and emerging adults with epilepsy during the years of transition: a	No/ineligible

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scoping review. <i>Developmental medicine and child neurology</i> . 2014;56(5):421–433.	intervention
Tong A, Wong G, Hodson E, Walker RG, Tjaden L, Craig JC. Adolescent views on transition in diabetes and nephrology. <i>European journal of pediatrics</i> . 2013;172(3):293–304.	No/ineligible intervention
Treadwell M, Telfair J, Gibson RW, Johnson S, Osunkwo I. Transition from pediatric to adult care in sickle cell disease: establishing evidence-based practice and directions for research. <i>American journal of hematology</i> . 2011;86(1):116–120.	Not a systematic review
Tso LS, Best J, Beanland R, et al. Facilitators and barriers in HIV linkage to care interventions: a qualitative evidence review. <i>AIDS (London, England)</i> . 2016;30(10):1639–1653.	Ineligible population
Turner JR, Schatz DA, Cusi K, Strumph P. Healthcare transition from pediatric to adult medical homes in diabetes mellitus. <i>Endocrine practice: official journal of the American College of Endocrinology and the American Association of Clinical Endocrinologists</i> . 2014;20(7):715–721.	Not a systematic review
van Rheenen PF, Aloï M, Biron IA, et al. European Crohn's and Colitis Organisation Topical Review on Transitional Care in Inflammatory Bowel Disease. <i>Journal of Crohn's &amp; colitis</i> . 2017;11(9):1032–1038.	Not a systematic review
von Gontard A, Cardozo L, Rantell A, Djurhuus JC. Adolescents with nocturnal enuresis and daytime urinary incontinence—How can pediatric and adult care be improved—ICI-RS 2015? <i>Neurourology and urodynamics</i> . 2017;36(4):843–849.	Not a systematic review
Vreeman RC, McCoy BM, Lee S. Mental health challenges among adolescents living with HIV. <i>Journal of the International AIDS Society</i> . 2017;20(Suppl 3):21497.	No/ineligible intervention
Wagner A, Brucker SY, Ueding E, et al. Treatment management during the adolescent transition period of girls and young women with Mayer-Rokitansky-Kuster-Hauser syndrome (MRKHS): a systematic literature review. <i>Orphanet journal of rare diseases</i> . 2016;11(1):152.	No/ineligible intervention
Watson AR, Harden PN, Ferris ME, Kerr PG, Mahan JD, Ramzy MF. Transition from pediatric to adult renal services: a consensus statement by the International Society of Nephrology (ISN) and the International Pediatric Nephrology Association (IPNA). <i>Kidney international</i> . 2011;80(7):704–707.	Not a systematic review
Welbourn R, Hopkins J, Dixon JB, et al. Commissioning guidance for weight assessment and management in adults and children with severe complex obesity. <i>Obesity reviews: an official journal of the International Association for the Study of Obesity</i> . 2018;19(1):14–27.	Not a systematic review
Westbrook JD, Fong CJ, Nye C, Williams A, Wendt O, Cortopassi T. Transition Services for Youth With Autism: A Systematic Review. <i>Research on Social Work Practice</i> . 2015;25(1):10–20.	No/ineligible intervention
White PH, Ardoïn S. Transitioning Wisely: Improving the Connection From Pediatric to Adult Health Care. <i>Arthritis &amp; rheumatology (Hoboken, NJ)</i> . 2016;68(4):789–794.	Not a systematic review
Wright C, Steinway C, Jan S. The genesis of systems of care for transition to adulthood services: emerging models in primary and subspecialty care. <i>Current opinion in pediatrics</i> . 2018;30(2):303–310.	Not a systematic review
Yu CH, Guarna G, Tsao P, et al. Incentivizing health care behaviors in emerging adults: a systematic review. <i>Patient preference and adherence</i> . 2016;10:371–381.	No/ineligible intervention
Zhang LF, Ho JS, Kennedy SE. A systematic review of the psychometric properties of transition readiness assessment tools in adolescents with chronic disease. <i>BMC pediatrics</i> . 2014;14:4.	No/ineligible intervention

