

Appendix 3A: Description of published studies characteristics and findings (chronological order)

References	[1]	[2]	[3]	[4]	[5]	[6]	[7]	[8]	[9]
Publication	1996	2002	2004	2004	2006	2006	2006	2006	2007
Populations									
Disease	T1DM	T1DM	T1DM	T1DM	T1DM	T1DM	T1DM	Kidney transplant	Cystic fibrosis
Enrolment age	NR	18-29	21-29	19	16-25	15-25	14-24	15-19	18-24
Comparison	Single group, pre- and post-intervention	3 centers with differing procedures	Single group, pre- and post-intervention	Single group, pre- and post-intervention	Historical cohort (other center)	Historical cohort	Non participants	Non participants	Single group, pre- and post-intervention
Intervention									
Age at transfer	16-18	14-22	20-23	19	NR	NR	NR	16-19	16-19
Interventions modalities	AYAC	AYAC	Joint consultation in pediatrics and in adults care	Formal assessment, Educational group sessions, Transition file, Information letter	AYAC, Educational tools, Information letter	AYAC, TC, Phone support service	AYAC, Joint consultation in pediatrics	Visit to the adult clinic, Joint consultation in adults care, Information letter	AYAC, TC, Formal assessment, Visit to the adult clinic
Persons involved									
Pediatric team	M, P	M	M	no	M, P	no	no	M	M, P
Adult team	M, P	M	M	M, P	M, P	M, P	M	M, P	M
Parents	yes	no	yes	yes	no	no	no	no	yes
Outcomes assessment									
Statistical comparison	All outcomes	All outcomes	HbA1c	All outcomes	All outcomes	All outcomes	All outcomes	Any outcomes	Any outcomes
Blinding	no	no	no	no	no	no	no	no	no
Health care provider's perspectives outcomes									
Improved*	-	-	HbA1c	HbA1c	Nephropathies	HbA1c	-	-	-
Not improved	HbA1c	HbA1c	-	-	Retinopathies AHT Total HbA1c	-	-	Stable state of health Compliance	FEV1 BMI
LDC (months)	12	24	24	12	NR	54	-	12	NR
Patient's perspectives outcomes									
Improved*	-	Satisfaction	-	Knowledge/ self-management abilities	-	-	-	-	Satisfaction
Not improved	-	-	Satisfaction	QoL	-	-	-	Satisfaction	QoL Fears
Who collected data	-	Research nurse	Nurse	Adult caregivers and Young people	-	-	-	Young people	Young people and parents
Collection method	-	Questionnaire + Structured interview with doctor	Qualitative interview	Questionnaire ^v	-	-	-	Questionnaire	Questionnaires ^v
LDC (months)	-	NR	NR	12	-	-	-	12	36
Policy maker's perspectives outcomes									
Improved*	-	-	-	-	Consultation attendance Complication screening	Admission for DKA	-	-	-
Not improved	-	Consultation attendance	Consultation attendance	-	-	Admission duration	Consultation attendance	-	-
LDC (months)	-	24	24	-	NR	54	18	-	-

T1DM: Type 1 diabetes mellitus; **NR:** Not Reported; **AYAC:** Adolescent or young adults clinics/consultations; **TC:** Transition coordinator; **M :** Medical professionals; **P :** Paramedical or social professionals; **LDC:** Last data collection after transfer; **HbA1c :** Glycated haemoglobin; **AHT :** Arterial hypertension; **FEV1** Forced Expiratory Volume in 1 Second; **BMI:** Body mass index; **QOL:** Quality of life; **DKA:** Diabetic ketoacidosis

* Improvement as reported by the authors ^S secondary criteria ^v at least one validated questionnaire

Appendix 3A (continued)

