

Supplementary File 2: Data Extraction Table

Author	Type of study	Setting	Patient group	Age mean (SD)	Population size, n	Instruments	Type of PROM	Why PROM used?	Method of administration	Timepoints
Abbott et al, 2009, UK	Prospective cohort	Inpatient	All Age	25.1 (7.1)	223	CFQOL SF-36	Specific Generic	HRQOL as a predictor	Not stated	At entry
Abbott et al, 2013, UK	Longitudinal	Outpatient Clinic	All Age	Not stated	234	CFQOL	Specific	Association between physical factors and HRQOL	Postal	7 assessments 2 yearly over 12 years
Abbott et al, 2015, UK	Longitudinal	Outpatient Clinic	All Age	28.5 (8.2)	234	CFQOL	Specific	Association between demographic factors and HRQOL	Postal	7 assessments 2 yearly over 12 years
Acaster et al, 2015, UK	Cross-sectional	National database	Adult	28.7 (8.88)	401	CFQ-R	Specific	Used to validate another PROM	Online	At entry
						EQ-5D	Generic	Economic evaluation		
Aguiar et al, 2017, Brazil	Cross-sectional	Outpatient Clinic	Adult	Not stated	52	CFQ	Specific	Correlate to another PROM	Software program	At entry
Alpern et al, 2015, US	Validation	RCT data	Child	2.28 (1.45)	314	CFQ-R Parent	Specific	Validate PROM in new age group	Not stated	5 assessments 12 weeks apart
Angelis et al, 2015, UK	Cross-sectional	National database	All Age	18.3 (15.1)	74	EQ-5D	Generic	HRQOL in a population	Postal and online	At entry
Ashish et al, 2012, UK	Cross-sectional	Outpatient Clinic	Adult	Not stated	157	CFQ-R	Specific	Association between physical factors and HRQOL	Paper	At entry

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Backstrom-Eriksson et al, 2016, Sweden	Cross-sectional	Outpatient Clinic	Adult	32.2	68	CFQ-R	Specific	Association between physical factors and HRQOL	Paper	At entry
						HADS	Generic	Association between physical factors and HRQOL	Paper	
Bhati et al, 2012, US	Longitudinal	Inpatient	Child	13.1 (3.8)	22	CFQ-R	Specific	Correlate to diagnostic test	Not stated	3 assessments 1 week apart
Blackwell et al, 2013, US	Longitudinal	RCT data	Child	15.8 (2.9)	95	CFQ-R	Specific	Association between physical factors and HRQOL	Not stated	3 assessments 3 months apart
Bodnar et al, 2014, Hungary	Cross-sectional	Outpatient Clinic	All Age	14.3 (4.81)	59	CFQ-R	Specific	Association between physical factors and HRQOL	Not stated	At entry
Bodnar et al, 2015, Hungary	Cross-sectional	Outpatient Clinic	Child	11.61 (2.56)	172	PedsQL	Generic	Association between physical factors and HRQOL	Not stated	At entry
Borawska-Kowalczyk et al, 2015, Poland	Cross-sectional	Outpatient Clinic	Child	14.41 (2.61)	70	CFQ-R	Specific	Association between physical factors and HRQOL	Not stated	At entry
Borawska-Kowalczyk et al, 2015, Poland and Hungary	Cross-sectional	Outpatient Clinic	Child	13.63 (2.93)	141	CFQ-R	Specific	HRQOL in a population	Not stated	At entry

