Online Supplement

Search strategies for electronic databases

PubMed

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

Records: 1475

Supplementary table 1. Search strategy PubMed

#1	„transition to adult care"[Mesh]
#2	„transitional care"[Mesh]
#3	„continuity of patient care"[Mesh]
#4	„patient transfer"[Mesh]
#5	#1 OR #2 OR #3 OR #4
#6	youth
#7	juvenile
#8	pediatirc OR paediatric
#9	„adolescent"[Mesh]
#10	„young adult"[Mesh]
#11	#6 OR #7 OR #8 OR #9 OR #10
#12	„chronic diesease"[Mesh]
#13	„long term care"[Mesh]
#14	#1 OR #12

#15	#6 AND #11 AND #14
#16	#6 AND #11

Web of Science Core Collection

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

Records: 1605

Supplementary table 2. Web of science Core Collection search strategy

#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

Embase

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

Records: 1805

Supplementary table 3. Embase search strategy

#1	'transitional care'/exp AND [2011-2018]/py
#2	'transition to adult care'/exp AND [2011-2018]/py
#3	adolescent'/exp AND [2011-2018]/py
#4	'young adult'/exp AND [2011-2018]/py
#5	'juvenile'/mj AND [2011-2018]/py
#6	'youth'/exp OR youth
#7	#6 AND (2011:py OR 2012:py OR 2013:py OR 2014:py OR 2015:py OR 2016:py OR 2017:py OR 2018:py OR 2019:py)
#8	p$ediatric*
#9	#8 AND (2011:py OR 2012:py OR 2013:py OR 2014:py OR 2015:py OR 2016:py OR 2017:py OR 2018:py OR 2019:py)
#10	#1 OR #2
#11	#3 OR #4 OR #5 OR #7 OR #9
#12	#10 AND #11

Cochrane

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

Records: 48

Supplementary table 4. Cochrane search strategy

#1	Transition to adult Care MeSH
#2	Transitional Care MesH
#3	#1 OR #2

Supplementary table 5. Characteristics of excluded studies

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 structures without evaluation of the interventions
Ernst 2017	Description of existing structures without evaluation of the interventions
Kreuzer 2015	Description of existing structures without evaluation of the interventions
Kreuzer 2016	Description of existing structures without evaluation of the interventions
McManus 2015	Description of an intervention, comparison does not correspond to the inclusion criteria
Gravelle 2015	Not enough data for a statistical evaluation available

Raina 2018	Study protocol, no data collected yet
Minden 2014	Study protocol, no data collected yet
Van Staa 2015	Comparison of patients in various hospitals with heterogeneous participation in different interventions
Schmidt 2018	Subgroup analysis of an included study (Schmidt 2016)
Hess 2015	Population does not correspond to the inclusion criteria, no English Abstract
Garvey 2012	Intervention does not correspond to the inclusion criteria
Maslow 2013	Intervention does not correspond to the inclusion criteria
Kuchenbuch 2013	Intervention does not correspond to the inclusion criteria
Habibi 2017	Comparison does not correspond to the inclusion criteria
Kime 2013	Comparison does not correspond to the inclusion criteria, no quantitative survey
Maturo 2015	Comparison does not correspond to the inclusion criteria
Okumura 2013	Comparison does not correspond to the inclusion criteria
Sagar 2015	Comparison does not correspond to the inclusion criteria
Woodward 2012	Comparison does not correspond to the inclusion criteria
Gorter 2015	Outcomes do not correspond to the inclusion criteria

Nieboer 2014	Study design dos not correspond to the inclusion criteria
Vaikunth 2018	Study design dos not correspond to the inclusion criteria
Sanabria 2015	No patient relevant outcome, no psychosocial outcomes or parameters of adherence
Sharma 2018	No patient relevant outcome, no psychosocial outcomes or parameters of adherence
Essessamm 2018	No psychosocial outcomes or parameters of adherence
Geradin 2018	No psychosocial outcomes or parameters of adherence
Harden 2012	No psychosocial outcomes or parameters of adherence
Paepegaey 2018	No psychosocial outcomes or parameters of adherence
Pape 2013	No psychosocial outcomes or parameters of adherence
Weitz 2015	No psychosocial outcomes or parameters of adherence