References	[10]	[11]	[12]	[13]	[14]	[15]	[16]	[17]	[18]
Publication	2007	2008	2008	2009	2009	2010	2012	2012	2012
Populations									
Disease	T1DM	T1DM	T1DM	T1DM	Renal diseases	Epilepsia	Sickle cell disease	Kidney transplant	Kidney transplant
Enrolment age	15-25	18-24	18	NR	NR	16-18	17-19	16-18	16
Comparison	Non participants	Single group, pre- and post-intervention	Historical cohort	Historical cohort	Single group, pre- and post-intervention	Single group, pre- and post-intervention	1: Historical cohort 2: Non-participants	Historical cohort	Historical cohort
Intervention									
Age at transfer	NR	NR	NR	18-20	18-23	NR	NR	16-18	18-20
Interventions modalities	AYAC, Individual and group educational sessions	AYAC, transition clinic, Joint consultation in adults care, Individual and group educational sessions	Educational group sessions, Phone and mail support service, Website, Newsletter	Joint consultation in pediatrics and in adults care, Transition file, TC, Information letter	Transition clinic, Educational sessions, Transition file, TC	Transition clinic, Joint consultation in adults care, Formal assessment, Individual educational sessions	TC, visit to the adult clinic	AYAC, transition clinic, visit to the adult clinic, Individual educational sessions, peer support	Transition clinic, Formal assessment, Individual educational sessions, Transition file, TC, email and text or call for support and education, paramedical transition
Persons involved									
Pediatric team	no	M, P	no	M	M, P	M, P	M, P	M, P	M, P
Adult team	M, P	M, P	P	M	M	M, P	M, P	M, P	P
Parents	no	no	no	no	no	yes	yes	yes	no
Outcomes assessment									
Statistical comparison	All outcomes	HbA1c	Hypoglycemia and DKA	All outcomes	Any outcomes	Any outcomes	Appointment	Graft survival	Time to death / graft loss and creatinine
Blinding	no	no	no	no	no	no	no	no	no
Health care provider's perspectives outcomes									
Improved*	-	HbA1c	-	HbA1c at 12 months	Creatinine Transplant rejection	-	-	Acute rejection Graft survival time	Time to death or graft loss
Not improved	HbA1c	-	DKA, severe hypoglycemia	HbA1c at 36 months	-	-	-	-	Creatinine
LDC (months)	36	36	12	36	12	-	-	26	24
Patient's perspectives outcomes									
Improved*	-	-	Experience of difficulties or frustration, program relevance	Opinion about transition	Health knowledge	Satisfaction Fears Knowledge of adult care Independence	Satisfaction	-	-
Not improved	-	-	-	-	Satisfaction Contact in adult care	-	-	-	-
Who collected data	-	-	Transition team	Caregivers	Young people	Young people and parents	Pediatric team	-	-
Collection method	-	-	Qualitative interview	Questionnaire	Questionnaire	Questionnaire	Questionnaire	-	-
LDC (months)	-	-	12	12	12	3	3	-	-
Policy maker's perspectives outcomes									
Improved*	-	Consultation attendance Complication screening	Number of medical and diabetes educator visits	Delay of transfer, Clinical attendance	Hospitalization	-	Appointment with adult caregivers ⁵	-	Cost
Not improved	-	-	-	-	Consultation attendance	-	Program participation	-	-
LDC (months)	-	36	12	36	12	-	3	-	24

T1DM: Type 1 diabetes mellitus; **NR:** Not Reported; **AYAC:** Adolescent or young adults clinics/consultations; **TC:** Transition coordinator; **AYA:** Adolescent or young adults, **M:** Medical professionals; **P:** Paramedical or social professionals; **LDC:** Last data collection after transfer; **HbA1c:** Glycated haemoglobin; **DKA:** Diabetic ketoacidosis

* Improvement as reported by the authors^S secondary criteria^V at least one validated questionnaire

Appendix 3A (continued)