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Bouka et al, 2012, Germany	Cross-sectional	Outpatient Clinic	Adult	34.4 (7.5)	55	CFQ-R	Specific	Association between physical factors and HRQOL	Not stated	At entry
Bradley et al, 2013, UK	Longitudinal	Not stated	All Age	28.5 (8.2)	94	EQ-5D	Generic	Economic evaluation	Not stated	At entry and 8-12 weeks later
						CFQ-R	Specific	Correlate to another PROM	Not stated	
Cavanaugh et al, 2016, US	Cross-sectional	Outpatient Clinic	Child	11.6 (3.6)	50	CFQ-R	Specific	Association between physical factors and HRQOL	Not stated	At entry
Chan et al, 2016, US	Cross-sectional	Outpatient Clinic	Child	12.9 (5.6)	47	SN-5	Respiratory	Association between physical factors and HRQOL	Paper	At entry
Chevreur et al, 2015, France	Retrospective cross-sectional	Outpatient Clinic, CF Society, patient association	All Age	15.4 (11.3)	240	EQ-5D	Generic	HRQOL in a population	Online	At entry
Chevreur et al, 2016, Multinational	Cross-sectional	Outpatient Clinic, national registries	All Age	18.5 (14.1)	905	EQ-5D	Generic	HRQOL in a population	Postal or Online	At entry
Cohen et al, 2010, Brazil	Cross-sectional	Outpatient Clinic	All Age	12.5 (5.1)	75	CFQ	Specific	HRQOL in a population	Paper and Interview	Not stated
Cronly et al, 2019, Ireland	Cross-sectional	Outpatient Clinic	Adult	30.5 (9.1)	147	HADS	Generic	Association between psychological	Paper and Online	At entry

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								factors and HRQOL		
						CFQ-R	Specific	Association between psychological factors and HRQOL	Paper and Online	At entry
Debska et al, 2014, Poland	Cross-sectional	Outpatient Clinic	Adult	Not stated	45	CFQOL	Specific	Association between physical factors and HRQOL	Not stated	At entry
Debska et al, 2015, Poland	Longitudinal	Inpatient	All Age	21.1 (5.1)	67	CFQOL	Specific	Association between physical factors and HRQOL	Not stated	At entry and one year later
del Corral et al, 2016, Spain	Validation	Inpatient	Child	11.7 (3.1)	58	LCQ	Respiratory	Validate PROM	Not stated	At entry and 2 weeks later
de Souza Serio dos Santos et al, 2013, Brazil	Validation	Not stated	Child	Not stated	51	DISABKIDS-CFM	Specific	Validate PROM	Not stated	At entry
de Souza Serio dos Santos et al, 2014, Brazil	Validation	Outpatient Clinic	Child	11.91 (2.79)	113	DISABKIDS-CFM	Specific	Validate PROM	Not stated	At entry and 3 months later
Dill et al, 2013, US	Longitudinal	Outpatient Clinic	Adult	32.52 (10.65)	333	CFQ-R	Specific	Examine trends in HRQOL over time	Postal	7 assessments 3 monthly

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Driscoll et al, 2015, US	Cross-sectional	RCT data	Child	3.82 (1.27)	73	CFQ-R	Specific	Association between social factors and HRQOL	Not stated	At entry
						PedsQL	Generic	Validate PROM in new age group		
Edwards et al, 2018, US	Qualitative	Outpatient Clinic	Child	Not stated	37	CFRSD	Specific	Develop PROM	Online	At entry
Eidt-Koch et al, 2009, Germany	Cross-sectional	Outpatient Clinic	Child	Not stated	96	EQ-5D	Generic	Validate PROM	Not stated	At entry
						CFQ	Specific	Used to validate another PROM		
Flume et al, 2018, US	Retrospective cross-sectional	RCT data	All Age	Not stated	80	CFQ-R	Specific	Association between physical factors and HRQOL	Paper	6 assessments Baseline, week 2, 4, 8, 16, 24
Forte et al, 2015, Brazil	Cross-sectional	Outpatient Clinic	Adult	25.1 (8.8)	51	WHOQOL-BREF	Generic	Association between physical factors and HRQOL	Not stated	At entry
						CFQOL	Specific	Association between physical factors and HRQOL		
Gancz et al, 2018, Brazil	Cross-sectional	Outpatient Clinic	Child	16.4 (2.3)	31	CFQ-R	Specific	Association between physical factors and HRQOL	Interview	At entry
Goldbeck et al, 2010, Germany	Cross-sectional	Outpatient Clinic	All Age	23.1 (9.1)	670	HADS	Generic	HRQOL in a population	Not stated	At entry

