

Category	Instrument or measure	Reviewed Studies Employing Instrument or Measure	Web Resources and Original Citations
HRQL			
Generic	Medical Outcomes Survey Short Form-36 (SF-36)	Archonti 2004; Beilby 2003; Cohen 1998; De Vito Dabbs 2009; Eskander 2011; Feurer 2004; Girard 2006; Goetzmann 2008; Hummel 2001; Ihle 2011; Kollner 2002; Kugler 2004; Kugler 2010; Langer 2009; Lobo 2004; Limbos 1997; Limbos 2000; Littlefield 1996; Lutogniewska 2010; Ortega 2009; Pinson 2000; Munro 2009; MacNaughton 1998; Nilsson 2011; Ricotti 2006; Rodrigue 2005; Rodrigue 2006; Rutherford 2005; Smeritschnig 2005; Stavem 2000; Vasiliadis 2006	<p>RAND Health Homepage:  “36-Item Short Form Survey from the RAND Medical Outcomes Study”.  <a href="http://www.rand.org/health/surveys_tools/mos/mos_core_36item.html">http://www.rand.org/health/surveys_tools/mos/mos_core_36item.html</a></p> <p>Original Citation:  Stewart, A. L., &amp; Kamberg, C. (1992). Measuring functional status and well-being: The Medical Outcomes Study approach. Durham, NC: Duke University Press.</p>
	Medical outcomes survey short form-20 (SF-20)	Gross 1995	<p>RAND Health Homepage:  “20-Item Short Form Survey from the RAND Medical Outcomes Study”.  <a href="http://www.rand.org/health/surveys_tools/mos/mos_core_20item.html">http://www.rand.org/health/surveys_tools/mos/mos_core_20item.html</a></p> <p>Original Citation:  Stewart, A. L., &amp; Kamberg, C. (1992). Measuring functional status and well-being: The Medical Outcomes Study approach. Durham, NC: Duke University Press.</p>
	Medical outcomes survey short form-12 (SF-12)	Kunsebeck 2007	<p>RAND Health Homepage:  “12-Item Short Form Survey from the RAND Medical Outcomes Study”.  <a href="http://www.rand.org/health/surveys_tools/mos/mos_core_12item.html">http://www.rand.org/health/surveys_tools/mos/mos_core_12item.html</a></p> <p>Original Citation:  Stewart, A. L., &amp; Kamberg, C. (1992). Measuring functional status and well-being: The Medical Outcomes Study approach. Durham, NC: Duke University Press.</p>
	Nottingham health profile (NHP)	Busschbach 1994; Caine 1991; O'Brien 1988; TenVergert 1998; TenVergert 2001; Van Den Berg 2000; Vermeulen 2003; Vermeulen 2004 <sup>1</sup> ; Vermeulen 2004 <sup>2</sup> ; Vermeulen 2005; Vermeulen 2007; Vermeulen 2008	<p>Galen Research Homepage:  <a href="http://www.galen-research.com/measures-database/">http://www.galen-research.com/measures-database/</a></p> <p>Original Citation:  Hunt, S M; McKenna, S P; McEwen, J; Backett, E M; Williams, J; Papp,</p>

			E (1980). "A quantitative approach to perceived health status: A validation study". <i>Journal of Epidemiology &amp; Community Health</i> 34 (4): 281–6.
	Quality of well being scale (QWB-SA)	Squier 1995; Stilley 1999	<p>"Quality of Well Being Self-Administered Scale (QWB-SA)". Health Services Research Center, University of California, San Diego. <a href="https://hoap.ucsd.edu/qwb-info/">https://hoap.ucsd.edu/qwb-info/</a></p> <p>Original Citation: Kaplan RM, Anderson JP, &amp; Ganiats TG. <i>The Quality of Well-being Scale: rationale for a single quality of life index</i>. In S.R. Walker &amp; R.M. Rosser (eds) <i>Quality of life assessment: Key issues in the 1990s</i>. London: Kluwer Academic Publishers, 1993, 65-94.</p>
	Quality of life profile for chronic diseases (PLC)	Ihle 2011; Kugler 2004; Kugler 2005; Kugler 2007; Tegbur 2004	<p>Patient Reported Outcome and Quality of Life Instruments Database (PROQOLID): "Quality of Life Profile for the Chronically Ill". <a href="http://www.proqolid.org/instruments/quality_of_life_profile_for_the_chronically_ill_plc">http://www.proqolid.org/instruments/quality_of_life_profile_for_the_chronically_ill_plc</a></p> <p>Original Citation: J. Siegrist, M. Broer, A. Junge. Profil der Lebensqualität chronisch Kranker: Manual zum Fragebogen. Beltz test, Göttingen (1996).</p>
	FLZ <sup>M</sup> questions on life satisfaction (health satisfaction Module) (FZL <sup>M</sup> )	Irani 2006	<p>Original Citation: Henrich G, Herschbach P. Questions on life satisfaction (FLZ)—a short questionnaire for assessing subjective quality of life. <i>Europ J Psychol Assess</i> 2000; 16: 150–159.</p>
Disease-specific: Respiratory	St George's respiratory questionnaire <sup>2</sup> (SGRQ)	Eskander 2011; Gerbase 2005; Gerbase 2008; Ihle 2011; Kugler 2004; Lutogniewska 2010; Ricotti 2006; Smeritschnig 2005; Stavem 2000	<p>"St. George's Respiratory Questionnaire". Health Status Research, St. George's University of London. <a href="http://www.healthstatus.sgul.ac.uk/">http://www.healthstatus.sgul.ac.uk/</a></p> <p>Original Citation: Jones PW, Quirk FH, Baveystock CM, Littlejohns P. A self-complete measure for chronic airflow limitation - the St George's Respiratory Questionnaire. <i>Am Rev Respir Dis</i> 1992;145: 1321-1327.</p>

