

Quality of life in childhood
(Volume 2)

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Appendix A:

Table A1: Studies excluded from the systematic review

Study	Reason for exclusion
Abu-Saad, H., & Holzmer, W.L. (1981). Measuring children's self-assessment of pain. <i>Issues in Comprehensive Pediatric Nursing</i> , 5, 337-49.	Child report over 9 years
Adams, C.D., Streisand, R., Zawaki, T., & Rodrigue, J.R. (1997). <i>Living with a chronic illness: A measure of social activities and competence for children and adolescents</i> . Poster presented at 31st Annual Meeting of the Association for the Advancement of Behavior Therapy, Miami, Florida, USA.	Child report over 8 years
Apajasalo, H.M., Sinkonen, J., Holmberg, C., Aalberg, V., Pihko, H., Simmes, M.A., Kaitila, I., Makela, A., Erkkila, K., Sintonen, J., & Rautonen, J. (1996). Quality of life in early adolescence: a 16-dimensional health-related measure (16D). <i>Quality of Life Research</i> , 5, 205-11.	Child report over 12 years
Apajasalo, M., Rautonen, J., Holmberg, C., & Sinkonen, J. (1996). Quality of life in pre-adolescence: a 17-dimensional health-related measure (17D). <i>Quality of Life Research</i> , 5, 532-8.	Child report over 8 years
Billson, A.L., & Walker, D.A. (1994). Assessment of health status in survivors of cancer. <i>Archives of Disease in Childhood</i> , 70, 200-4.	Child report over 8 years
Birleson, P., Hudson, I., Buchanan, D.G., & Wolff, S. (1987). Clinical Evaluation of a self-rating scale for depressive disorder in childhood (Depression Self-Rating Scale). <i>Journal of Child Psychology and Psychiatry</i> , 28, 43-60.	Child report over 8 years
Bossart, E. (1994). Stress appraisals of hospitalizes school-age children. <i>Children's Health Care</i> , 23, 33-49.	Child report over 8 years
Bouman, N.H., Koot, H.M., Van Gils, A.P.J.M., Verhulst, F.C. (1999). Development of a health-related quality of life instrument for children: the quality of life questionnaire for children. <i>Psychology and Health</i> , 14, 829-46.	Child report over 8 years
Boyle, M., Offord, D.R., Racine, V.A., & Fleming, J.F. (1993). Evaluation of the revised ontarion child health study scales. <i>Journal of Child Psychology and Psychiatry and Allied Disciplines</i> , 34, 189-213.	Child report over 12 years (4-16: parent report)
Boyle, M.H., Offord, D.R., Hoffman, H.G., Catlin, G.P., Byles, J.A., Cadman, D.T., Crawford, J.W., Links, P.S., Rae-Grant, N.I., & Szatmari, P. (1987). Ontario Child Health Study: I. Methodology. <i>Archives of General</i>	

<i>Psychiatry</i> , 44, 826-31.	
Chambers, C.T., Reid, G.J., McGrath, P.J., & Finley, G.A. (1996). Development and preliminary validation of a postoperative pain measure for parents. <i>Pain</i> , 68, 307-13.	Child report over 8 years
Clarizio, H.F. (1984). Childhood depression: Diagnostic considerations. <i>Psychology in the Schools</i> , 21, 181-97.	Child report over 9 years
Climent, J.M., Reig, A., Sanchez, J., & Roda, C. (1995). Construction and validation of a specific quality of life instrument for adolescents with spine deformities. <i>Spine</i> , 20, 2006-11.	Child report over 10 years
Coopersmith, S. (1981). <i>Manual for the Self-Esteem Inventories</i> . Consulting Psychologists Press, Palo Alto, California, USA.	Child report over 8 years
Coopersmith, S. (1967). <i>The antecedents of self-esteem</i> . W.H. Freeman & Co, San Francisco, California, USA.	Child report over 9 years
Cramer, J.A., Westbrook, L., Devinsky, O., Perrine, K., Glassman, M., & Camfield, C. (1999). Development of a quality of life in epilepsy inventory for adolescents: The QOLIE-AD-48. <i>Epilepsia</i> , 40, 1114-21.	Child report over 11 years
Cummins, R.A. (1997). Self-rated quality of life scales for people with an intellectual disability: a review. <i>Journal of Applied Research in Intellectual Disabilities</i> , 10, 199-216.	Adolescent measure
Dahlquist, L.M., Gil, K.M., Armstrong, D., Ginsberg, A., & Jones, B. (1985). Behavioral management of children's distress during chemotherapy. <i>Journal of Behavioral Therapy and Experimental Psychiatry</i> , 16, 325-9.	Child report over 11 years
Deluty, R.H. (1979). Children's Action Tendency Scale: A Self-report measure of aggressiveness, assertiveness, and submissiveness in children. <i>Journal of Consulting and Clinical Psychology</i> , 47(6), 1061-1071.	Child report over 8 years
Denholm, C. (1990). Memories of adolescent hospitalization for acute conditions. <i>Children's Health Care</i> , 19, 101-5.	Adolescent measure
Duffy, C.M., & Duffy, K.N. (1997). Health assessment in the rheumatic diseases of childhood. <i>Current Opinion in Rheumatology</i> , 9, 440-7.	Child report over 9 years
Eiser, C., Kopel, S., Cool, P., & Grimer, R. (1999). The perceived illness experience scale (PIE): reliability and validity revisited. <i>Child: Care, Health and Development</i> , 25, 179-90.	Child report over 8 years
Eiser, C., Havermans, T., Craft, A., & Kernhan, J. (1995). Development of a measure to assess the perceived illness experience after treatment for cancer. <i>Archives of the Disordered Child</i> , 72, 302-7.	
Feeny, D., Furlong, W., Barr, R.D., Torrance, G.W., Rosenbaum, P., & Weitzman, S. (1992). A comprehensive	Child report over 8

system for classifying the health status of survivors of childhood cancer. <i>Journal of Clinical Oncology</i> , 10, 923-8.	years
Feldman BM, Grundand B, McCullough L, Wright V. (2000). Distinction of quality of life, health related quality of life, and health status in children referred for rheumatologic care. <i>Journal of Rheumatology</i> , 27: 226-33.	Child report over 11 years
Felton, B.J., & Revenson, T.A. (1984). Coping with chronic illness: a study of illness controllability and the influence of coping strategies on psychological adjustment. <i>Journal of Consulting and Clinical Psychology</i> , 53, 343-53.	Child report over 9 years
Figa, L.E. (1979). <i>The ability of the student-teacher factor to discriminate between subjects on the Bickley Assessment of Self-Esteem</i> . Francis Marion College, Florence, South Carolina, USA.	Child report over 8 years
Forrest, C.B., Starfield, B., Riley, A.W., & Kang, M. (1997). The impact of asthma on the health status of adolescents. 99(2), E1.	Adolescent measure
Fox, J.E., & Houston, B.K. (1983). Distinguishing between cognitive and somatic trait and state anxiety in children. <i>Journal of Personality and Social Psychology</i> , 45, 862-70.	Child report over 9 years
Fox, J.E., Houston, B.K., & Pittner, M.S. (1983). Trait anxiety and children's cognitive behaviours in an evaluative situation. <i>Cognitive Therapy and Research</i> , 7, 149-54.	Child report over 9 years
Garber, J., Walker, L.S., & Zeman, J. (1991). Somatization symptoms in a community sample of children and adolescents: further validation of the Children's Somatization Inventory. <i>Psychological Assessment: A Journal of Consulting and Clinical Psychology</i> , 3, 588-95.	Child report over 8 years
Graham, P., Stevenson, J., & Flynn, D. (1997). A new measure of health-related quality of life for children: preliminary findings. <i>Psychology and Health</i> , 12, 655-65.	Child report over 9 years
Gross, A.L., & Bailiff, B. (1991). Children's understanding of emotion from facial expressions and situations: A review. <i>Developmental Review</i> , 11(4), 368-398.	Child report over 12 years
Grove, G.A., & Levinson, S. (1980). A re-examination of the validity of the Children's Personality Questionnaire. <i>Journal of Abnormal Child Psychology</i> , 8, 435-9.	Child report over 8 years
Gullone, E., & Cummins, R.A. (1999). The comprehensive quality of life scale: a psychometric evaluation with an adolescent sample. <i>Behavioural Change</i> , 16, 127-39.	Child report over 12 years
Ingersoll, G.M., & Marrero, D.G. (1991). A modified quality-of-life measure for youths: psychometric properties. <i>Diabetes Education</i> , 17, 114-18.	Child report over 11 years
Kazdin, A.E., & Petti, T.A. (1982). Self-report and interview measures of childhood and adolescent depression.	Child report over 9

<i>Journal of Child Psychology and Psychiatry</i> , 23, 437-57.	years
Kaplan, R.M., Bush, J.W., & Berry, C.C. (1976). Health status: types of validity and the index of well-being. <i>Health Services Research</i> , 11, 478-507.	Child report over 14 years
Kovacs, M., & Beck, A.T. (1977). An empirical-clinical approach towards a definition of childhood depression. In J.G. Schuller-Brandt & A. Raskin (Eds.). <i>Depression in children: Diagnosis, treatment and conceptual models</i> (pp. 1). Raven Press, New York, USA.	Child report over 10 years
Kovacs, M. (1981). Rating scales to assess depression in school aged children. <i>Acta Paedopsychiatrica</i> , 46, 305-215.	Child report over 10 years
Kovacs, M. (1983). <i>The Children's Depression Inventory: a self-rated depression scale for school-aged children</i> . University of Pittsburgh School of Medicine, USA.	Child report over 10 years
La Greca, A.M., & Stone, W.L. (1993). Social Anxiety Scale for Children-Revised: Factor Structure and Concurrent validity. <i>Journal of Clinical Child Psychology</i> , 22, 17-27.	Child report over 9 years
La Greca, A.M., & Lopez, N. (1998). Social anxiety among adolescents: linkages with peer relations and friendships. <i>Journal of Abnormal Child Psychology</i> , 26, 83-94.	Child report over 15 years
Langeveld, J.H., Koot, H.M., Loonen, M.C.B., Hazebroek-Kampschreur, A.A.J.M., & Passchier, J. (1996). A quality of life instrument for adolescents with chronic headache. <i>Cephalalgia</i> , 16, 183-96.	Child report over 12 years
Landgraf, J.M., Maunsell, E., Speechley, K.N., Bullinger, M., Campbell, S., Abetz, L., & Ware J.E. (1998). Canadian-French, German and UK versions of the Child Health Questionnaire: Methodology and preliminary item scaling results. <i>Quality of Life Research</i> , 7, 433-45.	Child report over 11 years
Landgraf, J.M., & Abetz, L.N. (1997). Functional status and well-being of children representing three cultural groups: Initial self-reports using the CHQ-CF87. <i>Psychology and Health</i> , 12, 839-54.	
Landgraf, J.M., Ware, J.E., Schor, E., Ros-Davies, A., & Rossiroh, K. (1993). <i>Comparison of Health Status profiles for children with medical conditions: preliminary psychometric and clinical results from a children's health and quality of life project</i> . Presented at Paper prepared for the 10th annual meeting for Health Services Research, Washington, USA.	Child report over 11 years (5-15: parent report)
Langraf, R.H., Bonsel, G.J., Gemke, R.J.B.J., & Essink-Bot, M.L. (2002). Reliability and validity of the child health questionnaire-child form (CHQ-CF87) in a Dutch adolescent population. <i>Quality of Life Research</i> , 11, 575-?.	Child report over 9 years
Lang, M., & Tisher, M. (1978). <i>Children's Depression Scale</i> . The Australian Council for Educational Research,	Child report over 9

Victoria, Australia.	years
Lotz, G. (1984). <i>LQ Fragenbogen zur Lebensqualität</i> . Presented at Stress, Bewältigung und soziale kompetenz bei Schülern, Frankfurt, Germany.	Child report over 10 years
Matson, J.L., Rotarori, A.F., & Halsel, W.J. (1983). Development of a rating scale to measure social skills in children: The Matson Evaluation of Social Skills with Youngsters. <i>Behavior Research and Therapy</i> , 21, 335-40.	Child report over 8 years
Maylath, N.S. (1990). Development of the Children's Health Rating Scales. <i>Health Education Quarterly</i> , 17, 89-97.	Child report over 10 years
Mindell, J.A., & Andrasik, F. (1987). Headache classification and factor analysis with a pediatric population. <i>Headache</i> , 27, 96-101.	Child report over 10 years
Ollendick, T.H. (1983). Development and validation of the Children's Assertiveness Inventory. <i>Child & Family Behavior Therapy</i> , 5(3), 1-15.	Child report over 8 years
Patrick, D.L., Connell, F.A., Edwards, T.C., Topolsko, T.D., & Huebner, C.E. (1998). <i>Age-appropriate measures of quality of life and disability outcomes among children: the youth quality of life study</i> . Centers for Disease Control and Prevention, Atlanta, GA, USA.	Child report over 12 years
Parkin, P.C., Kirpalani, H.M., Rosenbaum, P.L., Fehlings, D.L., Van Nie, A., Willan, A.R., & King, D. (1997). Development of a health-related quality of life instrument for use in children with spina bifida. <i>Quality of Life Research</i> , 6, 123-32.	Child report over 13 years (5-12 years: parent report)
Parish, T.S., & Rankin, C.I. (1982). The nonsexist personal attribute inventory for children: a report on its validity and reliability as a self-concept scale. <i>Educational and Psychological Measurement</i> , 42, 339-43.	Child report over 10 years
Parish, T.S., & Taylor, J.C. (1978). A further report on the validity and reliability of the personal attribute inventory for children as a self-concept scale. <i>Educational and Psychological Measurement</i> , 38, 1225-8.	Child report over 9 years
Piers, E.V. (1969). <i>The Piers-Harris Children's Self-Concept Scale</i> . Counselor Recordings and Tests, Nashville, Tennessee, USA.	Child report over 9 years
Platten, M.R., & Williams, L.R. (1979). A comparative analysis of the factorial structures of two administrations of the Piers-Harris children's self-concept scale to one group of elementary school children. <i>Educational and Psychological Measurement</i> , 39, 471-8.	
Pilpel, D., Leiberman, E., Zadik, Z., & Carel, C.A. (1995). Effect of growth hormone treatment on quality of life of short stature children. <i>Hormone Research</i> , 44, 1-5.	Child report over 8 years

Raat, H., Landgraf, J.M., Bonsel, G.J., Gemke, R.J.B.J., Essink-Bot, M.L. (2002). Reliability and validity of the child health questionnaire-child form (CHQ-CF87) in a Dutch population. <i>Quality of Life Research, 11</i> , 575-81.	Child report over 9 years
Rabbett, H., Elbadri, A., Thwaites, R., Northover, H., Dady, I., Firth, D., Hillier, V.F., Miller, V., & Thomas, A.G. (1996). Quality of life in children with Crohn's disease. <i>Journal of Pediatric Gastroenterology and Nutrition, 23</i> , 528-33.	Child report over 8 years
Raphael, D., Rulholm, E., Brown, I., & Hill-Bailey, P. (1996). The quality of life profile - adolescent version: background, description and initial validation. <i>Journal of Adolescent Health, 19</i> , 366-75.	Adolescent measure (child report over 14 years)
Ravens-Sieberer, U., Thomas, C., Kluth, W., Teschke, L., Lilienthal, S., & Bullinger, M. (2001). A disease-specific quality of life module for children with cancer - news from the KINDL-questionnaire - ABSTRACT. <i>Psycho-Oncology, 10</i> , S23.	Child report over 10 years
Ravens-Sieberer, U., & Bullinger, M. (1998). Assessing health-related quality of life in chronically ill children with the German KINDL: first psychometric and content analytical results. <i>Quality of Life Research, 7</i> , 399-407.	
Ravens-Sieberer, U., Theiling, S., & Bullinger, M. (1999). <i>Assessing quality of life in chronically ill children - the parents and the parents' view</i> . Presented at 11 th International Congress of the European Society for Child and Adolescent Psychiatry, September 15 th -19 th , Congress Centrum Hamburg, Germany.	
Redd, W.H., Jacobsen, P.B., Die-Trill, M., Dermatis, H., McEvoy, M., & Holland, J.C. (1987). Cognitive/attentional distraction in the control of conditioned nausea in pediatric cancer patients receiving chemotherapy. <i>Journal of Consulting and Clinical Psychology, 55</i> , 391-5.	Child report over 11 years
Reid, D.T., & Renwick, R.M. (1994). Preliminary validation of a new instrument to measure life satisfaction in adolescents with neuromuscular disorders. <i>International Journal of Rehabilitation Research, 17</i> (2), 184-8.	Child report over 12 years
Reynolds, C.R. (1982). Convergent and divergent validity of the Revised Children's Manifest Anxiety Scale. <i>Educational and Psychological Measurement, 42</i> , 1205-12.	Child report over 8 years
Riley, A.W., Forrest, C.B., Starfield, B., Green, B., Kang, M., & Ensminger, M. (1998). Reliability and validity of the adolescent health profile-types. <i>Medical Care, 36</i> , 1237-48.	Adolescent measure
Sears, P.S., & Sherman, V. (1964). <i>In pursuit of self-esteem</i> . Wadsworth, Belmont, California, USA.	Child report over 9

	years
Speltz, M.L., Gonzales, N., Sulzbacher, S., & Quan, L. (1990). Assessment of injury risk in young children: A preliminary study of the Injury Behavior Checklist. <i>Journal of Pediatric Psychology, 15</i> , 373-83.	Child report over 10 years
Soares, A.T., & Soares, L.M. (1980). <i>The Self-Perception Inventory Test Manual-Student Forms</i> . Soares Associates, Trunbull, CT, USA.	Child report over 9 years
Stanton, W.R., Willis, M., & Balanda, K.P. (2000). Development of an instrument for monitoring adolescent health issues. <i>Health Education Quarterly, 15</i> , 181-90.	Adolescent measure
Starfield, B., Riley, A.W., Green, B.F., Ensminger, M.E., Ryan, S.A., Kelleher, K., Kim-Harris, S., Johnston, D., & Vogel, K. (1995). The adolescent child health and illness profile. A population-based measure of health. <i>Medical Care, 18</i> , 465-72.	Adolescent measure
Starfield, B., Bergner, M., Ensminger, M., Riley, A., Ryan, S., Green, B., McGauhey, P., Skinner, A., Kim, S. (1993). Adolescent health status measurement: development of the Child Health and Illness Profile. <i>Pediatrics, 91</i> , 430-5.	
Starfield, B., Forrest, C.B., Ryan, S.A., Riley, A.W., Ensminger, M.E., & Green, B.F. (1996). Health status of well versus ill adolescents. <i>Archives of Pediatrics and Adolescent Medicine, 150</i> , 1249-56.	
Steiner, H., Pavelski, R., Pitts, T., & McQuivey, R. (1998). The juvenile wellness and health survey (JWS-76): a school-based screening instrument for general and mental health in high school students. <i>Child Psychiatry and Human Development, 29</i> , 141-55.	Child report over 10 years
Sullivan, B. (1979). Adjustment in diabetic adolescent girls: II. Adjustment, self-esteem, and depression in diabetic adolescent girls. <i>Psychosomatic Medicine, 41</i> , 127-38.	Adolescent measure
Sullivan, B. (1979). Adjustment in diabetic adolescent girls: I. Development of diabetic adjustment scale. <i>Psychosomatic Medicine, 41</i> , 119-26.	
Tesler, M.D., Savedra, M.C., Holzemer, W.L., Wilkie, D.J., Ward J.A., & Paul, S.M. (1991). The word-graphic rating scale as a measure of children's and adolescents' pain intensity. <i>Research in Nursing and Health, 14</i> , 361-71.	Child report over 8 years
Theunissen, N.C., Vogels, T., Koopman, H.M., Verrips, G.H., Zwinderman, K., Verloove-Vanhorick, S.P., & Wit, J.M. (1998). The proxy problem: child report versus parent report in health-related quality of life research.	Child report over 8 years

