Online supplement

Search strategies for electronic databases

PubMed

Time restrictions: June 1st 2011 until October 31st 2018

Records: 1078

Supplementary table 1. Search strategy PubMed

#1	Mesh: Adolescent
#2	Mesh: Young adult
#3	pediatric
#4	paediatric
#5	juvenile
#6	youth
#7	#1 OR #2 OR #3 OR #4 OR #5 OR #6
#8	Mesh: Transitional Care
#9	Mesh: Transition to Adult Care
#10	#8 OR #9
#11	#7 AND #10

Embase

Time restrictions: January 1st 2011 until October 31st 2018

Records: 1805

Supplementary table 2. Search strategy Embase

#1	‘adolescent‘/exp
#2	‘young adult‘/exp
#3	p$ediatric*
#4	‘juvenile’/mj
#5	‘youth’/exp OR youth
#6	#1 OR #2 OR #3 OR #4 OR #5

#7	'transitional care'/exp
#8	'transition to adult care'/exp
#9	#7 OR #8
#10	#7 AND #10

Web of Science Core Collection

Time restrictions: January 1st 2011 until October 31st 2018

Records: 1610

Supplementary table 3. Search strategy Web of Science

#1	**TOPIC**: (transitional care)
#2	**TOPIC**: ("transition to adult care")
#3	#1 OR #2
#4	**TOPIC**: (p?ediatric*)
#5	**TOPIC**: (youth)
#6	**TOPIC**: ("young adult*")
#7	**TOPIC**: (adolescen*)
#8	**TOPIC**: (juvenile*)
#9	#4 OR #5 OR #6 OR #7 OR #8
#10	#3 AND #9

Cochrane

Time restrictions: until October 31st 2018, no further time restrictions

Records: 48

Supplementary table 4. Search strategy Cochrane

#1	Mesh: transition to adult care
#2	Mesh: transitional care
#3	#1 OR #2

Supplementary table 5. Characteristics of excluded studies

Study	Reason for exclusion
De Hosson 2017	Full-text in Dutch
Gerfaud 2017	Full-text in French
Malivoir 2016	Full-text in French
Suris 2015	Full-text in French
Ernst 2016	Description of existing transition structures, no evaluation of interventions
Ernst 2017	Description of existing transition structures, no evaluation of interventions
Kreuzer 2016	Description of existing transition structures, no evaluation of interventions
Kreuzer 2015	Description of existing transition structures, no evaluation of interventions
McManus 2015	Description of an intervention, no comparison according to inclusion criteria
Gravelle 2015	Not enough data for statistical analysis
Raina 2018	Study protocol, no data has been collected yet
van Staa 2015	No evaluation of specific transition intervention, but comparison of patients from different hospitals with different interventions or no intervention
Schmidt 2018	Subgroup analysis of an included study (Schmidt 2016)
Hess 2015	No population according to inclusion criteria, no English abstract
Garvey 2012	No intervention according to inclusion criteria
Maslow 2013	No intervention according to inclusion criteria
Ciccarelli 2014	No comparison according to inclusion criteria
Habibi 2017	No comparison according to inclusion criteria
Kime 2013	No comparison according to inclusion criteria, no quantitative outcomes
Maturo 2015	No comparison according to inclusion criteria
Okumura 2013	No comparison according to inclusion criteria
Sagar 2015	No comparison according to inclusion criteria
Woodward 2012	Comparison with a population of another study, no comparison according to inclusion criteria
Bashore L, 2016	No somatic outcome.

Breakey 2014	No somatic outcome
Colver 2018	No somatic outcome
Chi 2014	No somatic outcome
Croteau 2016	No somatic outcome
Dingemann 2017	No somatic outcome
Disabato 2015	No somatic outcome
Fishman 2014	No somatic outcome
Fu 2017	No somatic outcome
Gleeson 2013	No somatic outcome
Hankins 2012	No somatic outcome
Jensen 2015	No somatic outcome
Kuchenbuch 2013	No somatic outcome
Ladouceur 2017	No somatic outcome
Mackie 2014	No somatic outcome
Mackie 2018	No somatic outcome
Menrath 2018	No somatic outcome
Sanabria 2015	No patient relevant outcomes, no somatic outcome
Schmidt 2016	No somatic outcome
Seeley 2017	No somatic outcome
Sharma 2018-118.	No patient relevant outcomes, no somatic outcome
Tong 2015	No somatic outcome
Walter 2018	No somatic outcome
Yerushalmy-Feler 2017	No somatic outcome

