

Short Form 36-Item Health Survey (SF-36)

Component of Multiple Sclerosis Quality of Life Inventory (MSQLI)

<p>Availability:</p>	<p>The CDEs posted with this version of the SF-36 are specific to the Multiple Sclerosis Quality of Life Inventory (MSQLI). The National Institute of Health Neurological Disorder and Stroke (NINDS) received permission to post only the SF-36 version 1 questions that are used on the MSQLI.</p> <p>The original SF-36 (i.e., SF-36 v1) is freely available in public domain: 36-Item Short Form Survey from the RAND Medical Outcomes Study</p> <p>Copyright holder: RAND Corporation – Please read Terms and Conditions for Using the 36-Item Short Form Health Survey</p> <p>Please note: The SF-36–version 2 is separately validated and copyrighted from SF-36v1. CDEs are not posted for the SF-36v2 since the NINDS does not have permission to post the content of this version of the instrument. Please contact the copyright holders for permissions for use.</p> <p>The Medical Outcomes Trust (MOT), Health Assessment Lab (HAL) and Quality Metric Health Outcomes Solutions, co-copyright holders of all SF-36v2®, SF-12v2® and SF-8™ Health Surveys, have merged their licensing and user registration programs, with the objectives of simplifying licensing and user registration and better meeting the needs of the many new academic, commercial, and other licensees. Use of SF-36 v2 and other SF Health Surveys versions require a signed license agreement.</p> <p>Licensing agreement information for the SF-36v2®, SF-12v2® and SF-8™ Health Surveys can be found on the QualityMetric website: Optum™ - Survey Request Form</p>
<p>Classification:</p>	<p>Supplemental – Highly Recommended: Parkinson’s Disease (PD)</p> <p>Supplemental: Amyotrophic Lateral Sclerosis (ALS), Chairi Malformation (CM), Facioscapulohumeral Muscular Dystrophy (FSHD), Friedreich's Ataxia (FA), Headache, Huntington's Disease (HD), Mitochondrial Disease (Mito), Multiple Sclerosis (MS), Myasthenia Gravis (MG), Myotonic Muscular Dystrophy (DM), Neuromuscular Diseases (NMD), Parkinson's Disease (PD), Spinal Muscular Atrophy (SMA), Stroke, and Traumatic Brain Injury (TBI).</p> <p>Exploratory: Cerebral Palsy (CP) and Spinal Cord Injury (SCI)-Pediatric</p>

Recommended Instrument in ALS, CM, CP, FSHD, FA, Headache, HD, Mito, MS, MG, DM, NMD, PD, SCI-Pediatric, SMA, Stroke and TBI.

Short Form 36-Item Health Survey (SF-36)

Component of Multiple Sclerosis Quality of Life Inventory (MSQLI)

<p>Short Description of Instrument:</p>	<p>Construct measured: Health-related quality of life</p> <p>Generic vs. disease specific: Generic</p> <p>Means of administration: Interview or Self-Administered</p> <p>Intended respondent: Patient</p> <p># of items: 36</p> <p># of subscales and names of sub-scales: 8 – Physical Functioning, Role – Physical, Bodily Pain, General Health, Vitality, Social Functioning, Role-Emotional, Mental Health</p> <p># of items per sub-scale: Varies</p>
<p>Commens / Special Instructions:</p>	<p>Scoring: The scoring system for the SF-36 is relatively complex and generates subscale scores for physical functioning, role limitations due to physical problems, bodily pain, general health perceptions, vitality, social functioning, role-limitations due to emotional problems, and mental health. There is no single overall score for the SF-36, instead, it generates 8 subscales and two summary scores. The physical component and the mental component summary scores, can also be derived from the SF-36.</p> <p>Scoring corresponds to the use of the instrument. For SF-36 v1, scoring instructions are publically available from the Rand Corporation.</p> <p>(Medical Outcomes Study: 36-Item Short Form Survey Scoring Instructions).</p> <p>Background: The Short Form-36 was derived from the General Health Survey of the Medical Outcomes Study by Stewart and colleagues (1988). It is one of the most widely used generic measures of health-related quality of life and has been shown to discriminate between subjects with different chronic conditions and between subjects with different severity levels of the same disease. This instrument addresses health concepts that are relevant to patients from the patient's perspective.</p>

Recommended Instrument in ALS, CM, CP, FSHD, FA, Headache, HD, Mito, MS, MG, DM, NMD, PD, SCI-Pediatric, SMA, Stroke and TBI.