	Seattle obstructive lung disease questionnaire (SOLQ)	Silvertooth 2004	<p>“Seattle obstructive lung disease questionnaire”. American Thoracic Society.  <a href="http://qol.thoracic.org/sections/instruments/pt/pages/soldq.html">http://qol.thoracic.org/sections/instruments/pt/pages/soldq.html</a></p> <p>Original Citation:  Tu S-P, McDonell MB, Spertus JA, Steele BG, Fihn SD. A new self-administered questionnaire to monitor health-related quality of life in patients with COPD. <i>Chest</i> 1997; 112:614-622.</p>
	Chronic respiratory questionnaire (CRQ)	Vivodtzev 2011	<p>“Chronic respiratory questionnaire”. American Thoracic Society.  <a href="http://qol.thoracic.org/sections/instruments/ae/pages/crq.html">http://qol.thoracic.org/sections/instruments/ae/pages/crq.html</a></p> <p>Original Citation:  Wijkstra, P. J., TenVergert, E. M., Van Altena, R., Otten, V., Postma, D. S., Kraan, J., Koeter, G. H. (1994). Reliability and validity of the chronic respiratory questionnaire (CRQ). <i>Thorax</i>, 49 (5), 465-467.</p>
	Pulmonary-specific Quality-of-Life Scale (PQLS)	Hoffman 2015	<p>Hoffman, B.M., Stonerock G.L., Smith, P.J., <i>et al.</i> Development and psychometric properties of the Pulmonary-specific Quality-of-Life Scale in lung transplant patients. <i>J Heart Lung Transplant</i>, 2015. 34(8): p. 1058-1065.</p>
Disease-specific: Gastrointestinal	Gastrointestinal quality of life index (GIQLI)	Robertson 2011	<p>Patient Reported Outcome and Quality of Life Instruments Database (PROQOLID): “Gastrointestinal quality of life index “.  <a href="http://www.proqolid.org/instruments/gastrointestinal_quality_of_life_index_giqli">http://www.proqolid.org/instruments/gastrointestinal_quality_of_life_index_giqli</a></p> <p>Original Citation:  Eypasch E, Williams JI, Wood-Dauphinee S, Ure BM, Schmölling C, Neugebauer E, Troidl H. Gastrointestinal Quality of Life Index: development, validation and application of a new instrument. <i>Br J Surg</i>. 1995;82:216–222.</p>
Lung Transplant Disability Measure	Lung Transplant Valued Life Activities (VLA)	Singer 2014	<p>Original Citation:  Singer JP, Blanc PD, Dean YM, Hays S, Leard L, Kukreja J, Golden J, Katz PP. Development and validation of a lung transplant specific disability questionnaire. <i>Thorax</i>. 2013 Dec 19 (Epub ahead of print)</p>

Health status	Sickness impact profile (SIP)	De Vito Dabbs 2003; De Vito Dabbs 2009; Lanuza 2000; Ramsey 1995; Stillely 1999	<p>Patient Reported Outcome and Quality of Life Instruments Database (PROQOLID): "Sickness Impact Profile".  <a href="http://www.proqolid.org/instruments/sickness_impact_profile_sip">http://www.proqolid.org/instruments/sickness_impact_profile_sip</a></p> <p>Original Citation:  Bergner M, Bobbitt RA, Carter WB, Gilson BS. The Sickness Impact Profile: development and final revision of a health status measure. <i>Med Care</i>. 1981 Aug; 19(8):787–805.</p>
Health utilities	Euroqol 5D (EQ-5D)	Anyanwu 2001; Busschbach 1994 (only Euroqol VAS); Eskander 2011; Santana 2010 <sup>3</sup> ; Santana 2010 <sup>4</sup>	<p>EuroQol Homepage:  <a href="http://www.euroqol.org/">http://www.euroqol.org/</a></p> <p>Original Citation:  Rabin R, de Charro F. EQ-5D: a measure of health status from the EuroQol Group. <i>Ann Med</i> 2001; <b>33</b>: 337–343</p>
	Standard gamble (SG)	Busschbach 1994; Eskander 2011; Ramsey 1995; Singer 2005; Vasiliadis 2005	<p>Original Citation:  Torrance GW, Furlong W, Feeny D, Boyle M. Multiattribute preference functions. Health Utilities Index. <i>Pharmacoeconomics</i> 1995; 7: 503-520.</p>
	Time trade-off (derived from Standard Gamble) (TTO)	Busschbach 1994	<p>Original Citation:  Burstrom et al.; Johannesson, M; Diderichsen, F (2006). "A comparison of individual and social time-trade-off values for health states in the general population". <i>Health Policy</i> 76 (3): 359–370.</p>
	Health utilities index 2 and 3 <sup>2</sup> (HUI2, HUI3)	Santana 2009; Santana 2010 <sup>3</sup> ; Santana 2010 <sup>4</sup>	<p>Health Utilities Incorporated Homepage:  <a href="http://www.healthutilities.com/">http://www.healthutilities.com/</a></p> <p>Original Citation:  Horsman J, Furlong W, Feeny W, Torrence G. The Health Utilities Index (HUI): concepts, measurement properties and applications. <i>Health Qual Life Outcomes</i>. 2003;13:54.</p>

