

Appendix A. References and description of measures reviewed.

Supplemental to:

Palermo, T. P., Long, A. C., Lewandowski, A. S., Drotar, D., Quittner, A.L., & Walker, L.S. (2008). Evidence based assessment of health-related quality of life and functional impairment in pediatric psychology. *Journal of Pediatric Psychology*.

General HROOL measures:

Child Health and Illness Profile (CHIP): Child, Adolescent and Parent-Report

Central references:

Riley, A. W., Forrest, C. B., Rebok, G. W., Starfield, B., Green, B. F., Robertson, J. A., et al. (2004). The child report form of the CHIP-Child Edition: Reliability and validity. *Med Care*, 42(3), 221-231.

Riley, A. W., Forrest, C. B., Starfield, B., Rebok, G. W., Robertson, J. A., & Green, B. F. (2004). The parent report form of the CHIP-Child Edition: Reliability and validity. *Med Care*, 42(3), 210-220.

Starfield, B., Riley, A. W., & Green, B. F. (1999). *Manual for the Child Health and Illness Profile: Adolescent Edition (CHIP-AE)*. Baltimore: The Johns Hopkins University.

Starfield, B., Riley, A. W., Green, B. F., Ensminger, M. E., Ryan, S. A., Kelleher, K., et al. (1995). The adolescent Child Health and Illness Profile. *Medical Care Research and Review*, 33, 553-566.

Purpose: The CHIP is a general measure developed to assess health status in children and adolescents. The measure includes parent, child and adolescent report forms and it was designed to assess all aspects of child health that can be influenced by health care and school systems (satisfaction, comfort, resilience, risk avoidance, achievement and disorders).

Cultural/language adaptations. Parent-report available in British English, Italian, Dutch, Danish, German, French; Child-report available in Spanish.

How to obtain manual and measure: <http://chip.jhu.edu>

Child Health Questionnaire (CHQ)

Central reference: Landgraf, J. M., Abetz, L., & Ware, J. E. (1996). *The CHQ user's manual* (1st ed.). Boston, MA: The Health Institute, New England Medical Center.

Purpose: The CHQ was developed to assess children's physical, emotional, and social well-being. The child-report version consists of 11 scales: physical functioning (PF), role/social functioning (RP), general health perceptions (GH), bodily pain (BP), role/social-emotional (RE), self-esteem (SE), mental health (MH), behavior (BE), family activities (FA), family cohesion (FC), and change in health (CH). The parent-report version has 13 subscales: physical functioning (PF), role/social functioning (RP), general health perceptions (GH), bodily pain (BP), parental impact-time (PT), parent impact-emotional (PE), role/social-emotional-behavioral (REB), self-esteem (SE), mental health (MH), general behavior (BE), family limitations in activities (FA), family cohesion (FC), and change in health (CH). Physical and psychosocial summary scores are calculated.

Cultural/language adaptations. Numerous translations available, see measure website www.healthact.com/chq.html

How to obtain manual and measure: The instrument and user's manual can be obtained by contacting the principal author and copyright holder: Jeanne M. Landgraf, CHQ Principal Developer, Health Act, 205 Newbury Street 4th Floor, Boston MA, 02116; www.healthact.com/chq.html

Pediatric Quality of Life Inventory (PedsQL 4.0) – Generic Core Scales

Central reference: Varni, J. W., Seid, M., & Rode, C. A. (1999). The PedsQL: Measurement model for the Pediatric Quality of Life Inventory. *Med Care*, 37(2), 126-139.

Purpose: The PedsQL Generic Core Scales are child self-report and parent proxy-report scales developed to measure HRQOL in youth. The Generic Core Scales (Physical, Social, Emotional, School) measure is applicable for use in healthy school and community populations, and pediatric populations with acute and chronic medical conditions. A short form of the measure is also available. Disease-specific modules (e.g. arthritis, asthma, brain tumor) are also available in toddler, young child, child and adolescent versions (see below for description of disease specific measures).

Cultural/language adaptations. Translated into multiple languages, see measure website: <http://www.pedsq.org/PedsQL-Translation-Tables.doc>

How to obtain manual and measure: Copy of sample measures (parent and child report) and scoring instructions are available at www.pedsq.org. To order the measure contact: Christelle Berne, Mapi Research Institute 27, rue de la Villette, 69003 Lyon, France; via email cberne@mapi.fr; phone +33 (0) 472 13 66 67; or fax +33 (0) 472 13 66 82.