Supplementary table 6. Characteristics of included studies

Study	Population	Intervention	Study design	Outcomes	Results	GRADE				Modified grading scale
						Risk of Bias	Indirectness	Imprecision	Total	
Agarwal 2017	n = 72 T1D[a]	Workshop, multidisciplinary appointments, transfer summary, web-based intervention, phone calls	Pre-post-comparison[b] in a single group design	HbA1c[c]	HbA1c decreased by 0.7%/ 8mmol/dl/ σ ($p < 0.001$)	+	-	+	Very low	2
Ammerlaan 2017	n = 72 IBD[d]	Web-based intervention	RCT[e]	Disease activity, fatigue	No significant differences	+	-	+	Low	5
Annunziato 2013	n = 34 liver transplant	Transition coordinator, transfer summary	NRCT[f] with historical control	Mortality	No deaths in intervention group, 4 deaths in control group ($p < 0.01$)	-	-	+	Very low	5
			Pre-post-comparison in intervention group	Physical health questionnaire	No significant differences					

Annunziato 2015	n = 22 renal transplant	Transition coordinator, transition checklist, transfer summary, multi-disciplinary appointments	NRCT, pre-post-comparison of all participants whether in intervention or control group	EGFR[g], blood pressure, graft rejection	No significant differences between groups, no significant differences in pre-post-comparison concerning eGFR/ graft rejection, blood pressure increased by 6.17 mmHg (p = 0.002)	+	-	+	Very low	4
Bauman 2016	n = 19 different chronic diseases requiring a warfarin therapy	Online program, workshop, transition plan, transfer summary, more time at medical appointments, individual time for transfer	Pre-post-comparison in a single group design	Complications (bleeding, thrombosis)	No significant differences	-	-	+	Very low	3
Chaudhry 2013	n = 91 CF[h]	Joint visits, workshop, transition plan, transition coordinator	NRCT	Perceived health status	Better perceived health status in intervention group before (p = 0.01) and	+	+	-	Very low	4

					after (p = 0.04) transfer					
Cole 2015	n = 72 IBD	Transition clinic, joint visits, transition plan, individual time for transfer multi-disciplinary appointments	NRCT with historical control	Achievement of mid-parental height within two standard deviations	No significant differences	+	-	+	Very low	3
Egan 2015	n = 29 T1D	Transition coordinator, phone calls, joint visits transfer summary, individual time for transfer	Pre-post-comparison in a single group design	HbA1c	No significant differences	-	-	+	Very low	3
Essadam 2018	n =65 T1D	Joint visits, transition pass, individual time for transfer	Pre-post-comparison in a single group design	HbA1c	HbA1c decreased by 0.93% (p < 0.001)	+	-	+	Very low	2
Fredericks 2015	n = 45 liver transplant	Transition readiness defines time for transfer, multi-disciplinary appointments	NRCT with historical control	AST[i], ALT[j], Bilirubin, graft rejection, mortality	No significant differences	-	-	-	Low	5
Geerlings	n = 66	Transition	Pre-post-	Medical	Score	+	-	+	Very	2

2016	epilepsy or non-epileptic seizures	clinic, multi-disciplinary appointments	comparison in a single group design	performance score (self-developed, includes seizure frequency and comorbidities)	increased (p = 0.001)				low	
Gérardin 2018	n = 66 CF	workshops, multi-disciplinary appointments	Pre-post comparisons in a single group design in two centres each	FEV1[k]	increased by 12% in Nantes and by 8% in Paris (no p-values given)	-	-	-	Very low	5
Harden 2012	n = 21 renal transplant	Transition clinic, joint visits, transition plan	NRCT with historical control	Graft rejection	Nobody in the intervention group and 3 patients in historical control had a rejection (no p-values given)	-	-	+	Low	5
				Renal allograft survival	Nobody in the intervention group and 6 patients in historical control lost renal graft (p = 0.015)					

Hergenroeder 2018	n = 45 congenital heart disease	Transition plan, multi-disciplinary appointments	NRCT with historical control	NYHAFS[l]	Decrease of NYHAFS in control, no decrease in intervention group (p = 0.042)	-	-	+	Low	4
Hilderson 2016	n = 78 JIA[m]	Transition coordinator, transition plan	NRCT	Fatigue	Small positive correlation (ES: 0.2-0.3)	+	-	+	Very low	3
			Pre-post-comparison in intervention group		No effect or small negative correlation (ES: 0.2)					
Huang 2014	n = 81 IBD, CF, T1D	SMS algorithm, web-based intervention	RCT	Disease status[n]	No significant differences	-	-	+	Low	6
Levy-Shraga 2016	n = 53 T1D	Transition clinic, transition coordinator, multi-disciplinary appointments	Pre-post-comparison in a single group design	HbA1c	HbA1c decreased by 13 mmol/mol (p < 0.0001)	-	-	+	Very low	3
				DKA[o], Hypo-glycaemia	2 years prior to transition (data for 27 patients only): 3 occurrences of DKA and 2 of hypoglycaemia During intervention: 2					

					occurrences of DKA and 6 of hypoglycaemia (no p-values given)					
				BMI[p]	No significant differences					
McQuillan 2015	n = 32 renal transplant	Transition clinic, transition coordinator, transition pass, case review (meeting of paediatric and adult team)	NRCT with historical control	EGFR, Creatinine	After one year median change of eGFR and creatinine better in intervention group, after 2 years no significant differences	-	-	+	Low	5
				Graft rejection, graft loss	Two rejections and one graft loss in intervention group, one rejection in control group (no p-values given)					