	Index of well being (also a HRQL instrument) (IWB)	Gross 1995; TenVergert 1998; TenVergert 2001; van den Berg 2000; Vermeulen 2003; Vermeulen 2004 <sup>1</sup> ; Vermeulen 2004 <sup>2</sup> ; Vermeulen 2008	Original Citation: Kaplan R, Bush J, Berry C. Health status: types of validity and the index of well-being. <i>Health Serv Res.</i> 1976;11:478–507.
	Visual Analog Scale (VAS)	Eskander 2011; Gerbase 2005; Gerbase 2008; Limbos 2000; Lobo 2004; Matthees 2001; Ricotti 2006; Shih 2002	Institute of Objective Measurement: Visual Analog Scales. <a href="http://www.rasch.org/rmt/rmt122s.htm">http://www.rasch.org/rmt/rmt122s.htm</a>  Original Citation: Freyd, M. (1923). The graphic rating scale. <i>Journal of Educational Psychology</i> , 43, 83 – 102.
Quality of life (not solely health-related)	Quality of life index (QLI)	Kurz 2001	“Ferrans and Powers: Quality of Life Index”. University of Illinois at Chicago. <a href="http://www.uic.edu/orgs/qli/">http://www.uic.edu/orgs/qli/</a>  Original Citation: Ferrans C, Powers M. Quality of Life Index: development and psychometric properties. <i>Adv Nurs.</i> 1985;8:15-24.
	FLZ <sup>M</sup> questions on life satisfaction (general life satisfaction module)	Irani 2006	Original Citation: Henrich G, Herschbach P. Questions on life satisfaction (FLZ)—a short questionnaire for assessing subjective quality of life. <i>Europ J Psychol Assess</i> 2000; 16: 150–159.
Psychological			
Depression and Anxiety	Spielberger's state trait anxiety inventory (STAI)	Cohen 1998; Girard 2006; Littlefield 1996; TenVergert 1998; TenVergert 2001; Van Den Berg 2000; Vermeulen 2003; Vermeulen 2004 <sup>1</sup> ; Vermeulen 2004 <sup>2</sup> ; Vermeulen 2005; Vermeulen 2007; Vermeulen 2008	Mind Garden: “State-Trait Anxiety Inventory for Adults”. <a href="http://www.mindgarden.com/products/staisad.htm">http://www.mindgarden.com/products/staisad.htm</a>  Original Citation: Spielberger, C.D., Sydeman, S.J. (1994). State-Trait Anxiety Inventory and State-Trait Anger Expression Inventory. In M.E. Maruish (Ed.), <i>The use of psychological testing for treatment planning and outcome assessment.</i> (pp. 292-321). Hillsdale, NJ: Lawrence Erlbaum Associates.

	Hospital anxiety and depression scale <sup>2</sup> (HADS)	Irani 2006; Irani 2010; Limbos 1997; Limbos 2000; Rutherford 2005; Santana 2009; Santana 2010 <sup>3</sup> ; Santana 2010 <sup>4</sup> ; Smeritschnig 2005; Stavem 2000	Original Citation: Zigmond, AS; Snaith, RP (1983). "The hospital anxiety and depression scale". <i>Acta Psychiatrica Scandinavica</i> 67 (6): 361–370.
	Zung self-rating depression scale (SDS)	TenVergert 1998; TenVergert 2001; Van Den Berg 2000; Vermeulen 2003; Vermeulen 2004 <sup>1</sup> ; Vermeulen 2004 <sup>2</sup> ; Vermeulen 2007; Vermeulen 2008	Zung Self-Rating Depression Scale: Medical University of South Carolina. <a href="http://academicdepartments.musc.edu/family_medicine/rcmar/zung.htm">http://academicdepartments.musc.edu/family_medicine/rcmar/zung.htm</a>  Original Citation: William WK Zung. <i>A Self-Rating Depression Scale</i> . 12: Arch Gen Psychiatry 63-70. 1965.
	Beck Depression Inventory (BDI or BDI-II)	Archonti 2004; Girard 2006; Kunsebeck 2007; Silvertooth 2004; Squier 1995	Pearson Clinical Homepage. <a href="http://www.pearsonclinical.co.uk/Psychology/AdultMentalHealth/AdultMentalHealth/BeckDepressionInventory-II(BDI-II)/BeckDepressionInventory-II(BDI-II).aspx">http://www.pearsonclinical.co.uk/Psychology/AdultMentalHealth/AdultMentalHealth/BeckDepressionInventory-II(BDI-II)/BeckDepressionInventory-II(BDI-II).aspx</a>  "Beck Depression Inventory". Medical University of South Carolina. <a href="http://academicdepartments.musc.edu/family_medicine/rcmar/beck.htm">http://academicdepartments.musc.edu/family_medicine/rcmar/beck.htm</a>  Original Citation: Beck, AT, CH Ward, M Mendelson, J Mock, and J Erbaugh. 1961. An inventory for measuring depression. <i>Arch Gen Psychiatry</i> 4: 561-571.
	Center of epidemiologic studies- depression scale (CESD-R)	Lobo 2004; Matthees 2001; Kunsebeck 2007	Center for Epidemiological Studies: Depression Scale. <a href="http://cesd-r.com">http://cesd-r.com</a>  Original Citation: Radloff LS. The CES-D scale: a self-report depression scale for research in the general population. <i>Applied Psychological Measurement</i> . 1977;1:385-401.
	Hamilton depression rating scale (HRSD or HAM-D)	Silvertooth 2004	Parkinson's Disease Biomarkers Program, National Institute of Neurological Disorders and Stroke, National Institutes of Health. <a href="https://pdpb.ninds.nih.gov/assets/crfs/Hamilton%20Depression%20Rating%20Scale%20(HDRS).pdf">https://pdpb.ninds.nih.gov/assets/crfs/Hamilton%20Depression%20Rating%20Scale%20(HDRS).pdf</a>