Youth Quality of Life

Central references:

Edwards, T. C., C. E. Huebner, et al. (2002). "Adolescent quality of life, Part I: Conceptual and measurement model. *J Adolesc* 25, 275-86.

Patrick, D. L., T. C. Edwards, et al. (2002). Adolescent quality of life, Part II: Initial validation of a new instrument. *J Adolesc* 25, 287-300.

Purpose: The YQOL was designed to assess youth QOL in four domains: sense of self, social relationships, environment, and general quality of life. Two formats are available, are available the full-length YQOL-R (research and program evaluation) and the shorter YQOL-S (surveillance) editions.

Cultural/language adaptations: American English, UK English, Brazilian Portuguese, Mexican Spanish.

How to obtain manual and measure: YQOL-S and YQOL Disability screener are available free of charge at: www.seaqolgroup.org. All other materials are available at: Seattle Quality of Life Group, 146 Canal St. Suite 313, Seattle, WA 98103, UW Box 358852; via phone: (206) 543-9932; or email: yqol@u.washington.edu.

Condition-specific HRQOL measures:

Child Health Assessment Questionnaire (CHAQ)

Central reference: Singh, G., Athreya, B. H., Fries, J. F., & Goldsmith, D. P. (1994). Measurement of health status in children with juvenile rheumatoid arthritis. *Arthritis Rheum*, 37(12), 1761-1769.

Purpose: The CHAQ is a parent and child-report measure designed to assess health status in children with JRA. The CHAQ contains two indices: Disability and Discomfort. The Disability section assesses functioning in 8 areas: dressing and grooming, arising, eating, walking, hygiene, reach, grip and activities, that are rated by 1) degree to which daily functions are difficult to perform, 2) reported use of special devices or aids, 3) activities in which assistance of another is required. Discomfort is determined by the presence of pain and its severity in the last week. A revision including 8 additional challenge items has also been developed. See reference below:

Lam, C., Young, N., Marwaha, J., McLimont, M., & Feldman, B. M. (2004). Revised versions of the Childhood Health Assessment Questionnaire (CHAQ) are

more sensitive and suffer less from a ceiling effect. *Arthritis Rheum*, 51(6), 881-889.

Cultural/language adaptations. Adapted into 32 different member countries of the Paediatric Rheumatology International Trials Organization (PRINTO).

How to obtain manual and measure: See central reference.

Cystic Fibrosis Questionnaire-Revised (CFQ-R)

Central references: Quittner, A. L., Buu, A., Messer, M. A., Modi, A. C., & Watrous, M. (2005). Development and validation of the Cystic Fibrosis Questionnaire in the United States: A health-related quality-of-life measure for cystic fibrosis. *Chest*, 128(4), 2347-2354.

Modi, A. C., & Quittner, A. L. (2003). Validation of a disease-specific measure of health-related quality of life for children with cystic fibrosis. *J Pediatr Psychol*, 28(8), 535-545.

Purpose: The Cystic Fibrosis Questionnaire-Revised is a disease-specific measure designed to measure quality of life for children and adults with cystic fibrosis. The questionnaires measure core domains of health-related quality of life, as well as domains specific to CF. The teen/adult, child and parent-report versions assess 12, 8, and 11 domains respectively. Scores can be compared to normative data provided in manual. CD-ROM is provided for data entry and scoring.

Cultural/language adaptations: UK English, French, Canadian French, Czech, German, Spanish (North American and Spain), Italian, Danish, Flemish, Dutch, Hebrew, Hungarian, Macedonian, Polish, Portuguese, Greek, Russian, Ukrainian, Serbian, Slovakian, Turkish

How to obtain manual and measure: Quittner, A. L., Modi, A., Watrous, M., & Davis, M. A. (2000). *Cystic Fibrosis Questionnaire-Revised: A health-related quality of life measure*. User Manual: English Version 2.0.

Diabetes Quality of Life for Youth (DQOLY)

Central reference: Ingersoll, G. M., & Marrero, D. G. (1991). A modified quality of life measure for youths: Psychometric properties. *Diabetes Care*, 9, 114-118.

