

SwiSCI Community Survey 2017 Questionnaire 1: Documentation of sources

Item N°	SwiSCI question	SwiSCI response options	Source (see footnote)	ICF main concept	SwiSCI 2012 survey	InSCI survey	Comments/rationale
Personal information							
1.	Please indicate your gender:	Male Female	- -	Personal Factor (PF)	Starter N°1	InSCI N°1	Basic sociodemographic characteristics
2.	Year of birth	(Free text) (Year)	MDS I1004	PF	Starter N° 2 (birthday)	InSCI N° 2 (birthday)	Basic sociodemographic characteristics
3.	What is your current marital status?	Single Married Cohabiting or in a partnership Separated or divorced Widowed	MDS1011, modified response options	PF	Starter N°3	InSCI N°4	Basic sociodemographic characteristics Original response option: Never married; Married; Cohabiting; Separated/divorced
4.	Do you live alone?	Yes >> Question 6 No, I live together with other persons No, I live in an institution e.g. retirement home, nursing home, assisted living >> Question 6	OECD/Euro Stat cut-points	PF	n/a	InSCI N°5 modified	Besides legal marital status, intimate relationship also important in light of care situation
5.	Who lives in your household with you ?	Check all that apply Children under 14 years of age, number: () Youth between 14 and 18 years of age, number: () Persons between 18 and 64 years of age, number: () Persons over 64 years of age, number: ()	OECD /Euro Stat cut-points	PF	n/a	InSCI N°5 modified	OECD/Euro Stat cut-points; relevant to calculate net-equivalent household income as basic socioeconomic characteristic; InSCI question: Who lives in your household besides you?
6.	Do you have biological children?	Yes No >> Question 8	MDS I3010, modified response options	PF	n/a	n/a	Support situation considered important from experts (meetings in Berlin/ Montreal)
7.	Please indicate the date of birth of your children. day/month/year e.g. 13.07.1990	Child 1: () Child 2 () Child 3: () Child 4: () Child 5: ()	New item developed by Rehabilitation Services & Care Unit	PF	n/a	n/a	

8.	Do you get assistance with your day-to-day activities at home or outside?	No Yes, I get assistance by the following persons: Check all that apply Spouse Family Friends Professionals or paid assistants Other, please specify: (✍)	MDS I3010 modified (source of support added)	e310; e315; e320; e340; e355; e360	Starter N°16	InSCI N°6	Support situation considered important from experts (meetings in Berlin/ Montreal); InSCI (Ehepartner, Partner; andere not as answering option)
9.	In which country were you born?	(Free text)	MDS I1006	n/a	n/a	InSCI N°3	
Work							
10.	What was the name or title of your main job immediately before your spinal cord injury? <i>Please be as specific as possible, e.g., not just 'clerk' but 'bank clerk'; not just 'manager' but 'sales manager'</i>	Job name/title (Free text) I was not engaged in paid work immediately before SCI >> proceed to question 15	ILIAS and SwiSCI community survey 2012, Work Module modified	d850	Work N°21	InSCI N°71	
11.	What is your current working situation?	Check all that apply Working for wages or salary with an employer (Employment contract), including paid vocational training : ... % workload Self-employed: ... % workload Unpaid work in family business Work in a sheltered workplace e.g., sheltered workshop Paid or unpaid vocational training, professional training or retraining Pupil, student e.g. high school, university of applied sciences, university Housewife, househusband Unemployed Disability pension recipient IV or other pensions Retired due to health condition Retired due to age Other, please specify (Free text)	MDS I2005, modified	d850	Starter N°8, modified	InSCI N°75	
12.	How many years were you engaged in paid work since your discharge from initial inpatient rehabilitation up to the present day?	(✍) (number of years)	SwiSCI community survey 2012 Basic Q3	d850	Basic N°3	n/a	

13.	What is the name or title of your current main job? <i>Please be as specific as possible, e.g., not just 'clerk' but 'bank clerk'; not just 'manager' but 'sales manager'</i>	Job name/title (Free text) I'm currently not engaged in paid work.	Based on ILIAS, SwiSCI Community Survey , Basic Module	d850	Basic N°5, modified	InSCI N°77	
14.	Would you like to work more, less or the same amount of hours as you currently do?	More hours >> Question 18 Less hours >> Question 18 The same amount >> Question 18	Based on ILIAS, SwiSCI Community Survey , Basic Module	PF, d850	Basic N°8	InSCI N°78	
15.	Would you like to have paid work?	Yes No	Based on ILIAS, SwiSCI Community Survey , Basic Module	d850	Basic N°9	InSCI N°84	
16.	Do you feel able to perform paid work?	Yes, 1-11 hours per week Yes, 12-20 hours per week Yes, more than 20 hours per week No, not at all	Based on ILIAS, SwiSCI Community Survey , Basic Module	d850	Basic N° 10	InSCI N°85	
17.	What are the reasons you are currently not working?	Check all that apply Health condition or disability Engaged in school or university Family commitments I did not find a suitable job I do not have a financial need Retired Insufficient transportation services Poor accessibility of potential workplaces e.g., access to building, offices or toilets Lack of assistive work devices Fear of losing pension e.g. IV pension, daily allowances I do not want to work Other, please specify: (free text)	MDS I2006 modified response options	d850		InSCI N°86	