<i>Quality of Life Research</i> , 7, 387-97.	
Tisher, M., & Lang, M. (1978). <i>Children's Depression Scale (Research Edition)</i> . Consulting Psychologists Press, Palo Alto, CA, USA.	Child report over 9 years
Varni, J.W., Katz, E.R., Seid, M., Quiggins, D.J., Friedman-Bender, A., & Castro, C.M. (1998). The pediatric cancer quality of life inventory (PCQL). i. instrument development, descriptive statistics, and cross-informant variance. <i>Journal of Behavioral Medicine</i> , 21, 179-204.	Child report over 8 years
Varni, J.W., Katz, E.R., Quiggins, D.J.L., & Friedman-Bender, A. (1998). The pediatric cancer quality of life inventory-32 (PCQL-32): i. reliability and validity. <i>Cancer</i> , 82, 1184-96.	
Vogels, T., Verrips, G.H., Verloove-Vanhorick, S.P., Fekkes, M., Kamphuis, R.P., & Koopman, H.M. (1998). Health-related quality of life measure for children - the TACQOL. <i>Journal of Applied Therapeutics</i> , 1, 357-60.	Child report over 8 years
Vogels, T., Verrips, G.H., Verloove-Vanhorick, S.P., Fekkes, M., Kamphuis, R.P., Koopman, H.M., & Theunissen, N.C. (1998). Measuring health-related quality of life in children: the development of the TACQOL parent form. <i>Quality of Life Research</i> , 7, 457-65.	
Walker, S., & Garber, J. (1993). <i>Children's Somatization Inventory: Preliminary manual</i> . Vanderbilt University Medical Center, Nashville, Tennessee, USA.	Child report over 8 years
Wasson, J.H., Kairys, S.W., & Nelson, E.C. (1995). Adolescent health and social problems: A method for detection and early management. <i>Archives of Family Medicine</i> , 4, 51-6.	Adolescent measure
Warren, A., Hulse-Trotter, K., & Tubbs, E.C. (1991). Inducing resistance to suggestibility in children. <i>Law and Human Behavior</i> , 15, 273-85.	

Figure A1: Example of the data extraction form

Details of publication

1.	Author:
2.	Title:
3.	Ref:
4.	Institution/contact address:
5.	Country:

Research Question

Need for new measure

Description of measure

1. Development of measure - pilot stages (if reported)
2. Response scale used (e.g. circle, linear VAS, faces):
3. Presentation style used
3. Age range of measure:
4. Total number of domains and items:

Psychometric investigation of measure

1. Sample characteristics		
N=		
(i) age range?		Mean age?
(ii) sex:	%female	%male
(iii) ethnicity		

2. Validity testing

- face validity established? (asked participants to assess presentation and relevance of measure)
- correlations between new scale and existing scales? (moderately high, but not too high else needless duplication) [convergent validity]
- no correlations to scales expected to differ from [discriminant validity]
- responsiveness/sensitivity to change/time shown? (longitudinal study? effect sizes?)

2. Reliability testing

- temporal reliability [reproducibility, test-retest reliability/ICC] (if scores stable across short time period)
- internal consistency (cronbach's alpha)
- inter-rater reliability (parent vs child report etc)

Reviewer's Decision

1. Conclusions

2. Limitations of study

3. Article to be included within review?

YES

NO

UNSURE

Figure A2: Breakdown of the number of measures using different response scale types

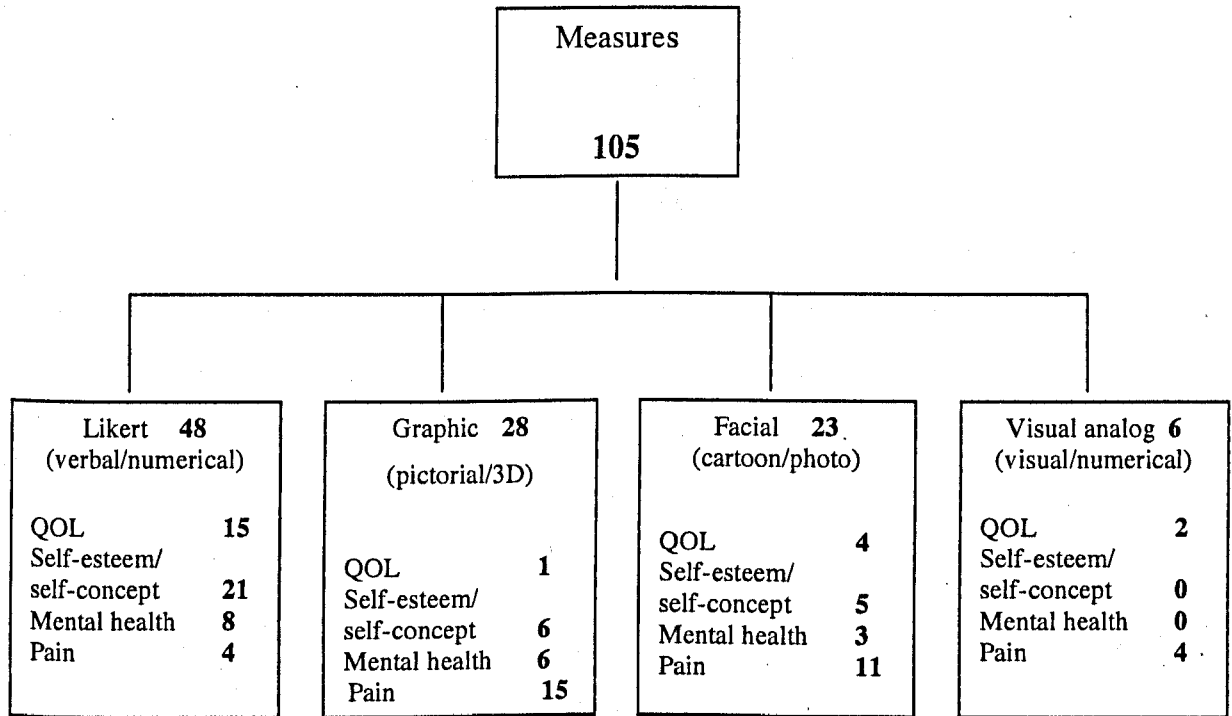


Figure A3: Breakdown of the number of measures using different presentation styles

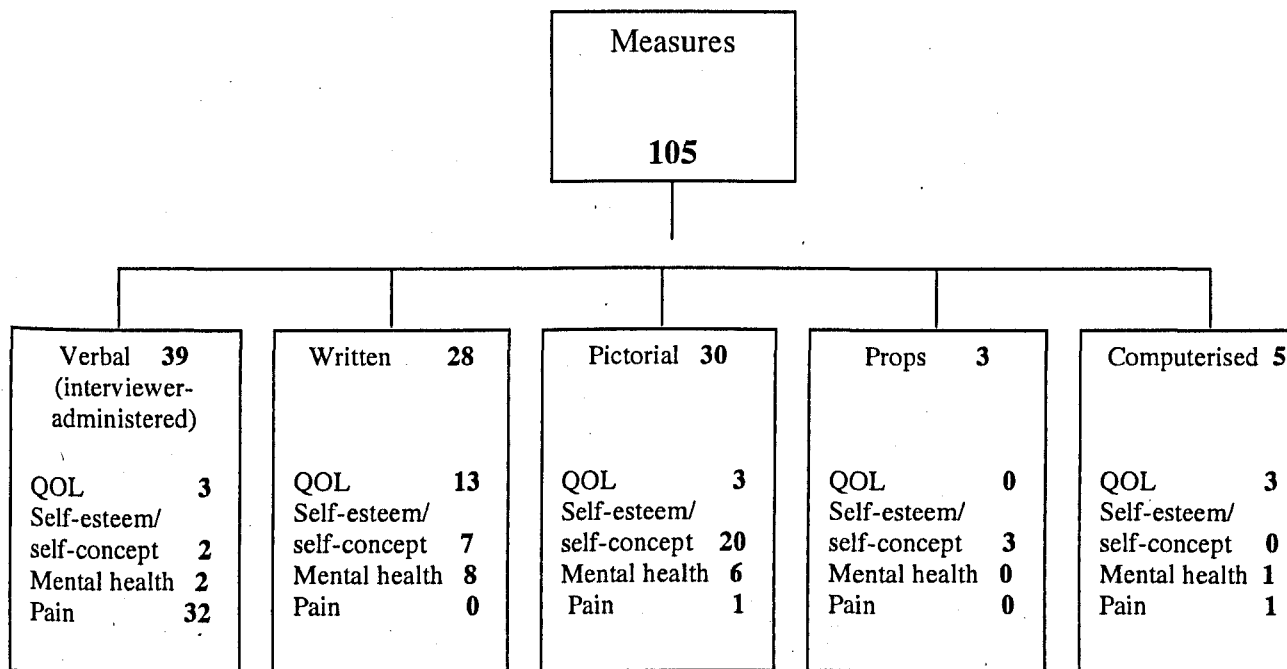


Table A2: Measures where authors reported items generation methods

Name of measure (study)	Age used with	Development stages of items					Items piloted (altered due to this)
		How items generated					
		Lit. Review	Existing child measures	Existing adult/adol. measures	Expert panel	Child gen.	
Quality of Life measures							
About my Asthma (Mishoe <i>et al.</i> , 1998)	6-12		*				7 children, checked vocab and wording of items
Children's Dermatology Life Quality Index (Lewis-Jones & Finlay, 1995)	3-16					*	40 children, minor alterations made to improve clarity of items
Child Health and Illness Profile (Rebok <i>et al.</i> , 2001)	6-11			*			'Think aloud' methodology used to ensure understanding of key terms
Child's Health Self-Concept Scale (Hester, 1984)	7-13					*	
Childhood Asthma Questionnaire (Christie <i>et al.</i> , 1993, French <i>et al.</i> , 1994)	4-7	*		*	*		Items piloted on 80 asthmatic and 103 healthy children
Cystic Fibrosis Questionnaire - Child Version (Quittner <i>et al.</i> , 1998, 2000, Henry <i>et al.</i> , 19970)	6-13	*				*	
C-QOL (Jirojanakul & Skevington, 2000)	5-8					*	Items piloted on 35 children (healthy and ill)
Exeter Health-Related Quality of Life measure (Eiser <i>et al.</i> , 2000)	6-12	*					
Generic Children's Quality of Life	6-14					*	

Questionnaire (Collier <i>et al.</i> , 1997, 2000)							
How are you? (Bruil , 1999, Le Coq <i>et al.</i> , 2000)	7-13				*		Items piloted on 89 chronically ill and 134 health children
Life Activities Questionnaire for Childhood Asthma (Creer <i>et al.</i> , 1993)	5-17					*	
Pictured Child's Quality of Life Self Questionnaire (Garcia <i>et al.</i> , 1998, Manificat <i>et al.</i> , 2002, 1995)	4-12		*			*	
Pediatric Asthma Quality of Life Questionnaire (Juniper <i>et al.</i> , 1992)	7-17				*	*	
Pediatric Quality of Life Questionnaire (Varni <i>et al.</i> , 1998, 1999, 2002)	5-18	*				*	Items piloted on children
Pediatric Rhinoconjunctivitis Quality of Life Questionnaire (Juniper <i>et al.</i> , 1998)	6-12			*	*	*	Items piloted on 10 children to ensure understood wording and concepts behind items
Personal Adjustment and Role Skills Scale (Ellsworth , 1981, Stein & Jessop, 1999, Walker <i>et al.</i> , 1990)	5-18		*			*	
Quality of Life Scale - 'Three wishes' and 'What worries you the most?' (Neff & Conkin Dale, 1990)	7-12		*				Item piloted on school age children to see ease of administration and appropriateness of items
Self-esteem/concept measures							
Brown IDS Self-Concepts Referents Test (Boger & Knight, 1969, Brown, 1969, Bridgeman & Shipman, 1978, Walker <i>et al.</i> , 1973)	3.5-6.5						Items piloted on children, found some unfamiliar vocab in half of items
Children's Physical Self-Concept Scale	6 up	*	*		*		Items piloted on children to

(Stein <i>et al.</i> , 1998)							reduce items
Competence Perceptions Subjective Task Value Beliefs (Eccles <i>et al.</i> , 1993)	6.5 up						Items piloted on 100 children to ensure understood items
Experimental Photographic Self Concept Test (Boger & Knight, 1969)	3 up	*					
McDaniel-Piers Young Children's Self-Concept Scale (McDaniel & Leddick, 1978, McDaniel, 1973)	4 up		*				
Maryland Pre-School Self-Concept Scale (Smith, 1978, Hughes, 1981, Hughes & Leatherman, 1982)	4-6		*				Items piloted and items with correlations with total score of over 0.50 kept in measure
North York Primary Self-Concept Test (Crawford, 1977)	6 up		*				Items piloted and measure normed for children from grades 2 upwards
Perez Self-Concept Inventory (Perez, 1982)	5.5 up	*	*		*		Items piloted on children and reduced in number
Pictorial Scale of Perceived Competence and Social Acceptance (Harter & Pike, 1984, Fantuzzo, <i>et al.</i> , 1996)	4-7	*	*				Two version of measure piloted
Pictorial Self-Concept Scale (Bolea <i>et al.</i> , 1971)	5-9		*		*		Piloted items on children and reduced in number
Piers Preschool Pictorial Self-Concept Scale (Jenson, 1983, 1985)	4 up	*			*		Piloted items on children and reduced in number, items with highest item-total correlations kept in measure
Preschool and Primary Self-Concept Scale (Stager & Young, 1982)	4-9						Piloted items on 3-4 year old children, 3 year olds dropped due to low levels of

							understanding
Purdue Self-Concept Scale for Preschool Children (Cicirelli, 1974, Samuels & Griffore, 1979)	4 up	*					Items piloted and altered
Reading Self-Concept Scale (Chapman & Tunmer, 1995)	5-8		*		*		Extensive piloting of items on children
Self-Description Questionnaire-I (Marsh <i>et al.</i> , 1991, 1998)	5-8					*	
Self-Interview (Eder, 1990)	3-8					*	Extensive interviews with children, children's statements used to develop items within measure
Mental health measures							
Children's Depression Inventory (Carey <i>et al.</i> , 1987, Edelsohn <i>et al.</i> , 1992, Ialongo <i>et al.</i> , 1993, Saylor <i>et al.</i> , 1984)	6 up						Items piloted on children, younger children given simple symbols and pictures to aid understanding
Children's Manifest Anxiety Scale (La Greca <i>et al.</i> , 1988, Reynolds, 1980, 1981, 1982, Reynolds & Richmond, 1978, 1979)	6-19				*		
Dominic Questionnaire-R (Valla, 2000, Breton <i>et al.</i> , 1999)	6-11	*			*		Items piloted on 150 children to test for acceptability and comprehension
Hospital Fears Questionnaire (Robert <i>et al.</i> , 1981)	5 up				*	*	
Pictorial Instrument for Child and Adolescent Psychiatry (Ernst <i>et al.</i> , 1994)	6-16						
Preschool Symptom Self-Report	3 up		*				

(Martini <i>et al.</i> , 1990)							
Scare Scale (Beyer & Arandine, 1988)	3-13						Items piloted on children to ensure acceptability, school children could do this alone, younger needed some help
Social Anxiety Scale for Children Revised (Watson & Friend, 1969, Warren <i>et al.</i> , 1984, La Greca <i>et al.</i> , 1988, La Greca & Lopez, 1998, La Greca & Stone, 1993)	7 up		*		*		
Pain measures							
Adu-Saad Paediatric Pain Assessment Tool (Abu-Saad, 1990, 1994)	5-15					*	Thirty-two word descriptors of pain generated, developed from children's spontaneous comments describing their pain, words sorted into categories and themes developed
Block Scale (Lehmann, 1990)	3-8					*	Children asked if ever experienced various pain situations, used ones that children showed best memory for, and experiences which were roughly similar in sensory quality
Charleston Pediatric Pain Pictures (Adesman & Walco, 1992, Belter <i>et al.</i> , 1988)	3-9.5				*		Cartoon pictures developed, reduced to seventeen by panel of child clinicians
Children's Anxiety and Pain Scale	3-17					*	Children given pairs of

(Kuttner & LePage, 1983, 1987, Goodneough <i>et al.</i> , 1998, 2000, Chambers <i>et al.</i> , 1999)							pictures and asked to rate the child who was most scared and who was hurting more
Waldron/Varni Pediatric Pain Coping Inventory (Varni <i>et al.</i> , 1996)	5-18					*	
Word Descriptor Scale (Fogel-Keck <i>et al.</i> , 1996)	3-18					*	Words used developed from spontaneous comments from children describing their pain

Appendix B:

Figure B1: Response sheet used to record children's TedQL.1 answers

Item code	Ability: (good=1 bad=0)		Really sad	A little bit sad	A little bit happy	Really happy
	0	1	0	1	2	3
T1: singing			Sad			Happy
PC1: running						
PC2: swinging						
PA1: having friends						
PA2: getting teased						
MA1: told off at home						
MA2: going on trips						
PF1: getting cross						
PF2: having bad dreams						
CF1: reading						

Figure B2: PedsQL™4.0 measure and response sheet as given to children (Study 1)

PedsQL™

Pediatric Quality of Life Inventory

Version 4.0

YOUNG CHILD REPORT (ages 5-7)

Instructions for interviewer:

I am going to ask you some questions about things that might be a problem for some children. I want to know how much of a problem any of these things might be for you.




