Table S1 – Included measures, brief description and full citation

#	Full name	Measure Abbrev	Brief Description	Citation
1	Bath adolescent pain questionnaire	BAPQ	Assessment tool designed specifically for use with adolescents who experience chronic pain. Assess the widespread deleterious impact of adolescent chronic pain in both a research and clinical setting.	The Bath Adolescent Pain Questionnaire (BAPQ): development and preliminary psychometric evaluation of an instrument to assess the impact of chronic pain on adolescents. Eccleston C, Jordan A, McCracken LM, Sleed M, Connell H, Clinch J. Pain. 2005 Nov;118(1-2):263-70
2	Caregiver Priorities and Child Health Index of Life with Disabilities	CPCHILD	Caregivers' perspectives on the health status, comfort, well being, and ease of care in children with severe disabilities	Narayanan U.G, Fehlings D, Weir S., Knights S,. Kiran S, & Campbell K. (2006). Initial development and validation of the caregiver priorities and child health index of life with disabilities (CPCHILD). *Developmental Medicine and Child Neurology*;48(10):804-12.
3	Caregiver Questionnaire	CQ	Measures the perceived level of caregiver difficulty in performing Activity of Daily Living for children with quadriplegic CP	Schneider JW, Gurucharri LM, Gutierrez AL, Gaebler-Spira DJ. (2001). Health-related quality of life and functional outcome measures for children with cerebral palsy. *Developmental Medicine and Child Neurology*;43(9):601-8.
4	Child Behaviour Checklist	CBCL	Checklist, parents report on emotional and behavioural problems in children and adolescents	Achenbach, T.M., & Rescorla, L. A. (2001). Manual for the ASEBA School-Age Forms and Profiles. Burlington, VT: University of Vermont, Research Center for Children, Youth, and Families.
5	Child Health Questionnaire	CHQ	Multidimensional quality of life instrument focuses on physical and psychosocial functioning and well-being.	Landgraf JM, Maunsell E, Speechley KN, Bullinger M, Campbell S, Abetz L, Ware JE. (1998). Canadian-french, german and UK versions of the child health questionnaire: Methodology and preliminary item scaling results. *Qual Life Res*;7(5):433-45.

6	Child self efficacy scale-Child version	CSES_Child	Self-report tool. Assess functioning despite pain in order to assess normal functioning (well behavior)	Preliminary validation of a self-efficacy scale for child functioning despite chronic pain (child and parent versions). Bursch B, Tsao JC, Meldrum M, Zeltzer LK. Pain. 2006 Nov;125(1-2):35-42.
7	Child self efficacy scale-Parent version	CSES_Parent	Proxy report tool. Assess functioning despite pain in order to assess normal functioning (well behavior)	Preliminary validation of a self-efficacy scale for child functioning despite chronic pain (child and parent versions). Bursch B, Tsao JC, Meldrum M, Zeltzer LK. Pain. 2006 Nov;125(1-2):35-42.
8	Face, Legs, Activity, Cry, Consolability scale	FLACC	Assesses pain intensity in children - Behavioural Scale scoring postoperative pain	Merkel S., et al. (1997). The FLACC: A behavioral scale for scoring postoperative pain in young children. *Pediatr Nurse* 23(3), p. 293-297.
9	Faces Pain Scale – Revised	FPS-R	Set of line drawings or photographs of faces that depict pain states	Chambers, C. T., Giesbrecht, K., Craig, K. D., Bennett, S. M., & Huntsman, E. (1999). A comparison of faces scales for the measurement of pediatric pain: Children's and parents' ratings. Pain, 83, 25–35.
10	Functional Disability Inventory	FDI	FDI is a commonly used measure of physical functioning and disability in youth with chronic pain	Walker LS, Greene JW. The functional disability inventory: measuring a neglected dimension of child health status. Journal of Pediatric Psychology. 1991;16(1):39–58. [PubMed]
11	General Health Questionnaire	GHQ	Describes two major areas: inability to carry out normal functions and appearance of new and distressing	Goldberg, D. P. & Williams, P. (1988). The User's Guide to the General Health Questionnaire. NFER-Nelson: Windsor.
12	Health Utilities Index-2	HUI2	HUI refers to both HUI Mark 2 (HUI2) and HUI Mark 3 (HUI3) instruments. The classification systems provide compact but comprehensive frameworks within which to describe health status. The multi-attribute utility functions provide all the information required to	Torrance, George W., David H. Feeny, William J. Furlong, Ronald D. Barr, Yueming Zhang, and Qinan Wang, "Multi-Attribute Preference Functions for A Comprehensive Health Status Classification System: Health Utilities Index Mark 2." Medical Care, Vol. 34, No. 7, July 1996, pp 702-722.

