

Table 3: Clinical evidence profile: Comparison 2.1. CF centre care versus shared care

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	CF centre care	Shared care (UK equivalent)	Relative (95% CI)	Absolute		
Change in FEV₁ (% predicted) (follow-up 1 year; range of scores: 0-100; Better indicated by higher values)												
1 (Van Koolwijk 2002)	observational studies	very serious ¹	no serious inconsistency	no serious indirectness	no serious imprecision	none	41	41	-	MD 0.5 lower (3.05 lower to 2.05 higher)	VERY LOW	CRITICAL
First to last FEV₁ (% per year) (follow-up 3 years; range of scores: 0-100; Better indicated by higher values)												
1 (Thomas 2008)	observational studies	very serious ²	no serious inconsistency	no serious indirectness	serious ³	none	67	30	-	MD 2.4 lower (5.72 lower to 0.92 higher)	VERY LOW	CRITICAL
Slope FEV₁ (% per year) (follow-up 3 years; range of scores: 0-100; Better indicated by higher values)												
1 (Thomas 2008)	observational studies	very serious ²	no serious inconsistency	no serious indirectness	serious ³	none	67	30	-	MD 2.2 lower (5.37 lower to 0.97 higher)	VERY LOW	CRITICAL
BMI (follow-up 1 year; Better indicated by higher values)												
1 (Van Koolwijk 2002)	observational studies	very serious ¹	no serious inconsistency	no serious indirectness	no serious imprecision	none	41	41	-	MD 0.12 lower (0.44 lower to	VERY LOW	IMPORTANT

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	CF centre care	Shared care (UK equivalent)	Relative (95% CI)	Absolute		
										0.2 higher)		
Quality of life: CFQ-Teen - Physical (range of scores: 0-100; Better indicated by higher values)												
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	serious ^{3, a}	none	24	10	-	MD 17.8 lower (30.28 to 5.32 lower)	VERY LOW	IMPORTANT
Quality of life: CFQ-Teen - Role (range of scores: 0-100; Better indicated by higher values)												
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	serious ^{3, a}	none	24	10	-	MD 10.4 lower (26.45 lower to 5.65 higher)	VERY LOW	IMPORTANT
Quality of life: CFQ-Teen - Vitality (range of scores: 0-100; Better indicated by lower values)												
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	serious ^{3, a}	none	24	10	-	MD 18.2 lower (32.5 to 3.9 lower)	VERY LOW	IMPORTANT
Quality of life: CFQ-Teen - Emotional (range of scores: 0-100; Better indicated by higher values)												
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	serious ^{3, a}	none	24	10	-	MD 5.5 lower (18.35 lower to 7.35 higher)	VERY LOW	IMPORTANT
Quality of life: CFQ-Teen - Social (range of scores: 0-100; Better indicated by higher values)												

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	CF centre care	Shared care (UK equivalent)	Relative (95% CI)	Absolute		
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	serious ^{3, a}	none	24	10	-	MD 17.6 lower (26.71 to 8.49 lower)	VERY LOW	IMPORTANT
Quality of life: CFQ-Teen - Body (range of scores: 0-100; Better indicated by higher values)												
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	very serious ^{5, a}	none	24	10	-	MD 4.5 lower (21.56 lower to 12.56 higher)	VERY LOW	IMPORTANT
Quality of life: CFQ-Teen - Eating (range of scores: 0-100; Better indicated by higher values)												
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	very serious ^{5, a}	none	24	10	-	MD 4.5 lower (21.56 lower to 12.56 higher)	VERY LOW	IMPORTANT
Quality of life: CFQ-Teen - TB (range of scores: 0-100; Better indicated by higher values)												
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	very serious ^{5, a}	none	24	10	-	MD 9.6 lower (28.01 lower to 8.81 higher)	VERY LOW	IMPORTANT
Quality of life: CFQ-Teen - Health (range of scores: 0-100; Better indicated by higher values)												
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	serious ^{3, a}	none	24	10	-	MD 14.8 lower (31.75	VERY LOW	IMPORTANT

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	CF centre care	Shared care (UK equivalent)	Relative (95% CI)	Absolute		
mas 2006)										lower to 2.15 higher)		
Quality of life: CFQ-Teen - Weight (range of scores: 0-100; Better indicated by higher values)												
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	serious ^{3, a}	none	24	10	-	MD 12.5 lower (29.45 lower to 4.45 higher)	VERY LOW	IMPORTANT
Quality of life: CFQ-Teen - Respiratory (range of scores: 0-100; Better indicated by higher values)												
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	serious ^{3, a}	none	24	10	-	MD 4.5 lower (15.25 lower to 6.25 higher)	VERY LOW	IMPORTANT
Quality of life: CFQ-Teen - Digestion (range of scores: 0-100; Better indicated by higher values)												
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	serious ^{3, a}	none	24	10	-	MD 7.9 lower (17.14 lower to 1.34 higher)	VERY LOW	IMPORTANT
Quality of life: CFQ-Child - Physical (range of scores: 0-100; Better indicated by higher values)												
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	very serious ^{5, a}	none	46	37	-	MD 1.2 lower (10.97 lower to	VERY LOW	IMPORTANT