Purpose: The DQOLY was adapted from the adult questionnaire the Diabetes Quality of Life Scale. The measure consists of 3 scales: diabetes life satisfaction, disease impact and diabetes-related worries, and includes a general self-rating of overall health.

Cultural/language adaptations: Spanish, French, Chinese (these versions are not available in any readily accessible site).

How to obtain manual and measure: The questionnaire is available in the original citation (Ingersoll & Marrero, 1991).

Miami Pediatric Quality of Life Questionnaire (MPQOLQ)

Central reference:

Armstrong, F. D., Toledano, S. R., Miloslavich, K., Lackman-Zeman, L., Levy, J. D., Gay, C. L., et al. (1999). The Miami Pediatric Quality of Life Questionnaire: Parent Scale. *International Journal of Cancer Supplement*, 12, 11-17.

Purpose: The MPQOLQ was designed to assess children's and parent's reports of quality of life. To date, it has only been used in children with cancer. The measure was designed to assess both objective reports of the child's functioning and subjective reports of the perceived importance of each item, comparing the child to healthy same-age peers. The measure was designed to be sensitive to late effects of treatment.

Cultural/language adaptations. None.

How to obtain manual and measure: Contact author, F. Daniel Armstrong, Ph.D., Department of Pediatrics (D-820), P.O. Box 016820, Miami, Florida 33101; email: darmstrong@miami.edu

Juvenile Arthritis Functional Assessment Report (JAFAR)

Central reference: Howe, S., Levinson, J., Shear, E., Hartner, S., McGirr, G., Schulte, M. et al. (1991). Development of a disability measurement tool for juvenile rheumatoid arthritis. The Juvenile Arthritis Functional Assessment Report for Children and their Parents. *Arthritis Rheum* 34, 873-80.

Purpose: The JAFAR was designed to assess mobility and the ability to complete self-care tasks in children and adolescents with juvenile rheumatoid arthritis. The 23-item instrument has parent and child versions and assesses a child's ability to perform tasks without assistance during the preceding week. Responses are summed to yield a total functioning score.

Cultural/language adaptations: None

How to obtain manual and measure: The measure can be obtained in the text of the original citation (Howe, Levinson, et al. 1991).

Pediatric Asthma Quality of Life Questionnaire

Central reference: Juniper, E. F., Guyatt, G. H., Feeny D.H., Ferrie, P. J., Griffith, L. E., & Townsend, M. (1996). Measuring quality of life in children with asthma. *Quality of Life Research* 5, 35-46.

Purpose: The PAQLQ was designed to assess problems associated with asthma in youth. The questionnaire assesses 3 domains: symptoms, activity limitations and emotional functioning. Three of the activity questions are “patient-specific” and are identified by the patient at the beginning of the study based on importance to the child. The questionnaire has both interview and self-report versions.

Cultural/language adaptations: Translated into multiple languages, see measure website: <http://www.qoltech.co.uk/PaedAsthma.htm#paqlq>

How to obtain manual and measure: The questionnaire is available via the author, Professor Elizabeth Juniper, juniper@qoltech.co.uk; see website: <http://www.qoltech.co.uk/contacts.htm>

Pediatric Quality of Life Inventory – Disease Specific Modules

Central reference: See www.pedsQL.org

Purpose: The PedsQL Disease Specific Modules are child self-report and parent proxy-report scales developed to measure disease specific HRQOL in youth. These modules can be used alone or in conjunction with the PedsQL 4.0 Generic Core Scales. There are 9 disease-specific modules (arthritis, asthma, asthma-short form, brain tumor, cancer, cerebral palsy, cardiac, diabetes, rheumatology) of varying lengths with different psychometric properties. The most widely used and empirically supported modules are: arthritis, asthma, and cancer.

Cultural/language adaptations. Several language adaptations, see measure website: <http://www.pedsq.org/PedsQL-Translation-Tables.doc>

How to obtain manual and measure: To order one of the disease-specific measures contact: Christelle Berne, Mapi Research Institute 27, rue de la Villette, 69003 Lyon, France, via email cberne@mapi.fr, phone +33 (0) 472 13 66 67, or fax +33 (0) 472 13 66 82.