			calculate single-summary scores of health-related quality of life (HRQL) for each health state defined by the classification systems.	
13	Health Utilities Index-3	HUI3	A system for measuring health status, health-related quality of life, and producing utility scores	Horsman J, Furlong W, Feeny D, Torrance G. (2003).The health utilities index (HUI): Concepts, measurement properties and applications. Health Qual Life Outcomes16;1:54.
14	impact of OSA symptoms on health-related QoL	OSA-18	Evaluates the impact of Obstructive Sleep Apnea symptoms on health-related quality of life	Strocker AM, Carrer A, Shapiro NL. (2005). The validity of the OSA-18 among three groups of pediatric patients. International Journal of Pediatric Otorhinolaryngology;69(2):241–247.
15	Non-Communicative Children's Pain Checklist revised	NCCPC-R	Designed to be used for children, aged 3 to 18 years, who are unable to speak because of cognitive (mental/intellectual) impairments or disabilities. It can be used whether or not a child has physical impairments or disabilities.	Breau, L.M., McGrath, P.J., Camfield, C.S. & Finley, G.A. (2002).
16	Pain coping questionnaire	PCQ	Assess children's pain coping strategies. The items are simple and relatively few, making it useful for assessing coping across a wide age range. It can be administered to children as young as 8 years of age in approximately 15 min.	Reid GJ, Gilbert CA, McGrath PJ. The pain coping questionnaire: preliminary validation. Pain 1998;76:83–96
17	Pain diary	Pain diary	Self-report Description of sleep pattern	na
18	Pain Indicator for communicativey impaired children	PICIC	Proxy measure - Parents of communicatively impaired children with severe cognitive impairments rate six core cues indicating definite or severe pain in their child	The development and evaluation of the pain indicator for communicatively impaired children (PICIC). Stallard P, Williams L, Velleman R, Lenton S, McGrath PJ, Taylor G. Pain. 2002 Jul;98(1-2):145-9.

19	Pain intensity self-report Visual analog scale	VAS	graphic representation of pain intensity by marking a point on a line	Huskisson EC. Visual analogue scales. In: Melzack R, editor. Pain measurement and assessment. New York, NY: Raven Press; 1983. pp. 33–37.
20	Pediatric Outcomes Data Collection Inventory	PODCI	Subjective measurement, assesses outcomes in pediatric musculoskeletal conditions	Daltroy, L. H., Liang, M. H., Fossel, A. H., & Goldberg, M. J. (1998). The POSNA pediatric musculoskeletal functional health questionnaire: Report on reliability, validity, and sensitivity to change. Journal of Pediatric Orthopaedics, 18(5), 561-571
21	Pediatric pain profile	PPP	Behaviour rating scale for assessing pain in children with severe physical and learning impairments.	Hunt, A., Mastroyannopoulou, K., Goldman, A., Seers, K., 2003. Not knowing - the problem of pain in children with severe neurological impairment. International Journal of Nursing Studies 40 (2), 171-183.
22	Pediatric Pain Questionnaire	PPQ	Assess pain intensity and location and the sensory, affective, and evaluative qualities of pain, appropriate for children and adolescents	Varni JW, Thompson KL, Hanson V. The Varni/Thompson Pediatric Pain Questionnaire. I.Chronic musculoskeletal pain in juvenile rheumatoid arthritis. Pain 1987;28:27–38.
23	Poker Chip Tool	Poker Chip Tool	Poker Chip scale uses four ‘poker chips’ as ‘pieces of hurt’ which the child uses to indicate how much pain they are feeling	Hester NO, Foster R, Kristensen K. Measurement of pain in children: Generalizability and validity of the pain ladder and the poker chip tool. In: Tyler DC, Crane EJ, editors. Advances in pain research and therapy. Vol. 15. New York: Raven; 1990. pp. 79–84.
24	Quality of life of children with CP	CPQOL	Measures the Quality of Life of children with cerebral palsy	Waters E., Maher E., Salmon L., Reddihough D., & Boyd R. (2005). Development of a condition-specific measure of quality of life for children with cerebral palsy: Empirical thematic data reported by parents and children. *Child Care Health Dev* ;31(2):127-35.
25	Single-item Pain question	Pain YES/NO	Self-developed question, e.g."are you experiencing pain?"	na

26	Sleep diary	Sleep diary	Self-report Description of sleep pattern	na
27	Oucher_photograph scale	The Oucher	The OUCHER is a poster developed for children to help them communicate how much pain or hurt they feel.	http://www.oucher.org/the_scales.html ©The Caucasian version of the OUCHER was developed and copyrighted by Judith E. Beyer, PhD, RN, USA, 1983.
28	The Pediatric Quality of Life Inventory	PEDSQL	Multidimentional measure of HRQOL in healthy children and adolescents and acute and chronic health conditions.	Varni JW, Burwinkle TM, Berrin SJ, Sherman SA, Artavia K, Malcarne VL, & Chambers HG. (2006). The PedsQL in pediatric cerebral palsy: Reliability, validity, and sensitivity of the generic core scales and cerebral palsy module. *Developmental Medicine and Child Neurology*48(6):442-9.
29	The Pediatric Quality of Life Inventory_CP module	PEDSQL_CP module	PEDSQL-module specific for CP	Varni et al
30	The Pediatric Quality of Life Inventory_PPQ	PEDSQL_PPQ	PEDSQL-module specific for pain	Varni et al
31	TNO-AZL questionnaire for Children's HRQOL	TACQOL	Measures health related quality of life of children	Verrips GH, Vogels AGC, Verloove-Vanhorick SP, Fekkes M, Koopman HM, Kamphuis RP, Theunissen NCM, Wit JM. (1998)Health-Related Quality of Life Measure for Children - the TACQOL. Journal of Applied Therapeutics; 1/4: 357-360

Table S2 Excluded measures

Abbreviation	**Full name**
CALI	Child Activity Limitations Interview
CPAQ	Chronic pain acceptance questionnaire
GCP	Graded chronic pain
PIPS	Psychological inflexibility in pain scale
PPCI	Pediatric pain coping inventory
PASS	Pain anxiety symptoms scales
PSOCQ	Pain stages of pain questionnaire for adolescents

Reasons for exclusion: measure not developed for children with disabilities, target adult population, no detailed psychometric testing