			<p>Original Citation: Hamilton, M (1980) Rating depressive patients. <i>Journal of Clinical Psychiatry</i>. 41: 21-24.</p>
	Hamilton anxiety rating scale (HAM-A)	Silvertooth 2004	<p>Parkinson's Disease Biomarkers Program, National Institute of Neurological Disorders and Stroke, National Institutes of Health. <a href="https://pdpb.ninds.nih.gov/assets/crfs/Hamilton%20Anxiety%20Rating%20Scale%20(HAM-A).pdf">https://pdpb.ninds.nih.gov/assets/crfs/Hamilton%20Anxiety%20Rating%20Scale%20(HAM-A).pdf</a></p> <p>Original Citation: Hamilton M. The assessment of anxiety states by rating. <i>Br J Med Psychol</i> 1959; 32:50–55.</p>
	Mental health inventory (MHI)	Cohen 1998; Littlefield 1996	<p>"MHI": National Multiple Sclerosis Society. <a href="http://www.nationalmssociety.org/ms-clinical-care-network/researchers/clinical-study-measures/mhi/index.aspx">http://www.nationalmssociety.org/ms-clinical-care-network/researchers/clinical-study-measures/mhi/index.aspx</a></p> <p>Original Citation: Ware JEJ, Johnston SA, Davies-Avery A, et al. Conceptualization and measurement of health for adults in the health insurance study (vol III): mental health. Santa Monica, Calif: RAND Corp, 1987.</p>
Sense of mastery	Sense of mastery scale	De Vito Dabbs 2003; Stilley 1999	<p>Original Citation: Pearlin L, Schooler C. The structure of coping. <i>J Health Soc Behav</i> 1978;19:2–21.</p>
Coping	Brief COPE scale (28-item)	Myaskovsky 2006	<p>"Brief COPE": University of Miami, Department of Psychology. <a href="http://www.psy.miami.edu/faculty/ccarver/sciBrCOPE.html">http://www.psy.miami.edu/faculty/ccarver/sciBrCOPE.html</a></p> <p>Original Citation: Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the Brief COPE. <i>International Journal of Behavioral Medicine</i>, 4, 92-100.</p>

	Coping Checklist (Billings and Moos Coping Checklist)	De Vito Dabbs 2003	Original Citation: Oxlad M, Miller-Lewis L, Wade TD. The measurement of coping responses: validity of the Billings and Moos Coping Checklist. <i>J Psychosom Res.</i> 2004 Nov; 57(5): 477-84.
	Coping with everyday life	Kunsebeck 2007	Original Citation: Bullinger M, Kirchberger I, von Steinbüchel N. Der Fragebogen Alltagsleben: ein Verfahren zur Erfassung der gesundheitsbezogenen Lebensqualität. <i>Z Med Psychol.</i> 1993; 2:121-131.
Self-esteem	Rosenberg Self-esteem scale (10-items)	Limbos 1997; Limbos 2000; Stilley 1999	“Rosenberg Self Esteem Scale”. Department of Sociology, University of Maryland. <a href="http://www.socy.umd.edu/quick-links/rosenberg-self-esteem-scale">http://www.socy.umd.edu/quick-links/rosenberg-self-esteem-scale</a>  Original Citation: Rosenberg, M. (1965). <i>Society and the adolescent self-image</i> . Princeton, NJ: Princeton University Press.
Life satisfaction	Summarized life satisfaction (LS)	Irani 2006	This instrument was developed within the reviewed article.
Social support	Social Support Questionnaire (F-SozU)	Archonti 2004; Irani 2006	Original Citation: Fydrich T, Geyer M, Hessel A, Sommer G, Brahler E. Social support questionnaire (F-SozU): Norms of a representative sample. <i>Diagnostica</i> 1999; 45: 212–216.
	Caregiver support assessment on caregiver social support (modeled on Spanier, Pearlin and Schooler)	Myaskovsky 2006; Stilley 1999	This instrument was modeled on the two instruments below. The instrument itself was developed within the reviewed article.  Original Citation for Pearlin and Schooler’s Mastery Scale: Pearlin, L. I., & Schooler, C. (1978). The structure of coping. <i>Journal of Health and Social Behavior</i> , 24, 2–15.