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Goss et al, 2009, US	Qualitative	Outpatient Clinic	All Age	12.1 (4)	15	CF Symptom Diary	Specific	Develop PROM	Not administered	Not administered
Groeneveld et al, 2012, Spain	Cross-sectional	Outpatient Clinic	Child	11.6 (3.1)	28	CFQ-R	Specific	Association between social and physical factors and HRQOL	Paper and Interview	At entry
Habib et al, 2015, Canada	Cross-sectional	Outpatient Clinic	Adult	34.9 (11.9)	103	CFQ-R	Specific	Association between physical factors and HRQOL	Paper	At entry
Havermans et al, 2009, Belgium	Cross-sectional	Outpatient Clinic	Adult	26.79 (8.15)	57	CFQ-R	Specific	Association between social factors and HRQOL	Not stated	At entry
Hebestreit et al, 2014, Germany	Non-randomised control trial	Outpatient Clinic	All Age	20.6 (5.8)	70	CFQ-R	Specific	Association between physical factors and HRQOL	Paper	At entry and 6 months
Hegarty et al, 2009, Australia	Cross-sectional	Outpatient and Inpatient	Child	12.06 (3.97)	33	CFQ-R	Specific	HRQOL in a population	Not stated	At entry
Hochwalder et al, 2017, Sweden	Validation	Outpatient Clinic	Adult	30.8 (11.98)	173	CFQ-R	Specific	Validate PROM	Not stated	At entry
Horck et al, 2017, Netherlands	Longitudinal	Outpatient Clinic	Child	10.3 (3.6)	49	CFQ-R	Specific	Association between physical factors and HRQOL	Paper and Interview	3 assessments 6 months apart
Ihle et al, 2015, Germany	Cross-sectional	Outpatient Clinic	Adult	50 (11.9)	152	SF-36	Generic	Association between physical and demographic	Paper	At entry

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								factors and HRQOL		
						SGRQ	Respiratory	Association between physical and demographic factors and HRQOL		
						PLC	Generic	Association between physical and demographic factors and HRQOL		
Iscar-Urrutia et al, 2018, Spain	Cross-sectional	Outpatient Clinic	Adult	32	23	CFQ-R	Specific	Association between physical factors and HRQOL	Paper	At entry
Kang et al, 2017, Brazil	Cross-sectional	Outpatient Clinic	All Age	25.71 (8.13)	91	SNOT-22	Respiratory	Association between physical factors and HRQOL	Not stated	At entry
Kelemen et al, 2011, Australia	Cross-sectional	Outpatient Clinic	Adult	29.4 (8.5)	73	CFQOL	Specific	Association between physical factors and HRQOL	Not stated	At entry
Kianifar et al, 2013, Iran	Cross-sectional	Outpatient Clinic	Child	5 (3.4)	36	PedsQL	Generic	HRQOL in a population	Not stated	Not stated
Kilcoyne et al, 2016	Cross-sectional	Outpatient and Inpatient	Adult	27.8 (7.9)	101	CFQ-R	Specific	Correlate to diagnostic test	Paper	At entry

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Kir et al, 2015, India	Cross-sectional	Inpatient	Child	11.5 (4.5)	59	CFQ-R	Specific	HRQOL in a population	Paper and Interview	At entry
Lectzin et al, 2016, US	Cross-sectional	Outpatient Clinic	Child	15.6 (2.5)	73	CFQ-R	Specific	Association between physical factors and HRQOL	Online	At entry
McHugh et al, 2016, UK	Cross-sectional	Online Support Group	Adult	29 (8.34)	122	CFQ-R	Specific	Association between psychological factors and HRQOL	Not stated	Not stated
Modi et al, 2009, US	Prospective cohort	Inpatient	Child	13.6 (3.7)	52	PedsQL	Generic	HRQOL as outcome of intervention	Paper	At entry and 2 weeks later
						CFQ-R	Specific	HRQOL as outcome of intervention		
Norrish et al, 2015, Oman	Development	Outpatient Clinic	Child	6	12	CF-SPS	Specific	Develop PROM	Interview	Not stated
Oliver et al, 2015, US	Longitudinal	Outpatient Clinic	All Age	19 (3.2)	71	HADS	Generic	Association between social factors and HRQOL	Paper and Online	3 assessments 6 months apart
						CFQ-R	Specific	Association between social factors and HRQOL		
Olveira et al, 2016, Spain	Cross-sectional	Outpatient Clinic	Adult	28.1 (8.2)	336	HADS	Generic	Association between psychological factors and HRQOL	Paper	At entry