Show the child the template and point to the responses as you read.

If it is not at all a problem for you, point to the smiling face

If it is sometimes a problem for you, point to the middle face

If it is a problem for you a lot, point to the frowning face

I will read each question. Point to the pictures to show me how much of a problem it is for you. Let's try a practice one first.

	Not at all	Sometimes	A lot
Is it hard for you to snap your fingers			

Ask the child to demonstrate snapping his or her fingers to determine whether or not the question was answered correctly. Repeat the question if the child demonstrates a response that is different from his or her action.

Think about how you have been doing for the last few weeks. Please listen carefully to each sentence and tell me how much of a problem this is for you.

After reading the item, gesture to the template. If the child hesitates or does not seem to understand how to answer, read the response options while pointing at the faces.

Physical Functioning (PROBLEMS WITH...)	Not at all	Some-times	A lot
1. Is it hard for you to walk	0	2	4
2. Is it hard for you to run	0	2	4
3. Is it hard for you to play sports or exercise	0	2	4
4. Is it hard for you to pick up big things	0	2	4
5. Is it hard for you to take a bath or shower	0	2	4
6. Is it hard for you to do chores (like pick up your toys)	0	2	4
7. Do you have hurts or aches (<i>Where?</i> _____)	0	2	4
8. Do you ever feel too tired to play	0	2	4

Remember, tell me how much of a problem this has been for you for the last few weeks.

Emotional Functioning (PROBLEMS WITH...)	Not at all	Some-times	A lot
1. Do you feel scared	0	2	4
2. Do you feel sad	0	2	4
3. Do you feel mad	0	2	4
4. Do you have trouble sleeping	0	2	4
5. Do you worry about what will happen to you	0	2	4

Social Functioning (PROBLEMS WITH...)	Not at all	Some-times	A lot
1. Is it hard for you to get along with other kids	0	2	4
2. Do other kids say they do not want to play with you	0	2	4
3. Do other kids tease you	0	2	4
4. Can other kids do things that you cannot do	0	2	4
5. Is it hard for you to keep up when you play with other kids	0	2	4

School Functioning (PROBLEMS WITH...)	Not at all	Some-times	A lot
1. Is it hard for you to pay attention in school	0	2	4
2. Do you forget things	0	2	4
3. Is it hard to keep up with schoolwork	0	2	4
4. Do you miss school because of not feeling good	0	2	4
5. Do you miss school because you have to go to the doctor's or hospital	0	2	4

Permission letter for parents (Study 1)

Dear Parent/Guardian,

I am writing to ask permission for your child to take part in a study that I will be conducting in the school where your child attends. I am currently studying for my PhD under Professor Christine Eiser, at the University of Sheffield. I am studying young children's development, specifically concerned with developing measures that allow young children to accurately and easily report their feelings, thoughts and perceptions on their lives.

I am conducting a study with school-age children, which uses a child friendly measure to ask the children a series of questions about their views and abilities. For example, the child will be asked whether they are good at running or not. Teddy bears are used to make the task more understandable for the child, and children generally enjoy taking part in this task. The task will take about 5-10 minutes to complete.

The study also involves a **simple questionnaire for parents to fill out**, asking a few questions about your child's abilities and competence. I would be grateful if you could complete this short questionnaire, and **return it as soon as possible to the school**. This enables me to have your views, as well as your child's views.

Both you and your child will remain anonymous throughout the study, and any results will be strictly confidential.

I hope this procedure will be useful in developing an appropriate measure of assessing young children's 'quality of life'. This can then be applied help young children facing chronic illnesses (such as cancer) and physical handicaps (such as cerebral palsy), by being able to understand more of their own views, thoughts and feelings.

Thank you for your time,

Yours faithfully,

Miss Joanne Lawford

Figure B3: PedsQLTM4.0 measure and response sheet as given to parents (Study 1)

PedsQLTM
**Pediatric Quality of Life
Inventory**

Version 4.0

PARENT REPORT for YOUNG CHILDREN (ages 5-7)

DIRECTIONS

On the following page is a list of things that might be a problem for **your child**. Please tell us **how much of a problem** each one has been for **your child** during the **past ONE month** by circling:

- 0 if it is **never** a problem
- 1 if it is **almost never** a problem
- 2 if it is **sometimes** a problem
- 3 if it is **often** a problem
- 4 if it is **almost always** a problem

There are no right or wrong answers.

If you do not understand a question, please ask for help.

In the past **ONE month**, how much of a **problem** has your child had with ...

Physical Functioning (PROBLEMS WITH...)	Never	Almost Never	Some-times	Often	Almost Always
1. Walking more than one block	0	1	2	3	4
2. Running	0	1	2	3	4
3. Participating in sports activity or exercise	0	1	2	3	4
4. Lifting something heavy	0	1	2	3	4
5. Taking a bath or shower by him or herself	0	1	2	3	4
6. Doing chores, like picking up his/her toys	0	1	2	3	4
7. Having hurts or aches	0	1	2	3	4
8. Low energy level	0	1	2	3	4

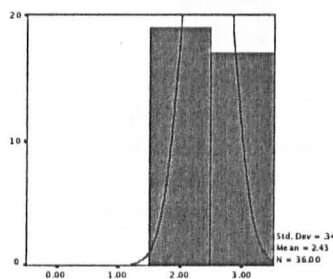
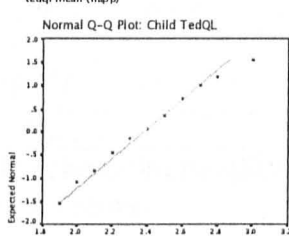
Emotional Functioning (PROBLEMS WITH...)	Never	Almost Never	Some-times	Often	Almost Always
1. Feeling afraid or scared	0	1	2	3	4
2. Feeling sad or blue	0	1	2	3	4
3. Feeling angry	0	1	2	3	4
4. Trouble sleeping	0	1	2	3	4
5. Worrying about what will happen to him/her	0	1	2	3	4

SOCIAL Functioning (PROBLEMS WITH...)	Never	Almost Never	Some-times	Often	Almost Always
1. Getting along with other children	0	1	2	3	4
2. Other kids not wanting to be his or her friend	0	1	2	3	4
3. Getting teased by other children	0	1	2	3	4
4. Not able to do things that other children his or her age can do	0	1	2	3	4
5. Keeping up when playing with other children	0	1	2	3	4

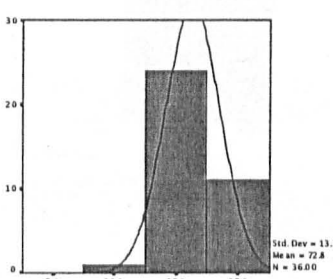
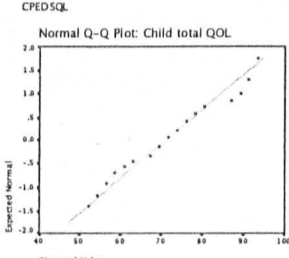
SCHOOL FUNCTIONING (PROBLEMS WITH...)	Never	Almost Never	Some-times	Often	Almost Always
1. Paying attention in class	0	1	2	3	4
2. Forgetting things	0	1	2	3	4
3. Keeping up with school activities	0	1	2	3	4
4. Missing school/daycare because of not feeling well	0	1	2	3	4
5. Missing school/daycare to go to the doctor or hospital	0	1	2	3	4

Study 1: Descriptive statistics – Means, SDs, distributions, and assessment of skew/kurtosis

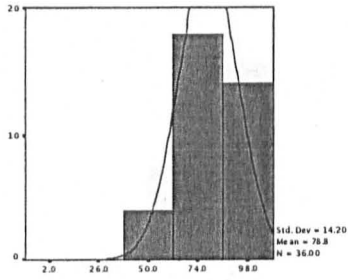
Child TedQL.1

Happiness scores	Descriptives
 <p>tedql mean (happ)</p> 	<p>Skewness = 0.14 SE of Skew = 0.39 z = 0.01 Kurtosis = -0.89 SE of Kurtosis = 0.77 z = -1.16</p>

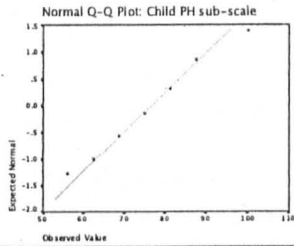
Child Parent PedsQLTM4.0

Total QOL scores	Descriptives
 <p>CPEDSQL</p> 	<p>Skewness = 0.13 SE of Skew = 0.39 z = 0.34 Kurtosis = -0.68 SE of Kurtosis = 0.77 z = -0.89</p>

Physical health summary sub-scale scores

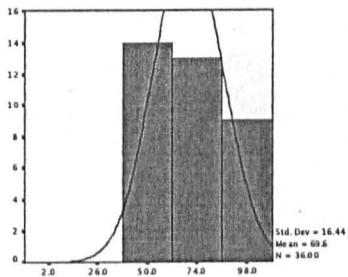


Child PH mean

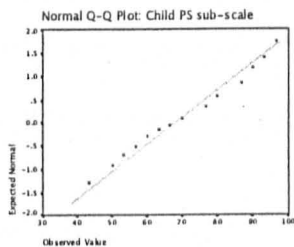


Skewness = -0.26
 SE of Skew = 0.39
 z = -0.67
 Kurtosis = -0.60
 SE of Kurtosis = 0.77
 z = -0.78

Psychosocial health summary sub-scale scores

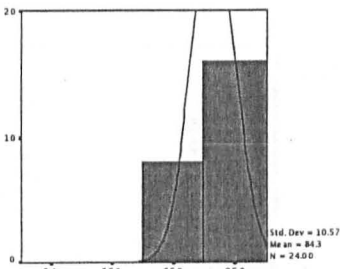
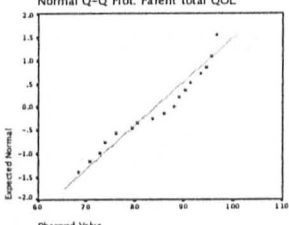
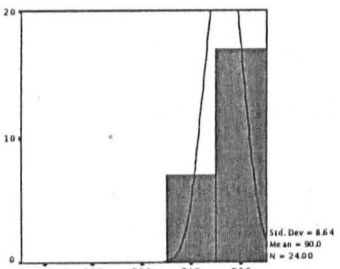
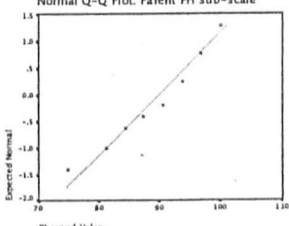


Child PS mean

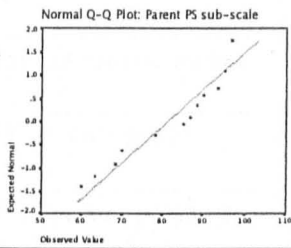
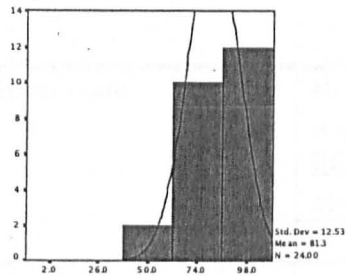


Skewness = 0.10
 SE of Skew = 0.39
 z = 0.26
 Kurtosis = -0.99
 SE of Kurtosis = 0.77
 z = -1.29

Parent Parent PedsQLTM4.0

<p>Total QOL scores</p>  <p>Std. Dev = 10.57 Mean = 84.3 N = 2400</p> <p>PedsQL</p> <p>Normal Q-Q Plot: Parent total QOL</p> 	<p>Descriptives</p> <p>Skewness = -0.80 SE of Skew = 0.47 z = -1.71 Kurtosis = -0.02 SE of Kurtosis = 0.92 z = -0.03</p>
<p>Physical health summary sub-scale scores</p>  <p>Std. Dev = 8.64 Mean = 90.0 N = 2400</p> <p>Parent PH mean</p> <p>Normal Q-Q Plot: Parent PH sub-scale</p> 	<p>Skewness = -1.11 SE of Skew = 0.47 z = -2.37 Kurtosis = 1.30 SE of Kurtosis = 0.92 z = 1.42</p>

Psychosocial health summary sub-scale scores



Skewness = -0.64
SE of Skew = 0.47
z = -1.37
Kurtosis = -0.60
SE of Kurtosis = 0.92
z = -0.66

Appendix C:

Figure C1: Example section of response sheet used to record children's TedQL.2 answers (Study 2)

Item code	Really not good/not like/always	A little bit/Sometimes	A little bit/sometimes	Really good/like/always
	0	1	2	3
T1: singing	Not good			Good
H1: favourite sweet	Don't like			Like
PC1: swinging	Not good			Good
PA1: likes playing with friends	Not at all			Alot
MA1: likes playing with mum	Not at all			Alot
PF1: is happy/sad	Sad			Happy
CF1: upset if can't do work	Never			Alot

Permission letter for parents (Study 2):

Dear Parent/Guardian,

I am writing to ask permission for your child to take part in a study that I will be conducting in the nursery where your child attends. I am currently studying for my PhD under Professor Christine Eiser, at the University of Sheffield. I am studying young children's development, specifically concerned with developing measures that allow young children to accurately and easily report their feelings, thoughts and perceptions on their lives.

I am conducting a study with nursery age children, which uses a child friendly measure to ask the children a series of questions about their views and abilities. For example, the child will be asked whether they are good at running or not. Teddy bears are used to make the task more understandable for the child, and children generally enjoy taking part in this task. The task will take about 15-20 minutes to complete.

The study also involves a **simple questionnaire for parents to fill out**, asking a few questions about your child's abilities and competence. I would be grateful if you could complete this short questionnaire, and **return it as soon as possible to the nursery**. This enables me to have your views, as well as your child's views.

Both you and your child will remain anonymous throughout the study, and any results will be strictly confidential.

I hope this procedure will be useful in developing an appropriate measure of assessing young children's 'quality of life'. This can then be applied help young children facing chronic illnesses (such as cancer) and physical handicaps (such as cerebral palsy), by being able to understand more of their own views, thoughts and feelings.

Thank you for your time,

Yours faithfully,

Miss Joanne Lawford

Figure C2: PedsQL™ measure and response sheet as given to parents (Study 2)

PedsQL™
**Pediatric Quality of Life
Inventory**

Version 4.0

PARENT REPORT for TODDLERS (ages 3-5)

DIRECTIONS

On the following page is a list of things that might be a problem for **your child**. Please tell us **how much of a problem** each one has been for **your child** during the **past ONE month** by circling:

- 0 if it is **never** a problem
- 1 if it is **almost never** a problem
- 2 if it is **sometimes** a problem
- 3 if it is **often** a problem
- 4 if it is **almost always** a problem

There are no right or wrong answers.

If you do not understand a question, please ask for help.

In the past **ONE month**, how much of a **problem** has your child had with ...

Physical Functioning (PROBLEMS WITH...)	Never	Almost Never	Some-times	Often	Almost Always
1. Walking more than one block	0	1	2	3	4
2. Running	0	1	2	3	4
3. Participating in sports activity or exercise	0	1	2	3	4
4. Lifting something heavy	0	1	2	3	4
5. Taking a bath or shower by him or herself	0	1	2	3	4
6. Doing chores, like picking up his/her toys	0	1	2	3	4
7. Having hurts or aches	0	1	2	3	4
8. Low energy level	0	1	2	3	4

Emotional Functioning (PROBLEMS WITH...)	Never	Almost Never	Some-times	Often	Almost Always
1. Feeling afraid or scared	0	1	2	3	4
2. Feeling sad or blue	0	1	2	3	4
3. Feeling angry	0	1	2	3	4
4. Trouble sleeping	0	1	2	3	4
5. Worrying about what will happen to him/her	0	1	2	3	4

SOCIAL Functioning (PROBLEMS WITH...)	Never	Almost Never	Some-times	Often	Almost Always
1. Getting along with other children	0	1	2	3	4
2. Other kids not wanting to be his or her friend	0	1	2	3	4
3. Getting teased by other children	0	1	2	3	4
4. Not able to do things that other children his or her age can do	0	1	2	3	4
5. Keeping up when playing with other children	0	1	2	3	4

NURSERY FUNCTIONING (PROBLEMS WITH...)	Never	Almost Never	Some-times	Often	Almost Always
1. Doing the same activities as peers	0	1	2	3	4
2. Missing school because of not feeling well	0	1	2	3	4
3. Missing school to go to the doctor or hospital	0	1	2	3	4

Study 2: Descriptive statistics – Means, SDs, distributions, and assessment of skew/kurtosis

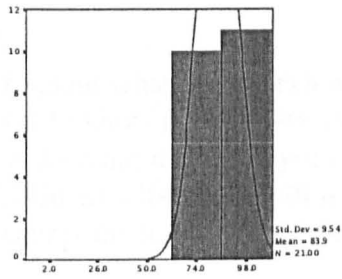
Child TedQL.2

Total scale scores	Descriptives
<p>Child TedQL mean</p> <p>Normal Q-Q Plot: Child TedQL</p> <p>Std. Dev = .29 Mean = 2.12 N = 28.00</p>	<p>Skewness = -0.27 SE of Skew = 0.44 z = -0.61 Kurtosis = 0.57 SE of Kurtosis = 0.86 z = 0.66</p>

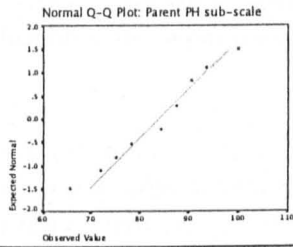
Parent PedsQLTM4.0

Total QOL scores	Descriptives
<p>Parent PedsQL mean</p> <p>Normal Q-Q Plot: Parent PedsQL</p> <p>Std. Dev = 9.57 Mean = 81.2 N = 21.00</p>	<p>Skewness = -0.11 SE of Skew = 0.50 z = -0.22 Kurtosis = -0.78 SE of Kurtosis = 0.97 z = -0.81</p>

Physical health summary sub-scale scores

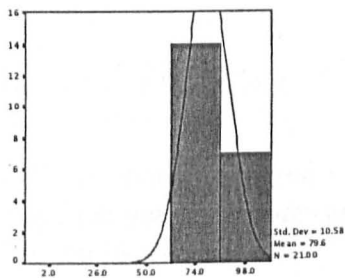


Parent PH mean

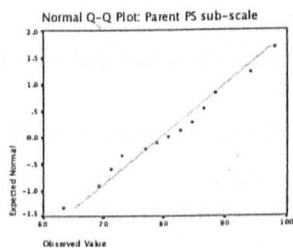


Skewness = -0.36
 SE of Skew = 0.50
 $z = -0.72$
 Kurtosis = -0.19
 SE of Kurtosis = 0.97
 $z = -0.20$

Psychosocial health summary sub-scale scores



Parent P5 mean



Skewness = -0.04
 SE of Skew = 0.50
 $z = -0.08$
 Kurtosis = -1.03
 SE of Kurtosis = 0.97
 $z = -1.07$

Appendix D:

Bruce's Story: Interview schedule – 3-8 year olds

Current health and functioning

Explain what the interview will be about (e.g. I would like to get to know you and you get to know me, and we can talk a bit about your life, and you can help me to understand me about you). Explain that you are here as a student learning about children's lives and will not tell anyone what they say unless something they tell me causes me to be concerned about their safety.