#### Appendix D. Summary of characteristics of primary studies included within the identified systematic reviews

First Author	Year	Diagnosis	N in the study	Provider type(s) involved	Primary outcome	Other outcome(s) reported	Number of reviews that cited the paper, n
Akchurin	2014	Renal transplant	97	Pediatric	Adherence (based on tacrolimus levels)	Graft survival	2
Annunziato	2007	Liver transplant	42	Both	Adherence (based on tacrolimus levels)	ALT levels, biopsy-proven rejection, retransplantation, mortality	1
Annunziato	2013	Liver transplant	34	Both	Adherence (based on tacrolimus levels)	Self-reported health care management, quality of life	5
Annunziato	2015	Renal transplant	22	Both	Adherence (based on tacrolimus levels)	Biopsy-proven rejection, creatinine, GFR, blood pressure	1
Bashore	2016	Cancer survivors	30	Pediatric	Patient level of worry	Transition readiness	1
Bauman	2016	Warfarin requirement	19	Both	Time in therapeutic INR range	Continued care with an adult provider, continuing warfarin treatment	1
Bent	2002	Multiple	254	Both	Participation in society	Cost	5
Betz	2010	Spina Bifida	65	Pediatric	Well-being	Role mastery, self-care	6
Brotzman	2001	Sickle cell	165	Adult	Proportion of patients on hydroxyurea	Patients not given Demerol, number of ED visits, number of hospital days, treatment costs	1
Bundock	2011	Multiple	60	Both	Patient satisfaction	n/a	3
Busse	2007	Type 1 diabetes	101	Pediatric	Number of health care providers after transfer	Satisfaction with transition, HbA1c	7
Cadario	2009	Type 1 diabetes	57	Both	Proportion of patients providing self-care without support	Number of each of the following in the last year: doctor's visits, HbA1cs, foot checks, eye exams, microalbumin tests; patient assessment of transition; HbA1c value; clinic attendance	15
Chaturvedi	2009	Renal transplant	11	Both	Creatinine	Number of rejection episodes, inpatient days, clinic attendance	6
Chaudry	2013	CF	91	Both	Anxiety about transition	Satisfaction w/ transition, perceived health status, level of independence, patient recollection of transition discussions	5
Cole	2015	IBD	72	Both	Hospitalizations	Surgeries, clinic attendance, self-reported adherence, school/employment status, growth status, radiation exposure	1
Cuttell	2005	Type 1 diabetes	11	Pediatric	Patient satisfaction	Patient knowledge	3
Dabadie	2008	IBD	34	Both	Patient perceptions of transition in general	Patient perceptions of the intervention	5

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First Author	Year	Diagnosis	N in the study	Provider type(s) involved	Primary outcome	Other outcome(s) reported	Number of reviews that cited the paper, n
Dugueperoux	2008	CF	68	Both	Time between 1st and 2nd adult appointments	Pulmonary function testing results, number of visits, education/employment status	4
Dyrlov	2000	Type 1 diabetes	76	Pediatric	HbA1c	Hospital days	1
Egan	2015	Type 1 diabetes	29	Both	Adherence to follow-up	Diabetes-related distress, quality of life, perceived health care provider autonomy support, A1C	1
Fredericks	2015	Liver transplant	45	Pediatric	Transition readiness	Adherence (based on chart review), immunosuppressant levels, clinic attendance, overall health status	2
Gilmer	2012	Mental health	2505	Adult	Mental health service utilization (inpatient, outpatient, ED, jail service days)	n/a	1
Gimenez	2013	Type 1 diabetes	189	Both	HbA1c	Number of hypoglycemic episodes, patient diabetes knowledge, number of home blood glucose measurements, quality of life	1
Gleeson	2013	CAH	39	Both	Clinic attendance	Loss to follow-up, overall health status	5
Gravelle	2015	CF	6	Both	Patient knowledge	n/a	1
Greveson	2011	IBD	25	Both	Patient knowledge	Effect of disease on daily life, transition readiness, anxiety around transition	1
Haber	2008	Mental health	193	Adult	Employment	Education attainment, Productivity, Criminal justice involvement, mental health interference, substance abuse interference	1
Hankins	2012	Sickle cell	158	Both	Patient satisfaction	Attendance in the adult clinic	9
Harden	2012	Renal transplant	21	Both	Transplant failure	Episodes of late acute rejection	4
Hilderson	2016	Rheumatologic disorders	78	Both	Health status (physical/psychosocial/rheumatic-specific)	Quality of life, parenting climate, medication adherence	2
Holmes-Walker	2007	Type 1 diabetes	191	Adult	HbA1c	Number and length of DKA admissions and readmissions, clinic follow-up	15
Hommel	2012	Type 1 diabetes	95	Both	HbA1c	Loss to follow-up, late complications of diabetes, patient satisfaction w/ transfer	1
Huang	2014	Multiple	81	Both	Disease self-management	Self-efficacy	4
Jensen	2015	Rheumatologic disorders	236	Pediatric	Transition success (defined as >1 adult appointment)	Satisfaction w/ transition process	1
Johnston	2006	Type 1 diabetes	33	Adult	Clinic attendance	HbA1c	10
Kipps	2002	Type 1 diabetes	229	Both	Age at transfer	Site of transfer (GP vs. specialty care), Clinic attendance, HbA1c, patient experience of transfer	15
Lane	2007	Type 1 diabetes	249	Adult	HbA1c	n/a	9
Levy-Shraga	2016	Type 1 diabetes	53	Both	HbA1c	Clinic attendance, diabetes-related quality of life, DKA episodes, hypoglycemia, BMI	1
Logan	2008	Type 1 diabetes	93	Both	Clinic attendance	HbA1c, Change in insulin regimen, uptake of screening for diabetes complications	5
Mackie	2014	Heart problems	58	Pediatric	Transition readiness	Cardiac-specific knowledge	2
Manteuffel	2008	Mental health	3613	Pediatric	Emotional well-being	Behavior	1
Markowitz	2012	Type 1 diabetes	15	Adult	Disease burden	Self-care skills, HbA1c, clinic attendance	3
Maslow	2013	Multiple	20	Pediatric	Loneliness	Transition readiness, educational/vocational attainment, site of health care (pediatric vs. adult)	2
McDonagh	2006	Rheumatologic disorders	308	Pediatric	Patient satisfaction	n/a	2
McDonagh	2007	Rheumatologic disorders	308	Pediatric	Health-related quality of life	Patient knowledge, patient satisfaction, independent health behaviors, pre-vocational experience	7
McQuillan	2015	Renal transplant	32	Both	Adherence (based on composite measure)	Change in creatinine, change in GFR, number of rejection episodes	2
Nakhla	2009	Type 1 diabetes	1507	Both	Diabetes-related hospitalizations	Screenings for retinopathy	5
Nieboer	2014	Multiple	242 adolescents +72 providers	Both	Patient experience of transition	n/a	3
Okumura	2014	CF	29	Both	Transition readiness	In-hospital vs. out-of-hospital transfer to adult care	3
Orr	1996	Type 1 diabetes	82	Both	HbA1c	n/a	9
Pape	2013	Renal transplant	66	Adult	Patient and graft survival	Acute rejection episodes, creatinine, GFR, mean arterial pressure, number of outpatient visits, patient satisfaction	4
Prestidge	2012	Renal transplant	45	Both	Death	Graft loss, cost of care	4
Rapley	2007	Type 1 diabetes	74	Both	HbA1c	n/a	1
Rapley	2013	Type 1 diabetes	43	Adult	Diabetes responsibility	HbA1c, clinic attendance	2
Remorino	2006	Renal transplant	16	Pediatric	Adherence	Graft stability, clinic attendance	2

