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Evaluating continuity during transfer to adult care: A Systematic Review

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CONTRIBUTOR'S STATEMENT

Dr Rachas conceptualized and designed the review, designed and tested the data collection form, reviewed all articles, carried out the analyses, drafted the initial manuscript, and approved the final manuscript as submitted.

Dr Lefeuvre reviewed articles and approved the final manuscript as submitted.

Dr Warszawski tested the data collection form, reviewed articles, drafted the initial manuscript and approved the final manuscript as submitted.

Drs Faye, Mahlaoui, de La Rochebrochard and Meyer reviewed and approved the final manuscript as submitted.

Dr Durieux conceptualized and designed the review, reviewed articles, and approved the final manuscript as submitted.

All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

ABSTRACT

Context. Appropriate outcomes are required to evaluate transition programs' ability to maintain care continuity during the transfer to adult care of youths with a chronic condition.

Objective. To identify the outcomes used to measure care continuity during transfer, and to analyze current evidence regarding the efficacy of transition programs.

Data Sources. Pubmed (1948-2014), Web of Science (1945-2014), EMBASE (1947-2014) and the reference lists of the studies identified.

Study Selection. Screening on titles and abstracts; full-text assessment by two reviewers independently.

Data Extraction. By two reviewers independently, using a Cochrane form adapted to observational studies, including bias assessment.

Results. Among the 23 studies retrieved, all but five were monocentric, 16 were cohorts (15 retrospective), six cross-sectional studies and one randomized trial. The principal disease studied was diabetes ($n=11$). We identified 24 indicators relating to two main aspects of continuity of care: engagement and retention in adult care. As designed, most studies probably overestimated engagement. A lack of adjustment for confounding factors was the main limitation of the few studies evaluating the efficacy of transition programs.

Limitations. The assessment of bias was challenging, due to the heterogeneity and observational nature of the studies.

Conclusions. This review highlights the paucity of knowledge about the efficacy of transition programs for ensuring care continuity during the transfer from pediatric to adult care. The outcomes identified are relevant and not specific to a particular disease. However, the prospective follow-up of patients initially recruited in pediatric care should be encouraged to limit an overestimation of care continuity.

INTRODUCTION

In high-income countries, the prognosis of childhood-onset chronic conditions has improved in recent decades, such that larger numbers of patients now reach adulthood. For instance, the proportion of cystic fibrosis patients reaching adulthood (> 18 years of age) increased from 27% to 56% between 1982 and 2007 (UK CF Registry, *Annual Data Report 2008*, Cystic Fibrosis Trust 2009) and forecasts indicate an expected increase in the overall number of adult cystic fibrosis patients of about 75% by 2025 in Western European countries¹. It is estimated that almost 90% of children with congenital heart diseases will survive into adulthood², together with 94% of children with sickle cell anemia³. The population of perinatally HIV-infected patients is also ageing⁴.

For several reasons, including the occurrence of adult-specific issues, such as reproduction, these patients need to be transferred from pediatric to adult care. However, several studies have suggested that this transfer may be associated with poor outcomes including a low frequency of medical visits^{5,6}, a lack of compliance with treatment regimens^{7,8} and a higher risk of unplanned healthcare use^{9,10}. It has been recommended, to avoid such events, the planning and implementation of the transfer into adult care should be carefully prepared and smoothed¹¹. The concept of 'transition to adult care' covers the purposeful process beginning in childhood and ending in adulthood during which the patient switches to, and is accepted by, adult healthcare services.

In a comprehensive approach to patient management, evaluations of successful transition to adult care should be multidimensional, both for individual patients and for evaluations of the transition program. Relevant outcomes, identified by Delphi method¹² and literature reviews^{13,14}, may include the patient building a trusting relationship with an adult care provider, continuing attention to self-management, clinical outcomes (such as unplanned

health care use), biological outcomes (HbA1c in diabetes), the satisfaction of patients and their parents, quality of life and continuity of care.

Experts have almost unanimously identified one particular indicator as critical: the patients lost to follow-up¹². Indeed, continuity of care is a core issue for patients transferring from pediatric to adult care systems. It has been shown to be related to patient satisfaction, a lower frequency of hospital admissions and emergency department visits and a greater use of preventive services¹⁵. Appropriate outcomes are therefore required for the evaluation of continuity of care in patients with childhood-onset chronic diseases transferring to adult care. Such outcomes are required, in particular, for the comparison of processes and transfer success by time period, country and care organization with or without structured transition programs, and according to disease-related and socio-demographic factors. Appropriate outcomes are also required for evaluating the efficacy of transition programs in randomized studies.

In 2006, a systematic review identified various continuity of care indices used in pediatric studies, which could be grouped into five categories: duration, density, dispersion, sequence, and subjective¹⁶. The most common were density indices, measuring contacts with the usual provider of care. However, this review did not focus on patients with chronic diseases and, more importantly, did not consider continuity of care at the time of transfer to adult care. As this period may correspond to changes in the medical team and, in some cases, in the geographic site at which care is provided, specific continuity of care outcomes would probably be more appropriate.

We carried out a systematic literature review, addressing the issue of care continuity in patient with a chronic disease, during the transfer to adult care. Our main objective was to identify the strengths and limitations of the various continuity of care outcomes used in both interventional and non-interventional studies, to harmonize and improve the quality of future

research on the transition to adult care. A secondary objective was to analyze whether published studies provide evidence regarding the efficacy of structured transition programs in terms of care continuity.

METHODS

Criteria for the identification of studies for this review

We considered original studies (interventional or non-interventional) including quantitative data and addressing the transition from pediatrics to adult care of patients with chronic diseases.

Studies had to meet the following criteria for inclusion in this review: 1) Some or all of the patients included had to have a long-term health condition requiring ongoing healthcare; 2) Patient care was initiated in a pediatric department; 3) At least one indicator of continuity of care with the usual provider of care was reported; 4) The study was not limited to continuity of care in a pediatric department.

We excluded studies that included only fully institutionalized patients, patients suffering from a primary mental disease, or treated for cancer in childhood. In the two first cases, the conditions concerned have a direct impact on the autonomy of the patient in terms of care continuity and transfer to adult services. For cancer patients, long-term follow-up is justified principally by the need to check for relapses and complications of treatment in the long term.

Search methods for identification of studies

We searched for references with Pubmed (1948-2014), Web of Science (1945-2014) and EMBASE (1947-2014), using the search strategy described in Supplemental Table 6 together with an algorithm developed by McPheeters *et al.*¹³. Sensitivity was maximized by the use of an algorithm searching for articles addressing the topic of the transition to adult care. As we wished to identify all the studies dealing with chronic diseases, no matter what the disease, and all the continuity of care outcomes studied, we did not use keywords to select specific

diseases or specific outcomes. The papers selected had to have been published in English or French. Finally, we searched the reference lists of the selected articles.

Data collection and analysis

Selection of studies

One reviewer (the first author, AR) downloaded all records identified by the electronic searches to the reference management database Zotero (version 4.0), and removed duplicates. He performed a preliminary screening of the titles and abstracts and excluded irrelevant references (those not corresponding to original articles addressing any aspect of the transition to adult care in patients with a chronic condition). The full-text manuscripts of the selected references were downloaded when possible. If not, we contacted the corresponding authors by e-mail to obtain a copy of the article. If no response had been obtained after two e-mails had been sent, the article was considered to be unavailable.

Two reviewers, systematically including AR and one of DL, JW and PD, independently assessed the full texts for the inclusion criteria and extracted data, and evaluated the risks of bias of each of the studies included. Disagreements were resolved by discussion between reviewers, or arbitration by a third reviewer.

Data extraction and management

A standardized electronic data extraction form was adapted from the Cochrane Effective Practice and Organization of Care (EPOC) data extraction form (<http://epoc.cochrane.org/epoc-specific-resources-review-authors>), which was created for reviews of interventional studies. AR and JW tested this form with three articles and adapted it according to the results obtained. The data extracted included study design and settings,

study population, continuity of care outcomes, their mode of collection and a comprehensive risk of bias assessment.