Supplementary table 6. Characteristics of included studies

Study	Population	Intervention	Comparison/ Study design	Outcomes	Results	Grade	Modified grading scale	Recommendation
Agarwall 2017	n= 72 DMT1 Age:	Scheduled 1st appointment Transition Clinic	Pre-post-Comparison	Daily measurement of	Significant improvement P<0.001	Very low	2 points	+ weak

	18-25	Workshop Multidisciplinary Appointments Transfer summary Phone calls Web based intervention		blood glucose level				
Ammerlaan 2017	N=72 IBD Age: 16-25	Web-based intervention	RCT	Self-efficacy QoL Self-management Medication-adherence	No significant change	low	5 points	- strong
Annunziato 2013	N=34 liver transplant mean age 22	Transition coordinator Transfer summary Transfer plan	Historical control Pre-post-comparison	Medication adherence Lost to follow up QoL	Significant improvement Significant improvement Stable (pre-post comparison)	Very low	4/5 points	+ strong
Annunziato 2015	N=22 Renal transplant	Transfer summary Transfer plan Social worker	Pre-post comparison	Medication adherence	Significant deterioration P=0,0007	Very low	4 points	- weak
Baumann 2016	N=19 Different chronic diseases having Warfarin therapy Age: 11-28	Transition plan Transition summary Online program Workshop Individual transition time	Pre-post-comparison	Adherence INR measurement and documentation Follow up	Significant decrease P=0,0006 No difference	Very low	3 points	- weak
Breakey 2014	n=29 haemophilia Age: 13-18	Online program Transition coordinator	RCT	Disease specific knowledge Self-efficacy	Significant improvement P=0,01 Significant improvement P=0,004	low	5 points	+ strong

				Self-management	Significant improvement P=0,007			
				Transition preparedness	Significant improvement P=0,02			
				QoL	No significant change			
Chaudry 2013	N=91 Cystic fibrosis Age: 15-25	Coordinator Multidisciplinary appointments Joint visits Workshop Transition plan	Controlled trial without randomization	Satisfaction with transfer	Significant improvement p=0,01	Very low	4 points	+ weak
				Independence	No significant change			
Cole 2015	N=72 IBD Age: 15-22	Transition Clinic Multidisciplinary appointments Joint visits Individual Plan Readiness	Historical control	Medication adherence	Significant improvement P=0,002	Very low	3 points	+ weak
				Missed first appointment	Significant improvement P=0,001			
Colver 2018	N=374 DMT1 Cerebral palsy Autism spectrum disorders Age: 14-18	Different components of transition	Comparison of different transition components and associations	Association of parental involvement and service satisfaction and wellbeing	Significant P<0,01 P=0,03	Very low	4 points	weak
				Association of self- efficacy promotion and service satisfaction	Significant P=0,04			
				Association of meeting with new	Significant P<0,01			

				treatment team and autonomy for appointments				
Disabato 2015	N=32 Epilepsy Age: 16+	Improved internal processes Summary Workshop Social worker	Pre-post-comparison	Use of social worker	Significant increase P=0,004	Very low	1 point	No recommend ation
				Patient activation	No significant change			
Egan 2015	N=29 DMT1 Age: 18-28	Transition coordinator Phone reminder Joint visits Transfer summary Individual time for transfer	Pre-post-comparison	Adherence to follow up	100%	Very low	3 points	+ weak
				Diabetes distress scale	Significant improvement P=0,021			
				QoL	No significant change			
Fishman 2014	N=415 IBD	Conferences for paediatrician about transition	Controlled trail without randomization	Self-management (self-declaim)	No significant change	Very low	4 points	- weak
Fredericks 2015	N=45 Liver transplant Age: 11+	Individual transfer Multidisciplinary appointments	Historical control	Attendance of first appointment	Significant improvement P=0,008	low	6 points	+ strong
				correlation between knowledge and appointment perception	Positive			
				Medication adherence	No significant change			
Fu 2017	N=112 IBD	Transition clinic Transfer summary	Age matched control group from another treatment center	Beliefs about medicine	significant improvement p=0,0035	Very low	4 points	- weak
				Disease specific knowledge	No significant change			