References	[19]	[20]	[21]	[22]	[23]	[24]	[25]	[26]	
Publication	2013	2013	2013	2013	2014	2014	2015	2015	
Populations									
Disease	Liver transplant	Cystic fibrosis	CAH	Kidney transplant	MED	T1DM	Rheumatological diseases	T1DM	
Enrolment age	19-20	20-34	18	NR	16-20	16-19	15-26	19-25	
Comparison	Historical cohort	Historical cohort (same and other center)	Historical cohort and non participants	2 different care settings	Historical cohort	Randomized	Non participants	Centre with differing procedures	
Intervention									
Age at transfer	NR	17-21	NR	NR	NR	NR	NR	NR	
Interventions modalities	Formal assessment, Transition file, TC, social networking website	Joint consultation in pediatrics, visit to the adult clinic, Formal assessment, Individual educational sessions, TC	AYAC, Joint consultation in pediatrics	AYAC, alternating appointments	TC, Formal assessment	TC, Phone support service, USB stick with contact details, websites of useful services and information	Formal assessment, TC, Information letter for patients	AYAC, Individual educational sessions, TC, peer support, transition resource website, social networking website	
Persons involved									
Pediatric team	P	M, P	M, P	M	TC	P	SW	P, M	
Adult team	no	M, P	M, P	M	no	no	no	no	
Parents	yes	yes	no	no	yes	no	yes	no	
Outcomes assessment									
Statistical comparison	Healthcare outcomes	All outcomes	All outcomes	Creatinine, GFR, AHT, Treatment use, Satisfaction	Length of time to transition	All outcomes	Appointments	All except number of routine diabetes clinic visits	
Blinding	no	no	no	no	no	no	no	no	
Health care provider's perspectives outcomes									
Improved*	Medication adherence, deaths and grafts lost ^S	-	-	-	Rejection and graft loss	-	HbA1c ^S	≥2 adult provider appointments	HbA1c ^S , incidence of hypoglycemia ^S
Not improved	-	-	-	-	Creatinine levels and GFR values, AHT, treatment use	-	Complications ^S (not applicable comparison)	-	-
LDC (months)	12	-	-	12	-	12	6-8	12	
Patient's perspectives outcomes									
Improved*	Concerns	Self-perceived health and satisfaction pre T	-	Transfer perceived as a large change	-	-	-	Past month Well-being ^S	
Not improved	Preferences about transition ^S Health care management ^S QoL ^S	Independence and anxiety pre T and post T Self-perceived health and satisfaction post T	-	Other satisfaction measures	-	Global self-worth ^S	Satisfaction (Not Compared)	Other psychosocial measures ^S	
Who collected data	Pediatric caregivers	Young people	-	Young people	-	Young people	Young people	Young people	
Collection method	Questionnaire ^V	Questionnaire	-	Questionnaire	-	Questionnaire ^V	Questionnaire	Questionnaire ^V	
LDC (months)	12	96	-	NR	-	12	3	12	
Policy maker's perspectives outcomes									
Improved*	-	-	-	-	Length of time to transition	-	-	-	
Not improved	-	-	Lost patients	Number of outpatient clinic visits	Continuity of care	Engagement and retention in the adult service Hospitalizations ^S	-	Number of routine visits and transfers Health-care utilization ^S	
LDC (months)	-	-	36	12	NR	12	-	3-12	

CAH : Congenital adrenal hyperplasia ; MED : mental or emotional disorder ; T1DM: Type 1 diabetes mellitus; NR: Not Reported; TC: Transition coordinator; SW: social worker, AYAC: Adolescent or young adults clinics/consultations; P : Paramedical or social professionals; M : Medical professionals; LDC: Last data collection after transfer; GFR: Glomerular filtration rate; AHT : Arterial Hypertension HbA1c : Glycated haemoglobin; QOL: Quality of life; Pre-T/ Post-T: Before/ After transfer

* Improvement as reported by the authors^S secondary criteria^V at least one validated questionnaire

Appendix 3B : Description of studies in progress characteristics (no final results published)

References	[27]	[28]	[29]*	[30]	[31]	[32]	[33]
Publication	2006	2010	2011	2012	2012	2012	2012
Populations							
Disease	IBD	T1DM or T2D managed with insulin	IBD	Asthma	Congenital heart disease, cardiomyopathy.	All chronic condition or cognitive Disability	Acquired brain injury and cerebral palsy
Enrolment age	16	16-29	>16	17-19	15-17	>19	16-17
Comparison	Randomized	Parallel group not randomized	Single group, pre- and post-intervention	Randomized	Randomized	Randomized	1: Historical cohort 2: Service with differing procedures (youths with spina bifida)
Intervention							
Interventions modalities	Joint consultation in pediatrics	Intervention 1 : Educational and behavioral sessions in group, peer support (Intervention 2 : educational sessions , transition clinic, behavioral evaluation)	Transition clinic, joint consultation in pediatrics, Formal assessment at the time of transition	Education sessions	Individual educational and self management sessions, Follow up by the nurse	Transition clinic, Educational group sessions, Transition file, TC, Information letter for patients, Peer support	Formal assessment, Individual educational sessions, Transition file, TC, peer support
Persons involved							
Pediatric team	M	P, (M)	P,M	NR	P	M, P	M,P
Adult team	M	(M)	P, M	no	no	no	M,P
Parents	no	no	no	no	no	no	yes
Outcomes assessment							
Blinding	no	no	no	no	no	no	no
Health care provider's perspectives outcomes							
Reported	IBD flare	HbA1c ^s	-	Asthma Control ^s	-	-	-
LDC (months)	12	12	-	12	-	-	-
Patient's perspectives outcomes							
Reported	-	Self-efficacy, diabetes knowledge, QoL, family conflict, treatment satisfaction, using some form of social networking ^s	Disease and medication knowledge, effects of disease on daily living, sources of support and advice, readiness, transition anxiety	QoL	Disease knowledge ^s , self-management and self-advocacy skills ^s	Self-care and transition related skills	Perceived health and well-being ^s , social participation ^s , transition readiness ^s
Who collected data	-	NR	Young people	NR	NR	Member of the research team	Young people
Collection method	-	NR	Questionnaires	Questionnaire ^v	NR	Questionnaire ^v (phone or online)	Questionnaire ^v
LDC (months)	-	12	NR	12	6 - 18 months post enrolment	6	12
Policy maker's perspectives outcomes							
Reported	-	Kind of provider ^s ; provider and educator time devoted ^s	-	-	Excess time to first ACHD clinic appointment	At least 1 visit with an adult provider within 10 months of the baseline visit.	Maintenance of continuous care, health care utilization ^s
LDC (months)	-	6-12	-	-	12 - 24 months post enrolment	10	12