Assessment of the risk of bias for the studies included

We used the criteria defined in the “Cochrane handbook for systematic reviews of interventions” (<http://handbook.cochrane.org/>). However, these criteria were defined for interventional trials and do not cover all potential sources of bias found in observational studies. We therefore assessed four additional standardized criteria: inadequate measurement of risk factors (whereas only the inadequate measurement of outcomes was considered in the Cochrane Handbook), inappropriate eligibility criteria according to the target population, lack of participation of eligible subjects, and confounding bias (which is not explicitly mentioned in the Cochrane Handbook). Each type of bias was assessed only when appropriate, according to the study design. For instance, risk of confounding was assessed for non-randomized comparative studies only. The detailed definitions and applicability of the risk of bias assessment are reported in Supplemental Table 7.

Review synthesis

We first described the characteristics of the studies included. By informal consensus, we grouped the indicators used in the different studies into several types of outcome corresponding to different aspects of continuity of care. The results of the studies are presented by type of outcome and according to whether or not the patients were cared for within a structured transition program, i.e., which refers to an explicit transition policy¹³. For example, this was the case in a study evaluating a young person clinic (structured transition) compared to no young person clinic (unstructured transition)⁵. Because of the heterogeneity of

the study designs, we assessed the risks of bias separately for cross-sectional studies (repeated or not), cohort studies, and randomized controlled trials, using Cochrane reports figures.

Justifications given by the authors who assessed the risks of bias were also summarized.

The review protocol is available on demand (in French).

RESULTS

Results of the search

As shown on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA, <http://prisma-statement.org>) flow chart (Figure 1), the electronic searches yielded 3736 non-duplicate records, 3539 of which were deemed irrelevant following a preliminary screening of titles and abstracts. We excluded 173 of the remaining 197 records after full-text assessment: 168 of the excluded studies focused exclusively on outcomes other than continuity of care, such as readiness for transfer, patient satisfaction, quality of life, perceived needs, biological (often HbA1c in patients with diabetes) or clinical health status. Finally, 24 articles relating to 23 studies were considered eligible and were included in this review. Two articles reported results from the same study^{17,18}. No additional articles were retrieved from searches of the reference lists of these 24 articles.

Study designs, settings and study populations

The objective was exclusively descriptive in four studies (17%). In the others, the aim was to identify factors associated with outcome (12 studies, 52%) or to evaluate structured transition programs (7 studies, 30%) (Supplemental Tables 8 and 9). With the exception of one randomized trial, all the studies were observational: 15 retrospective cohorts, one cohort that was both retrospective and prospective and six cross-sectional studies. Most of the studies were performed in North America and Europe ($N=22$). Three of the studies focused on the general population, whereas the others involved patient recruitment at hospitals (pediatric units in 8 studies, adult care units in 6, and both types of unit in 4). All but five of the studies were carried out at single centers. The principal diseases studied were diabetes (11 studies^{6,17,19–27} with 26 to 250 patients; 1148 overall), congenital heart disease (4 studies^{28–31}

with 153 to 794 patients; 1465 overall) and sickle cell disease (3 studies³²⁻³⁴ with 18 to 83 patients; 148 overall). The other diseases studied were rheumatic diseases (131 patients in 2 studies^{35,36}), congenital adrenal hyperplasia (53 patients⁵) and cystic fibrosis (68 patients³⁷). One study³⁸ included youths with special health care needs ($n=1865$ participants) due to various diseases (i.e., it was not specific to a particular disease).

Outcomes measuring continuity of care

A total of 24 different indicators of continuity of care were reported in the included studies (Table 1): 7 related to engagement in adult care, 14 to retention in adult care and 3 corresponding to a combination of outcomes. Engagement in adult care comprised indicators of attendance at the first or the first two adult care unit visits and indicators of time between the last pediatric and the first adult visit. Retention in adult care was measured by the frequency of visits and attendance at scheduled clinic appointments.

Engagement in adult care

The percentages of patients attending the first or the first two adult care visits were reported in eight studies (Table 2). The proportion of patients attending the first adult care visit ranged from 56% to 79% with a structured transition and from 47% to 100% with an unstructured transition. The proportion of patients attending the first two adult care visits was reported in only one study: 56% of 34 patients with congenital adrenal hyperplasia⁵. Two studies, including the latter, compared structured and unstructured transitions and reported no significant difference between these two types of transition^{5,21}.

The time between the last pediatric visit and the first adult visit, reported in 10 studies (Table 3), was highly variable, as were the results, even for a single disease. Structured and

unstructured transitions were compared in three studies: there was a shorter time between these two visits in structured transition conditions in two studies, on diabetes²⁵ and sickle cell disease³³, whereas no significant difference was found between structured and unstructured transitions in the third study²¹, which focused on diabetes.

Retention in adult care after transfer

Retention in adult care once the first contact had been established was reported in 14 studies, evaluated at one year after transfer in eight studies, 15-18 months in one study, two years in three studies and at least three years after transfer in four studies.

The frequency of visits, reported in eight studies (Table 4), was lower in adult than pediatric care in two studies on diabetes^{6,23}, whereas it was the opposite in one study on cystic fibrosis³⁷. The frequency of adult care visit did not differ significantly between structured and unstructured transitions in two studies^{19,21}.

Attendance at scheduled clinic appointments after transfer, reported in five studies (Table 5), was measured as the mean percentage of scheduled appointments attended per year in two studies^{5,25}, as the proportion of patients attending appointments at one year³⁵ or two years³⁶, or as the number of failed appointments²⁶. One study on diabetes found a trend towards better attendance after structured than after unstructured transition²⁵.

Combined outcomes (not shown in tables)

Three studies used more complex outcomes (Table 1). In one study, also cited in Tables 2 and 5, the authors defined a combined indicator based on both engagement and retention in adult care: “failure to make initial contact with an adult rheumatologist, or failure to continue to follow-up with an adult rheumatologist two years after transfer (no contact for a one year

period after the last scheduled appointment)”³⁶. The other two studies are cited in Table 1 only. The first addressed current follow-up in adult care, without indicating the proportions of patients lost-to-follow up before and after the first contact with the adult care unit³¹. The second used a composite outcome including clinical attendance, access to a health insurance, self-perception of care and delayed care³⁸.

Risk of bias

The risks of bias are presented by study on Figure 2 and according to type of design in Supplemental Figures 3 and 4.

All cross-sectional studies presented a high risk of selection bias, because they involved the recruitment of patients from adult services. Those who were lost to clinical follow-up during the transfer were thus missing. There was a high risk of confounding for all studies with comparative objectives, because multivariate analyses were either absent or inappropriate in these studies (often due to the limited data or number of patients included). Classification bias due to errors in the measurement of outcome and/or risk factors, which were collected retrospectively by interview, were also frequent.

In cohort studies, the most frequent bias was confounding, for the same reasons as in cross-sectional studies. The second main limitation was a potential selection bias due to high non-participation rates for eligible patients (e.g., 82.5% in Oswald 2013³⁸). In most of these studies, patients were identified retrospectively from their previous pediatric files and some did not respond to letters or phone calls, with these attempts at contact made several years after transfer to adult care in some cases. Finally, there may have been a potential classification bias, due to the retrospective collection of data relating to transfer history.

The main limitation of the only randomized trial included in this review related to the extremely low proportion of eligible patients who agreed to participate, corresponding to only half the planned number, resulting in insufficient statistical power and calling into question the generalizability of the results.

DISCUSSION

We retrieved only 23 studies addressing the issue of care continuity in youths with chronic conditions transferring from pediatric to adult healthcare services. Although the transition issue concerns a large spectrum of chronic diseases, most of these studies included patients with diabetes or congenital heart disease, and many chronic diseases were not studied (HIV infection, hemophilia, inflammatory bowel disease, etc.). All the studies reported indicators related to either engagement or retention in adult care.

Engagement in adult care was measured using probability of, and/or time to, attendance at the first visit to adult care. Delays in adult care attendance has been pointed out by a panel of experts, who considered as “very important” to measure “patient’s first visit in adult care no later than 3-6 months after transfer”¹². This was done in five of the studies reported here.