Short Form 36-Item Health Survey (SF-36)

Component of Multiple Sclerosis Quality of Life Inventory (MSQLI)

<p>Rationale / Justification:</p>	<p>Strengths/ Weaknesses:</p> <p>The SF-36 is easy to administer, covers a broad range of domains of health-related quality of life, and is among the most widely used of such measures. Availability of population-based normative data makes the SF-36 useful for comparative purposes. The availability of several subscales may be useful to investigators interested in testing hypotheses concerning these different areas of function.</p> <p>The SF-36 is the most extensively evaluated health status survey, it is brief, and data can be compared to the U.S. normative population and across disease states. To keep the instrument brief, some health status concepts are missing, e.g., family functioning, sexual functioning, cognitive functioning, and sleep disorders. It is suitable for self-administration, computerized administration or administration by a trained interviewer in person or by telephone. It has been previously used in multiple myotonic dystrophy clinical trials; however, its responsiveness to change and relevance to this population is still unknown.</p> <p>Psychometric Properties: To date the properties of the SF-36 have not been evaluated in the mitochondrial disease population. In an multiple sclerosis (MS) population, the Cronbach's alphas for the various subscales of the SF-36 range from 0.67 to 0.94. There is considerable evidence for the validity of the SF-36 in a variety of populations including MS. (Vickrey et al., 1995) In this study, the physical functioning and role limitations due to physical problems subscales were the ones that best discriminated between MS patients and the normative U.S. population.</p> <p>Administration: Administration time is approximately 10 minutes. The SF-36 is a structured, self-report questionnaire that the patient can generally complete with little or no intervention from an interviewer. However, patients with visual or upper extremity impairments may need to have the SF-36 administered by a trained interviewer.</p>
--	---

Short Form 36-Item Health Survey (SF-36)

Component of Multiple Sclerosis Quality of Life Inventory (MSQLI)

References:	<p>Hays RD. (1994). The Medical Outcomes Study (MOS) Measures of Patient Adherence. Santa Monica, CA: RAND Corporation Retrieved from https://www.rand.org/content/dam/rand/www/external/health/surveys_tools/mos/mos_adherence_survey.pdf</p> <p>Hays RD, Shelbourne CD, Mazel R. (1995). User's Manual for the Medical Outcomes Study (MOS) Core Measures of Health-Related Quality of Life. Santa Monica, CA: RAND corporation.</p> <p>McHorney CA, Ware JE, Jr., Raczek AE. The MOS 36-Item Short-Form Health Survey (SF-36): II. Psychometric and clinical tests of validity in measuring physical and mental health constructs. <i>Med Care.</i> 1993;31(3):247–263.</p> <p>Stewart AL, Hays RD, Ware JE, Jr. The MOS short-form general health survey. Reliability and validity in a patient population. <i>Med Care.</i> 1998;26(7):724–735.</p> <p>Vickrey BG, Hays RD, Harooni R, Myers LW, Ellison GW. A health-related quality of life measure for multiple sclerosis. <i>Qual Life Res.</i> 1995;4(3):187–206.</p> <p>Ware JE, Jr. & Sherbourne CD. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. <i>Med Care.</i> 1992;30(6):473–483.</p> <p>Ware JE, Jr., Snow KK, Kosinski M, Gandek B. (1993). <i>SF-36 Health Survey: Manual and Interpretation Guide.</i> Boston, MA: The Health Institute.</p> <p>Ware JE, Jr., Kosinski M, Keller SD. (1994). <i>SF-36® Physical and Mental Health Summary Scales: A Users' Manual.</i> Boston, MA: The Health Institute.</p> <p>Ware JE, Jr., Kosinski M, Dewey JE. (2000). <i>How to Score Version 2 of the SF-36® Health Survey.</i> Retrieved from Lincoln, RI: Quality Metric Inc.</p> <p>Ware JE, Jr. (2001). <i>SF-36 Physical and Mental Health Summary Scales: A Manual for Users of Version 1 (2nd Edition ed.).</i> Lincoln, RI: Quality Metric Inc.</p>
--------------------	---

Recommended Instrument in ALS, CM, CP, FSHD, FA, Headache, HD, Mito, MS, MG, DM, NMD, PD, SCI-Pediatric, SMA, Stroke and TBI.