			<p>Original Citation for Spanier Dyadic Adjustment Scale: Spanier, G. B. (1977). Measuring dyadic adjustment: New scales for assessing the quality of marriage and similar dyads. <i>Journal of Marriage &amp; the Family</i> 38, 15-28.</p>
	UCLA loneliness scale-revised	Littlefield 1996	<p>Original Citation: Russell, D , Peplau, L. A.. &amp; Ferguson, M. L. (1978). Developing a measure of loneliness. <i>Journal of Personality Assessment</i>, 42, 290-294.</p>
Multidimensional	Brief symptoms inventory (BSI)	Limbos 2000; Lanuza 2000	<p>Pearson Clinical Homepage: <a href="http://www.pearsonclinical.com/psychology/products/100000450/brief-symptom-inventory-bsi.html">http://www.pearsonclinical.com/psychology/products/100000450/brief-symptom-inventory-bsi.html</a></p> <p>Original Citation: Derogatis LR, Melisaratos N (1983) The Brief Symptom Inventory: an introductory report. <i>Psychological Medicine</i> 13: 595–605.</p>
	Symptom checklist-90-revised (SCL-90-R)	De Vito Dabbs 2003; De Vito Dabbs 2009; Stillely 1999	<p>Pearson Clinical Homepage: <a href="http://www.pearsonclinical.com/psychology/products/100000645/symptom-checklist-90-revised-scl90r.html?Pid=PAg514">http://www.pearsonclinical.com/psychology/products/100000645/symptom-checklist-90-revised-scl90r.html?Pid=PAg514</a></p> <p>Original Citation: L.R. Derogatis. SCL-90-R. Administration, scoring and procedure manual—II (2nd ed.)Clinical Psychometrics Research, Towson, MD (1983)</p>
Friend support	Friend support assessment	Myaskovsky 2006	<p>Original Citation: Dew MA, Ragni M, Nimorwicz P. Infection with human immunodeficiency virus and vulnerability to psychiatric distress: A study of men with hemophilia. <i>Arch Gen Psychiatry</i> 1990; 47: 737.</p>
Optimism/Pessimism	Life orientation test (LOT)	Irani 2006; Myaskovsky 2006	<p>University of Miami, Department of Psychology: <a href="http://www.psy.miami.edu/faculty/ccarver/sciLOT-R.html">http://www.psy.miami.edu/faculty/ccarver/sciLOT-R.html</a></p> <p>Original Citation:</p>

			Scheier MF, Carver CS. Optimism, coping, and health: Assessment and implications of generalized outcome expectancies. <i>Health Psychol</i> 1985; 4: 219.
Adjustment to illness	Psychosocial adjustment to illness scale (PAIS)	Feurer 2004; Pinson 2000	Derogatis Tests Homepage: <a href="http://www.derogatis-tests.com/pais_synopsis.asp">http://www.derogatis-tests.com/pais_synopsis.asp</a>  Original Citation: Derogatis LR: The psychosocial adjustment to illness scales (PAIS). <i>J Psychosom Res</i> 1986, 30:77-91.
Perceived control	Perception of self-care agency scale (PSCA)	De Vito Dabbs 2009	Original Citation: Hanson B, Bickel L. Development and testing on perception of self-care agency. In: Riehl-Sisca J, editor. <i>The Science and Art of Self-Care</i> . Norwalk, Connecticut: Appleton-Century-Crofts; 1985. pp. 271–278.
Desire for control	Desire for control (DC) scale	Kurz 2001	Original Citation: Burger J, Cooper H. The desirability of control. <i>Motivation Emotion</i> . 1979;3(4):381-393.
	Multidimensional health locus of control scales	Cohen 1998	Vanderbilt University School of Nursing: <a href="http://www.nursing.vanderbilt.edu/faculty/kwallston/mhlcscscales.htm">http://www.nursing.vanderbilt.edu/faculty/kwallston/mhlcscscales.htm</a>  Original Citation: Wallston KA, Wallston BS, DeVellis R. Development of the Multidimensional Health Locus of Control (MHLC) Scales. <i>Health Edu Monogr</i> 1978; 6(2): 160-70.
Perceived impact of illness	Illness intrusion rating scale (IIRS)	Littlefield 1996; Lobo 2004; Matthees 2001	Original Citation: Devins GM. Illness intrusiveness and the psychosocial impact of lifestyle disruptions in chronic life-threatening disease. <i>Adv Renal Replace Ther</i> 1994; 1:251-263.