				Medication adherence (self-declaim)	No significant change			
Geerlings 2016	N=66 Epilepsy Age: 15-25	Transition clinic Multidisciplinary appointments	Pre-post comparison	Independence	Significant improvement P=0,04	Very low	2 points	+ weak
Gleeson 2013	N=61 CAH Age: 16+	Joint visits Multidisciplinary appointments	Controlled trial without randomization	Loss to follow up	No significant change	Very low	4 points	- weak
				Correlation between young age and non-attendance	Positive correlation			
Hankins 2012	N=83 Sickle cell anemia Age: 17-19	Trip to new treatment center with nurse First appointment with reminder	Controlled trial without randomization	Attendance of first appointment within 3 months	Significant improvement P=0,0002	Very low	5 points	+ strong
Hergenroe der 2018	N=45 Congenital Heart disease Age: 25	Transition plan Multidisciplinary appointments	Historical control	Shorter period between last paediatric appointment and first cardiology appointment	Significant improvement P=0,019	low	4 points	+ weak
Hilderson 2016	N=78 JIA Age: 14-16	Transition coordinator Transition plan	Controlled trial without randomization and pre-post comparison	QoL	Positive and negative effects, depending on questionaire	Very low	2 points	No recommend ation due to diverse results
				Disease specific knowledge	Small effects			
				independence	Different effects,			

					depending on analsys		
Huang 2024	N=81 IBD DMT1 CF Age: 12-20	Web based intervention Sms algorithm	RCT	Disease related self-management	Significant improvement P=0,01	low	6 points	+ strong
				Health related self-efficacy	Significant improvement P<0,01			
				QoL	No change			
Jensen 2015	N=210 Rheumatology patients Age 16+	Social worker with routinely meeting 1st appointment Workbook Individual transfer time	Controlled trial without randomization	Successfully transferred (at least 2 appointment at new treatment center)	Significant improvement P=0,002	Very low	4 points	+ weak
Ladouceur 2017	N=115 Congenital heart disease Age: 15-19	Structured workshops Group meetings Risk identification Workbook	Controlled trial without randomization	Disease specific knowledge	Significant improvement P<0,001	Very low	4 points	+ weak
Levy-Shraga 2016	N=53 DMT1 Mean age: 22	Transition clinic Transition coordinator Multidisciplinary appointments	Pre-post comparison	QoL	No significant change	Very low	3 points	- weak
Mackie 2014	N=66 Congenital heart disease Age: 15-17	Workshop Myhealth passport Information Theming transition	RCT	TRAQ: Self-management	Significant improvement P=0,048	low	5 points	+ strong
				Disease specific knowledge	Significant improvement P=0,019			
Mackie 2018	n=121 congenital heart disease Age:	Nurse led Workshops sms/email interaction after workshop	RCT	Shorter period between last paediatric appointment and	Significant improvement P=0,018	low	6 points	+ strong

				first appointment at new treatment center				
16-17				Disease specific knowledge	Significant improvement P<0,0001			
				Self-management	Significant improvement P=0,032			
McQuillan 2015	N=32 Renal transplant	Transition clinic Transition pass Coordinator Case review with new team	Historical control	Non adherence	Significant improvement P=0,03	low	5 points	+ strong
Menrath 2018	N=300 Chronic diseases 15-23	2 -day workshop for patients and 1-day workshopt for parent Website access handouts	Controlled trial without randomization and pre-post comparison	Transition specific knowledge	Significant change P<0,0001	Very low	5 points	+ strong
				Transition competence	Significant improvement P<0,001			
				HRQoL	No significant change			
Dingemann 2017	N=10 additional patients to Menrath Esophagial atresia	Subgrup analysis of Menrath study Same intervention	Controlled trial without randomization	Satisfaction of patients Parents	No significant difference	Very low	3 points	+ weak
				Transition specific knowledge	Significant improvement P=0,004			
				Self-management	No significant change			
				HrQoL				

