

Patient-Reported Outcome Scales on the SCDIC-II Patient Surveys

<i>Measurement and Domain</i>	<i>Completeness of Measure</i>	<i>Enrollment Survey Questions</i>	<i>FU Survey Questions</i>	<i>Variable Names</i>
ASCQ-ME v2.0				
Pain Episode Frequency and Severity	5/5	A12 – A16	A2 – A6	p3f1q03_v3v4 p3f1q04_v3v4 p3f1q05_v3v4 p3f1q06_v3v4 p3f1q07_v3v4
Pain Impact Short Form (SF)	2/5	A19a, A19b	A9a, A9b	p3f1q08a_v3v4 p3f1q08b_v3v4
Pain Impact (time frame 6 mo)	2/5	A20a, A20b	A10a, A10b	p3f1q09a_v3v4 p3f1q09b_v3v4
SCD Medical History Checklist (time frame last 12 mo instead of ever)	9/9	A11, B23, B26, B28a, B28b, B28c, B28d, B28h, B28i	A1, B13, B16, B18a, B18b, B18c, B18d, B18h, B18i	p3f1q01_v3v4 p3f1q12_v3v4 p3f1q17b_v3v4 p3f1q16a_v3v4 p3f1q16b_v3v4 p3f1q16c_v3v4 p3f1q16d_v3v4 p3f1q16h_v3v4 p3f1q16i_v3v4
Stiffness Impact SF	5/5	G67a-e	G56a-e	p3f1q65a_v3v4 p3f1q65b_v3v4 p3f1q65c_v3v4 p3f1q65d_v3v4 p3f1q65e_v3v4
Emotional Impact SF	2/5	F58e-f	F47e-f	p3f1q34e_v3v4 p3f1q34f_v3v4
Sleep Impact SF	5/5	H68a-e	H57a-e	p3f1q32a_v3v4 p3f1q32b_v3v4 p3f1q32c_v3v4 p3f1q32d_v3v4 p3f1q32e_v3v4
Social Functioning SF	5/5	F63a-e	F52a-e	p3f1q38a_v3v4 p3f1q38b_v3v4 p3f1q38c_v3v4 p3f1q38d_v3v4 p3f1q38e_v3v4
PROMIS				
Pain Interference SF 4a	4/4	A18a-d	A8a-d	p3f1q09a2_v3v4 p3f1q09b2_v3v4 p3f1q09c2_v3v4 p3f1q09d2_v3v4
Neuropathic Pain Quality 5a	1/5	A17a	A7a	p3f1q10a_v3v4
Nociceptive Pain Quality 5a	1/5	A17b	A7b	p3f1q10b_v3v4
Fatigue SF4a	4/4	F59a-d	F48a-d	p3f1q57a_v3v4 p3f1q57b_v3v4 p3f1q57c_v3v4 p3f1q57d_v3v4

Fatigue – one extra from bank	1/1	F59e	F48e	p3f1q48e_v3v4
Emotional Distress – Anxiety SF 4a	4/4	F60a-d	F49a-d	p3f1q35a_v3v4 p3f1q35b_v3v4 p3f1q35c_v3v4 p3f1q35d_v3v4
Emotional Distress – Depression SF 4a	4/4	F58a-d	F47a-d	p3f1q34a_v3v4 p3f1q34b_v3v4 p3f1q34c_v3v4 p3f1q34d_v3v4
Emotional Support SF 4a	4/4	F57a-d	F46a-d	p3f1q33a_v3v4 p3f1q33b_v3v4 p3f1q33c_v3v4 p3f1q33d_v3v4
Social Isolation SF 4a	1/4	F64f	F53f	p3f1q39f_v3v4
Global Health 10	5/10	F56a-b, G66a-c	F45a-b, G55a-c	p3f1q54b_v3v4 p3f1q53d_v3v4 p3f1q41_1a_v3v4 p3f1q41_1b_v3v4 p3f1q41_2b_v3v4
Self-Efficacy for Managing Medications and Treatments SF 4a	4/4	E55a-d	E44a-d	p3f1q53a_v3v4 p3f1q53b_v3v4 p3f1q53c_v3v4 p3f1q54a_v3v4
Neuro-QoL				
Cognition Function SF	8/8	F61a-d, F62a-d	F50a-d, F51a-d	p3f1q36a_v3v4 p3f1q36b_v3v4 p3f1q36c_v3v4 p3f1q36d_v3v4 p3f1q37a_v3v4 p3f1q37b_v3v4 p3f1q37c_v3v4 p3f1q37d_v3v4
NIH Toolbox				
Loneliness (ages 18+) Fixed Form	5/5	F64a-e	F53a-e	p3f1q39a_v3v4 p3f1q39b_v3v4 p3f1q39c_v3v4 p3f1q39d_v3v4 p3f1q39e_v3v4
Other				
Brief Resilience Scale	6/6	F65a-f	F54a-f	p3f1q40a_v3v4 p3f1q40b_v3v4 p3f1q40c_v3v4 p3f1q40d_v3v4 p3f1q40e_v3v4 p3f1q40f_v3v4
Chronic Pain	1/1	A21	A11	p3f1q12_2_v3v4