Family unit based approach to problem solving	Family crisis oriented personal evaluation scale (FCOPES)	Kurz 2001	Original Citation: McCubbin H, Olsen D, Larsen A. F-COPES. In: McCubbin H, Thompson A, eds. Family Assessment Inventories for Research and Practice. Madison, Wis: The University of Wisconsin-Madison; 1983:203-216.
Body image	Body cathexis scale	Limbos 1997; Limbos 2000	Participation and Quality of Life (PARQOL) Homepage: <a href="http://www.parqol.com/page.cfm?id=71">http://www.parqol.com/page.cfm?id=71</a>  Original Citation: Secord P, Jourard S. The appraisal of body cathexis: Body cathexis and the self. J Consult Psychol 1953;17:343-7.
Psychiatric	Renard diagnostic interview form	De Vito Dabbs 2003; Stilley 1999	Original Citation: Helzer JE, Robins LN, Croughan JL, et al. Renard diagnostic interview: its reliability and procedural validity with physicians and lay interviewers. Arch Gen Psychiatry 1981;38:393-8
	General health questionnaire (GHQ-30)	Ricotti 2006	Australian Council for Educational Research (ACER) Homepage. <a href="https://shop.acer.edu.au/acer-shop/group/SD/X;jsessionid=22C625F2E5DBECB0ECA28D88B3C8C5B">https://shop.acer.edu.au/acer-shop/group/SD/X;jsessionid=22C625F2E5DBECB0ECA28D88B3C8C5B</a>  Original Citation: Goldberg DP. The detection of psychiatric illness by questionnaire. Oxford University Press, Oxford 1972.
	Impact of event scale (IES-R)	Kollner 2002	Original Citation: Horowitz M, Wilner N, Alvarez W (1979) Impact of Event Scale - a measure of subjective stress. Psychosom Med 41: 209-218.
	Structured clinical interview for DSM-III-R	De Vito Dabbs 2003; Kollner 2002	Original Citation: R.L. Spitzer, J.B.W. Williams, M. Gibbon et al. The structured clinical

			interview for DSM-III-R (SCID): history, rationale, and description. Arch Gen Psychiatry, 49 (1992), pp. 624–629
Transplant specific	General health/QOL rating scale	Lanuza 2000	This instrument was developed within the reviewed article.
	Hannover transplantation rating scale	Kunsebeck 2007	Original Citation: Kuensebeck HW, Pethig K, Haverich A. Psychosozialer 1-Jahres-Posttransplantationsstatus als Prädiktor für physische und psychische Morbidität im 10-Jahresverlauf nach Herztransplantation. <i>Psychother Psychosom Med Psychol.</i> 2000;50:109-113.
	Transplant effects questionnaire	Goetzmann 2008	Original Citation: J. P. Ziegelmann, K. Griva, M. Hankins et al., “The transplant effects questionnaire (TxEQ): the development of a questionnaire for assessing the multidimensional outcome of organ transplantation—example of end stage renal disease (ESRD),” <i>The British Journal of Health Psychology</i> , vol. 7, no. 4, pp. 393–408, 2002.
	Perceived threat of the risk for graft rejection (PTGR)	Nilsson 2011	This instrument was developed within the reviewed article.
Symptoms			
dyspnea	Baseline dyspnea index (BDI)	Lutognewska 2010	“Comparison of Baseline Dyspnea Index (BDI) & Transition Dyspnea Index (TDI)”. American Thoracic Society. <a href="http://www.thoracic.org/assemblies/srn/questionnaires/bdi-tdi.php">http://www.thoracic.org/assemblies/srn/questionnaires/bdi-tdi.php</a>  Patient Reported Outcome and Quality of Life Instruments Database (PROQOLID): Baseline and Transition Dyspnea Indexes (BDI-TDI). <a href="http://www.proqolid.org/instruments/baseline_and_transition_dyspnea_indexes_bdi_tdi">http://www.proqolid.org/instruments/baseline_and_transition_dyspnea_indexes_bdi_tdi</a>  Original Citation: Mahler DA, Weinberg DH, Wells CK, Feinstein AR. The measurement of

			dyspnea. Contents, interobserver agreement, and physiologic correlates of two new clinical indexes. <i>Chest</i> 1984, 85: 751-758.
	Borg scale	Lutognewska 2010; Ricotti 2006; Vivodtzev 2011	Borg Scale: Center of Disease Control. <a href="http://www.cdc.gov/physicalactivity/everyone/measuring/exertion.html">http://www.cdc.gov/physicalactivity/everyone/measuring/exertion.html</a>  Original Citation: Borg G.A. Psychophysical bases of perceived exertion. <i>Medicine and Science in Sports and Exercise</i> . 1982; 14:377-381.
	Dyspnea scale (DS)	Lobo 2004	Original Citation: Comstock GW, Tockman MS, Helsing KJ, Hennesy KM. Standardized respiratory questionnaires: Comparison of the old with the new. <i>Am Rev Respir Dis</i> 1979; 119: 45-53.
	Medical Research Council breathlessness scale (mMRC)	Lutognewska 2010	Original Citation: Fletcher CM, Elmes PC, Fairbairn MB, et al. The significance of respiratory symptoms and the diagnosis of chronic bronchitis in a working population. <i>Br Med J</i> 1959;2:257-266.
	Oxygen cost diagram (OCD)	Lutognewska 2010; Stavem 2000	Original Citation: McGavin CR, Artvinli M, Naoe H, McHardy GJR. Dyspnoea, disability and distance walked: comparison of estimates of exercise performance in respiratory disease. <i>Br Med J</i> 1978; 2: 241–243.
	BOS score	Rutherford 2005	Original Citation: Estenne M, Maurer JR, Boehler A, Egan JJ, Frost A, Hertz M, Mallory GB, Snell GI, Yousem S: Bronchiolitis obliterans syndrome 2001: an update of the diagnostic criteria. <i>J Heart Lung Transplant</i> 2002, <b>21</b> :297-310.
	Pulmonary scale (4 items from Symptom Distress Scale as well as the Dyspnea scale)	Lobo 2004	This instrument is derived from the Symptom Distress Scale and the Dyspnea Scale.