	Health						
18.	In general, would you say your health is	Excellent (1) Very good Good Fair Poor (5)	SF-12 V2, general health	nd_general health		InSCI N° 124	International comparability Feasibility: translations in many languages available
19.	Compared to one year ago, how would you rate your health in general now?	Much better (1) Somewhat better About the same Somewhat worse Much worse (5)	SF-36 V2, health transition	nd_general health		InSCI N° 125	International comparability Feasibility: translations in many languages available
20.	How would you rate your quality of life?	Very poor (1) Poor Neither poor nor good Good Very good (5)	WHOQoL BREF 5 item selection, MDS I7001 (bad/poor, reverse order)	nd_QoL	Basic N° 43	InSCI N°118	MDS I7001 (bad/poor, reverse order); This item is repeated in questionnaire 2 2017, (see N° 107)
21.	Please indicate the cause of your spinal cord injury: Check all that apply <i>For example if you check the box 'accident during work', please also specify if it was a fall or another cause of injury.</i>	<i>Cause by injury:</i> Accident during sports Accident during leisure activity Accident during work Traffic accident Injury due to violence e.g., gunshot wound Fall from less than 1 meter Fall from more than 1 meter Other cause of injury: () <i>Caused by disease:</i> Degeneration of the spinal column Tumor – benign Tumor – malignant (cancer) Vascular problem e.g., ischemia, hemorrhage, malformations Infection e.g., bacterial, viral Other disease: ()	ISCoS Basic Dataset classification revised for self-report		Starter N° 11	InSCI N° 13	Aetiology of SCI

For the following health problems please rate how much of a problem it was for you in the <u>last 3 months</u> . If you have experienced the health problem please indicate whether you have received treatment or not (e.g., taking a medication or getting treatment by doctors or other health professionals).						
22.	Pressure sores, decubitus	Not experienced, insignificant problem (0) Mild or infrequent problem Moderate or occasional problem Significant or chronic problem (3) Do/did you receive treatment for it? (Yes/No)	SCI-SCS (item and response scale for severity of problem), SCQ (response scale treatment yes; no)	hc, b810	Basic N° 11	InSCI N° 31
23.	Urinary tract infections e.g., kidney or bladder infection.	"	SCI-SCS, SCQ	hc, b620	Basic N° 12	InSCI N° 26
24.	Sexual dysfunction e.g., difficulty with sexual arousal, erection, lubrication, and reaching orgasm.	"	SCI-SCS, SCQ	hc, b640	Basic N° 13	InSCI N° 28
25.	Muscle spasms, spasticity This refers to uncontrolled, jerky muscle movements, such as uncontrolled muscle twitches or spasms.	"	SCI-SCS, SCQ	hc, b735	Basic N° 14	InSCI N° 30
26.	Respiratory problems Symptoms of respiratory infections or problems include difficulty in breathing and increased secretions.	"	SCI-SCS, SCQ	hc, b449	Basic N° 16	InSCI N° 32
27.	Sleep problems e.g., problems falling asleep or sleeping through the night and waking up early.	"	SCI-SCS like, SCQ (treatment), response options MDS	hc, b134	Basic N° 17	InSCI N° 24
28.	Injury caused by loss of sensation e.g., burns from carrying hot liquids in the lap or sitting too close to a heater or fire.	"	SCI-SCS like, SCQ	hc, b270	Basic N° 18	InSCI N° 33
29.	Contractures This is a limitation in the range of motion of a joint.	"	SCI-SCS, SCQ	hc, b710	Basic N° 19	InSCI N° 29
30.	Heterotopic bone ossification This is an overgrowth of bone, often occurring after a fracture. This condition must be diagnosed by a physician.	"	SCI-SCS, SCQ	hc, b729, s7700	Basic N° 20	n/a
31.	Bladder dysfunction e.g., incontinence ('accidents'), bladder or kidney stones, kidney problems, urine leakage and urine back up.	"	SCI-SCS, SCQ	hc, b620	Basic N° 21	InSCI N° 27
32.	Bowel dysfunction e.g., diarrhea, stool incontinence ('accidents') and constipation.	"	SCI-SCS, SCQ	hc, b525	Basic N° 22	InSCI N° 25