Pediatric Oncology Quality of Life Scale (POQOLS)

Central reference: Goodwin, D. A. J., Boggs, S. R., & Graham-Pole, J. (1994). Development and validation of the Pediatric Oncology Quality of Life Scale. *Psychological Assessment*, 6, 321-328.

Purpose: The POQOLS was developed to measure quality of life in pediatric oncology patients. Provides three factors that assess physical function and role restriction, emotional distress, and reaction to current medical treatment.

Cultural/language adaptations. Spanish language version.

How to obtain manual and measure: The measure is available in the central reference.

Play Performance Scale for Children (PPSC)

Central reference: Lansky, L. L., List, M. A., Lansky, S. B., Cohen, M. E., & Sinks, L. F. (1985). Toward the development of a Play-Performance Scale for Children (PPSC). *Cancer, 56*, 1837 - 1840.

Purpose: The PPSC was developed to assess the performance status of children using activity level during play, particularly in pediatric cancer patients. Children's activity level during play is described in terms of active play, quiet play, degree of physical limitation, and degree of independence. The scale is not designed to determine if a child's play is developmentally appropriate, but to compare children to their own baseline.

Cultural/language adaptations. None.

How to obtain manual and measure: Measure described in central reference.

Quality of Life Headache in Youth (QLH-Y)

Central reference: Langeveld, J. H., Koot, H. M., Loonen, M. C., Hazebroek-Kampschreur, A. A., & Passchier, J. (1996). A quality of life instrument for adolescents with chronic headache. *Cephalalgia, 16*(3), 183-196

Purpose: The QLH-Y was developed to measure quality of life in adolescents with chronic headaches or migraine. Thirteen subscales assess four components of quality of life: psychological functioning, functional status, physical status, and social functioning.

Cultural/language adaptations. Dutch, Italian, English.

How to obtain manual and measure: Contact J. H. Langeveld or J. Passchier, Institute of Medial Psychology and Psychotherapy, Erasmus University, P.O. Box 1738, 3000 DR Rotterdam, The Netherlands. Phone: 031-10-4-807. Fax: 031-10-4363.

Functional Disability Measures

Child Activity Limitations Interview (CALI)

Central reference: Palermo, T. M., Witherspoon, W., Valenzuela, D., & Drotar, D. (2004). Development and validation of the Child Activity Limitations Interview: a measure of pain-related functional impairment in school-age children and adolescents. *Pain* 109, 461-70.

Purpose: CALI was developed to assess functional impairment due to recurrent pain in school-age children and adolescents. The measure is designed to be used in interview format, and assesses a child's level of difficulty performing activities.

Cultural/language adaptations: None.

How to obtain manual and measure: The measure is available in the primary citation.

Functional Disability Inventory (FDI)

Central references: Claar, R. L., & Walker, L. S. (2006). Functional assessment of pediatric pain patients: Psychometric properties of the Functional Disability Inventory. *Pain*, 121(1-2), 77-84.

Mulvaney, S., Lambert, E. W., Garber, J., & Walker, L. S. (2006). Trajectories of symptoms and impairment for pediatric patients with functional abdominal pain: A 5-year longitudinal study. *J Am Acad Child Adolesc Psychiatry*, 45(6), 737-744.

Walker, L. S. & Greene, J. W. (1991). The Functional Disability Inventory: measuring a neglected dimension of child health status. *J Pediatr Psychol* 16, 39-58.

Purpose: The FDI was designed as a global measure of functional disability to assess the impact of physical health status on children's abilities in age-appropriate physical and psychosocial functioning in everyday social roles.

Cultural/language adaptations. None.

How to obtain manual and measure: The FDI can be obtained in the appendix of the original citation.

Functional Status II (R)

Central reference: Stein, R. E. K. & Jessop, D.J. (1990). Functional Status II (R) A measure of health status. *Medical Care* 28, 1041-1055. (Instrument was developed from an earlier version designed by R.E.K. Stein and C.K. Riessman).

Purpose: The Functional Status II (R) was developed to evaluate health status in relation to functioning in social roles in children. It was developed in children with and without chronic health conditions.

Cultural/language adaptations. Has been translated into many languages. For details, contact the senior author.

How to obtain manual and measure: The instrument is copyrighted and cannot be used without permission from the authors. A manual is available from the senior author. Contact: rstein@aecom.yu.edu