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						CFQ-R	Specific	Association between psychological factors and HRQOL		
Platten et al, 2013, UK	Cross-sectional	National database	Adult	27.8 (9.2)	74	CFQ-R	Specific	Association between psychological factors and HRQOL	Online	At entry
						CORE-OM	Generic	HRQOL in a population		
Quittner et al, 2009, US and Australia	Validation	RCT data	All Age	Not stated	200	CFQ-R	Specific	Determine MCID	Not stated	Not stated
Quittner et al, 2010, US	Cross-sectional	Longitudinal cohort study data	All Age	Not stated	4751	CFQ-R	Specific	Association between demographic factors and HRQOL	Paper and Interview	At entry
Quittner et al, 2012, US	Validation	Longitudinal cohort study data	All Age	Not stated	7330	CFQ-R	Specific	Validate PROM	Interview for children, other not stated	At entry
Quon et al, 2015, US	Cross-sectional	Outpatient Clinic	Adult	28.6 (8.8)	153	PHQ-9	Generic	HRQOL in a population	Not stated	At entry
						GAD-7	Generic	HRQOL in a population		
Ricotti et al, 2017, Italy	Longitudinal	Outpatient Clinic	Adult	49.87 (11.8)	57	SF-36	Generic	HRQOL in a population	Interview	Four assessments Before LTx and 6,12, 24 months after LTx
						SGRQ	Respiratory	HRQOL in a population		
						GHQ	Generic	HRQOL in a population		

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Salek et al, 2012, UK	Cross-sectional	Outpatient and Inpatient	Adult	26.1 (7.3)	70	UKSIP	Generic	Used to validate another PROM	Postal and interview	At entry
						CFQOL	Specific	Validate PROM		
Sawicki et al, 2009, US	Cross-sectional	Longitudinal cohort study data	Adult	35.4 (10)	204	CFQ-R	Specific	HRQOL in a population	Not stated	At entry
Sawicki, 2011, US	Cross-sectional	Outpatient Clinic	Adult	35.8 (10.3)	199	CFQ-R	Specific	Association between psychological factors and HRQOL	Not stated	Not stated
Sawicki et al, 2011, US	Longitudinal	National database	All Age	Not stated	1366	CFQ-R	Specific	Association between physical factors and HRQOL	Not stated	At entry and one year later
Schmidt et al, 2009, Germany	Validation	Outpatient Clinic	Child	10.2 (1.9)	136	CFQ-R	Specific	Validate PROM	Paper and Interview	At entry
Schmidt et al, 2011, Denmark	Non-randomised control trial	Outpatient Clinic	All Age	Not stated	38	CFQ-R	Specific	Association between physical factors and HRQOL	Not stated	At entry and 3 months later
Shoff et al, 2013, US	Longitudinal	RCT data	Child	13.5	95	CFQ	Specific	Association between social factors and HRQOL	Paper and Interview	3 assessments Yearly
Simon et al, 2011, US	Cross-sectional	Outpatient Clinic	Child	13.6 (2.3)	54	CFQ-R	Specific	Association between psychological factors and HRQOL	Paper	At entry