	from the epidemiology standardization project)		For Symptom Distress Scale (SDS) citations, please see Zung self-rating depression scale (SDS).  For Dyspnea Scale citations, please see Resources for Dyspnea Scale (DS).
Pain	Brief pain inventory	Girard 2006	MD Anderson Cancer Center, University of Texas. <a href="http://www.mdanderson.org/education-and-research/departments-programs-and-labs/departments-and-divisions/symptom-research/symptom-assessment-tools/brief-pain-inventory.html">http://www.mdanderson.org/education-and-research/departments-programs-and-labs/departments-and-divisions/symptom-research/symptom-assessment-tools/brief-pain-inventory.html</a>  Original Citation: Keller S, Bann CM, Dodd SL, et al. Validity of the brief pain inventory for use in documenting the outcomes of patients with noncancer pain. Clin J Pain 2004; 20: 309-318.
Gastroesophageal reflux disease (GERD)	DeMeester reflux questionnaire	Robertson 2011	Original Citation: DeMeester T, Wang CI, Wernly JA, et al. Technique, indication, and clinical use of 24 hour esophageal pH monitoring. J Thorac Cardiovasc Surg 1980;79: 656-670.
	Reflux symptom index (RSI)	Robertson 2011	Original Citation: Belafsky PC, Postma GN, Koufman JA, et al. Validity and reliability of the reflux symptom index (RSI). J Voice 2002; 16: 274-277.
Multidimensional	Zerssen symptom checklist	Kunsebeck 2007	Original Citation: Zerssen D. Die Beschwerden-Liste. Weinheim, Germany: Beltz; 1976.
	Cardiac symptom inventory (developed at the Toronto Hospital)	Cohen 1998	Original Citation: Irvine J. Quality of life in cardiovascular disease. Presented at the Health Related Quality- of Life Conference, The Toronto Hospital, Toronto, Canada, 1993.
Transplant specific	Symptom frequency and distress scale	Matthees 2001; Kugler 2007; Lobo 2004; MacNaughton 1998	Original Citation:

			Lough ME, Lindsey AM, Shinn JA, Stotts NA. Impact of symptom frequency and symptom distress on self-reported quality of life in heart transplant recipients. <i>Heart Lung</i> 1987; 16: 193-200.
	Simmons' Posttransplant symptom inventory	De Vito Dabbs 2003	Original Citation: Simmons RG, Klein-Marine SG, R.L. Simmons RL. <i>Gift of life</i> 1987. Transaction Books, New Brunswick: NJ.
Functioning			
general	Karnofsky functional performance index (KPS)	Busschbach 1994; Feurer 2004; Gross 1995; Matthees 2001; Pinson 2000; TenVergert 1998; TenVergert 2001; Vermeulen 2003; Vermeulen 2004 <sup>1</sup> ; Vermeulen 2008	HIV/AIDS Bureau, Health Resources and Services Administration. <a href="http://hab.hrsa.gov/deliverhivaidscares/clinicalguide11/cg-211_karnofsky_scale.html">http://hab.hrsa.gov/deliverhivaidscares/clinicalguide11/cg-211_karnofsky_scale.html</a>  Original Citation: Karnofsky DA, Burchenal JH: The clinical evaluation of chemotherapeutic agents in cancer. In <i>Evaluation of chemotherapeutic agents</i> . Edited by MacLeod CM. New York: Columbia University Press; 1949::191-205.
	Activities of daily living (ADLs)	TenVergert 1998	Original Citations: Katz, S. (1983). Assessing self-maintenance: Activities of daily living, mobility and instrumental activities of daily living. <i>JAGS</i> , 31(12), 721-726.  Katz, S., Down, T.D., Cash, H.R., & Grotz, R.C. (1970) Progress in the development of the index of ADL. <i>The Gerontologist</i> , 10(1), 20-30.
	Sleep disturbance (7-item scale)	Littlefield 1996	This instrument is taken from the Toronto General Health Survey.  Original Citation: Irvine J, Logan S, Olmsted M: Development of the Toronto General Health Survey. Unpublished manuscript, Department of Psychology, The Toronto Hospital, Toronto, Canada, 1994.