Explain that we are going to look at a storybook together and talk about their lives, their hobbies and what they are like. (Read the book together with child)

General information and self-esteem

I am a spaniel sort of dog.

I am a golden brown colour.

I am nearly five years old.

Tell me about yourself – what are you like, what do you like to do. What are you like – are usually a quiet or a loud person? Do you think you are clever?

About your home

When I was four Celia, Ziggi and I all moved to a new house near Newcastle.

Tell me about your house. Do you have a garden to play in? If not, where else do you play? Do you have your own bedroom? If not, why and would you like your own room? Do you like your house?

Material Issues

I like my red collar and the nice garden that I now have to play in.

What things do you have that you like? What games and activities do you like to play? Are there any things that you can't do that you would like to be able to do? What other things do you like to do?

School life

When I lived on our warm kennels I liked the food and having lots of playmates.

Tell me about school/nursery. Do you like going? What do you like doing best there? What do you dislike doing there?

Peer relationships

I am generally a happy dog.

I like playing with my friends and meeting new people.

Tell me about your friends - do you have friends in your class? Do you get on well with them? What do you like to play with your friends? Do any of your friends visit your house?

Social functioning

My mum is a very special person to me.

Sometimes I am naughty and she tells me off.

When I make her angry it does not last long.

I like it best when she gives me a cuddle and says how pleased she is that I am her dog.

Tell me about your family. What do you like to do with your mum/dad? Do you tell them what you have been doing at school/nursery? Who else do you see in your family? Do you argue much with them?

Feelings and thoughts

I was frightened when I went on a long journey in a big dark box.

I did not know where I was going.

Tell me if you have ever been frightened. Why? What happened? What makes you sad? What makes you happy? Do you worry about anything? What makes you cross?

Earliest memories

The earliest thing I remember is living with my birth family on a farm in the Orkney Islands.

I remember sleeping in a big basket with my Mum and brothers and sisters.

Tell me the earliest things that you can remember.

Future events

I am also learning to do new things.

I am learning how to play with my ball and fetch sticks.

What new things are you learning to do? Are you good at reading? Writing? Drawing? What do you like to draw/write? Who is helping you to learn new things?

Any other comments

We have talked a lot you and things you like to do. Is there anything you'd like to talk about or add before we finish? Is there anything else about your life that you would like to talk about with me? Is there anything else that you would like me to know about you?

Thank you very much for talking to me today!

Permission letter to parents (Study 3)

Dear Parent/Guardian,

I am writing to ask permission for your child to take part in a study that I will be conducting in the nursery where your child attends. I am currently studying for my PhD under Professor Christine Eiser, at the University of Sheffield. I am studying young children's development, specifically concerned with developing measures that allow young children to accurately and easily report their feelings, thoughts and perceptions on their lives.

I am conducting a study with young children, which uses a child friendly approach to ask the children a series of questions about their views and abilities. For example, the child will be asked what sports they like to do or who they like to play with. A short storybook is used to make the task more understandable for the child, and children generally enjoy taking part in this task. The task will take about 10 -15 minutes to complete.

I assure you that your child will remain anonymous throughout the study, and any results will be strictly confidential.

I hope this procedure will be useful in developing an appropriate measure of assessing young children's 'quality of life'. This can then be applied help young children facing chronic illnesses (such as cancer) and physical handicaps (such as cerebral palsy), by being able to understand more of their own views, thoughts and feelings.

Thank you for your time,

Yours faithfully,

Miss Joanne Lawford

Please return this form to your child's teacher.

I DO/DO NOT wish my child,, to take part in this study.

Signed (Parent/Guardian)

Example of a transcription from a child

Transcription of interview with TL, on 23/4/01.

JL: Interviewer

TL: Child initials

JL: Ok, it says, I am spaniel sort of dog, I a golden brown colour, I am nearly five years old. Can you tell me how old you are?

TL: Eight

JL: Eight, and when was your birthday?

TL: Um, 11th March

JL: Ok and what kind of person do you think you are? Do you think you are quite quiet or quite loud?

TL: Half, half

JL: Ok, half and half, why are you loud when you are loud?

TL: (pause)

JL: Are you loud with your family or your friends?

TL: Friends

JL: And when are you quiet?

TL: In class

JL: Ok and do you work hard at school?

TL: Yes, very

JL: Ok, coz you like to do well, do you?

TL: Yep

JL: Ok, let's have a look at the next page. When I was four, my mum, my family and I all moved to new house near Newcastle. Can you tell me about your house, what's it like?

TL: Um, well it's not that big, but it's not that small

JL: So it's kind of in between is it?

TL: Yeah

JL: And do you have your own room?

TL: Mmmm (nods)

JL: Ok, and do you like having your own room?

TL: Yeah

JL: Have you got brothers and sisters as well?

TL: Yeah I got two brothers

JL: What are they called?

TL: Mark and Ryan

JL: Are they older or younger than you?

TL: Older

JL: So do you play with them at all, or not?

TL: I did play with them, but they keep, after a little while they get bored of me and they just ...

JL: Ok, right, and do you have a garden at your house?

TL: Yep

JL: Do you like your house where you live now?

TL: Yep

JL: Ok, let's have a look on the next page. What things and what games do you like to play with your friends?

TL: Erm, when my friends' round I like playing like dancing to S Club Seven and like... playing down the cellar

JL: What sorry?

TL: Playing down the cellar

JL: Ok, and what do you play down there?

TL: All sorts of games like hangman..

JL: Ok

TL: Stuff like that

JL: Ok so you like S Club Seven then, do you like any other music?

TL: Um... erm....(pause)

JL: Do you know all the words for S Club Seven?

TL: Most of it

JL Do you? Have you been to see them before?

TL: No

JL: Would you like to?

TL: Yeah (nods)

JL: Ok, that's cool, let's have a look at the next page. When I lived in the warm kennels, I liked the food and having lots of playmates. Can you tell me about school, do you like coming to school?

TL: Um sometimes, sometimes not (laugh)

JL: Ok, so you prefer to be on holiday or... what do you like about school?

TL: Um, I like all the lessons and I like to learn

JL: Do you? So what things do you like best?

TL: Maths and, maths and science

JL: Ok, really? And what subjects do you not like, is there any subjects you don't like?

TL: I don't much like, um, um, English

JL: Why don't you like English

TL: Coz um, I am not very good at writing...

JL: Oh right, ok, but you are learning are you?

TL: Yeah

JL: Ok, I am generally a happy dog, I like playing with my friends and meeting new people, can you tell me about your friends, have you got friends in your class?

TL: Quite a lot

JL: Ok, yeah and have you got a best friend?

TL: Yeah

JL: Whose your best friend?

TL: Hannah Tumber

JL: Ok and is she in your class as well?

TL: Yeah

JL: Ok and do you get on well with your friends?

TL: Yeah... sometimes we do have little arguments

JL: Do you, what do you have arguments about?

TL: We always get back together – it is mostly about like, it I not much really...

JL: Just little things that you argue about?

TL: Yeah

JL: do you like to play with your friends in the playground?

TL: Yeah but sometimes I am not allowed to go out coz I got asthma

JL: Oh right, ok, so you find that a bit annoying if you can't go?

TL: Yeah

JL: What do you do when you don't go out?

TL: Um, there's a club called smiley club and I go to that
JL: Oh right, is that in break time?
TL: Yes
JL: And what do you do at your smiley club?
TL: Um not much really
JL: So does it, do you find it annoying that you've got asthma and you can't go out sometimes?
TL: Sometimes, but I do really like smiley club, so it don't really bother me
JL: Ok, so it makes up for it, ok. Is there anything else that you can't do coz you've got asthma that you would like to be able to do?
TL: Um sometimes PE I can't
JL: Right
TL: Then Miss, lets us, she like takes us round the playground and playing follow the leader, sometimes it's bad weather but she makes us put our coats on, but sometimes she don't let us...
JL: Ok so when it's summer do you get you asthma more?
TL: No it's when I like been running for quite a long time
TL: And erm I have got hayfever sometimes when like all the flowers come out..
JL: Oh yeah, I get hayfever too, it's quite bad isn't it, when you are trying to work you keep sneezing and all that
TL: (laughs)\
JL: Ok, what about your friends do any of them visit your house at all?
TL: Yeah most of the time my erm Hannah comes round and like some of the others come round
JL: Do you like people visiting your house?
TL: Yes
JL: Do you like going to visit Hannah as well?
TL: Yes
JL: Have you stayed over there?
TL: No
JL: Not yet, no
JL: Ok, do you think you would like to?
TL: Yes (nods)
JL: Ok, so do you prefer to play with your friends or on your own?
TL: Yeah, with my friends (laughs)
JL: Ok, my mum is a very special person to me, sometimes I am naughty and she tells me off when I make her angry it does not last long, I like it best when she gives me a cuddle and says how pleased she is that I am her dog. Can you tell me about your family. Do you live with your mum and your dad?
TL: Yeah
JL: And do you get on well with them?
TL: Yeah
JL: Do you talk to them quite a bit?
TL: (nods)
JL: And do you feel like you can tell them things?
TL: Yeah
JL: And who else is there in your family, is there anyone else?
TL: My brothers and my auntie and my Nan
JL: So you see them quite a bit do you?
TL: yeah

JL: What do you do when you go to your nan's?
TL: Um, most of the time my Nan comes down ours
JL: Oh right and how old are your brothers?
TL: My oldest brother is... fourteen going on the fifteen this year. And my other one is eleven going on to twelve.
JL: Right so they are a bit older than you?
TL: Yeah
JL: Do they play with you?
TL: sometimes
JL: But sometimes they don't?
TL: Only on playstation though
JL: Do you like playing on the playstation?
TL: Yep
JL: is it yours?
TL: No
JL: Whose is it?
TL: My brothers yeah
JL: Ok
TL: And I like playing football with them
JL: Do you?
JL: And do you play football with your friends as well?
TL: Sometimes
JL: What about a bike, do you ride a bike at all?
TL: Yep
JL: Ok, and what about, do you argue much with your mum and dad?
TL: Sometimes
JL: ok, what do you argue with them about?
TL: Um nearly everything! (giggles)
JL: k, but you make up with them afterwards?
TL: Yeah (nods)
JL: Ok, I was frightened when I went on a long journey in a big dark box, I did not know where I was going. Have you ever been frightened on a journey?
TL: Yeah sometimes .. um we are going no holiday this year on the plane but I am bit scared coz
JL: Are you?
TL: Coz I think the plane might crash
JL: Have you ever been on a plane?
TL: No
JL: So it might be quit scary?
TL: Mmm (nods)
JL: Exciting when it takes off though. Ok what makes you sad, do any things make you sad?
TL: Some things make me sad, like when when my brothers pick on me
JL: Oh right so you don't like that. What do you do when they do that?
TL: I go and tell my mum and dad
JL: And what makes you cross?
TL: Um when my brothers take my stuff and they don't give it back, I fight for it
JL: What things, do you worry about any things?
TL: Um... sometimes I worry
JL: What do you worry about?

TL: Like I worry about nearly everything (shrugs)
JL: Ok (laughs) What things make you happy, what do you like best?
TL: Um nearly everything makes me happy, but
JL: What
TL: Nearly everything makes me glad and nearly everything makes me cross
JL: So you are quite up and down, are you?
TL: yeah
JL: What is the thing you like doing mots, if you could chose one thing?
TL: Um, I really like going swimming, but my favourite thing would be, like meeting S Club Seven
JL: Oh wow, right, so do you go swimming much?
TL: Yeah , every Tuesday, with the school, and every Tuesday with my nanny
JL: Oh right twice in one day/
TL: Yeah
JL: you go in the afternoon and then do you go after school as well?
TL: yeah (nods)
JL: Ok, are you going today swimming?
TL: yeah
JL: Ok, the earliest thing I remember is living with my family on a farm in the Orkney Islands, I remember sleeping with my mum and brothers and sister in a big basket. Can you tell me what you can remember from when were very little?
TL: Um (pause) I don't remember much, but I do remember that my mum moved, moved to the house were are in now
JL: When you were little?
TL: yeah and I do remember that my granddad died
JL: Oh was that sad?
TL: Yeah but I was only one though
JL: Right so you didn't remember that well?
TL: Yeah
JL: Ok, I am also learning to do new things, I am learning how to play with my balls an fetch sticks. What new things are you learning to do?
TL: I am learning to like read and write
JL: At school?
TL: Yeah
JL: What about at home are you learning any new things?
TL: Sometimes they teach me stuff
TL: There's not much, like they help me with my homework
JL: Right, and are you learning to ride a bike or something like that?
TL: I know how to ride my bike really easy but I am learning to like go on a skateboard...
JL: Oh right whose teaching you that?
TL: My dad
JL: Oh right, erm, and is there anything that you would like to be able to do that other people can do?
TL: Um - er there's not much coz if I can't do that, I always do something else
JL: Instead?
TL: Yeah
JL: Ok, thank you.....

Figure D1: Example of data coding table (Study 3)

Data coding table for:

<p>1) What sort of person are you? Quiet/loud: Clever:</p>
<p>2) Can you tell me about your house? Big/small: Own room/share: Garden: Like house:</p>
<p>3) What games do you like to play?</p>
<p>4) Can you tell me about school? Like going: Favourite subject/time: Least favourite subject/time:</p>
<p>5) Can you tell me about your friends? Have lots/a few friends: Best friends: Come to your house: Go to theirs: Get on well with them: Argue with them:</p>
<p>6) Can you tell me about your family? Mentioned mum: Mentioned dad: Argue with parents: Mentioned siblings: Mentioned grandparents:</p>

Mentioned cousins:
Mentioned other:
Pets:
7) Emotions:
Scared:
Cross/angry:
Sad:
Happy:
8) What is the earliest thing you can remember?
9) What new things are you learning to do?
10) Is there anything that you haven't got, that you would like to have?
What do you want to be when you grow-up? (if asked – extra)

Appendix E:

Figure E1: Teacher questionnaire used in Study 4

For each of the children in your class that I have interviewed, please indicate whether there has been any MAJOR changes in their lives, behaviour or close relationships IN THE LAST WEEK which you are aware of.....

(It is not necessary to detail what may have happened, but simply to indicate whether any changes have occurred to any of the children which may dramatically alter their answers to my questions about their lives, thoughts, feelings and behaviour)

Please TICK/MARK one of the four boxes for each child:

Child's name	No changes	Minor changes (in classroom/playground and behaviour – e.g. caught fighting in playground, fallen out with best friend)	Health-related changes (e.g. child missed school due to cold/flu/other minor illness)	Major changes (e.g. child/parent/caregiver taken ill for major illness, major problems with parents/other family members/caregivers)
1.				
2.				
3.				
4.				
5.				
6.				
7.				
8.				
9.				
10.				
11.				
12.				

Figure E2: Example section of response sheet used to record children's TedQL.3 answers (Study 4)

Item code	Really not good/not like/always	A little bit/sometimes	A little bit/sometimes	Really good/like/always	Don't know
	0	1	2	3	
T1: hopping	Not			Good	
H1: sweet					
H2: toy (N)					
N1: sky is purple/orange	Purple			Orange	
PC1: swinging	Not			Good	
PA1: has friends to plays with/play on own	None/own			Lots	
CF1: able to do jigsaws/board games	Not			Good	
PF1: quiet/loud person	Quiet			Loud	
FA1: mum/dad/other plays with them	No			Yes	
N2: socks happy/sad	Sad			Happy	

Permission letter for parents (Study 4)

Dear Parent/Guardian,

I am writing to ask permission for your child to take part in a study that I will be conducting in the school where your child attends. I am currently studying for my PhD under Professor Christine Eiser, at the University of Sheffield. I am studying young children's development, specifically concerned with developing measures that allow young children to accurately and easily report their feelings, thoughts and perceptions on their lives.

I am conducting a study with young children, which uses a child friendly approach to ask the children a series of questions about their views and abilities. For example, the child will be asked what sports they like to do or who they like to play with. Teddy bears are used to make the task more understandable for the child, and children generally enjoy taking part in this task. The task will take about 10 -15 minutes to complete.

I assure you that your child will remain anonymous throughout the study, and any results will be strictly confidential.