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First Author	Year	Diagnosis	N in the study	Provider type(s) involved	Primary outcome	Other outcome(s) reported	Number of reviews that cited the paper, n
Rettig	1991	Rheumatologic disorders	180	Both	Follow-up in adult care	n/a	3
Sawyer	1998	Spina Bifida	10	Both	Patient perception of the transition process	n/a	3
Schmidt	2016	Multiple	325	Pediatric	Health-related transition competence	Self-efficacy, satisfaction w/ care, patient activation, quality of life	1
Sequeira	2015	Type 1 diabetes	81	Pediatric	Clinic visits	HbA1c, hypoglycemia, health care use, psychosocial well-being	2
Shaw	2007	Rheumatologic disorders	308	Pediatric	Patient satisfaction	n/a	5
Smith	2011	Sickle cell	33	Pediatric	Sickle-cell knowledge	Concerns regarding transition	5
Steinbeck	2015	Type 1 diabetes	26	Adult	Engagement and retention in adult care	HbA1c, diabetes-related hospitalizations, microvascular complication appearance, global self-worth	5
Steinkamp	2001	CF	44	Both	Patient satisfaction	n/a	6
Styron	2006	Mental health	60	Adult	Quality of life	Patient satisfaction, loneliness, self-reported functioning, number of arrests, psychiatric ER visits, psychiatric hospitalizations	2
Vanelli	2004	Type 1 diabetes	73	Both	Patient satisfaction	HbA1c, clinic attendance	7
VanWalleghem	2008	Type 1 diabetes	165	Adult	Attendance in adult clinic	Diabetes-related complications, DKA episodes, hypoglycemia	13
VanWalleghem	2011	Type 1 diabetes	165	Adult	Clinic attendance	DKA episodes, diabetes-related complications	3
VanWalleghem	2012	Type 1 and 2 diabetes	165	Adult	Clinic attendance	n/a	1
Vidal	2004	Type 1 diabetes	80	Both	HbA1c	Hypoglycemia, total daily insulin dose, ability to self-adjust insulin, quality of life	8
Weitz	2015	Renal transplant	59	Pediatric	Change in GFR	Acute rejection episodes, protein-to-creatinine ratio, blood pressure	2
Wiener	2007	HIV	51	Pediatric	Transition readiness	Anxiety, barriers to transition	8

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