					No significant change			
Okumura 2014	N=18 Cystic fibrosis Age: 15-26	Transition workbook Joint meetings	Pre-post comparison	TRAQ Transition readiness assessment questionnaire	No significant change	Very low	2 points	- weak
Schmidt 2016	N=274 DMT1 CF IBD Age: 15+	2 day workshop Standardized program	RCT	Transition competence	Significant improvement P<0,0001	low	7 points	+ strong
				Self-efficacy	Significant improvement P<0,001			
				Patient activation	No significant change			
				QoL	No significant change			
Seeley 2017	N=9 Spina bifida Age: 11-17	Nurse transition coordinator Monthly contact Individual transition plan	Pre-post comparison	TRAQ Transition readiness assessment questionnaire	Improved, no p given	Very low	2 points	weak
Sequeira 2015	N=81 DMT1 Age: 19-25	Workshop Transiton coordinator Multidisciplinary appointments Website	Controlled trial without randomization	Global well being	Significant improvement P=0,02	Very low	3 points	+ weak
Pyatak 2017	N=24 additional patients to Sequeira DMT1	Subgroup analysis Of Sequeira study	Pre-post comparison	Life satisfaction	Significant improvement P=0,006	Very low	1 point	No recommendation
				Diabetes specific knowledge	Significant improvement P=0,002			

Author / Year	Population	Intervention	Design	Outcome	Result	Quality	Points	Recommendation
				Depressive symptoms	No significant change			
Weigens-berg 2018	N=9 additional patients to Sequeira DMT1	Subgroup analsys Of Sequeira study Additional Workshop	Controlled trial without randomization	Depressive symptoms	Significant improvement P=0,04	Very low	2 points	No recommendation
				Well being	No significant change			
Skov 2018	N=40 CF Age: 12-18	Multidisciplinary appointments Theming transition	Pre-post comparison	Transition readiness	Significant improvement P=0,002	Very low	3 points	+ weak
				QoL	Stable			
				Loss to follow up	No loss to follow up			
Steinbeck 2015	N=26 DMT1 Age: 17-18	Transition coordinator Standardized phone calls	RCT	Successfully transferred	No significant change	low	4 points	- weak
				Self esteem	No significant change			
				Time span between last paediatric appointment and first appointment at new treatment center	No significant change			
Tong 2015	N=15 Chronical kidney disease Age: 18-26	Transition clinic Multidisciplinary team workshop	Pre-post comparison	QoL	No significant change	Very low	3 points	- weak
				Medication adherence	No significant change			
Walter 2018	N=154 JIA Age: 12-23	Transition clinic Multidisciplinary team Individual transfer time	Historical control	Drop-out rate	No significant change	Very low	4 points	- weak
				Self-efficacy				

		Transition plan			No significant change			
				Self-management	No significant change			
White 2017	N=120 DMT1 Age: 17-19	Phone calls/sms Rescheduling after missed appointments Transfer of medical data Individual transition plan	RCT	Successfully transferred	No significant change	Very low	6 points	+ strong
				Drop out	Significant improvement P=0,03			
Yerushalmy-Feler 2017	N=36 IBD Age: 17+	Transition clinic Multidisciplinary team	Pre-post comparison	Self-efficacy	Significant improvement P<0,0001	Very low	1 point	No recommendation
				Disease specific knowledge	No significant change			