I hope this procedure will be useful in developing an appropriate measure of assessing young children's 'quality of life'. This can then be applied help young children facing chronic illnesses (such as cancer) and physical handicaps (such as cerebral palsy), by being able to understand more of their own views, thoughts and feelings.

Thank you for your time,

Yours faithfully,

Miss Joanne Lawford

Please return this form to your child's teacher.

I DO/DO NOT wish my child,, to take part in this study. (delete as appropriate)

Signed (Parent/Guardian)

Figure E3: Example section of response sheet used to record children's 'think aloud' answers to TedQL.3 items (Study 4)

Item code	Really not good/not like/always	A little bit/sometimes	A little bit/sometimes	Really good/like/always
	0	1	2	3
PF5: gets cross/angry a lot (N)	Never			Yes alot
CF5: remembers what told to do	Never			Yes alot
PC6: bike riding/scooter/other	Not			Good
PA5: friends boss/tease them (N)	Never			Yes alot
PF6: worries about losing things (N)	Never			Yes alot
CF6: reading (pictures/words)	Not			Good

Figure E4: Example of coding table with transcript ‘copied and pasted’ into it (Study 4)

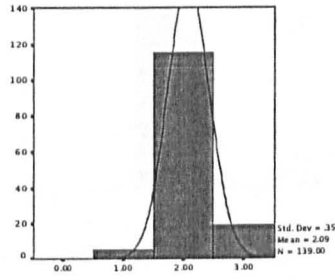
PC5 – Running: Examples from Year 3, Time 1

<p>No answer given (DK or just repeated response options with no further explanation given)</p>	<p>“Not good... DK” “Good, DK, fast” “Little bit, coz...” “Really good, coz I DK, just good” “In between... coz... DK” “Quite good” “Really good” “Little bit good”</p>
<p>Social comparison used (answer included a social comparison e.g. to friends, siblings, parents)</p>	<p>“Coz when race friends used to be faster, faster now than then” “Really good... play races, always win, haven’t lose running once” “Quite good... want to be even better to catch people” “Good... coz races with Nathan and he’s fast, am getting better” “Good, coz race friends between the wall, and sometimes win” “Very good, coz quite a lot of races with year 6, with boys too, and won them” “Very good, once had race and won all 21 in our class”</p>

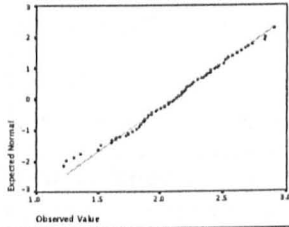
Study 4: Descriptive statistics – Means, SDs, distributions, and assessment of skew

Child TedQL.3

**Actual QOL scores
Time 1, Year 1**



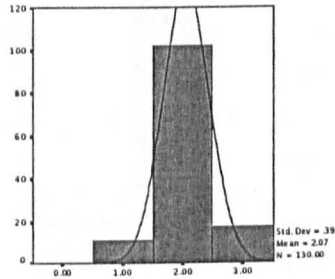
actual QOL mean
Normal Q-Q Plot: Yr1, T1, Actual QOL



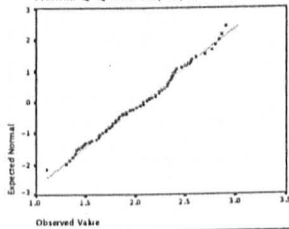
Descriptives

Skewness = -0.17
SE of Skew = 0.21
z = -0.81
Kurtosis = 0.03
SE of Kurtosis = 0.41
z = 0.08

Time 2, Year 1



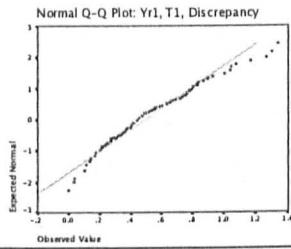
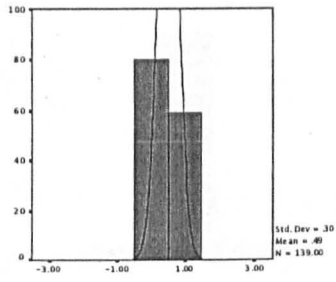
actual QOL mean
Normal Q-Q Plot: Yr1, T2, Actual QOL



Skewness = -0.41
SE of Skew = 0.21
z = -1.96
Kurtosis = -0.40
SE of Kurtosis = 0.41
z = -0.98

Discrepancy scores

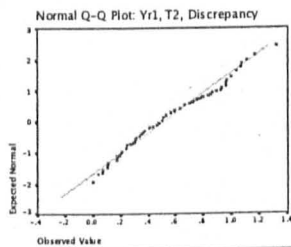
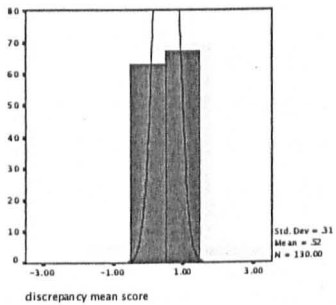
Time 1, Year 1



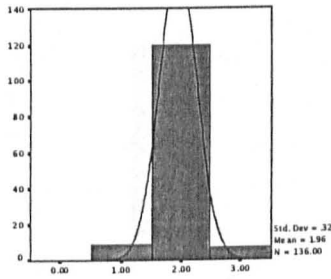
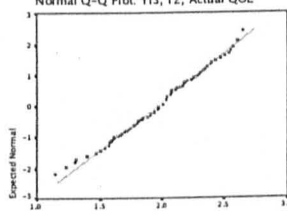
Descriptives

Skewness = -0.61
SE of Skew = 0.21
z = -2.90
Kurtosis = -0.12
SE of Kurtosis = 0.41
z = -0.30

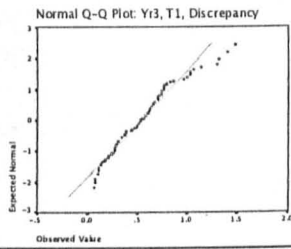
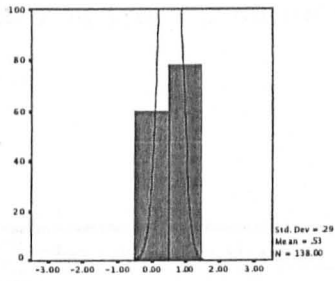
Time 2, Year 1



Skewness = 0.34
SE of Skew = 0.21
z = 1.62
Kurtosis = -0.69
SE of Kurtosis = 0.41
z = -1.69

Actual QOL scores Time 1, Year 3	Descriptives
<p>Time 2, Year 3</p>  <p>actual QOL mean</p>  <p>Normal Q-Q Plot: Yr3, T2, Actual QOL</p>	<p>Skewness = -0.27 SE of Skew = 0.21 z = -1.29 Kurtosis = 0.10 SE of Kurtosis = 0.41 z = 0.25</p>

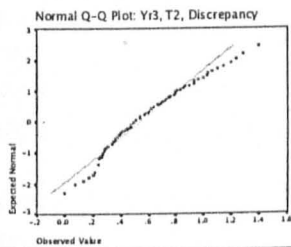
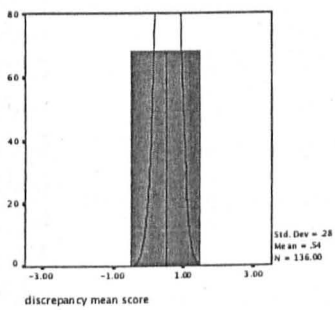
**Discrepancy scores
Time 1, Year 3**



Descriptives

Skewness = 0.81
 SE of Skew = 0.21
 $z = 3.86$
 Kurtosis = 0.96
 SE of Kurtosis = 0.41
 $z = 2.35$

Time 2, Year 3



Skewness = 0.72
 SE of Skew = 0.21
 $z = 3.43$
 Kurtosis = 0.26
 SE of Kurtosis = 0.41
 $z = 0.64$

Table E1: Item analysis - item-total correlations by response scale type (Year 3, Study 4)

Item in TedQL.3 measure	Time 1		Time 2	
	Spearman's correlation coefficient (ρ)		Spearman's correlation coefficient (ρ)	
	Actual QOL	Ideal QOL	Actual QOL	Ideal QOL
Circles response scale	n=49		n=44	
PC1	0.24	0.20	0.44**	0.39**
PC2	0.54**	0.41**	0.65**	0.32*
PC3	0.44**	0.41**	0.23	0.32*
PC4	0.52**	0.36**	0.44**	0.28
PC5	0.45**	0.40**	0.47**	0.26
PC6	0.36**	0.28*	0.63**	0.15
PA1	0.34*	0.50**	0.39**	0.49**
PA2	0.18	0.23	0.06	0.36**
PA3	0.48**	0.56**	0.30*	0.14
PA4	0.44**	0.41**	0.24	0.29
PA5	0.48**	0.60**	0.30*	0.48**
FA1	0.28*	0.40**	0.09	0.40**
FA2	0.30*	0.30*	0.06	0.49**
FA3	0.49**	0.51**	0.17	0.16
FA4	0.26	0.15	0.29	0.15
FA5	0.23	0.41**	0.24	0.33*
FA6	0.30*	0.38**	0.54**	0.18
FA7	-0.02	0.21	0.23	0.20
PF1	-0.84	0.11	0.22	-0.08
PF2	0.21	0.44**	0.45*	0.23
PF3	0.28	0.44**	0.40**	0.40
PF4	0.11	0.26	-0.12	0.18
PF5	0.24	0.18	0.10	0.45
PF6	0.42**	0.52**	0.21	0.40
CF1	0.44**	0.62**	0.56**	0.29
CF2	0.69**	0.41**	0.29	0.17
CF3	0.19	0.49**	0.15	0.53**
CF4	0.20	0.24	0.26	0.50**
CF5	0.26	0.22	0.38**	0.12
CF6	0.35**	0.14	0.20	-0.03
Faces response scale	n=46		n=48	
PC1	0.27	0.27	0.26	0.34*
PC2	0.39**	0.39**	0.30*	0.21
PC3	0.26	0.26	0.43**	0.23
PC4	0.20	0.20	0.43**	0.33*
PC5	0.35*	0.35*	0.44**	0.30*
PC6	0.32*	0.32*	0.28	0.16
PA1	0.49**	0.23	0.32*	0.51**

PA2	0.12	-0.10	0.24	0.23
PA3	0.37**	0.37**	0.35*	0.59**
PA4	0.56**	0.37**	0.44**	0.45**
PA5	0.41**	0.35*	0.33*	-0.05
FA1	0.34*	0.46**	0.54**	0.42**
FA2	0.48**	0.50**	0.27	0.09
FA3	0.62**	0.58**	0.35*	0.42**
FA4	0.27	0.18	0.21	0.11
FA5	0.30*	0.21	0.41**	0.50**
FA6	-0.05	0.09	0.14	0.21
FA7	0.32*	0.24	0.18	0.15
PF1	-0.33	-0.25	0.01	0.04
PF2	0.28	0.20	0.30*	0.18
PF3	0.29	0.10	0.19	0.38**
PF4	0.07?	0.56**	0.11	0.46**
PF5	0.17	0.42**	0.34*	0.08
PF6	0.46**	0.30*	0.42**	0.29*
CF1	0.04	0.25	0.04	0.46**
CF2	0.14	0.40**	0.33*	0.46**
CF3	0.18	0.30*	0.22	0.24
CF4	0.13	0.20	0.33*	0.26
CF5	0.27	0.42**	0.43**	0.22
CF6	0.32*	0.48**	0.31*	0.07
Thermometer response scale	n=43		n=44	
PC1	0.10	0.20	0.07	0.30*
PC2	0.35*	0.08	0.44**	0.38**
PC3	0.22	0.07	0.11	0.22
PC4	0.25	0.08	0.35*	0.21
PC5	0.10	-0.04	0.63**	0.33*
PC6	0.21	0.20	0.56**	0.33*
PA1	0.37*	0.17	0.60**	0.51**
PA2	0.18	0.38**	-0.05	0.08
PA3	0.48**	0.22	0.31*	0.21
PA4	0.39**	0.42**	0.62**	0.53**
PA5	0.23	0.27	0.59**	0.39**
FA1	0.22	0.49**	0.32*	0.25
FA2	0.22	0.44**	0.20	0.26
FA3	0.15	0.64**	0.46**	0.26
FA4	0.46**	0.57**	0.41**	0.43**
FA5	0.37**	0.43**	0.33*	0.41**
FA6	0.16	0.47**	0.08	0.08
FA7	0.26	0.49**	0.38*	0.24
PF1	0.33*	-0.23	0.21	0.28
PF2	0.39**	0.31*	0.39**	0.16
PF3	0.35**	0.42**	0.08	0.09
PF4	-0.57	0.12	0.40**	0.58**
PF5	0.04	0.53**	-0.11	0.02
PF6	0.30	0.28	0.42**	0.29

CF1	0.37**	0.26	0.17	0.21
CF2	0.10	0.15	0.50**	0.25
CF3	0.14	0.20	0.38**	0.36*
CF4	0.55**	0.17	0.49**	0.27
CF5	0.44**	0.30	0.44**	0.43**
CF6	0.24	0.33*	0.17	0.09

Note. * $p < .05$, ** $p < .01$

Italics = correlation coefficient below .20 criterion level

Table E2: Item analysis – item-total correlations by response scale type (Year 1, Study 4)

Item in TedQL.3 measure	Time 1		Time 2	
	Spearman's correlation coefficient (ρ)		Spearman's correlation coefficient (ρ)	
	Actual QOL	Ideal QOL	Actual QOL	Ideal QOL
Circles response scale	n=50		n=45	
PC1	0.19	0.40**	0.46**	0.30*
PC2	0.28*	0.22	0.55**	0.40**
PC3	0.46**	0.39**	0.31*	0.27
PC4	0.56**	0.42**	0.27	0.19
PC5	0.43**	0.05	0.48**	0.31*
PC6	0.21	0.08	0.43**	0.15
PA1	0.22	0.27	0.43**	0.35*
PA2	0.01	0.20	0.10	0.19
PA3	0.38**	0.55**	0.15	0.45**
PA4	0.09	0.22	0.52**	0.33*
PA5	0.26	0.08	0.43**	0.36*
FA1	0.43**	0.39**	0.18	0.23
FA2	0.31*	0.24	0.28	0.51**
FA3	0.22	0.20	0.11	0.50**
FA4	0.35**	0.28*	0.47**	0.27
FA5	0.26	0.39**	0.24	0.09
FA6	0.20	0.26	0.30*	0.16
FA7	0.15	0.04	0.37*	0.21
PF1	0.29*	0.13	0.07	0.30*
PF2	0.39*	0.39**	0.29*	0.10
PF3	0.41**	0.20	0.27	0.41**
PF4	0.06	0.41**	0.09	0.15
PF5	0.33*	0.38**	0.34*	0.38**
PF6	0.45**	0.32*	0.30*	0.27
CF1	0.29*	0.05	0.39**	0.46**
CF2	0.33*	0.23	0.45**	0.48**
CF3	0.45**	0.35**	0.44**	0.56**
CF4	0.51**	0.36**	0.37**	0.30*
CF5	0.36**	0.30*	0.48**	0.36*
CF6	0.46**	0.41**	0.34*	0.36*
Faces response scale	n=49		n=40	
PC1	0.45**	0.24	0.36*	0.28
PC2	0.32*	0.13	0.34*	0.09
PC3	0.47**	0.12	0.42**	0.35*
PC4	0.30*	0.18	0.41**	0.30
PC5	0.32*	-0.04	0.35*	0.20
PC6	0.45**	0.16	0.47**	0.14
PA1	0.39**	0.36**	0.59**	0.32*

PA2	0.17	0.27	0.02	0.29
PA3	0.41**	0.39**	0.15	0.24
PA4	0.43**	0.43**	0.47*	0.38*
PA5	0.60**	0.33*	0.59**	0.23
FA1	0.39**	0.49**	0.34*	0.45**
FA2	0.28*	0.30*	0.33*	0.18
FA3	0.35*	0.47**	0.41*	0.39*
FA4	0.26	0.39**	0.63**	0.42**
FA5	0.26	0.23	0.49**	0.39*
FA6	0.50**	0.26	0.54**	0.21
FA7	0.48**	0.26	0.27	0.20
PF1	-0.23	0.02	-0.19	-0.10
PF2	0.30*	0.14	0.44**	-0.01
PF3	0.48**	0.37**	0.62**	0.32*
PF4	0.23	0.13	0.15	0.41**
PF5	0.48**	0.46**	0.35*	0.48**
PF6	0.46**	0.46**	0.10	0.07
CF1	0.33*	0.26	0.18	0.08
CF2	0.32*	0.24	0.52**	0.41**
CF3	0.46**	0.46**	0.47**	0.11
CF4	0.30*	0.25	0.46**	0.52**
CF5	0.35**	0.28*	0.32*	-0.05
CF6	0.25	0.28*	0.48**	-0.08
Thermometer response scale	n=40		n=45	
PC1	0.34*	0.26	0.08	-0.10
PC2	0.40**	0.25	0.17	0.23
PC3	0.12	0.18	0.20	0.18
PC4	0.49**	0.37*	0.32*	-0.03
PC5	-0.05	0.30*	0.36*	0.21
PC6	0.35*	0.18	0.49**	-0.03
PA1	0.34*	0.18	0.40**	0.16
PA2	0.31*	0.26	0.33*	0.16
PA3	0.34*	0.24	0.49**	0.36*
PA4	0.22	0.31*	0.37**	0.33*
PA5	0.49**	0.44**	0.21	0.04
FA1	0.32*	0.17	0.53**	0.48**
FA2	0.29	0.37*	0.50**	0.32*
FA3	0.31	0.42**	0.54**	0.47**
FA4	0.22	0.15	0.43**	0.34*
FA5	0.40**	0.15	0.42**	0.19
FA6	0.46**	0.59**	0.50**	0.33*
FA7	0.29	-0.13	0.50**	0.32*
PF1	-0.13	0.15	0.21	0.32*
PF2	0.31*	0.17	0.37**	0.39**
PF3	0.08	0.32*	0.20	0.26
PF4	0.08	0.07	0.39**	0.42**
PF5	0.53**	0.45**	0.46**	0.27
PF6	0.36*	0.45**	0.17	0.19

CF1	0.33*	0.26	0.41**	0.35*
CF2	0.39**	0.35*	0.43**	0.23
CF3	0.47**	0.27	0.55**	0.31*
CF4	0.27	0.35*	0.24	0.31*
CF5	0.46**	0.38*	0.47**	0.40**
CF6	<i>0.16</i>	<i>0.16</i>	0.41**	<i>0.14</i>

Note. * $p < .05$, ** $p < .01$

Italics = correlation coefficient below .20 criterion level

Table E3: Percentage of 'don't know' answers on TedQL.3 items (All children, Study 4)

TedQL.3 item	% of DK answers
PC1	1%
PC2	1%
PC3	0.5%
PC4	23%
PC5	0.7%
PC6	2.5%
PA1	0.7%
PA2	1%
PA3	0.5%
PA4	0.7%
PA5	1%
FA1	1.4%
FA2	1.8%
FA3	11%
FA4	1%
FA5	0.7%
FA6	0%
FA7	12%
PF1	0.7%
PF2	1%
PF3	1%
PF 4	0.7%
PF5	0.7%
PF6	1.4%
CF1	1.8%
CF2	1.8%
CF3	0.7%
CF4	1.4%
CF5	2.2%
CF6	1.8%

Appendix F:

Figure F1: Example section of response sheet used to record children's TedQL.4 answers (Study 5)

Item code	Really not good/not like/ always	A little bit/ Sometimes	A little bit/ sometimes	Really good/like/ always	Don't know
	0	1	2	3	
H1: losing favourite toy	Sad			Happy	
T1: hopping	Not good			Good	
1: swinging	Not good			Good	
2: playing ball games	Not good			Good	
3: climbing high things	Not good			Good	
4: running	Not good			Good	
5: bike riding	Not good			Good	

Permission letter for parents (Study 5)

Dear Parent/Guardian,

I am writing to ask permission for your child to take part in a study that I will be conducting in Bridge and Patricxbourne School, where your child attends. I am currently studying for my PhD under Professor Christine Eiser, at the University of Sheffield. I am studying young children's development, specifically concerned with developing ways for young children to report their perceptions on their lives.