IBD: Inflammatory Bowel Disease; **T1DM:** Type 1 diabetes mellitus, **T2D:** type 2 diabetes; **NR:** Not Reported; **TC:** Transition coordinator; **P :** Paramedical or social professionals; **M :** Medical professionals; **LDC:** Last data collection after transfer; **HbA1c :** Glycated haemoglobin; ; **QOL:** Quality of life; **ACHD :** adult congenital heart disease;

^s secondary criteria ^v at least one validated questionnaire

* Greveson study is not strictly at protocol stage but results available were not the definitive ones

Appendix 3B (continued)

References	[34]	[35]	[36]	[37]	[38]	[39]
Publication	2013	2013	2013	2014	2014	2015
Populations						
Disease	Juvenile idiopathic arthritis	IBD	T1DM	Kidney transplantation	heart transplantation	SCD
Enrolment age	14–16	16-18	17-20	16-22	≥18	18-23
Comparison	Centers with differing transition procedures	Randomized	Randomized	Randomized	Randomized	Single group, pre- and post-intervention
Intervention						
Interventions modalities	Visit to the adult clinic, Educational group sessions, Educational tools, TC, Information letter, Phone support service, Peer support	Transition file, Educational tools, Phone and mail support service	Individual educational sessions, Educational tools, TC, Phone, mail or text support service	Apps designed to support the documentation and transfer of clinical data and to facilitate appointment scheduling	Phone support service, computer-based education modules with associated self-tests	Music therapy, Educational group sessions
Persons involved						
Pediatric team	P,M	P	P	no	P	no
Adult team	P,M	no	no	no	P	P
Parents	yes	no	no	no	no	no
Outcomes assessment						
Blinding	no	no	Analysts and outcome assessors	no	Subject	no
Health care provider's perspectives outcomes						
Reported	-	Medication Adherence, Disease Activity ^s	HbA1c testing ^s , HbA1c levels ^s	Therapy adherence, change in eGFR ^s , serum creatinine levels ^s , transplant survival ^s , patient survival ^s , acute rejection ^s , death ^s transplant loss ^s	Immunosuppressant levels and blood draws ^s , medication adherence ^s , acute rejection ^s	-
LDC (months)	-	12 months post randomization	24	12	6	-
Patient's perspectives outcomes						
Reported	Self perceived health status, health status as perceived by parents ^s , medication adherence ^s , QoL ^s , illness-related knowledge ^s , Fatigue ^s , parenting outcomes ^s	Satisfaction Transition Readiness ^s , QoL ^s , Knowledge of Disease ^s	Satisfaction and perception of the care ^s	Satisfaction ^s , QoL ^s , social integration ^s	-	Trust in health care providers, sickle cell self-efficacy and knowledge
Who collected data	Young people +/- Parents	Young people	Young people	Young people	-	NR
Collection method	Questionnaires ^v	Questionnaires ^v	Questionnaires	Questionnaires	-	Questionnaires ^v
LDC (months)	3	12 months post randomization	24	12	-	12
Policy maker's perspectives outcomes						
Improved*	-	Non-Routine Healthcare Utilization	At least one outpatient adult specialist visit, testing for complications, foot, and retinal examinations ^s , emergency visits and hospitalizations ^s	Healthcare utilization ^s	Transition program adherence	Rate of adherence to clinic appointments ^s
LDC (months)	-	12 months post randomization	24	12	6	12

IBD: Inflammatory Bowel Disease ; **T1DM**: Type 1 diabetes mellitus; **SCD** : sickle cell disease; **TC**: Transition coordinator; **P** : Paramedical or social professionals; **M** : Medical professionals; **LDC**: Last data collection after transfer; **HbA1c** : Glycated haemoglobin; **GFR**: Glomerular filtration rate; **QOL**: Quality of life; **NR**: Not Reported;

^s secondary criteria ^v at least one validated questionnaire

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