Short Form 36-Item Health Survey (SF-36)

Component of Multiple Sclerosis Quality of Life Inventory (MSQLI)

Stroke-Specific References:	Stroke-Specific: <p>Anderson C, Laubscher S, Burns R. Validation of the Short Form 36 (SF-36) health survey questionnaire among stroke patients. <i>Stroke</i>. 1996;27(10):1812–1816.</p> <p>Hobart JC, Williams LS, Moran K, Thompson AJ. Quality of life measurement after stroke: uses and abuses of the SF-36. <i>Stroke</i>. 2002;33(5):1348–1356.</p> <p>Lai, SM, Perera S, Duncan PW, Bode R. Physical and social functioning after stroke: comparison of the Stroke Impact Scale and Short Form-36. <i>Stroke</i>. 2003;34(2):488–493.</p> <p>O'Mahony PG, Rodgers H, Thomson RG, Dobson R, James OF. Is the SF-36 suitable for assessing health status of older stroke patients? <i>Age Ageing</i>. 1998;27(1):19–22.</p> <p>Williams LS. Health-related quality of life outcomes in stroke. <i>Neuroepidemiol</i>. 1998;17(3):116–120.</p>
Huntington's Disease-Specific References:	Huntington's Disease-Specific: <p>Ho AK, Gilbert AS, Mason SL, Goodman AO, Barker RA. Health-related quality of life in Huntington's disease: Which factors matter most? <i>Mov Disord</i>. 2009;4(4):574–578.</p> <p>Ho AK, Robbins AO, Walters SJ, Kaptoge S, Sahakian BJ, Barker RA. Health-related quality of life in Huntington's disease: a comparison of two generic instruments, SF-36 and SIP. <i>Mov Disord</i>. 2004;19(11):1341–1348.</p> <p>Tabrizi SJ, Scahill RI, Durr A, Roos RA, Leavitt BR, Jones R, Landwehrmeyer GB, Fox NC, Johnson H, Hicks SL, Kennard C, Craufurd D, Frost C, Langbehn DR, Reilmann R, Stout JC; TRACK-HD Investigators. Biological and clinical changes in premanifest and early stage Huntington's disease in the TRACK-HD study: the 12-month longitudinal analysis. <i>Lancet Neurol</i>. 2011;10(1):31–42.</p> <p>Tabrizi SJ, Langbehn DR, Leavitt BR, Roos RA, Durr A, Craufurd D, Kennard C, Hicks SL, Fox NC, Scahill RI, Borowsky B, Tobin AJ, Rosas HD, Johnson H, Reilmann R, Landwehrmeyer B, Stout JC; TRACK-HD investigators. Biological and clinical manifestations of Huntington's disease in the longitudinal TRACK-HD study: cross-sectional analysis of baseline data. <i>Lancet Neurol</i>. 2009;8(9):791–801.</p>

Recommended Instrument in ALS, CM, CP, FSHD, FA, Headache, HD, Mito, MS, MG, DM, NMD, PD, SCI-Pediatric, SMA, Stroke and TBI.

Short Form 36-Item Health Survey (SF-36)

Component of Multiple Sclerosis Quality of Life Inventory (MSQLI)

Myotonic Dystrophy-Specific References:	<p>Myotonic Dystrophy-Specific:</p> <p>Antonini G, Soscia F, Giubilei F, De Carolis A, Gragnani F, Morino S, Ruberto A, Tatarelli R. Health-related quality of life in myotonic dystrophy type 1 and its relationship with cognitive and emotional functioning. <i>J Rehabil Med.</i> 2006;38(3):181–185.</p> <p>Laberge L, Mathieu J, Auclair J, Gagnon É, Noreau L, Gagnon C. Clinical, psychosocial, and central correlates of quality of life in myotonic dystrophy type 1 patients. <i>Eur Neurol.</i> 2013;70(5-6):308–315.</p> <p>Peric S, Nisic T, Milicev M, Basta I, Marjanovic I, Peric M, Lavrnica D, Rakocevic Stojanovic V. Hypogonadism and erectile dysfunction in myotonic dystrophy type 1. <i>Acta Myol.</i> 2013;32(2):106–109.</p> <p>Peric S, Stojanovic VR, Basta I, Peric M, Milicev M, Pavlovic S, Lavrnica D. Influence of multisystemic affection on health-related quality of life in patients with myotonic dystrophy type 1. <i>Clin Neurol Neurosurg.</i> 2013;115(3):270–275.</p> <p>Peric' S, Rakocevic-Stojanovic V, Stevic Z, Basta I, Pavlovic S, Vujanac V, Marjanovic L, Lavrnica D. Health-related quality of life in patients with myotonic dystrophy type 1 and amyotrophic lateral sclerosis. <i>Acta Neurol Belg.</i> 2010;110(1):71–77.</p> <p>Tieleman AA, Jenks KM, Kalkman JS, Borm G, van Engelen BG. High disease impact of myotonic dystrophy type 2 on physical and mental functioning. <i>J Neurol.</i> 2011;258(10):1820–1826.</p>
--	--