I am conducting a study with children below eight years, which uses a child friendly approach to ask the children about their views and abilities. For example, the child will be asked what sports they like to do or who they like to play with. Teddy bears are used to make the task more understandable for the child, and children generally enjoy taking part in this task. The task will take about 10 minutes to complete.

I hope this procedure will be useful in developing an appropriate measure of assessing young children's 'quality of life'. This can then be applied help young children facing chronic illnesses (such as cancer) and physical handicaps (such as cerebral palsy), by being able to understand more of their own views and feelings.

I assure you that your child will remain anonymous throughout the study, and any results will be strictly confidential.

Thank you for your time,

Yours faithfully,

Miss Joanne Lawford

Please return this form to your child's teacher.

I DO/DO NOT wish my child,, to take part in this study.

Signed (Parent/Guardian)

Letter to parents detailing Study 5:

Dear Parent/Guardian,

As you may remember, I contacted you about your child taking part in a study I am conducting in your child's school, over June 2003. I have been interviewing children from Years 1-3 about their thoughts and feelings on their lives.

I hope this procedure will be useful in developing an appropriate measure of assessing young children's 'quality of life'. This can then be applied help young children facing chronic illnesses (such as cancer) and physical handicaps (such as cerebral palsy), by being able to understand more of their own views, thoughts and feelings.

I am also interested in parents' views about their children. I have included some questionnaires which I would be entirely grateful if you could complete, in relation to your child, and either return using the stamped addressed envelope included or bring back to school. Your views will be very helpful in allowing comparisons between parents' and children. If you can take the time to complete the questionnaires, I do appreciate your help.

Any information you provide will be kept strictly confidential, and no names will be used in any reports of the study.

The following page explains my study in more detail, and will hopefully answer any questions you may have. Otherwise, please do not hesitate to contact me at the address and telephone number at the top of this letter.

Yours faithfully,

Miss Joanne Lawford

Gaining information about your children's lives.

What is this study about?

The aim of the study is to find the best ways to gain information from young children about their lives. My research has been focused on developing measures which allow young children to easily and accurately report their feelings and thoughts on their lives.

I want to find out about what children think about their lives, and also what parents' think about their children's lives. I am interested in comparing children's and parents' views. I will be interviewing children in Bridge & Patixbourne School, and I also would like to find out what parents' think, using questionnaires.

What will be involved if I agree to take part?

If you agree to take part in this study, I would like you to complete the enclosed questionnaire and return it by post. A stamped addressed envelope has been included so it can be easily posted back to us (you don't have to add a stamp). Or, if you prefer, you can return the questionnaire directly to the school, to your child's teacher, and they will pass it on to me.

Will the information obtained in the study be confidential?

All of the information you provide by answering the questionnaire will be anonymised and kept strictly confidential. I will give you an ID number (on the corner of your questionnaire sheets) which will simply be used to link your questionnaire to the information gained from your child (as I need to be able to compare parent and child reports).

Anything you report in the questionnaire will be treated in confidence. No names will be mentioned in any reports of the study, and care will be taken so that individuals cannot be identified from details in reports of results of the study.

What if I wish to gain more information on this study?

If you wish to talk in more detail with anyone about this study, I (Joanne Lawford) will be available to talk to any parents between 9th June and 4th July at the school (either during or after school hours). Or you can contact me anytime at the address or telephone number at the top of this letter. I will be more than happy to talk to you.

Thank you for your help, it is much appreciated.

Figure F2: Questionnaire version of TedQL.4 measure as given to parents (Study 5)

We are interested in what you think your child is like. **On the following pages are a list of questions about your child.** These questions are taken from conversations with children, and reflect the kinds of activities that children at this age do.

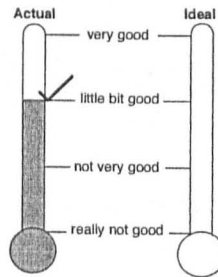
Please answer the questions **how you think your child would answer them** by marking the correct place on the thermometer scale. Think about how your child has been **in the last week** when answering the questions.

Here is an example to help show you how to answer the questions.

For example, we might ask:

a) How good is your child at catching balls?

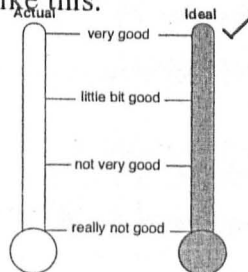
If you think your child would say that they were quite good at catching balls, then you would mark the first 'actual' thermometer like this:



We will also ask a second question about each activity:

b) How would your child **like to be** at catching balls?

If you think your child would like to be really good at catching balls, then you would mark the second 'ideal' thermometer like this:



(there is no need to colour in all the thermometer, you can just tick or mark the correct point)

There will be two parts to each question, the first asking about how they actually are (actual), and the second asking how they would like to be (ideal).

Remember to think about the **last week**, and answer the questions **how you think your child would answer**.

1a) How good is your child at swinging
(e.g. on swings at the park)?

1b) How would your child **like to be** at swinging?

Actual Ideal

— very good —

— little bit good —

— not very good —

— really not good —

2a) How good is your child at playing ball games?

2b) How would your child **like to be** at playing ball games?

Actual Ideal

— very good —

— little bit good —

— not very good —

— really not good —

3a) How good is your child at climbing high things?

3b) How would your child **like to be** at climbing high things?

Actual Ideal

— very good —

— little bit good —

— not very good —

— really not good —

4a) How good is your child at running?

4b) How would your child **like to be** at running?

Actual Ideal

— very good —

— little bit good —

— not very good —

— really not good —

5a) How good is your child at bike riding?

5b) How would your child **like to be** at bike riding?

Actual Ideal

— very good —

— little bit good —

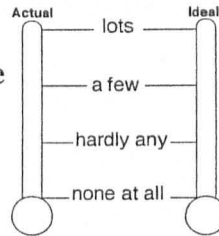
— not very good —

— really not good —

Remember to think about the **last week**, and answer the questions **how you think your child would answer**.

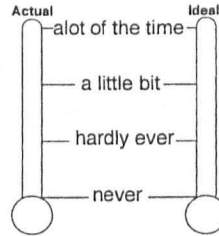
6a) How many friends **does** your child have to play with at school?

6b) How many friends would your child **like to have** to play with at school?



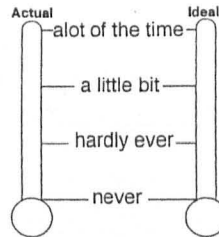
7a) How much **do** your child's friends come over to play at your house?

7b) How much does your child **want** their friends to come over to play at your house?



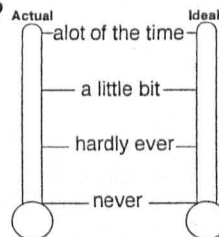
8a) How much **does** your child get teased by their friends?

8b) How much does your child **want to be** teased?



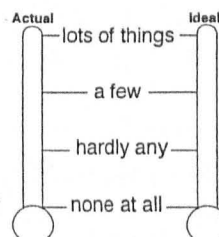
9a) How much **do** you play with your child at home?

9b) How much does your child **want you to play** with them at home?



10a) How much **does** your child tell you about what they have been doing at school?

10b) How much does your child **want to tell you** about what they have been doing at school?

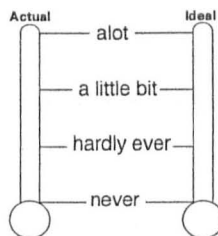


Remember to think about the **last week**, and answer the questions **how you think your child would answer**.

Do they have brothers/sisters? If yes, see Q11 and Q12, If no, go to Q13.

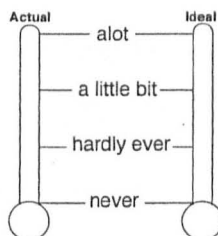
11a) How much **does** your child play with their brothers/sisters?

11b) How much does your child **want to** play with them?



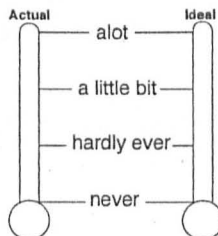
12a) How much **does** your child get bossed around by their brothers/sisters?

12b) How much does your child **want to** get boss around by them?



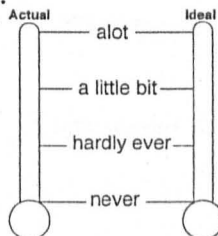
13a) How much **does** your child see their grandparents?

13b) How much does your child **want to** see their grandparents?



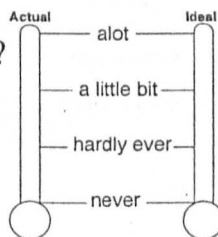
14a) How much **does** your child get told off at home?

14b) How much does your child **want to** get told off at home?



15a) How much **does** your child feel scared?

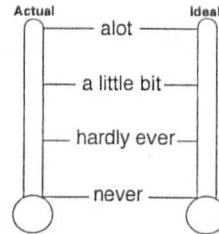
15b) How much does your child **want to** feel scared?



Remember to think about the **last week**, and answer the questions **how you think your child would answer**.

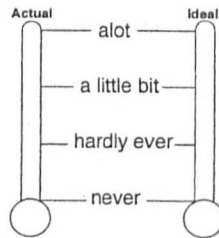
16a) How much **does** your child have bad dreams at night?

16b) How much does your child **want to** have bad dreams at night?



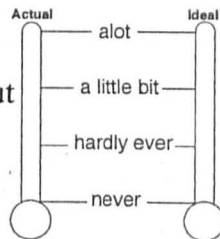
17a) How much **does** your child feel cross/angry?

17b) How much does your child **want to** feel cross/angry?



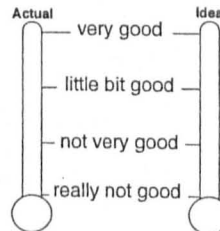
18a) How much **does** your child worry about losing their things (like toys/clothes)?

18b) How much does your child **want to** worry about losing their things?



19a) How good **is** your child at doing numbers at school? (e.g. like adding and taking away)

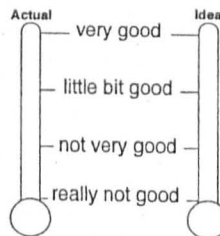
19b) How would your child **like to be** at doing numbers at school?



20a) How good **is** your child at writing?

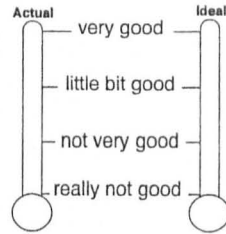
(e.g. spelling words, writing neatly)

20b) How would your child **like to be** at writing?

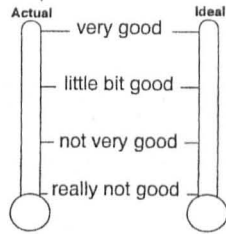


Remember to think about the **last week**, and answer the questions **how you think your child would answer**.

- 21a) How good is your child at drawing?
21b) How would your child **like to be** at drawing?

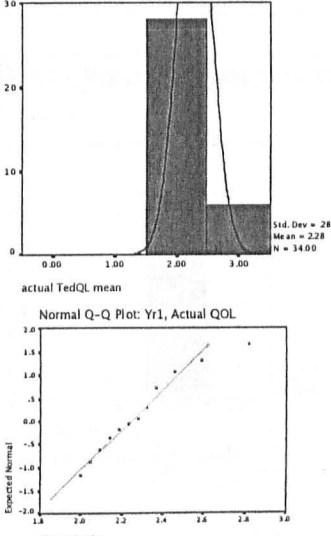
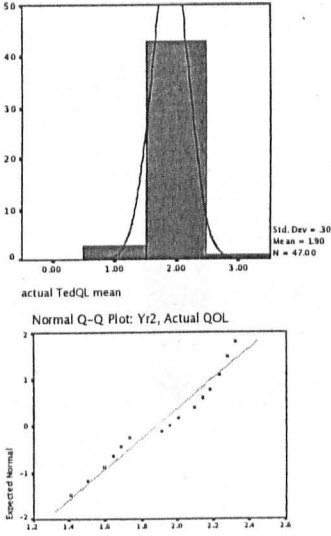
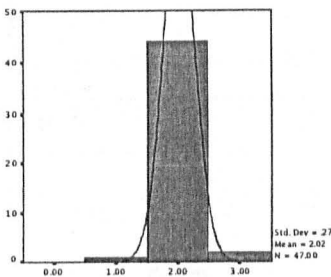


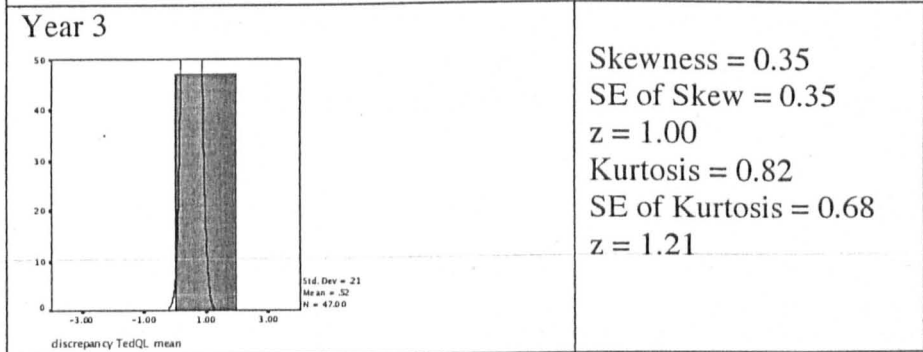
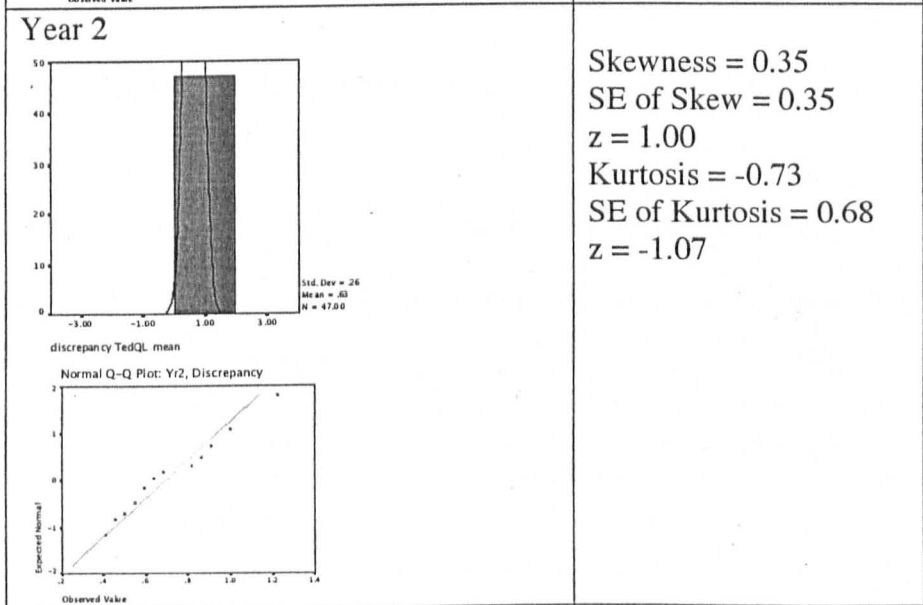
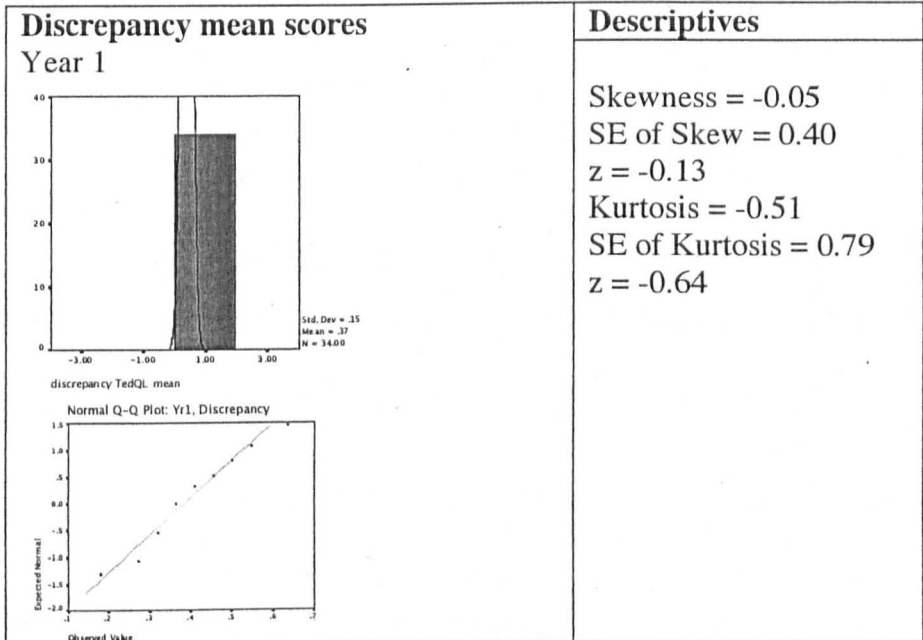
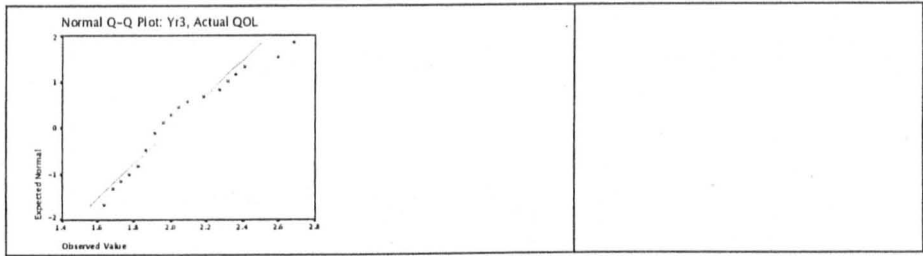
- 22a) How good is your child at reading?
(e.g. reading a story book aloud to you at home)
22b) How would your child **like to be** at reading?

