

D.5 Transition from paediatric to adult services

Item	Details
Key issue in the scope	-
Review question in the scope	What parts of the transition from children's to adult services are most important for young people with cystic fibrosis and their family members and carers?
Review question for protocol	What parts of the transition from children's to adult services are most important for young people with cystic fibrosis and their family members and carers?
Objectives	To identify elements of the transition process (for example, transition planning involvement) from paediatric to adult services from perspectives of young people with cystic fibrosis and their family and carers.
Language	English
Study design	<p>Study designs to be considered:</p> <ul style="list-style-type: none"> • Qualitative studies (for example, interviews, focus groups, observations) • Surveys (which include qualitative data) <p>Excluded:</p> <ul style="list-style-type: none"> • Purely quantitative studies (including surveys with only descriptive quantitative data)
Population and directness	<ul style="list-style-type: none"> • Children, young people and young adults with cystic fibrosis aged 12 to 25 years who are using or receiving health or social care services. • Family members and carers of children, young people and young adults with cystic fibrosis undergoing transition from children's to adult services. <p>Population size and indirectness:</p> <ul style="list-style-type: none"> • No sample size specification. • Studies with indirect population will not be considered (however we will include studies with mixed population if quotes are reported separately).
Stratified and subgroup adjusted	<p>Age ranges:</p> <ul style="list-style-type: none"> • Adolescents: 12 to 16 years • Young people: 16 to 18 years • Young people: 18 to 25 years <p>Subgroups:</p> <p>People with mental health support needs and those who are looked after by parents/carers.</p>
Context and likely themes	<p>Context:</p> <p>Transition to adult services.</p> <p>Themes will be identified from the literature, but expected themes are:</p> <ul style="list-style-type: none"> • Transition clinic: Transition lead (consultant/social worker) preparation of plan of transition for individual and family/carers, MDT structured approach. • Health care professional training in transition to improve practice. • Transition programme/preparation period and education programme (for young person to be able to function in the adult clinic, and able to manage illness mostly independently of parents and staff). Use of transition questionnaires. • Involvement of young people and family/carer in planning, implementing and reviewing transition. • Communication point of contact information (written, verbal, and email format), and clarity about process (eg, nurse rehabilitation specialist, community paediatrician). • Key transition therapist as part of paediatric and adult service.

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	<ul style="list-style-type: none"> • Involvement of multiagency: health care, social care and education and passing information to adult services (e.g., admin support for records and appointments, transfer checklist, medical and MDT summaries before transfer). • Communication/co-ordination between paediatric and adult services. • Timing of transition with education and other agencies (eg social services) to make it as seamless and as flexible as possible (e.g., a joint transition clinic that consists of both paediatric and adult team members). • Information for young people and carers/family about health needs of cystic fibrosis as an adult, about treatment centres, available support services and resources and funding, may need to be in different format if they can't read. • Delivering information to the adult services- for example, booklet or passport for young people carry with them when attending hospital and other appointments. • Timing (age of transition) to take account of individual circumstances and problems.
Setting	All health and social care settings ideally in a UK context, but evidence from other countries will be considered if there is insufficient direct evidence.
Search strategy	<p>Sources to be searched: Medline, Medline In-Process, Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews, Cochrane Database of Abstracts of Reviews of Effectiveness, Health Technology Database, Embase</p> <p>Limits (e.g. date, study design): Apply standard exclusions and English language filters.</p> <p>Supplementary search techniques: No supplementary search techniques will be used.</p> <p>See appendix E.4 for full strategies</p>
Review strategy	<p>Appraisal of methodological quality:</p> <ul style="list-style-type: none"> • The methodological quality of each study will be assessed using a qualitative study quality checklists as set out in the Developing NICE Guidelines Manual 2014 (CASP checklist for qualitative studies). • The quality of the evidence will be assessed by a modified GRADE approach (GRADE-CERQual) for each theme. <p>Data synthesis:</p> <p>Thematic analysis of the data will be conducted and findings presented.</p> <p>Review process:</p> <ul style="list-style-type: none"> • A list of excluded studies will be provided following weeding. • Evidence tables and an evidence profile will be used to summarise the evidence.
Equalities	<ul style="list-style-type: none"> • Psychological and behavioural issues are more likely in people with a lower socioeconomic status. • Gender- outcomes are worse for women although there is no evidence that this is a consequence of difference in care. • Geographical issues – care is given through specialist centres and this may be a problem if a person with CF is living in an isolated location.
Notes/additional information	<p>References:</p> <ul style="list-style-type: none"> • Transition from children's to adult services. NICE guideline. Publication expected February 2016. <p>Other notes:</p>

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	<ul style="list-style-type: none">• Transition is considered as timely planned movement of adolescents and young people from child-centred to adult-orientated health care.• Models of transition: LIFEsplan, Moving on well (DH)• Transition should be flexible and gradual, and timing of transition should depend on developmental needs, health status and readiness of the individual.• The number of visits to the transition clinic would be important, and dependent on individual needs.• An introduction to adult services (with carer/patient) may reduce anxiety about being moved to adult services, clarity of roles and expectations from MDTs.• Training of paediatric and adult medical teams for care and transition, disability diversity, and communication skills.• Understand cultural differences, dialect, sensory deprivation, environmental issues, hearing, vision, health problems.• Resources should be tailored to needs (eg, community services/outpatient).