Furthermore, these timelines seem to reflect follow-up periods advocated by various disease organizations^{39,40}. Using a - partly arbitrarily - time cutoff provides a goal to be achieved in transition programs. Follow-up of patients initially recruited in a pediatric department and the use of survival analysis to take into account censored data due to deaths and patients lost-to-follow up are required to avoid an overestimation of the probability of attendance and underestimation of transfer time. Nine cohorts that included patients in pediatrics measured engagement, but none of them performed a survival analysis.

Retention in adult care after transfer was measured using the frequency of visits and the attendance at scheduled appointments. Both are indicators of healthcare use, which is likely to be positively associated with disease severity. Attendance at scheduled appointments measures more specifically compliance with care and was considered as very important by the panel of experts, who defined it as “no missed consultations previously canceled and rescheduled”¹². It was reported in five of the studies reviewed here. However, such an indicator is hard to collect because missed visits are rarely indicated in patient records.

Measuring retention indicators in both pediatric and adult department for each patient, as done in 7 studies, is the only way to study whether adherence with care is maintained, improved or altered after transfer.

Interestingly, engagement and retention in adult care correspond to two key challenges of transfer: ensuring continuity between pediatric and adult care, a type of “cross-boundary continuity”⁴¹, and build a new patient-provider relationship, i.e., initiate a new “relational continuity”^{42,43}. Some authors have also considered informational continuity, corresponding to the availability of information about medical history to ensure appropriate care⁴². This aspect was not described in the studies reviewed here.

Several instruments measuring care continuity have been developed in other contexts, including the Diabetes Continuity of Care Questionnaire, Alberta Continuity of Services Scale-Mental Health, Heart Continuity of Care Questionnaire, and Nijmegen Continuity Questionnaire⁴¹. Their relevance to the transfer to adult care and their validity in youths with chronic diseases should be evaluated. Besides, several authors suggest to develop subjective measures of continuity^{41,42}.

There was little data available to evaluate the difference in continuity of care outcomes between structured and unstructured programs. Two studies found a shorter transfer time^{25,33} and better attendance in adult care³³ for patients involved in a structured transition program than those with no structured transition. However, both studies were not randomized, so we cannot exclude that these encouraging results are partly explained by an indication bias. No difference was reported in the three other studies that compared structured and unstructured transition, including the randomized controlled trial^{5,19,21}. Nevertheless they concerned small numbers of patients. We cannot rule out that there would have been a significant difference if the studies had been more highly powered. Finally, it seems impossible to perform inter-study comparisons of continuity of care across various types of transition, because of the large

heterogeneity of care context, study populations, designs, and indicators used. The methodological limitations of the studies impede the extrapolation of the results for the same disease in other contexts, and even more so for other diseases.

One limitation of this review is the lack of inclusion of grey literature (kind of material that is not published in easily accessible journals or databases). However, our electronic search strategy was very sensitive, as reflected by the lack of identification of any other eligible studies in the reference lists of the articles included. Assessment of the risk of bias was challenging, due to the heterogeneity and observational nature of the studies included. We tried to limit the subjective dimension of assessment, by developing a standardized questionnaire based on the Cochrane risk of bias assessment, with additional criteria more specific to observational epidemiologic studies (Supplemental Table 7). This questionnaire was completed independently, by two reviewers. This extended risk of bias assessment tool is not specific to the issue addressed here. It could thus be used in systematic reviews of observational studies in other contexts.

CONCLUSIONS

This review highlights the current lack of knowledge about the efficacy of structured transition programs for ensuring continuity of care during transfer from pediatric to adult care. The outcomes identified in this review are relevant and can be used for any other chronic conditions or other types of healthcare transitions, because they are not specific to a particular disease. This may facilitate comparisons of results obtained in different contexts and at different times. To avoid an overestimation of successful engagement in adult care, all patients lost to clinical follow-up during the transfer from pediatric care have to be identified. However, there are few prospective cohorts with the initial recruitment of patients in pediatric departments. Such designs and randomized trials are needed to compare adherence with care before and after the transfer and to evaluate the role of structured transition programs.

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Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow chart

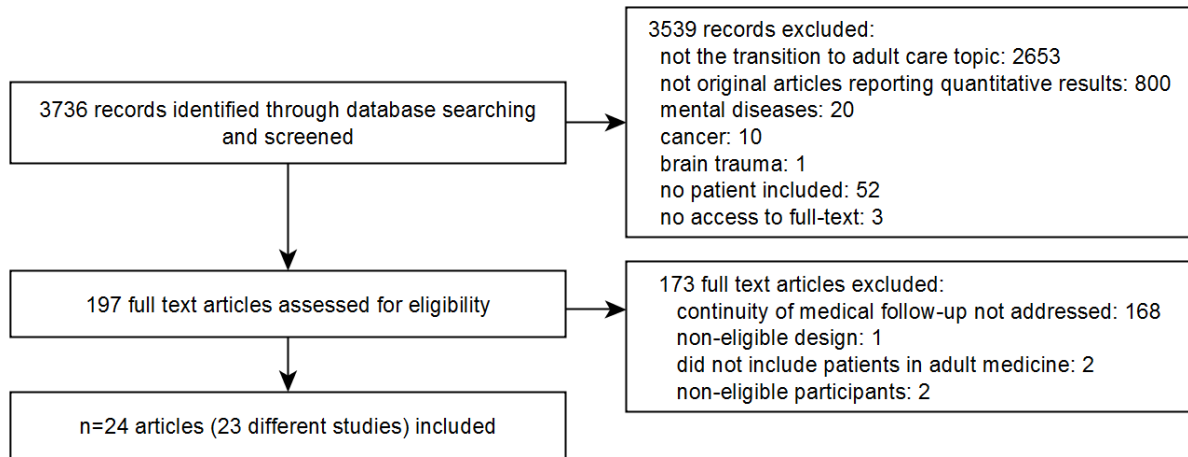


Figure 2. Risk of bias summary

Review authors' judgements about each risk of bias item for each included study. Red circles: high risk; green circle: low risk; yellow circles: unclear; empty: not concerned

	Eligibility criteria (selection bias)	Recruitment (selection bias)	Incomplete outcome data (attrition bias)	Outcome assessment (classification bias)	Measure of risk factors (classification bias)	Confounding	Random sequence generation (selection bias)	Allocation concealment (selection bias)	Blinding of participants and personnel (performance bias)	Selective reporting (reporting bias)	Other bias
Andemariam 2014	?	-	+	+	?	-				+	+
Busse 2007	-	-	+	-						?	+
Cadario 2009	-	+	?	+		-				+	-
Dugueperoux 2008	-	+	+	+	+	-				?	+
Garvey 2012	-	-	+	-	-	-				?	+
Garvey 2013	+	-	+	-	-	-				?	+
Gleeson 2013	+	+	+	+	+	-				-	+
Goossens 2011	+	+	+	+	+	-				?	+
Hankins 2012	+	+	+	?		-				?	-
Hazel 2010	+	+	-	-	+	-				?	+
Hersh 2009	-	+	-	+	-	-				?	+
Johnston 2006	+	+	?	+						+	+
Kipps 2002	+	+	+	+		-				?	+
Norris 2013	+	-	+	-						?	+
Oswald 2013	+	-	?	+	-	-				+	+
Pacaud 2005	+	-	+	-	+	-				+	+
Reid 2004	+	+	+	+	+	-				?	+
Stanczyk 2014	+	-	?	-	-	-				-	+
Steinbeck 2014	+	-	-	?			+	+	?	?	+
Vanelli 2004	-	-	+	-						?	+
Van Wallegghem 2008	?	?	-	-						?	+
Wojciechowski 2002	-	-	+	+						?	+
Yeung 2008	-	+	+	-	?	-				?	+