Okumura 2014	n = 29, CF	Transition work book, meeting of paediatric and adult team	NRCT with historical control	BMI	No significant differences	+	-	+	Very low	4
Paepegaey 2018	n = 95, Prader-Willi syndrome	Transfer of medical data from paediatric to adult team, multi-disciplinary appointments	NRCT	Anthropometric parameters (i.e. BMI, fat mass, overweight)	BMI, fat mass and weight were significantly better in intervention group (p = 0.01, 0.01, 0.001 respectively)	+	-	-	Very low	5
				Metabolic parameters (i.e. diabetes mellitus, cholesterol, triglycerids, AST, ALT, blood pressure)	No significant differences in metabolic blood parameters and occurrence of diabetes, control group had about 8 times more often high blood pressure (p = 0.02)					
				Endocrine parameter	GH[q] before transition,					

				(i.e. diagnosis of hypogonadism, hypothyroidism)	number of diagnosis: no significant differences; GH, thyroid hormone, cortisol and sexual hormones after transition: no significant differences					
Pape 2013	n = 66 renal transplant	Transition clinic	NRCT	Mortality	No significant differences, all patients survived	+	-	-	Very low	5
				GFR	No significant differences					
Pyatak 2016	n = 24 T1D	Web-based intervention, transition coordinator, workshop	Pre-post-comparison in a single group design	HbA1c	HbA1c decreased by 0.77% (p = 0.02)	+	+	+	Very low	1
Sequeira 2015	n = 81 T1D	Web-based intervention, transition coordinator, workshop	NRCT	HbA1c	More improvement in intervention group (p = 0.01), no significant differences in absolute levels	+	-	+	Very low	3

				Hypoglycaemia	Less occurrence in intervention group (p = 0.02)					
Skov 2018	n = 40 CF	Multi-disciplinary appointments, more time at medical appointment	Pre-post-comparison in a single group design	Lung function, BMI	No significant differences	-	-	+	Very low	4
Steinbeck 2015	n = 26 T1D	Transition coordinator phone calls	RCT	HbA1c, Complications	No significant differences	+	-	+	Very low	4
Weigensberg 2018	n = 51 T1D	SMS, group meetings	NRCT	HbA1c	No significant differences	+	-	+	Very low	2
Weitz 2015	n = 59 renal transplant	Individual time for transfer, transition plan, more time at medical appointments	NRCT with historical control	EGFR	No significant differences of absolute levels, smaller decrease of eGFR in intervention group (p = 0.004)	+	-	-	Very low	5
				Graft rejection	Less rejections in intervention group (p < 0.05)					
				Blood pressure, proteinuria	No significant differences					

White 2017	n = 120 T1D	Phone calls, SMS, transition plan, transfer of medical data from paediatric to adult team	RCT	HbA1c	No significant differences	+	-	+	Low	6

[a] Type 1 Diabetes mellitus
[b] Measurements before and after the intervention
[c] Haemoglobin A1c
[d] Inflammatory Bowel Disease
[e] Randomized controlled trial
[f] Non-randomized controlled trial
[g] Estimated glomerular filtration rate
[h] Cystic Fibrosis
[i] Aspartate transaminase
[j] Alanine transaminase
[k] Forced expiratory volume
[l] New York Heart Association Functional Classification of Heart Failure
[m] Juvenile Idiopathic Arthritis
[n] Pediatric Ulcerative Colitis Activity Index, Pediatric Crohn's Disease Activity Index, Diabetes Quality of Life, Brief Clinical Inventory, Cystic Fibrosis Clinical Score, FEV1, HbA1c
[o] Diabetic ketoacidosis
[p] Body mass index
[q] Growth hormone

Supplementary table 7. Outcome parameters

Outcome parameter	Number of studies
Mortality	3
Complications	
- **Diabetes-associated**	4
- **Graft rejection, graft survival**	6
- **Bleeding, Thrombosis**	1
- **Adipositas-associated**	1
Laboratory values, tests, scores	
- **HbA1c**[a]	9
- **eGFR**[b]	4
- **Creatinine**	1
- **Transaminases**	2
- **Lung function, FEV1**[c]	2
- **Blood pressure**	3
- **BMI**[d]	4
- **Body height**	1
- **NYHAFS**[e]	1
- **Medical performance score**	1
Symptoms	
- **Fatigue**	2
- **Proteinuria**	1
Questionnaires	
- **Perceived health**	2
- **Disease activity**	1
Other	
- **Being diagnosed with an endocrine disease**	1
- **Combined outcome measures (disease status)**	1

[a] Haemoglobin A1c
[b] Estimated Glomerular Filtration Rate
[c] Forced Expiratory Volume
[d] Body Mass Index
[e] New York Heart Association Functional Classification of Heart Failure