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Sole et al, 2016, Spain	Longitudinal	Outpatient Clinic	Adult	25.4 (8.5)	152	CFQ-R	Specific	HRQOL as a predictor	Not stated	12 assessments 3 monthly
Sole et al, 2018, Spain	Validation	Outpatient Clinic	All Age	Not stated	50	e-CFQ-R	Specific	Validate PROM	Software program	At entry and 15 days later
Solem et al, 2016, US	Longitudinal	RCT data	All Age	25.5 (9.5)	161	EQ-5D	Generic	Association between physical factors and HRQOL	Not stated	8 assessments Baseline, day 15, week 8, every 8 weeks after through 48 weeks
Stofa et al, 2016, Greece	Cross-sectional	Not stated	Adult	Not stated	77	CFQOL	Specific	HRQOL in a population	Not stated	At entry
Tepper et al, 2013, Netherlands	Retrospective cross-sectional	Outpatient Clinic	Child	13.4	72	CFQ-R RSS	Specific	Correlate to diagnostic test	Paper	3 assessments Yearly
Tibosch et al, 2011, Netherlands	Cross-sectional	Healthy school children	Child	14.52 (3.16)	478	CFQ	Specific	HRQOL in a population	Paper and Interview	At entry
Tluczek et al, 2011, US	Longitudinal	Longitudinal cohort study data	Child	13.5 (2.8)	95	CFQ	Specific	Association between demographic factors and HRQOL	Paper and Interview	Not stated
Tluczek et al, 2013, US	Longitudinal	Longitudinal cohort study data	Child	13.3 (2.7)	92	CFQ	Specific	Assess parent-proxy reporting	Paper and Interview	Not stated
Tomaszek et al, 2018, Poland	Cross-sectional	Outpatient Clinic	All Age	19	95	CFQOL	Specific	Association between physical factors and HRQOL	Not stated	Not stated

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						HADS	Generic	Association between psychological factors and HRQOL		
Toth et al, 2016, Hungary	Cross-sectional	Not stated	Adult	28.25 (8.95)	57	CFQ-R	Specific	HRQOL in a population	Paper	At entry
Trinick et al,	Cross-sectional	Outpatient Clinic	Child	Not stated	63	LRSQ	Respiratory	Validate PROM in new age group	Not stated	At entry
Uchmanowicz et al, 2014, Poland	Cross-sectional	Outpatient Clinic	Adult	24.83 (6.98)	30	SF-36	Generic	HRQOL in a population	Not stated	Not stated
Uchmanowicz et al, 2015, Poland	Cross-sectional	Outpatient Clinic	Adult	24.83 (6.98)	30	CFQOL	Specific	Association between demographic factors and HRQOL	Not stated	Not stated
Vandeleur et al, 2018, Australia	Cross-sectional	Outpatient Clinic	Child	Not stated	87	CFQ-R	Specific	Association between physical factors and HRQOL	Not stated	Not stated
						PedsQL	Generic	Association between physical factors and HRQOL		
Ward et al, 2017, Australia	Validation	Outpatient and Inpatient	Adult	29 (9.3)	59	LCQ	Respiratory	Validate PROM	Paper	3 assessments At entry, one week later and four weeks later
						ReS-CF	Specific	Develop PROM		
						CFQ-R	Specific	Used to validate another PROM		

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Xie et al, 2017, US	Validation	Not stated	Child	8.7 (5.28)	165	SN-5	Respiratory	Validate PROM in new age group	Not stated	At entry and median 7 months later
Yohannes et al, 2011, UK	Validation	Outpatient Clinic	Adult	29.6 (8.9)	121	Single item QOL scale	Generic	Develop PROM	Paper	At entry and 10 days later
						CFQOL	Specific	Used to validate another PROM		
						HADS	Generic	Used to validate another PROM		
Yohannes et al, 2012, UK	Cross-sectional	Outpatient Clinic	Adult	30 (8.8)	121	CFQOL	Specific	Association between psychological factors and HRQOL	Paper	At entry
						HADS	Generic	HRQOL in a population		
Young et al, 2011, Australia	Cross-sectional	Outpatient Clinic	Adult	31 (8)	60	CFQOL	Specific	Association between physical factors and HRQOL	Not stated	Not stated
Yuksel et al, 2013, Turkey	Validation	Outpatient Clinic	Child	9.8 (2.6)	51	CFQ-R	Specific	Validate PROM	Not stated	Not stated
						KINDL	Generic	Used to validate another PROM		