Table 1. Reported outcomes and indicators of continuity of care

Type of outcome	Outcome	Indicator	References	
Engagement in adult care	Attendance at the first visit in adult care	Proportion	Andemariam 2014, Kipps 2002, Hazel 2010, Hersh 2009, Reid 2004, Wojciechowski 2002, Steinbeck 2014	
	Attendance at the first two visits in adult care	Proportion	Gleeson 2013	
	Time between the last pediatric visit and the first adult visit	Mean (+/- SD)		Vanelli 2004, Wojciechowski 2002, Cadario 2009
		Median (+/- IQR)		Hersh 2009, Wojciechowski 2002, Yeung 2008, Steinbeck 2014
		Proportion < 3 months		Stanczyk 2014, Hankins 2012
		Proportion < 6 months		Garvey 2012 & 2013a, Garvey 2013b, Stanczyk 2014
	Proportion < 24 months		Yeung 2008	
Retention in adult care	Frequency of visits	Mean (+/- SD) per year	Dugueperoux 2008, Busse 2007	
		Median (+/- IQR) per year	Steinbeck 2014	
		Proportion \geq 3-4 monthly	Kipps 2002	
		Proportion \geq 6 monthly	Kipps 2002	
		Proportion with \geq 1 cardiology clinic visit within 2 years of study interview	Norris 2013	
		Proportion with no 2-year interval without cardiac care	Norris 2013	
		Proportion with no delay >12 months between 2 visits	Pacaud 2005	
		Proportion with \geq 1 visits per year	Van Wallegghem 2008	
		Proportion with \geq 2 visits per year	Pacaud 2005	
	Proportion with 1-2 or \geq 3 visits per year	Stanczyk 2014		
	Attendance at scheduled clinic appointments	Mean percentage of scheduled clinic appointments attended by year		Gleeson 2013, Cadario 2009
		Proportion with 0-1/2/ \geq 3 failed appointments		Johnston 2006
Proportion attending at least one scheduled clinic appointment in the 2 years following transfer			Hazel 2010	

		Proportion attending all their scheduled clinic appointments	Hersh 2009
Other	Unsuccessful transfer: failure to make initial contact with an adult rheumatologist, or failure to continue to follow-up with an adult rheumatologist two years after transfer (no contact for a one year period after the last scheduled appointment)	Proportion	Hazel 2010
	Follow-up in adult care: patients indicated that they were currently in cardiac follow-up or they could be contacted by mail or phone.	Proportion	Goossens 2011
	Successful transition: (has usual health care source or has usual routine preventive care source or has a personal doctor or nurse) and (his/her doctor does not treat only children, teens, or young adults) and (he/she has had continuous health insurance coverage for the past 12 months) and (health insurance benefits meet his/her needs) and (he/she had at least 1 preventive health care visit in the last 12 months) and (he/she is satisfied with health services) and (needed health care was not delayed/foregone in the last 12 months)	Proportion	Oswald 2013

Table 2. Engagement in adult care: attendance at the first or first two adult care visits (n=8 studies)

Reference	Population and design	Data collection	Type of transition	Indicator of attendance at the first ^a adult care visit
Andemariam 2014	SCD; USA; Retrospective cohort; N=47	Retrospective chart review	Structured	Proportion: 68%
Kipps 2002	Diabetes; UK; Retrospective cohort; N=141	Retrospective chart review	Structured	Proportion: 79%
Hazel 2010	Rheumatic disease; Canada; Retrospective cohort; N=100	Retrospective chart review, Interview with healthcare provider	Unstructured	Proportion: 83%
Hersh 2009	Rheumatic disease; USA; Cross-sectional; N=31	Retrospective chart review, administrative database	Unstructured	Proportion: 71%
Reid 2004	CHD; Canada; Retrospective cohort; N=360	Administrative database	Unstructured	Proportion: 47%
Wojciechowski 2002	SCD; USA; Retrospective cohort; N=47	Interview with health care provider	Unstructured	Proportion: 61%
Gleeson 2013	CAH; UK; Retrospective cohort; N=34	Retrospective chart review, administrative database	Young person clinic vs. no young person clinic	Proportion: 56% ^{\$\$} (not reported by group)
Steinbeck 2014	Diabetes; Australia; RCT; N=26	Unclear	Comprehensive transition program vs. standard clinical practice	Proportions: 79% vs. 100% ^{\$\$}

*p<0.05; **p<0.01; ***p<0.001; \$p<0.10; \$\$p≥0.10 (or reported as no significant difference with no p-value). ^aexcepted for Gleeson 2013, which reported attendance at the first two adult care visits. Abbreviations: CAH, congenital adrenal hyperplasia; CHD, congenital heart disease; RCT, randomized controlled trial; SCD, sickle cell disease

Table 3. Engagement in adult care: time between last pediatric and first adult visit (n=10 studies)

Reference	Population and design	Data collection	Type of transition	Indicators of time between last pediatric and first adult visit
Vanelli 2004	Diabetes; Italy; Cross-sectional; N=64	Telephone interview with the patient	Structured	Mean±SD: 26.4 ± 25.2 months
Garvey 2012 & 2013a	Diabetes; USA; Cross-sectional; N=250	Web-based and non-web-based autoquestionnaires	Unstructured	Proportion ≤ 6 months: 66%
Garvey 2013b	Diabetes; USA; Retrospective cohort; N=61	Web-based and non-web-based autoquestionnaires	Unstructured	Proportion ≤ 6 months: 74%
Hersh 2009	Rheumatic disease; USA; Cross-sectional; N=31	Retrospective chart review, administrative database	Unstructured	Median: 7.1 months
Stanczyk 2014	Diabetes; Poland; Retrospective cohort; N=114	Telephone interview with the patient, non-web-based autoquestionnaire	Unstructured	Proportion < 3 months: 84% Proportion ≤ 6 months: 91%
Wojciechowski 2002	SCD; USA; Retrospective cohort; N=18	Interview with healthcare provider	Unstructured	Mean±SD: 6.2 ± 7.7 months Median: 2 months
Yeung 2008	CHD; USA; Cross-sectional; N=158	Face-to-face interview with the patient, proxy interview (parents, etc.)	Unstructured	Proportion < 24 months: 37% Median: 120 months
Hankins 2012	SCD; USA; Retrospective cohort; N ^a	Unclear	Before Transition Pilot Program implementation: unstructured (N=75)	Proportion < 3 months: 15%
			Participation to Transition Pilot Program vs. no participation (N=83)	Proportions < 3 months: 74% vs. 33% ^{***}
Cadario 2009	Diabetes; Italy; Cross-sectional; N=62	Administrative database	Structured vs. unstructured transition	Mean±SD: 9.6 ± 7.2 months vs. 55.2 ± 14.4 months ^{***}
Steinbeck 2014	Diabetes; Australia; RCT; N=18	Unclear	Comprehensive transition program vs. standard clinical practice	Median (IQR): 3.4 (1.8-4.4) months vs. 3.2 (2.5-4.6) months ^{\$\$}

* p<0.05; ** p<0.01; *** p<0.001; \$p<0.10; \$\$p≥0.10 (or reported as no significant difference with no p-value). ^aN specified in “type of transition” column. Abbreviations: CHD, congenital heart disease; IQR, interquartile range; RCT, randomized controlled trial; SCD, sickle cell disease; SD, standard deviation

Table 4. Retention in adult care after transfer: frequency of visits (n=8 studies)

Reference	Population and design	Data collection	Type of transition	Indicators of frequency of visits ^a
Dugueperoux 2008	CF; France; Repeated cross-sectional; N=68	Retrospective chart review	Structured	1y before transfer: mean 3.8 /y 1y after transfer: mean 8.7 /y ^{***}
Kipps 2002	Diabetes; UK; Retrospective cohort; N=96	Retrospective chart review	Structured	Proportion ≥ 3-4 monthly: 2y before transfer: 77% 1y before transfer: 54% 1y after transfer: 45% 2y after transfer: 24% ^{***} Proportion ≥ 6 monthly: 2y before transfer: 98% 1y before transfer: 87% 1y after transfer: 81% 2y after transfer: 61% ^{***}
Busse 2007	Diabetes; Germany; Retrospective cohort; N=101	Telephone interview with the patient, retrospective chart review	Unstructured	Before transfer: mean±SD: 8.5 ± 2.3 /y After transfer: mean±SD: 6.7 ± 3.2 /y [*]
Norris 2013	CHD; USA; Retrospective cohort; N=153	Telephone interview with the patient, retrospective chart review, proxy interview (parents, etc.)	Unstructured	Proportion with ≥ 1 cardiology clinic visit within 2 years of study interview: 82%; Proportion with no 2-year interval without cardiac care: 76%
Pacaud 2005	Diabetes; Canada; Retrospective cohort; N=214	Non-web-based autoquestionnaire	Unstructured	Proportion with no delay >12 months between 2 visits: 90%; proportion with ≥2 visits/y: 87%
Stanczyk 2014	Diabetes; Poland; Retrospective cohort; N=132	Telephone interview with the patient, non-web-based autoquestionnaire	Unstructured	Proportion with 1-2 visits/y: 87% ≥ 3 visits/y: 13%
Steinbeck 2014	Diabetes; Australia; RCT; N=18	Unclear	Comprehensive transition program vs. standard clinical practice	Median (IQR): 3 (2-5) /y vs. 2 (1-4) /y ^{\$\$}
Van Wallegghem 2008	Diabetes; Canada; Retrospective and prospective cohort; N=64	Telephone interview with the patient, retrospective chart review, administrative database	Before vs. after Maestro	Proportion with ≥ 1 visits /y: 89% vs. 95% ^{\$\$}

*p<0.05; **p<0.01; ***p<0.001; \$p<0.10; \$\$p≥0.10 (or reported as no significant difference with no p-value). ^ain adult care unless otherwise specified.