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	CF centre care	Shared care (UK equivalent)	Relative (95% CI)	Absolute		
										8.57 higher)		
Quality of life: CFQ-Child - Emotional (range of scores: 0-100; Better indicated by higher values)												
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	no serious imprecision ^a	none	46	37	-	MD 1.3 higher (5.13 lower to 7.73 higher)	VERY LOW	IMPORTANT
Quality of life: CFQ-Child - Social (range of scores: 0-100; Better indicated by higher values)												
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	serious ^{3, a}	none	46	37	-	MD 1.7 lower (9.46 lower to 6.06 higher)	VERY LOW	IMPORTANT
Quality of life: CFQ-Child - Body (range of scores: 0-100; Better indicated by higher values)												
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	serious ^{3, a}	none	46	37	-	MD 2.8 lower (13.64 lower to 8.04 higher)	VERY LOW	IMPORTANT
Quality of life: CFQ-Child - Eating (range of scores: 0-100; Better indicated by higher values)												
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	very serious ^{5, a}	none	46	37	-	MD 0.5 lower (11.94 lower to 10.94 higher)	VERY LOW	IMPORTANT

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	CF centre care	Shared care (UK equivalent)	Relative (95% CI)	Absolute		
Quality of life: CFQ-Child - TB (range of scores: 0-100; Better indicated by higher values)												
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	serious ^{3, a}	none	46	37	-	MD 4.7 higher (5.88 lower to 15.28 higher)	VERY LOW	IMPORTANT
Quality of life: CFQ-Child - Respiratory (range of scores: 0-100; Better indicated by higher values)												
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	serious ^{3, a}	none	46	37	-	MD 3.9 higher (5.69 lower to 13.49 higher)	VERY LOW	IMPORTANT
Quality of life: CFQ-Child - Digestion (range of scores: 0-100; Better indicated by higher values)												
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	serious ^{3, a}	none	46	37	-	MD 4 higher (8.38 lower to 16.38 higher)	VERY LOW	IMPORTANT
Quality of life: CFQ-Parent - Physical (range of scores: 0-100; Better indicated by higher values)												
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	serious ^{3, a}	none	45	35	-	MD 2.5 higher (6.96 lower to 11.96 higher)	VERY LOW	IMPORTANT
Quality of life: CFQ-Parent - Vitality (range of scores: 0-100; Better indicated by higher values)												

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	CF centre care	Shared care (UK equivalent)	Relative (95% CI)	Absolute		
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	no serious imprecision ^a	none	45	35	-	MD 0.7 lower (7.78 lower to 6.38 higher)	VERY LOW	IMPORTANT
Quality of life: CFQ-Parent - Emotional (range of scores: 0-100; Better indicated by higher values)												
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	serious ^{3, a}	none	45	35	-	MD 1.1 higher (7.52 lower to 9.72 higher)	VERY LOW	IMPORTANT
Quality of life: CFQ-Parent - Body (range of scores: 0-100; Better indicated by higher values)												
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	very serious ^{5, a}	none	45	35	-	MD 3 higher (9.12 lower to 15.12 higher)	VERY LOW	IMPORTANT
Quality of life: CFQ-Parent - Eating (range of scores: 0-100; Better indicated by higher values)												
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	serious ^{3, a}	none	45	35	-	MD 7.5 lower (20.22 lower to 5.22 higher)	VERY LOW	IMPORTANT
Quality of life: CFQ-Parent - TB (range of scores: 0-100; Better indicated by higher values)												

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	CF centre care	Shared care (UK equivalent)	Relative (95% CI)	Absolute		
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	serious ^{3, a}	none	45	35	-	MD 6.2 lower (14.63 lower to 2.23 higher)	VERY LOW	IMPORTANT
Quality of life: CFQ-Parent - Health (range of scores: 0-100; Better indicated by higher values)												
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	very serious ^{5, a}	none	45	35	-	MD 1.1 higher (8.6 lower to 10.8 higher)	VERY LOW	IMPORTANT
Quality of life: CFQ-Parent - Weight (range of scores: 0-100; Better indicated by higher values)												
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	very serious ^{5, a}	none	45	35	-	MD 0.8 lower (16.4 lower to 14.8 higher)	VERY LOW	IMPORTANT
Quality of life: CFQ-Parent - Respiratory (range of scores: 0-100; Better indicated by higher values)												
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	very serious ^{5, a}	none	45	35	-	MD 0.5 lower (10.33 lower to 9.33 higher)	VERY LOW	IMPORTANT
Quality of life: CFQ-Parent - Digestion (range of scores: 0-100; Better indicated by higher values)												

Quality assessment							No of patients		Effect		Quality	Importance
No of studies	Design	Risk of bias	Inconsistency	Indirectness	Imprecision	Other considerations	CF centre care	Shared care (UK equivalent)	Relative (95% CI)	Absolute		
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	serious ^{3, a}	none	45	35	-	MD 0.6 lower (8.76 lower to 7.56 higher)	VERY LOW	IMPORTANT
Quality of life: CFQ-Parent - School function (range of scores: 0-100; Better indicated by higher values)												
1 (Thomas 2006)	observational studies	very serious ⁴	no serious inconsistency	no serious indirectness	very serious ^{5, a}	none	45	35	-	MD 0.60 lower (11.63 lower to 10.43 higher)	VERY LOW	IMPORTANT

Abbreviations: BMI: body mass index; CI: confidence interval; CF: cystic fibrosis; CFQ: cystic fibrosis questionnaire; FEV₁: forced expiratory volume in 1 second; IV: intravenous; MD: mean difference

1 The quality of the evidence was downgraded by 2 because of the differences between groups.

2 The quality of the evidence was downgraded by 2 due to high risk of bias in relation to the selection of the population and high loss to follow-up

3 The quality of the evidence was downgraded by 1 as the 95% CI crossed 1 clinical MID

4 The quality of the study was downgraded by 2 due to high risk of bias in relation to comparability of the groups, and significant differences at follow-up between groups

5 The quality of the evidence was downgraded by 2 as the 95% CI crossed 2 clinical MIDs

a Imprecision for quality of life was assessed using a clinical MID of 8.5 because the paper by Thomas et al. uses the CFQ- Teen, CFQ-Child and CFQ-Parent (Quittner et al. 2005)