Sexual	Derogatis sexual functioning inventory (DSFI)	<a href="#">Limbos 1997</a> ; <a href="#">Limbos 2000</a>	<p>Derogatis Tests Homepage, DSFI Synopsis.  <a href="http://www.derogatis-tests.com/dsfi_synopsis.asp">http://www.derogatis-tests.com/dsfi_synopsis.asp</a></p> <p>Original Citation:  Derogatis, L.R. &amp; Mellisaratos, N. (1979). The DSFI: A Multidimensional Measure of Sexual Functioning. <i>J. of Sex &amp; Marital Therapy</i>, <i>5</i>, 244-281.</p>
	Designed for individual study	<a href="#">Smeritschnig 2005</a>	This instrument was developed within the reviewed article.
Qualitative	Semistructured interview	<a href="#">Festle 2002</a>	No original citations for semi-structured interview were offered in the reviewed article. However, this instrument can be found in the author's book: Festle, MJ. <i>Second Wind: Oral Histories of Lung Transplant Survivors</i> . Palgrave MacMillan, 2012 Feb 15.
Other			
Medication adherence	Medication adherence questionnaire	<a href="#">Santana 2009</a> ; <a href="#">Santana 2010<sup>3</sup></a>	<p>Original Citation:  Morisky DE, Green LW, Levine DM. Concurrent and predictive validity of a self-reported measure of medication adherence. <i>Med Care</i> 1986; 24:67-74.</p>
	Medication taking scale	<a href="#">Matthees 2001</a>	<p>Original Citation:  Morisky DE, Green LW, Levine DM. Concurrent and predictive validity of a self-reported measure of medication adherence. <i>Med Care</i> 1986; 24:67-74.</p>
	8-area measure of difficulties with adherence	<a href="#">Littlefield 1996</a>	This instrument was developed within the reviewed article.
Work	Employment status index	<a href="#">Kugler 2010</a>	This instrument was developed within the reviewed article.



Olfactory performance	Olfactory test battery	Irani 2010	Original Citations: M. Wolfensberger, I. Schnieper, A. Welge-Lussen. Sniffin' Sticks: a new olfactory test battery. Acta Otolaryngol, 120 (2000), pp. 303–306.
Health habits	Health habits assessment	De Vito Dabbs 2009	Original Citation: Simmons RG, Abress L, Anderson CR. Quality of life after kidney transplantation. Transplantation 1988; 45: 415.
Exercise	Leisure time exercise questionnaire	Santana 2009; Santana 2010 <sup>3</sup>	Original Citation: Godin G, Shephard RJ. A simple method to assess exercise behavior in the community. Can J Applied Sport Sciences 1985; 10: 141-6.
Religiosity	3 items adapted from King and Hunt <sup>5</sup>	Myaskovsky 2006	Original Citation: King M, Hunt R. Measuring the religious variable: National replication. J Sci Study Religion 1975; 14:13.
Opinion of health care provider	Consumer assessment of healthcare providers (CAHPS)	Santana 2010 <sup>3</sup>	Original Citation: Consumer Assessment of Healthcare Providers and Systems Clinician and Group Survey, CAHPS. Available from: <a href="https://www.cahps.ahrq.gov/">https://www.cahps.ahrq.gov/</a> . Accessed 8 Jan 2005.
Interview based	Semistructured interview	Kugler 2004 (based on the Illness Belief Model); Shih 2002	Original Citation for Kugler 2004, based on the Illness Belief Model: Wright LM, Watson WL, Bell JM. Beliefs. The Heart of Healing in Families and Illness. New York, NY: Basic Books; 1996.  No original citation for Shih 2002: this instrument was developed within the reviewed article.
Specific to individual study	Satisfaction with transplant outcome, adverse effects of immunosuppression	Smeritschnig 2003	This instrument was developed within the reviewed article.

	Complementary and alternative medicine	<a href="#">Matthees 2001</a>	<p>This instrument was developed within the reviewed article. It was based upon two citations:</p> <p>National Center for Complementary and Alternative Medicine: Dossey B. American holistic nurses' association core curriculum for holistic nursing practice. Gaithersberg (MD): Aspen; 1997.</p> <p>Eisenberg D, Davis R, Ettner S, Appel S, Wilkey S, Rompay MV, et al. Trends in alternative medicine use in the United States, 1990-1997: results of a follow-up national survey. JAMA 1998; 280: 1569-75.</p>
	Two open-ended questions concerning women	<a href="#">Limbos 1997</a>	This instrument was developed within the reviewed article.

<sup>1</sup> Vermeulen KM, van der Bij 2004, Erasmus ME, Koeter GH, TenVergert EM. Improved quality of life after lung transplantation in individuals with cystic fibrosis. *Pediatr Pulmonol* 2004; 37: 419-426.

<sup>2</sup> Vermeulen KM, Groen H, van der Bij W, Erasmus ME, Koeter GH, TenVergert EM. The effect of bronchiolitis obliterans syndrome on health related quality of life. *Clin Transplant* 2004; 18: 377-383.

<sup>3</sup> Santana M-J, Feeny D, Johnson J, et al. Assessing the use of health-related quality of life measures in the routine clinical care of lung-transplant recipients. *Quality of Life Research* 2010; 19: 371-379.

<sup>4</sup> Santana MJ, Feeny D, Ghosh S, et al. The construct validity of the health utilities index mark 3 in assessing health status in lung transplantation. *Health and Quality of Life Outcomes* 2010; 8: 1-10.

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