Abbreviations: CF, cystic fibrosis; CHD, congenital heart disease; IQR, interquartile range; RCT, randomized controlled trial; SD, standard deviation

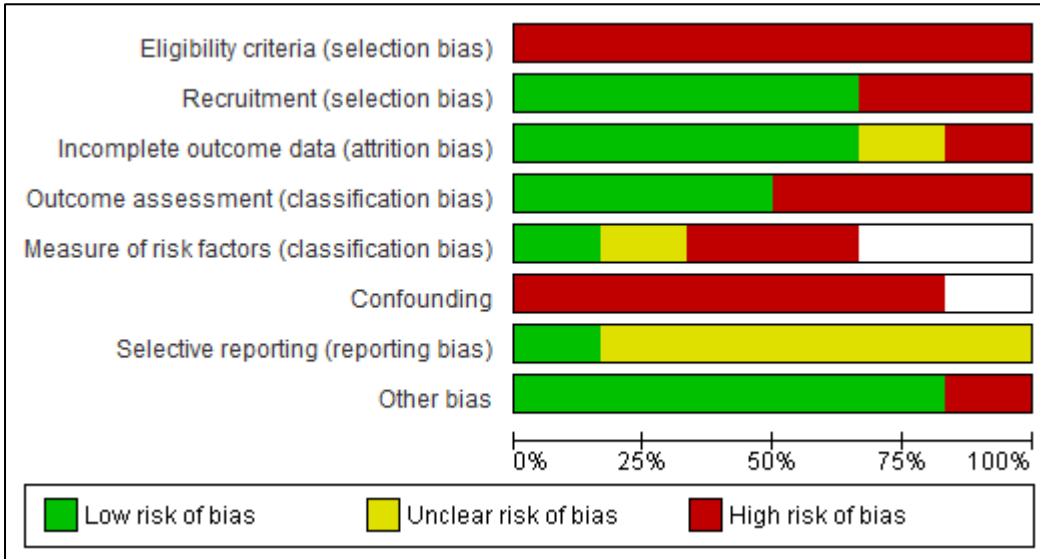
Table 5. Retention in adult care after transfer: attendance at scheduled clinic appointments (n=5 studies)

Reference	Population and design	Data collection	Type of transition	Indicators of attendance at scheduled clinic appointments ^a
Gleeson 2013	CAH; UK; Retrospective cohort; N=23	Retrospective chart review, administrative database	Structured	Mean percentage of scheduled clinic appointments attended by year ^b : 3y before transfer: 81% 2y before transfer: 90% 1y before transfer: 90% 1y after transfer: 20% 2y after transfer: 25% 3y after transfer: 40% ^{**}
Johnston 2006	Diabetes; UK; Retrospective cohort; N=33	Administrative database	Structured	2y before transfer, proportion with 0-1 failed appointment: 52% 2 failed appointments: 18% ≥3 failed appointments: 30% 15-18m after transfer, proportion with 0-1 failed appointment: 20% 2 failed appointments: 40% ≥3 failed appointments: 40%
Hazel 2010	Rheumatic disease; Canada; Retrospective cohort; N=100	Retrospective chart review, interview with the healthcare provider	Unstructured	Proportion attending at least one scheduled clinic appointment in the 2 years following transfer: 65%
Hersh 2009	Rheumatic disease; USA; Cross-sectional; N=31	Retrospective chart review, administrative database	Unstructured	Proportion attending all their scheduled clinic appointments: 1y before transfer: 68% 1y after transfer: 68%
Cadario 2009	Diabetes; Italy; Cross-sectional; N=62	Administrative database	Structured Vs. unstructured transition	Mean±SD percentage of scheduled clinic appointments attended by year: Before transfer: 79% ± 3% vs. 80% ± 4% ^{\$\$} After transfer: 80% ± 12.5% vs. 57% ± 5% [*]

* p<0.05; ** p<0.01; *** p<0.001; \$ p<0.10; \$\$ p≥0.10 (or reported as no significant difference with no p-value). ^ain adult care unless otherwise specified. ^bvalues not given (approximations from a figure). Abbreviations: CAH, congenital adrenal hyperplasia; RCT, randomized controlled trial; SD, standard deviation

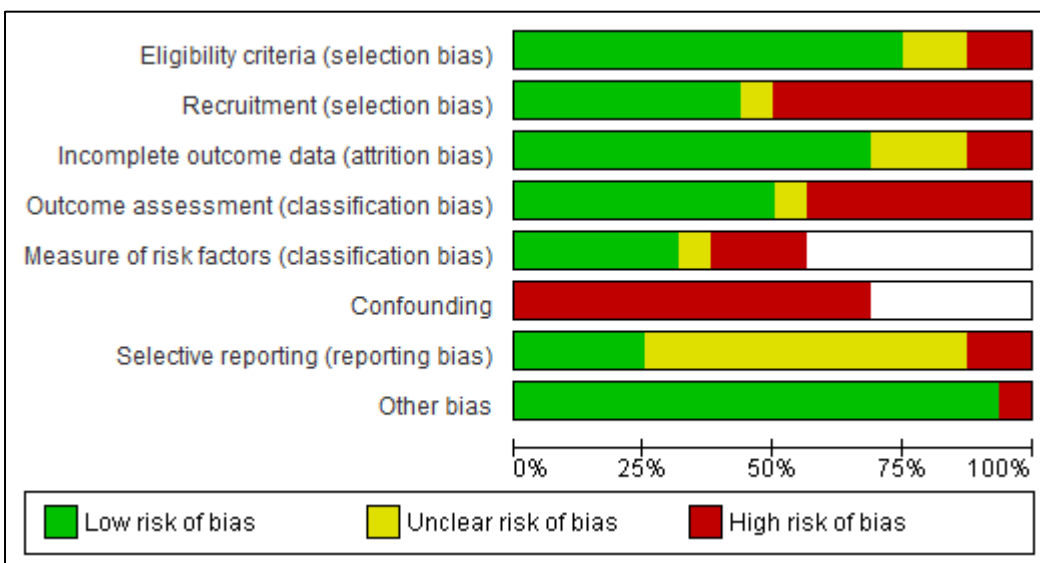
Supplementary Data

Supplemental Figure 3. Risk of bias graphs in cross-sectional studies (N=6)



Review authors' judgement about each risk of bias item presented as percentages across all included cross-sectional studies. White corresponds to the studies that were not concerned by the corresponding type of bias.

Supplemental Figure 4. Risk of bias graphs in cohort studies (N=15)



Review authors' judgement about each risk of bias item presented as percentages across all included cohort studies. The randomized trial is counted in the studies of this figure (Steinbeck 2014). White corresponds to the studies that were not concerned by the corresponding type of bias.