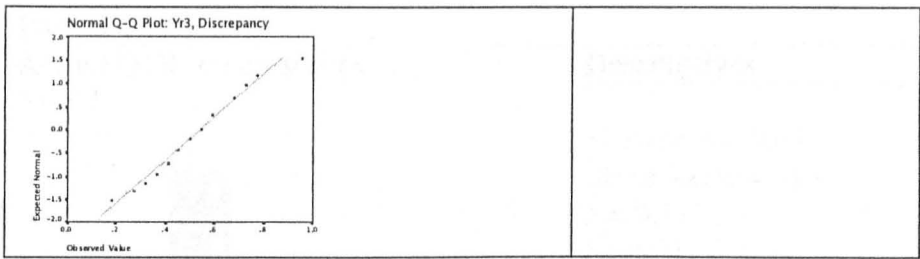


Study 5: Descriptive statistics – Means, SDs, distributions, and assessment of skew/kurtosis

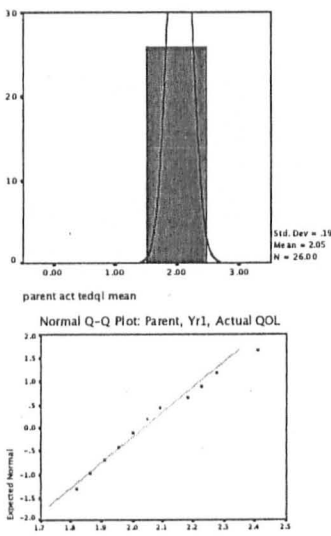
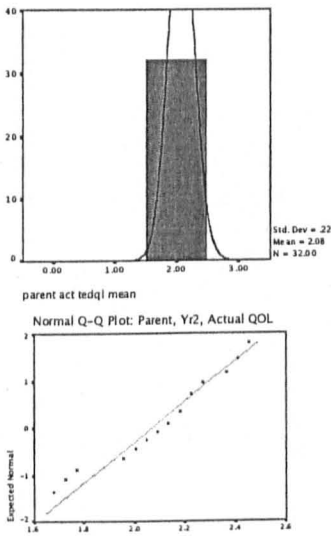
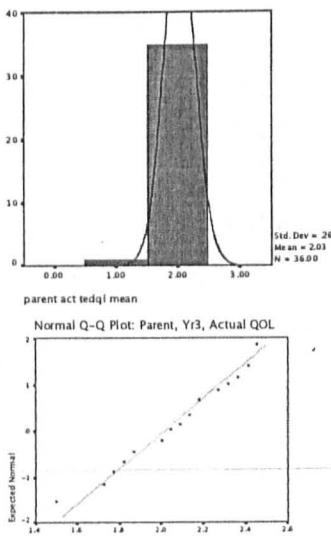
Child TedQL.4

Actual QOL mean scores	Descriptives
<p>Year 1</p>  <p>actual TedQL mean</p> <p>Normal Q-Q Plot: Yr1, Actual QOL</p>	<p>Skewness = 0.46 SE of Skew = 0.40 z = 1.15 Kurtosis = -0.09 SE of Kurtosis = 0.79 z = 0.11</p>
<p>Year 2</p>  <p>actual TedQL mean</p> <p>Normal Q-Q Plot: Yr2, Actual QOL</p>	<p>Skewness = -0.27 SE of Skew = 0.35 z = -0.77 Kurtosis = -0.43 SE of Kurtosis = 0.68 z = -0.63</p>
<p>Year 3</p>  <p>actual TedQL mean</p>	<p>Skewness = 0.37 SE of Skew = 0.35 z = 1.06 Kurtosis = 0.06 SE of Kurtosis = 0.68 z = 0.09</p>





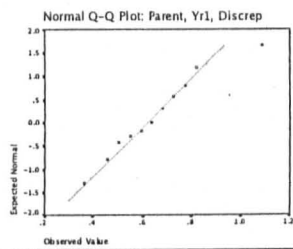
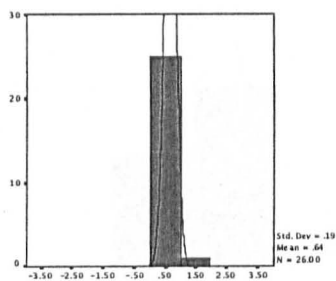
Parent TedQL.4

<p>Actual QOL mean scores</p> <p>Year 1</p> 	<p>Descriptives</p> <p>Skewness = 0.05 SE of Skew = 0.46 z = 0.11 Kurtosis = -0.31 SE of Kurtosis = 0.89 z = -0.35</p>
<p>Year 2</p> 	<p>Skewness = -0.49 SE of Skew = 0.41 z = -1.20 Kurtosis = -0.38 SE of Kurtosis = 0.81 z = -0.47</p>
<p>Year 3</p> 	<p>Skewness = -0.46 SE of Skew = 0.39 z = -1.18 Kurtosis = -0.33 SE of Kurtosis = 0.77 z = -0.43</p>

Parent TedQL.4

Discrepancy mean scores

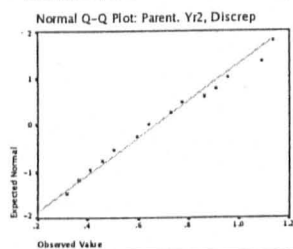
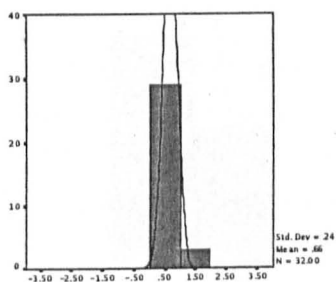
Year 1



Descriptives

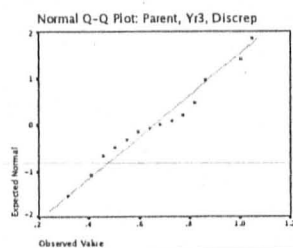
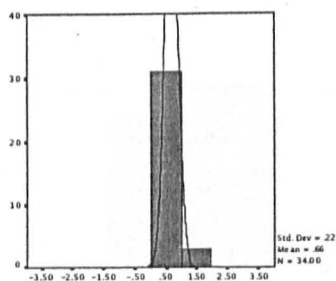
Skewness = 0.33
 SE of Skew = 0.46
 $z = 0.72$
 Kurtosis = -0.07
 SE of Kurtosis = 0.89
 $z = -0.08$

Year 2



Skewness = 0.26
 SE of Skew = 0.41
 $z = 0.63$
 Kurtosis = -0.58
 SE of Kurtosis = 0.81
 $z = -0.72$

Year 3

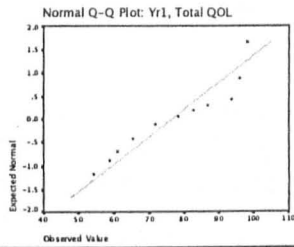
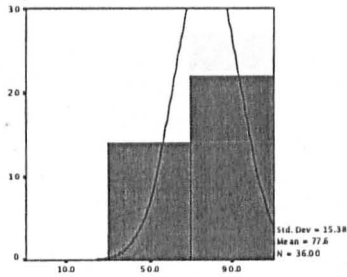


Skewness = -0.42
 SE of Skew = 0.40
 $z = -1.05$
 Kurtosis = -1.07
 SE of Kurtosis = 0.79
 $z = -1.35$

Child PedsQLTM4.0

Total QOL scores

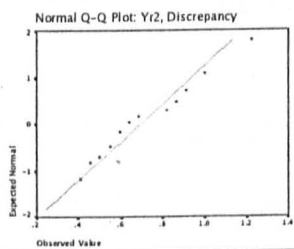
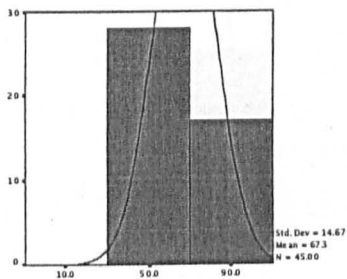
Year 1



Descriptives

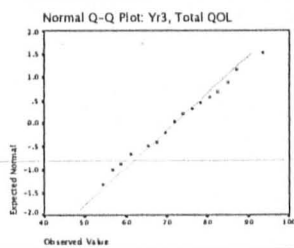
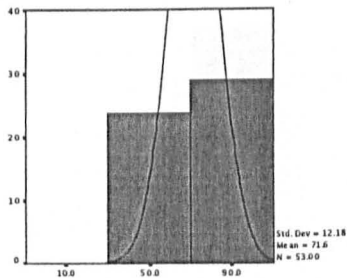
Skewness = -0.17
 SE of Skew = 0.39
 z = -0.44
 Kurtosis = -1.36
 SE of Kurtosis = 0.77
 z = -1.77

Year 2



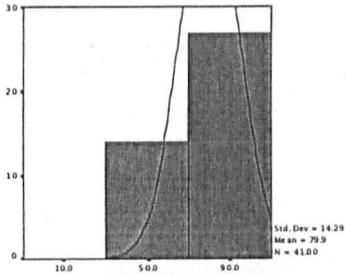
Skewness = 0.01
 SE of Skew = 0.36
 z = 0.03
 Kurtosis = -0.48
 SE of Kurtosis = 0.70
 z = -0.69

Year 3

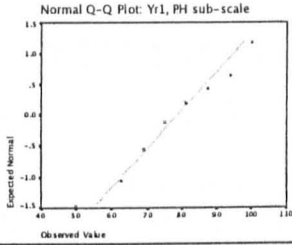


Skewness = -0.09
 SE of Skew = 0.33
 z = -0.27
 Kurtosis = -0.82
 SE of Kurtosis = 0.64
 z = -1.28

Physical health summary mean scores
Year 1



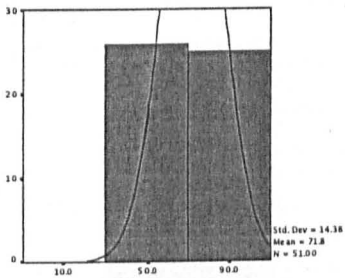
physical functioning mean score



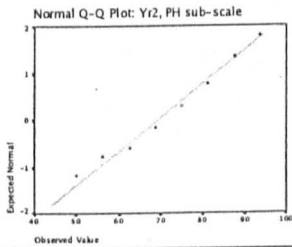
Descriptives

Skewness = -0.22
SE of Skew = 0.37
z = -0.59
Kurtosis = -0.92
SE of Kurtosis = 0.72
z = -1.28

Year 2

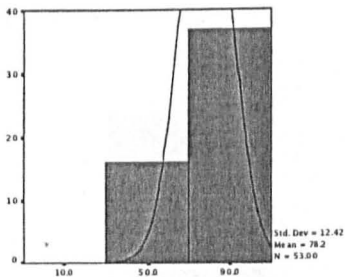


physical functioning mean score

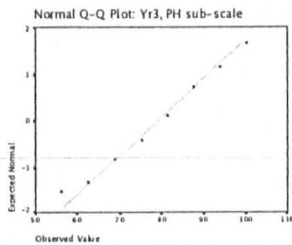


Skewness = -0.46
SE of Skew = 0.33
z = -1.39
Kurtosis = -0.29
SE of Kurtosis = 0.66
z = -0.44

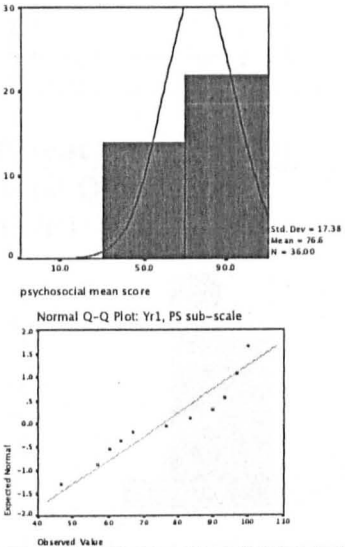
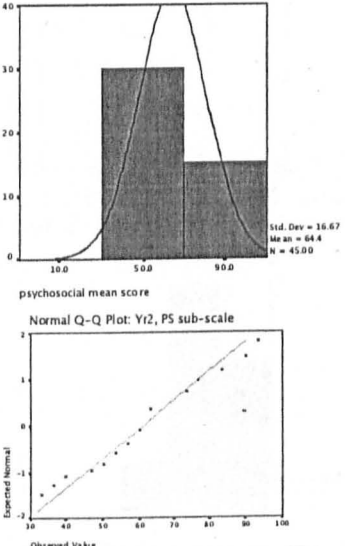
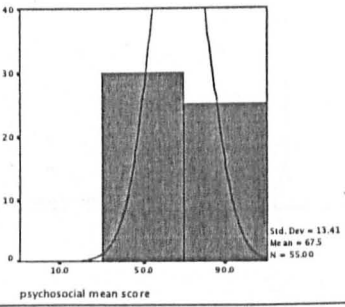
Year 3

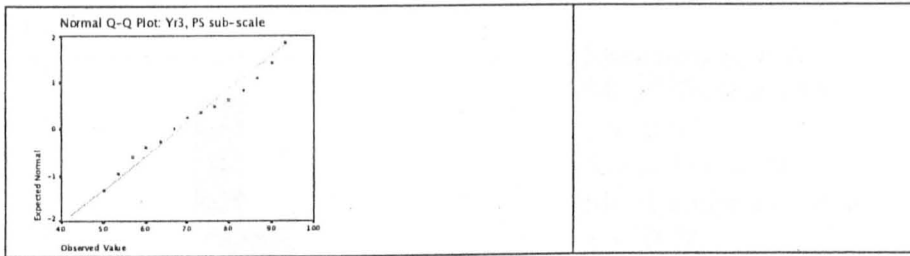


physical functioning mean score



Skewness = -0.40
SE of Skew = 0.33
z = -1.21
Kurtosis = -0.24
SE of Kurtosis = 0.65
z = -0.37

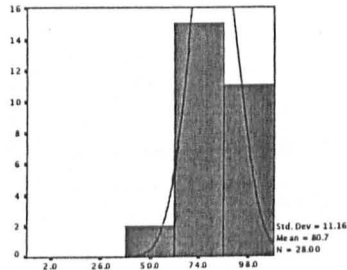
<p>Psychosocial health summary sub-scale scores</p> <p>Year 1</p> 	<p>Descriptives</p> <p>Skewness = -0.36 SE of Skew = 0.39 z = -0.92</p> <p>Kurtosis = -0.96 SE of Kurtosis = 0.77 z = -1.25</p>
<p>Year 2</p> 	<p>Skewness = 0.14 SE of Skew = 0.36 z = 0.39</p> <p>Kurtosis = -0.43 SE of Kurtosis = 0.70 z = -0.61</p>
<p>Year 3</p> 	<p>Skewness = 0.04 SE of Skew = 0.32 z = 0.13</p> <p>Kurtosis = -0.77 SE of Kurtosis = 0.63 z = -1.22</p>



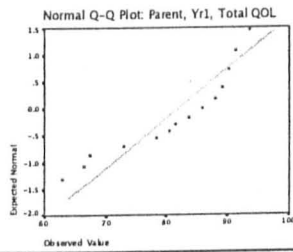
Parent PedsQLTM4.0

Total QOL scores

Year 1



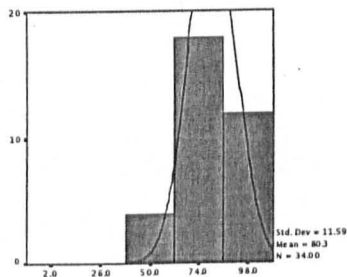
parent pedsqimn



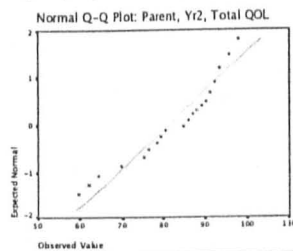
Descriptives

Skewness = -0.75
 SE of Skew = 0.44
 z = -1.70
 Kurtosis = -0.35
 SE of Kurtosis = 0.86
 z = -0.41

Year 2

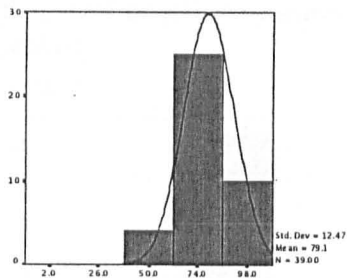


parent pedsqimn



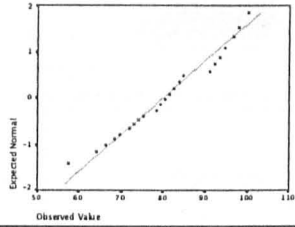
Skewness = -0.66
 SE of Skew = 0.40
 z = -1.65
 Kurtosis = -0.17
 SE of Kurtosis = 0.79
 z = -0.22

