

D.2 Information and support

Item	Details
Key issue in the scope	Provision of information and support for infants, children, young people and adults, and their carers.
Review question in the scope	What information and support should be offered to people with cystic fibrosis?
Review question for the review	What information and support should be given to children, young people and adults with cystic fibrosis?
Objectives	To identify the information and support that should be provided to people with cystic fibrosis and their parents 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	<p>Children, young people and adults with cystic fibrosis and their parents and carers.</p> <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 analyses	<p>Age ranges:</p> <ul style="list-style-type: none"> • Children: up to 12 years • Young people: 12 to 18 years • Adults: 18 and above years
Context and likely themes	<p>Context: Information content and type of support with regards to cystic fibrosis.</p> <p>Themes will be identified from the literature, but expected themes are:</p> <ul style="list-style-type: none"> • Psychosocial support <ul style="list-style-type: none"> ○ Trained staff to provide counselling and support on the social and psychosocial issues of life limiting illness and mortality. ○ Provision of communication and dissemination of information to families of people with CF. ○ Input of psychologists, social workers, nutritionists ○ Timing of when support is given (for example, diagnosis, transition). ○ Regular formal assessments tailored to needs (for example, managing pain, when condition is directly impacting on mood, general health and wellbeing). ○ Family centred care. ○ Support groups/programmes and frequency of meetings. ○ Support at home (for example, outreach services).

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	<ul style="list-style-type: none"> ○ Support at school (nursing staff, teacher). ● Patient/carer information: <ul style="list-style-type: none"> ○ Information about named individual for point of contact. ○ Information at the time of diagnosis. ○ Clear and accurate information about cystic fibrosis (different formats such as written, video, online, audio, languages, age, gender, culture and stage of life of person). ○ Social media, apps and technology. ○ Discussion about planning management of cystic fibrosis. ○ Checklists to remind children, young people, healthcare professionals and parents/carers about information that should be discussed during consultations. ○ Information for access to resources for managing co-morbidities. ○ Information on pregnancy and fertility. ○ Education and healthcare at school. ○ Lifestyle, leisure and social issues (for example sleep deprivation). ○ Social security benefits and social services. ○ Information about organisations. ○ Support groups and charitable organisations and how to contact them.
Setting	Healthcare (community, primary, secondary care) ideally in UK setting, 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, PsycINFO, CINAHL, AMED, HMIC</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.2 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> <ul style="list-style-type: none"> ● Thematic analysis of the data will be conducted and findings presented. <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.

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Notes/additional information	Refer to CF trust