Supplemental 6. Pubmed search algorithm

1.	("Transition to adult care" [Mesh] OR "Transition to adult care" [Title/Abstract] OR transition* [Title] OR transfer* [Title] OR "continuity" [Title/Abstract] OR "continuity of patient care" [Mesh] OR "continuity of patient care" [Title/Abstract] OR "patient transfer" [Mesh] OR "patient transfer" [Title/Abstract] OR "patient care planning" [Mesh] OR "patient care planning" [Title/Abstract])
2.	("adolescent" [Mesh] OR "adolescent" [Title/Abstract] OR "young adult" [Mesh] OR "young adult" [Title/Abstract] OR "adolescents" [Title/Abstract] OR "adolescence" [Title/Abstract] OR "teen" [Title/Abstract] OR "teens" [Title/Abstract] OR "teenage" [Title/Abstract] OR "teenager" [Title/Abstract] OR "juvenile" [Title/Abstract] OR "youth" [Title/Abstract] OR "young person" [Title/Abstract] OR "young persons" [Title/Abstract] OR "young people" [Title/Abstract] OR "young adult" [Title/Abstract] OR "young adults" [Title/Abstract] OR "young adulthood" [Title/Abstract] OR "young men" [Title/Abstract] OR "young women" [Title/Abstract] OR "young male" [Title/Abstract] OR "young males" [Title/Abstract] OR "young female" [Title/Abstract] OR "young females" [Title/Abstract] OR "pediatric" [Title/Abstract] OR "pediatrics" [Mesh] OR "pediatrics" [Title/Abstract] OR "paediatric" [Title/Abstract] OR "paediatrics" [Title/Abstract] OR "adolescent medicine" [Mesh] OR "adolescent medicine" [Title/Abstract] OR "adolescent health services" [Mesh] OR "adolescent health services" [Title/Abstract] OR "hospitals, pediatric" [Mesh] OR "hospitals, pediatric" [Title/Abstract])
3.	adult* [Title/Abstract]
4.	("health facilities" [Mesh] OR "patient care management" [Mesh] OR "medicine" [Title/Abstract] OR "care" [Title/Abstract] OR "health care" [Title/Abstract] OR "healthcare" [Title/Abstract] OR "service" [Title/Abstract] OR "services" [Title/Abstract] OR "centre" [Title/Abstract] OR "centres" [Title/Abstract] OR "center" [Title/Abstract] OR "centers" [Title/Abstract] OR "clinic" [Title/Abstract] OR "clinics" [Title/Abstract] OR "facility" [Title/Abstract] OR "facilities" [Title/Abstract] OR "unit" [Title/Abstract] OR "units" [Title/Abstract] OR "department" [Title/Abstract] OR "departments" [Title/Abstract] OR "hospital" [Title/Abstract] OR "hospitals" [Title/Abstract] OR program* [Title/Abstract])
5.	English [la] OR French [la]
6.	1. AND 2. AND 3. AND 4. NOT "review" [Publication Type]

Supplemental Table 7. Definitions of the risks of bias

Domain	Concerned studies	Support for Judgement	Review authors' judgement	Criteria for the judgement of 'High risk' of bias.	Criteria for a judgement of 'Low risk' of bias.	Criteria for the judgement of 'Unclear risk' of bias
Inappropriate eligibility criteria	Non-randomized studies	List inclusion and exclusion criteria	Study population not representative of target population	At least one inclusion or exclusion criterion that is not related to target population and that could be associated with the outcome (continuity of care)	Inclusion and exclusion criteria are not likely to select a particular population which would be different from the target population for characteristics related to the outcome (continuity of care)	Insufficient information to permit judgement of 'Low risk' or 'High risk' (eg, inclusion and exclusion criteria not specified or target population difficult to define).
Participation	Non-randomized studies	Describe the method used to recruit subjects.	Included subjects not representative of eligible subjects	The recruitment did not allow to make a representative sample of the study population. Participants that were recruited were likely to differ from those who were not for characteristics related to the outcome. This bias should be suspected, for example, when there is one or several of these elements: - a high rate of non-response or non-participation, - a recruitment that was not at random - the study was not proposed to consecutive eligible subjects	Recruitment that is likely to have resulted in a representative sample of the study population	Insufficient information to permit judgement of 'Low risk' or 'High risk' (eg, recruitment not described).

Supplementary Table 7. (continued)

Domain	concerned studies	Support for judgement	Review authors' judgement	Criteria for the judgement of 'High risk' of bias.	Criteria for a judgement of 'Low risk' of bias.	Criteria for the judgement of 'Unclear risk' of bias
Incomplete outcome data	All	Describe the completeness of outcome data for each main outcome, including attrition and exclusions from the analysis. State whether attrition and exclusions were reported, the numbers in each intervention group (compared with total randomized participants), reasons for attrition/exclusions where reported, and any re-inclusions in analyses performed by the review authors.	Attrition bias due to amount, nature or handling of incomplete outcome data.	<p>Any one of the following:</p> <ul style="list-style-type: none"> - Reason for missing outcome data likely to be related to true outcome, with either imbalance in numbers or reasons for missing data across intervention groups; - For dichotomous outcome data, the proportion of missing outcomes compared with observed event risk enough to induce clinically relevant bias in intervention effect estimate; - For continuous outcome data, plausible effect size (difference in means or standardized difference in means) among missing outcomes enough to induce clinically relevant bias in observed effect size; - 'As-treated' analysis done with substantial departure of the intervention received from that assigned at randomization; - Potentially inappropriate application of simple imputation. 	<p>Any one of the following:</p> <ul style="list-style-type: none"> - No missing outcome data; - Reasons for missing outcome data unlikely to be related to true outcome (for survival data, censoring unlikely to be introducing bias); - Missing outcome data balanced in numbers across intervention groups, with similar reasons for missing data across groups; - For dichotomous outcome data, the proportion of missing outcomes compared with observed event risk not enough to have a clinically relevant impact on the intervention effect estimate; - For continuous outcome data, plausible effect size (difference in means or standardized difference in means) among missing outcomes not enough to have a clinically relevant impact on observed effect size; - Missing data have been imputed using appropriate methods. 	<p>Any one of the following:</p> <ul style="list-style-type: none"> - Insufficient reporting of attrition/exclusions to permit judgement of 'Low risk' or 'High risk' (e.g. number randomized not stated, no reasons for missing data provided); - The study did not address this outcome.

Supplementary Table 7. (continued)

Domain	concerned studies	Support for judgement	Review authors' judgement	Criteria for the judgement of 'High risk' of bias.	Criteria for a judgement of 'Low risk' of bias.	Criteria for the judgement of 'Unclear risk' of bias
Classification bias for outcome assessment	All	Describe the method used to collect and measure outcomes, including blinding of outcome assessment in comparative studies	Classification bias due to inadequate measure of outcomes, including lack of blinding in comparative studies	Any one of the following: - Collected by interview with healthcare provider or the patient (or parents) - In comparative studies, no blinding of outcome assessment (or blinding broken), and the outcome measurement is likely to be influenced by lack of blinding	Any one of the following: - Collected in an exhaustive source (eg, registry, electronic database) - Collected in patient's chart and the review authors judge that the outcome measurement is not likely to be biased AND, in comparative studies, one of the following: - Blinding of outcome assessment ensured, and unlikely that the blinding could have been broken. - Blinding of outcome assessment not ensured, but the review authors judge that the outcome measurement is not likely to be influenced by lack of blinding;	Insufficient information to permit judgement of 'Low risk' or 'High risk';
Assessment of risk factors	observational comparative	Describe the method used to collect and measure risk factors	Classification bias due to inadequate measure of risk factors	One of the following: - collected retrospectively in patient's chart or by interview with healthcare provider or the patient (or parents), unless the measure was obvious (sex, age...) - declared prospectively but subjective	One of the following: - collected prospectively in an adequate manner - collected retrospectively in an exhaustive source (eg, registry, electronic database) - objective (sex, age...)	Insufficient information to permit judgement of 'Low risk' or 'High risk'. Eg, measurement of risk factors not described
Confounding	observational comparative, non randomized evaluation	Describe the method used to take into account potential confounders	Confounding due to confounders that were not accounted for	Any one of the following: - no particular method to account for confounders - no multivariate model - multivariate model that missed important confounders	Multivariate model that included at least the most relevant confounders	Insufficient information to permit judgement of 'Low risk' or 'High risk'

Supplementary Table 7. (continued)