Year 3

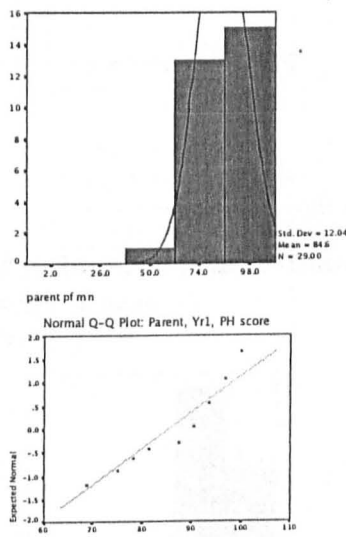
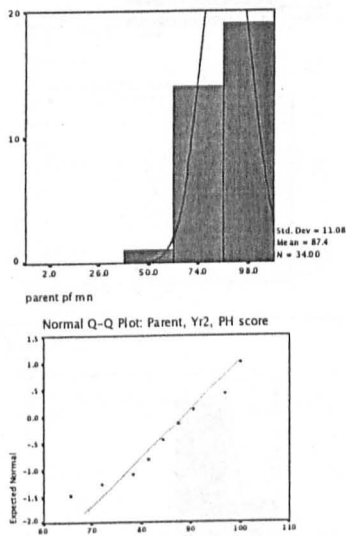
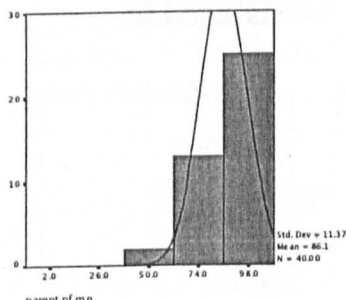


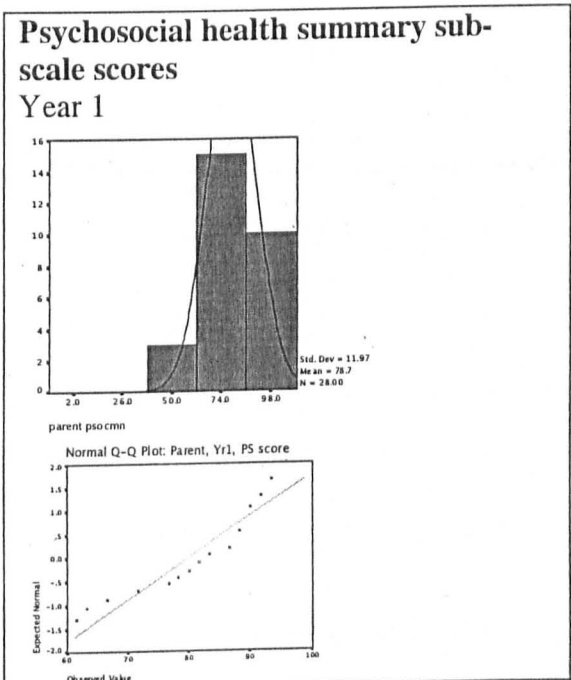
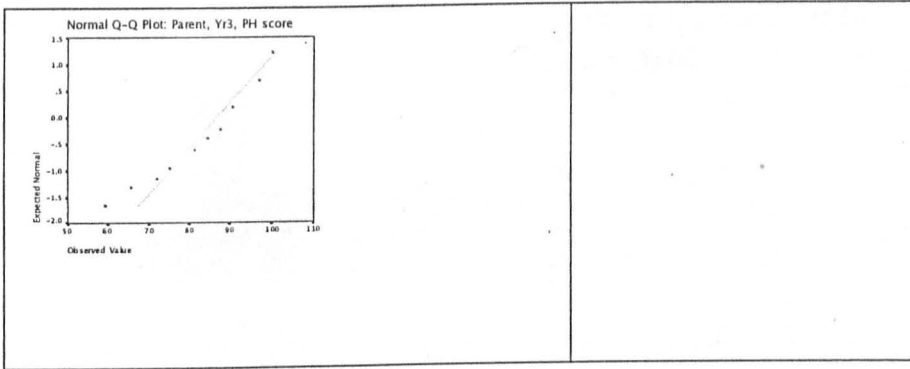
parent pedsqimn

Normal Q-Q Plot: Parent, Yr3, Total QOL



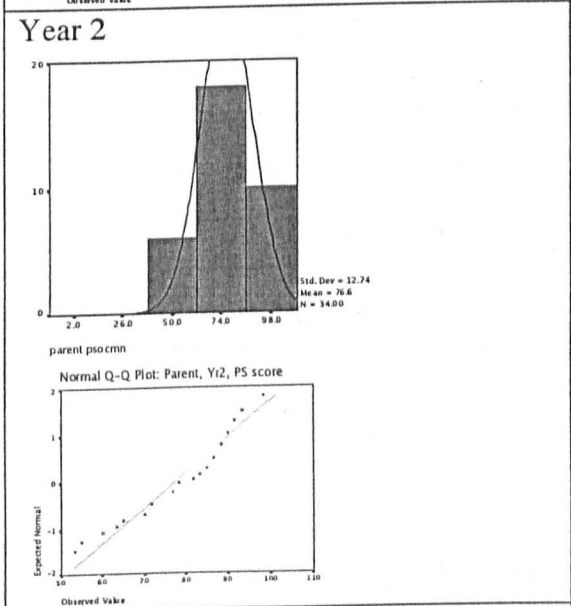
Skewness = -0.20
SE of Skew = 0.38
z = -0.53
Kurtosis = -0.56
SE of Kurtosis = 0.74
z = -0.76

<p>Physical health summary sub-scale scores</p> <p>Year 1</p>  <p>parent pf mn</p> <p>Normal Q-Q Plot: Parent, Yr1, PH score</p> <p>Expected Normal</p> <p>Observed Value</p> <p>Std. Dev = 12.04 Mean = 84.6 N = 29.00</p>	<p>Descriptives</p> <p>Skewness = -1.30 SE of Skew = 0.43 z = -3.02 Kurtosis = 2.09 SE of Kurtosis = 0.85 z = 2.46</p>
<p>Year 2</p>  <p>parent pf mn</p> <p>Normal Q-Q Plot: Parent, Yr2, PH score</p> <p>Expected Normal</p> <p>Observed Value</p> <p>Std. Dev = 11.08 Mean = 87.4 N = 34.00</p>	<p>Skewness = -0.84 SE of Skew = 0.40 z = -2.10 Kurtosis = 0.40 SE of Kurtosis = 0.79 z = 0.51</p>
<p>Year 3</p>  <p>parent pf mn</p> <p>Normal Q-Q Plot: Parent, Yr3, PH score</p> <p>Expected Normal</p> <p>Observed Value</p> <p>Std. Dev = 11.37 Mean = 86.1 N = 40.00</p>	<p>Skewness = -0.76 SE of Skew = 0.37 z = -2.05 Kurtosis = -0.47 SE of Kurtosis = 0.73 z = -0.64</p>



Descriptives

Skewness = -0.75
SE of Skew = 0.44
z = -1.70
Kurtosis = -0.22
SE of Kurtosis = 0.86
z = -0.26



Skewness = -0.54
SE of Skew = 0.40
z = -1.35
Kurtosis = -0.44
SE of Kurtosis = 0.79
z = -0.56

Year 3

Skewness = -0.19
SE of Skew = 0.38
z = -0.50
Kurtosis = -0.46

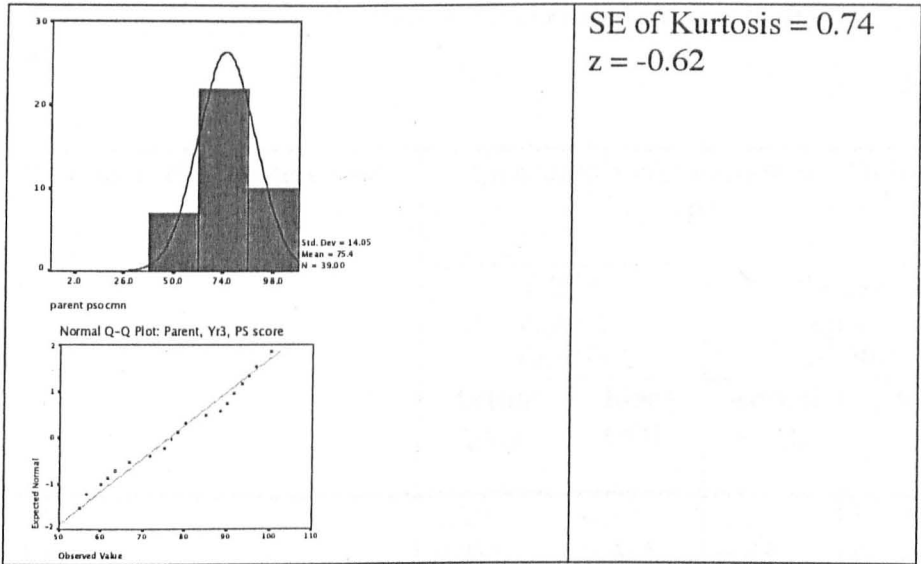


Table F1: Item analysis - item-total correlations for TedQL.4 items (Year 1, Study 5)

Year 1:

Item in TedQL.4 measure	Spearman's correlation coefficient (ρ)			
	Child report (n=41)		Parent report (n=29)	
	Actual QOL	Ideal QOL	Actual QOL	Ideal QOL
T1	0.29	0.29	<i>0.14</i>	0.37
T2	0.41*	0.42*	0.49*	0.29
T3	0.27	0.43*	0.52**	0.39*
T4	0.20	0.26	<i>0.03</i>	0.33
T5	<i>0.13</i>	<i>0.19</i>	0.30	0.25
T6	0.56**	0.46**	0.52**	0.45*
T7	<i>0.14</i>	0.27	<i>0.11</i>	0.51**
T8	0.32	0.22	0.40*	0.37
T9	0.28	0.37*	0.26	<i>0.11</i>
T10	<i>0.18</i>	0.37*	<i>0.18</i>	<i>0.11</i>
T11	0.31	0.37*	<i>0.07</i>	<i>0.13</i>
T12	0.57**	0.46**	0.49**	0.31
T13	0.42*	0.42*	<i>0.12</i>	0.39*
T14	0.35*	0.30*	<i>0.08</i>	<i>0.08</i>
T15	<i>0.14</i>	<i>0.16</i>	0.27	0.36
T16	0.35*	0.36*	0.26	<i>0.08</i>
T17	0.21	0.35*	0.42*	0.41*
T18	0.36*	0.30*	0.40*	0.27
T19	<i>0.13</i>	0.29	0.27	0.44*
T20	0.31*	<i>0.08</i>	0.60**	0.40*
T21	0.48**	0.30	<i>0.08</i>	0.27
T22	0.38**	0.34*	0.44*	0.45*

Note. * $p < .05$, ** $p < .01$

Italics = correlation coefficient below .20 criterion level

Table F2: Item analysis - item-total correlations for TedQL.4 items (Year 2, Study 5)

Year 2:

Item in TedQL.4 measure	Spearman's correlation coefficient (ρ)			
	Child report (n=53)		Parent report (n=34)	
	Actual QOL	Ideal QOL	Actual QOL	Ideal QOL
T1	<i>0.03</i>	0.21	0.41*	<i>0.03</i>
T2	0.52**	0.54**	0.27	0.27
T3	0.26	<i>0.04</i>	<i>0.18</i>	0.41*
T4	0.42**	<i>0.14</i>	0.44*	<i>0.16</i>
T5	0.44**	0.39**	0.31	0.23
T6	0.40**	0.31*	0.59**	0.34*
T7	<i>0.12</i>	<i>0.18</i>	<i>0.04</i>	0.34*
T8	0.35*	<i>0.04</i>	0.51**	0.63**
T9	<i>0.05</i>	0.28	0.44*	<i>0.12</i>
T10	0.48**	0.59**	0.38*	0.35*
T11	0.35*	0.36*	0.37*	0.41*
T12	0.50**	0.41**	0.39*	0.48**
T13	0.31*	<i>0.14</i>	<i>-0.01</i>	<i>-0.02</i>
T14	<i>0.05</i>	0.35*	0.35*	0.44*
T15	0.22	<i>0.14</i>	0.32	0.31
T16	0.44**	0.40**	0.36*	0.31
T17	0.35*	0.26	0.57**	0.45**
T18	0.41**	0.49**	0.53**	0.44*
T19	<i>0.19</i>	0.37**	<i>0.09</i>	0.27
T20	0.27	0.42**	0.39*	0.22
T21	<i>0.18</i>	0.42**	0.56**	0.26
T22	<i>0.11</i>	0.38**	0.28	<i>0.00</i>

Note. * $p < .05$, ** $p < .01$

Italics = correlation coefficient below .20 criterion level

Table F3: Item analysis - item-total correlations for TedQL.4 items (Year 3, Study 5)

Year 3:

Item in TedQL.4 measure	Spearman's correlation coefficient (ρ)			
	Child report (n=55)		Parent report (n=40)	
	Actual QOL	Ideal QOL	Actual QOL	Ideal QOL
T1	<i>0.17</i>	<i>0.02</i>	0.36*	0.32
T2	<i>0.18</i>	0.23	0.44*	0.29
T3	0.24	<i>0.07</i>	0.51**	0.52**
T4	0.31*	0.26	0.33*	<i>0.16</i>
T5	0.42**	0.23	0.49**	0.37*
T6	<i>0.13</i>	0.40**	0.53**	0.36*
T7	0.31*	0.24	0.58**	0.36*
T8	0.34*	0.36*	0.48*	0.23
T9	0.30*	<i>0.15</i>	0.33*	0.33
T10	0.52**	0.56**	0.39*	0.21
T11	0.30	0.25*	0.24	0.36*
T12	0.23	0.34*	<i>0.11</i>	0.38*
T13	0.29*	0.35*	0.34*	0.36*
T14	0.34*	<i>0.16</i>	0.40*	0.35*
T15	0.25	<i>0.10</i>	0.43**	0.54**
T16	0.34*	0.31*	0.37*	0.34*
T17	0.21	<i>0.08</i>	0.35*	0.65**
T18	0.28	0.28*	<i>0.17</i>	0.43*
T19	0.26	<i>0.03</i>	0.40*	-0.08
T20	0.33*	0.58**	0.32	<i>0.18</i>
T21	0.3**	0.58**	0.31	<i>0.18</i>
T22	<i>0.16</i>	0.29*	0.41*	0.24

Note. * p<.05, **p<.01

Italics = correlation coefficient below .20 criterion level

Table F4: Item analysis - item-total correlations of PedsQL_{TM}4.0 measure (Year 1, Study 5)

Year 1:

Item in PedsQL measure	Spearman's correlation coefficient (ρ)	
	Child report (n=41)	Parent report (n=29)
	Total QOL	Total QOL
PF1	<i>0.06</i>	0.41*
PF2	<i>0.14</i>	0.27
PF3	0.32	0.44*
PF4	0.48**	0.55**
PF5	0.52**	0.30
PF6	<i>0.18</i>	0.66**
PF7	0.52**	0.54**
PF8	0.58**	0.74**
EF1	0.34*	0.71**
EF2	0.62**	0.70**
EF3	0.57**	0.56**
EF4	0.32	0.51**
EF5	0.63**	0.57**
SF1	0.55**	0.82**
SF2	0.59**	0.51**
SF3	0.75**	0.69**
SF4	0.42*	0.49**
SF5	0.26	0.65**
SCHF1	0.59**	0.63**
SCHF2	0.49**	0.54**
SCHF3	0.59**	0.65**
SCHF4	0.49**	0.43*
SCHF5	0.52**	<i>0.15</i>

Note. * $p < .05$, ** $p < .01$

Italics = correlation coefficient below .20 criterion level

Table F5: Item analysis - item-total correlations for TedQL.4 items (Year 2, Study 5)

Year 2:

Item in PedsQL measure	Spearman's correlation coefficient (ρ)	
	Child report (n=53)	Parent report (n=34)
	Total QOL	Total QOL
PF1	0.48**	0.32
PF2	0.40**	0.33
PF3	0.33*	0.46**
PF4	0.48**	0.50**
PF5	<i>0.16</i>	0.46**
PF6	0.24*	0.69**
PF7	0.39**	0.59**
PF8	0.54**	0.63**
EF1	0.53**	0.73**
EF2	<i>0.12</i>	0.60**
EF3	0.46**	0.52**
EF4	0.50**	0.56**
EF5	0.62**	0.43*
SF1	0.60**	0.40*
SF2	0.46**	0.52**
SF3	0.60**	0.62**
SF4	0.39**	0.82**
SF5	0.49**	0.54**
SCHF1	0.34**	0.62**
SCHF2	0.46**	0.78**
SCHF3	0.40**	0.66**
SCHF4	0.43**	0.38*
SCHF5	0.26	0.66*

Note. * $p < .05$, ** $p < .01$

Italics = correlation coefficient below .20 criterion level

Table F6: Item analysis - item-total correlations for TedQL.4 items (Year 3, Study 5)

Year 3:

Item in PedsQL measure	Spearman's correlation coefficient (ρ)	
	Child report (n=55)	Parent report (n=40)
	Total QOL	Total QOL
PF1	0.27	0.37*
PF2	<i>0.08</i>	0.53**
PF3	0.37**	0.55**
PF4	0.72**	0.58**
PF5	0.44*	0.43**
PF6	0.39*	0.60**
PF7	0.34*	0.66**
PF8	0.29*	0.67**
EF1	0.61**	0.75**
EF2	0.39**	0.83**
EF3	0.31*	0.52**
EF4	0.46**	0.50**
EF5	0.27	0.64**
SF1	0.42**	0.73**
SF2	0.35*	0.63**
SF3	0.62**	0.66**
SF4	0.37**	0.75**
SF5	0.40**	0.77**
SCHF1	0.50**	0.41**
SCHF2	0.23	0.60**
SCHF3	0.41**	0.53**
SCHF4	0.42**	0.57**
SCHF5	0.32*	0.62**

Note. * $p < .05$, ** $p < .01$

Italics = correlation coefficient below .20 criterion level