Domain	concerned studies	Support for judgement	Review authors' judgement	Criteria for the judgement of 'High risk' of bias.	Criteria for a judgement of 'Low risk' of bias.	Criteria for the judgement of 'Unclear risk' of bias
Random sequence generation	RCT	Describe the method used to generate the allocation sequence in sufficient detail to allow an assessment of whether it should produce comparable groups.	Selection bias (biased allocation to interventions) due to inadequate generation of a randomised sequence.	<p>The investigators describe a non-random component in the sequence generation process. Usually, the description would involve some systematic, non-random approach, for example:</p> <ul style="list-style-type: none"> - Sequence generated by odd or even date of birth; - Sequence generated by some rule based on date (or day) of admission; - Sequence generated by some rule based on hospital or clinic record number. <p>Other non-random approaches happen much less frequently than the systematic approaches mentioned above and tend to be obvious. They usually involve judgement or some method of non-random categorization of participants, for example:</p> <ul style="list-style-type: none"> - Allocation by judgement of the clinician; - Allocation by preference of the participant; - Allocation based on the results of a laboratory test or a series of tests; - Allocation by availability of the intervention. 	<p>The investigators describe a random component in the sequence generation process such as:</p> <ul style="list-style-type: none"> - Referring to a random number table; - Using a computer random number generator; - Coin tossing; - Shuffling cards or envelopes; - Throwing dice; - Drawing of lots; - Minimization*. <p>*Minimization may be implemented without a random element, and this is considered to be equivalent to being random.</p>	Insufficient information about the sequence generation process to permit judgement of 'Low risk' or 'High risk'.

Supplementary Table 7. (continued)

Domain	concerned studies	Support for judgement	Review authors' judgement	Criteria for the judgement of 'High risk' of bias.	Criteria for a judgement of 'Low risk' of bias.	Criteria for the judgement of 'Unclear risk' of bias
Allocation concealment	RCT	Describe the method used to conceal the allocation sequence in sufficient detail to determine whether intervention allocations could have been foreseen in advance of, or during, enrolment.	Selection bias (biased allocation to interventions) due to inadequate concealment of allocations prior to assignment.	Participants or investigators enrolling participants could possibly foresee assignments and thus introduce selection bias, such as allocation based on: <ul style="list-style-type: none"> - Using an open random allocation schedule (e.g. a list of random numbers); - Assignment envelopes were used without appropriate safeguards (e.g. if envelopes were unsealed or nonopaque or not sequentially numbered); - Alternation or rotation; - Date of birth; - Case record number; - Any other explicitly unconcealed procedure. 	Participants and investigators enrolling participants could not foresee assignment because one of the following, or an equivalent method, was used to conceal allocation: <ul style="list-style-type: none"> - Central allocation (including telephone, web-based and pharmacy-controlled randomization); - Sequentially numbered drug containers of identical appearance; - Sequentially numbered, opaque, sealed envelopes. 	Insufficient information to permit judgement of 'Low risk' or 'High risk'. This is usually the case if the method of concealment is not described or not described in sufficient detail to allow a definite judgement – for example if the use of assignment envelopes is described, but it remains unclear whether envelopes were sequentially numbered, opaque and sealed.
Blinding of participants and personnel	RCT	Describe all measures used, if any, to blind study participants and personnel from knowledge of which intervention a participant received. Provide any information relating to whether the intended blinding was effective.	Performance bias due to knowledge of the allocated interventions by participants and personnel during the study.	Any one of the following: <ul style="list-style-type: none"> - No blinding or incomplete blinding, and the outcome is likely to be influenced by lack of blinding; - Blinding of key study participants and personnel attempted, but likely that the blinding could have been broken, and the outcome is likely to be influenced by lack of blinding. 	Any one of the following: <ul style="list-style-type: none"> - No blinding or incomplete blinding, but the review authors judge that the outcome is not likely to be influenced by lack of blinding; - Blinding of participants and key study personnel ensured, and unlikely that the blinding could have been broken. 	Any one of the following: <ul style="list-style-type: none"> - Insufficient information to permit judgement of 'Low risk' or 'High risk'; - The study did not address this outcome.

Supplementary Table 7. (continued)

Domain	concerned studies	Support for judgement	Review authors' judgement	Criteria for the judgement of 'High risk' of bias.	Criteria for a judgement of 'Low risk' of bias.	Criteria for the judgement of 'Unclear risk' of bias
Selective reporting	All	State how the possibility of selective outcome reporting was examined by the review authors, and what was found.	Reporting bias due to selective outcome reporting.	Any one of the following: <ul style="list-style-type: none"> - Not all of the study's pre-specified primary outcomes have been reported; - One or more primary outcomes is reported using measurements, analysis methods or subsets of the data (e.g. subscales) that were not pre-specified; - One or more reported primary outcomes were not pre-specified (unless clear justification for their reporting is provided, such as an unexpected adverse effect); - One or more outcomes of interest in the review are reported incompletely so that they cannot be entered in a meta-analysis; - The study report fails to include results for a key outcome that would be expected to have been reported for such a study. 	Any of the following: <ul style="list-style-type: none"> - The study protocol is available and all of the study's pre-specified (primary and secondary) outcomes that are of interest in the review have been reported in the pre-specified way; - The study protocol is not available but it is clear that the published reports include all expected outcomes, including those that were pre-specified (convincing text of this nature may be uncommon). 	Insufficient information to permit judgement of 'Low risk' or 'High risk'. It is likely that the majority of studies will fall into this category.
Other sources of bias	All	State any important concerns about bias not addressed in the other domains in the tool. If particular questions/entries were pre-specified in the review's protocol, responses should be provided for each question/entry.	Bias due to problems not covered elsewhere in the table.	There is at least one important risk of bias. For example, the study: <ul style="list-style-type: none"> - Had a potential source of bias related to the specific study design used; or - Has been claimed to have been fraudulent; or - Had some other problem. 	The study appears to be free of other sources of bias.	There may be a risk of bias, but there is either: <ul style="list-style-type: none"> - Insufficient information to assess whether an important risk of bias exists; or - Insufficient rationale or evidence that an identified problem will introduce bias.

Abbreviation: RCT, randomized controlled trial

Supplementary Table 8. Characteristics of the studies

	Studies reporting outcome that measures				
	All studies	Attendance at the first or first two adult care visits	Time between last pediatric and first adult visit	Frequency of visits	Clinic appointments attended
	N=23	N=8	N=10	N=8	N=5
Type of objective - % (<i>n</i>)					
descriptive	17% (4)	1	1	2	1
identification of risk factors	52% (12)	4	4	3	2
evaluation of intervention	30% (7)	3	4	3	2
Condition(s) of interest - % (<i>n</i>)					
diabetes	48% (11)	2	6	6	2
congenital heart disease	17% (4)	1	1	1	-
sickle cell disease	13% (3)	2	2	-	-
rheumatic disease	9% (2)	2	1	-	2
congenital adrenal hyperplasia	4% (1)	1	-	-	1
cystic fibrosis	4% (1)	-	-	1	-
not specific	4% (1)	-	-	-	-
Study design - % (<i>n</i>)					
cross-sectional study	26% (6)	1	5	1	2
unique	22% (5)	1	5	-	2
repeated	4% (1)	-	-	1	-
cohort	70% (16)	7	5	7	3
retrospective	65% (15)	6	4	5	3
retrospective and prospective	4% (1)	-	-	1	-
randomized controlled trial	4% (1)	1	1	1	-
Country - % (<i>n</i>)					
USA	39% (9)	3	6	1	1
Canada	17% (4)	2	-	2	1
Europe	39% (9)	2	3	5	3
Australia	4% (1)	1	1	-	-
Number of participants					
median	83	50	63	117	53
interquartile range	53 - 158	29 - 121	31 - 132	66 - 147	33 - 62
Settings - % (<i>n</i>)					
hospital pediatric care	35% (8)	4	4	2	2
hospital adult care	22% (5)	1	4	1	1
hospital pediatric and adult care	17% (4)	2	2	-	2
primary care and hospital adult care	4% (1)	-	-	1	-
non-medical settings	17% (4)	1	-	3	-
unclear	4% (1)	-	-	1	-
No. of centers - % (<i>n</i>)					
general population	13% (3)	1	-	1	-
single center	78% (18)	5	8	6	5
multicenter	9% (2)	2	2	1	-

Supplementary Table 8. (continued)

	Studies reporting outcome that measures				
	All studies	Attendance at the first or first two adult care visits	Time between last pediatric and first adult visit	Frequency of visits	Clinic appointments attended
Data collection					
Retrospective chart review - % (<i>n</i>)	43% (10)	5	2	5	3
Administrative database - % (<i>n</i>)	30% (7)	3	2	1	4
Telephone interview with the patient - % (<i>n</i>)	26% (6)	-	2	4	-
Non-web-based autoquestionnaire - % (<i>n</i>)	22% (5)	-	3	2	-
Web-based autoquestionnaire - % (<i>n</i>)	13% (3)	-	2	-	-
Proxy interview (parents, etc.) - % (<i>n</i>)	13% (3)	-	1	1	-
Interview with healthcare provider - % (<i>n</i>)	9% (2)	2	1	-	1
Face-to-face interview with the patient - % (<i>n</i>)	4% (1)	-	1	-	-
Unclear - % (<i>n</i>)	9% (2)	1	2	1	-

Supplementary Table 9. Description of the studies included: design, settings and study population

Reference	Disease	Study design	Country	Settings and study population			
				Settings	No. of centers ^a	Age (years)	Detailed population description
Andemariam 2014	Sickle cell disease	Retrospective cohort	USA	Hospital pediatric and adult care	1	Range 16-24	Patients aged 16 years or older attending a pediatric sickle cell disease center
Busse 2007	Diabetes	Retrospective cohort	Germany	Primary care and hospital adult care	1	Mean 22.1; SD 2.4; range 18-28	Patients aged 18+ with diabetes, at least 6 months after their transfer to adult care
Cadario 2009	Diabetes	Cross-sectional	Italy	Hospital pediatric and adult care	1	Mean 19; SD 2.8	Adolescents and young adults discharged from the pediatric diabetes service to the adult diabetic service of the same hospital (Maggiore della Carità Hospital, Novara, Italy) from 1994 to 2004
Duguepeux 2008	Cystic fibrosis	Repeated cross-sectional	France	Hospital adult care	1	Median 21; range 18-35; mean 21.6	Patients attending the Cochin adult cystic fibrosis center, transferred from one of the three pediatric cystic fibrosis centers in Paris between January 2001 and June 2004
Garvey 2012 & 2013a	Diabetes	Cross-sectional	USA	Hospital adult care	1	Range 22-30 ; mean 26.7 ; SD 2.4	Young adults (22-30 years old) with type 1 diabetes diagnosed before the age of 18, who had received pediatric diabetes care and were under the care of an adult diabetes specialist at the Joslin Diabetes Center
Garvey 2013 b	Diabetes	Retrospective cohort	USA	Hospital pediatric care	1	Mean 26.6; SD 3.0	Young adults with type 1 diabetes, who had previously been followed at the pediatric diabetes clinic at Boston Children's Hospital between June 2000 and May 2010 and were at least 15 years old at the last diabetes clinic visit
Gleeson 2013	Congenital adrenal hyperplasia	Retrospective cohort	UK	Hospital pediatric care	1	Median 25.5 years (range 18.4-47.8)	Patients aged 16 years and older with congenital adrenal hyperplasia who had attended the adrenal clinic at the Royal Manchester Children's Hospital between 1992 and 2009
Goossens 2011	Congenital heart disease	Retrospective cohort	Belgium	Hospital pediatric care	1	Range 21-25	Patients with congenital heart disease examined and/or treated at a tertiary care center between 2000 and 2004, aged 21 years or older in 2009 and not cured in childhood

Supplementary Table 9. (continued)

Reference	Disease	Study design	Country	Settings and study population			
				Settings	No. of centers ^a	Age (years)	Detailed population description
Hankins 2012	Sickle cell disease	Retrospective cohort	USA	Hospital pediatric care	1	Median 18.4 ; range 17-19	Patients from a pediatric sickle cell center, aged 17 to 19 years, and sufficiently medically stable for transfer to another health care provider
Hazel 2010	Rheumatic disease	Retrospective cohort	Canada	Hospital pediatric care	1	Not available	Patients with juvenile idiopathic arthritis who attended the MCH JIA clinic and who were subsequently transferred to the care of adult rheumatologists between 1992-2005
Hersh 2009	Rheumatic disease	Cross-sectional	USA	Hospital adult care	1	Mean age at last pediatric rheumatology visit: 19.5; range 17.4-22.0	Patients ≤ 30 years old who transferred from the pediatric to adult rheumatology clinics at University of California San Francisco between 1995 and 2005 (at least one scheduled adult rheumatology clinic visit)
Kipps 2002	Diabetes	Retrospective cohort	UK	Not medical settings	General population	Mean 22.1; range 18.2-28.7	Patients aged 18 years or older with a Type 1 diabetes diagnosed at <16 years of age between 1985 and 1995
Johnston 2006	Diabetes	Retrospective cohort	UK	Hospital pediatric and adult care	1	Range 14-24	All type 1 diabetic patients who transferred from pediatric to adult diabetic clinic services between 1 January 2000 and 31 December 2001 at Royal Belfast Hospital for Sick Children, UK
Norris 2013	Congenital heart disease	Retrospective cohort	USA	Not medical settings	1	Mean 24.5; range 21.7-27.2	Young adults (aged 21-28 years) with congenital heart disease of moderate or severe complexity and an index cardiology clinic visit at the cardiac center during adolescence in 2001 or 2002 (at age 14-18 years)
Oswald 2013	Not specified	Retrospective cohort	USA	Not medical settings	General population	Range 19-23	Children and youths with special health care needs who participated in the 2001 National Survey of Children with Special Health Care Needs
Pacaud 2005	Diabetes	Retrospective cohort	Canada	Not medical settings	General population	Mean 20.5; SD 2.2	All patients with diabetes who had been transferred from pediatric-care to adult-care services by the diabetes clinic of the Alberta Children's Hospital from June 1992 to June 1997
Reid 2004	Congenital heart disease	Retrospective cohort	Canada	Hospital pediatric care	1	Range 19-21	Young adults (19-21) with complex congenital heart disease in Canada

Supplementary Table 9. (continued)

Reference	Disease	Study design	Country	Settings and study population			
				Settings	No. of centers ^a	Age (years)	Detailed population description
Stanczyk 2014	Diabetes	Retrospective cohort	Poland	Hospital pediatric care	1	Mean 20.4; SD 1.2	Patients with type 1 diabetes, aged 18 years or older, transferred from the regional outpatient diabetes clinic at the Upper Silesian Center of Child Health in Katowice, Poland (2003–2007)
Steinbeck 2014	Diabetes	Randomized controlled trial	Australia	Hospital pediatric and adult care	2	Range 17.3-18.8	Young people with type 1 diabetes, identified by their diabetes specialists as ready to leave the pediatric diabetes service and transfer to adult care.
Van Walleghe 2008	Diabetes	Retrospective and prospective cohort	Canada	Unclear	1	18 years old for one cohort; 19-25 for the other	Young adults with type 1 diabetes who transferred from pediatric to adult care. Two cohorts of participants: 1) a younger group (aged 18 years, $n=82$) assisted by a navigator during the transition from pediatric care and 2) an older group (aged 19–25 years) who were transferred to adult care without this initial support but were later enrolled in the program
Vanelli 2004	Diabetes	Cross-sectional	Italy	Hospital adult care	1	Mean 26.5 ; SD 2.6 ; range 21-29	Patients with type 1 diabetes transferred from the Pediatric Diabetes Center to the Adult Diabetes Clinic of the University Hospital of Parma
Wojciechowski 2002	Sickle cell disease	Retrospective cohort	USA	Hospital pediatric care	3	Mean 20.3 ; range 18-24	Patients with sickle cell disease, aged 18-24, who had transferred to adult care within the past 3 years were chosen from three acute-care academic hospitals involved in treating children with sickle cell disease, from a large Midwestern city
Yeung 2008	Congenital heart disease	Cross-sectional	USA	Hospital adult care	1	Range 16-71	Patients with moderate- or high-complexity congenital heart disease diagnosed in childhood and seen at a regional adult congenital heart disease clinic from 2002 to 2005

^awhen a study was performed in a pediatric and an adult center working together, they were counted together as a single center (i.e., one care pathway)