33.	Autonomic dysreflexia Symptoms are sudden rises in blood pressure and sweating, skin blotches, goose bumps, pupil dilation and headache	"	SCI-SCS, SCQ	hc, b429	Basic N° 23	InSCI N° 35	
34.	Postural hypotension This involves a strong sensation of light-headedness following a change in position. It is caused by a sudden drop in blood pressure.	"	SCI-SCS, SCQ	hc, d4201	Basic N° 24	InSCI N° 36	
35.	Circulatory problems This involves the swelling of veins, feet, legs or hands, or the occurrence of blood clots.	"	SCI-SCS, SCQ	hc,	Basic N° 25	InSCI N° 34	
36.	Pain	"	SCI-SCS (without 'chronic', SCQ, explanation MDS inspired I4019	b280	Basic N° 15	InSCI N° 37	
37	Please rate your pain by circling the number that best describes your pain at its worst in the last week.	No pain (0) – Pain as bad as you can imagine (10)	BPI	b280	Basic N° 34	InSCI N° 38	Also in SwiSCI questionnaire 2 2017, N° 160
The following questions refer to other, general diseases. Please indicate, whether or not you suffer the respective disease. If you suffer the disease please indicate whether or not you receive medication or some other sort of treatment for it.							
38.	Diabetes	Do you suffer this disease? (Yes/No) Do/did you receive treatment for it? (Yes/No)	SCQ	hc, b540	Basic N° 26	n/a	
39.	Heart disease	"	SCQ	hc, b410	Basic N° 27	n/a	
40.	Cancer	"	SCQ	hc, b	Basic N° 28	n/a	
41.	Depression	"	SCQ	hc, b199	Basic N° 29	n/a	
42.	Please name up to five additional health problems, that were not listed above that also bother you:	No additional health problem experienced (Free text)	New item developed by SwiSCI Study Center	hc, b	Basic N°	InSCI N° 39	Assessment of additional body functions or health conditions
43.	Please indicate your current smoking status:	Never smoked (1) Former smoker Current smoker (including occasional smoker) (3)	SwiSCI Community Survey 2012, HBPF Module	PF, d570	Personal Factors N° 30	InSCI N° 40	

Energy and feelings							
	<p>These questions are about how you have felt and how things have been with you during the <u>last 4 weeks</u>. For each question, please give the one answer that comes closest to the way you have been feeling.</p> <p>How much of the time during the last 4 weeks...</p>					<p>Reference times were harmonized in InSCI</p> <p>Introduction: "These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks..."</p>	
44.	Did you feel full of life?	All of the time (1) Most of the time Some of the time A little of the time None of the time (5)	SF-36 V2 Vitality Subscale	b130		InSCI N° 15	Comparability with general population reference values; generic instrument; feasibility concerns: translations available
45.	Have you been very nervous?	"	SF-36 V2 Mental Health Subscale	b152	Basic N° 38	InSCI N° 16	
46.	Have you felt so down in the dumps that nothing could cheer you up?	"	SF-36 V2 Mental Health Subscale	b152	Basic N° 39	InSCI N° 17	
47.	Have you felt calm and peaceful?	"	SF-36 V2 Mental Health Subscale	b152	Basic N° 40	InSCI N° 18	
48.	Did you have a lot of energy?	"	SF-36 V2 Vitality Subscale	b130		InSCI N° 19	
49.	Have you felt downhearted and depressed?	"	SF-36 V2 Mental Health Subscale	b152	Basic N° 41	InSCI N° 20	
50.	Did you feel worn out?	"	SF-36 V2 Vitality Subscale	b130		InSCI N° 21	
51.	Have you been happy?	"	SF-36 V2 Mental Health Subscale	b152	Basic N° 42	InSCI N° 22	
52.	Did you feel tired?	"	SF-36 V2 Vitality Subscale	b130		InSCI N° 23	
53.	How confident are you that you can find the means and ways to get what you want if someone opposes you?	Not at all (1) – Completely (5)	MDS I7009 modified	PF		InSCI N° 108	
54.	How confident are you that you could deal efficiently with unexpected events?	Not at all (1) – Completely (5)	MDS I7009 modified	PF		InSCI N° 109	
55.	Do you often have negative feelings such as having the blues, being desperate, suffering from anxiety or depression?	Never (0) – All the time (10)	SHP 2012/5	b152			

Independence in activities of daily living						
For each item, please check the box next to the statement that best reflects your current situation. Please read the text carefully and only check one box in each section.						
56.	Eating and drinking	<p>I need artificial feeding or a stomach tube (1)</p> <p>I need total assistance with eating / drinking</p> <p>I need partial assistance with eating / drinking or for putting on/taking off adaptive devices</p> <p>I eat / drink independently, but I need adaptive devices or assistance for cutting food, pouring drinks or opening containers</p> <p>I eat / drink independently without assistance or adaptive devices. (5)</p>	SCIM-SR	d550	Basic N° 48	InSCI N° 59
57.	Washing your upper body and head <i>This includes soaping and drying, and using a water tap</i>	<p>I need total assistance (1)</p> <p>I need partial assistance</p> <p>I am independent but need adaptive devices or specific equipment e.g., bars, chair</p> <p>I am independent and do not need adaptive devices or specific equipment (4)</p>	SCIM-SR	d510	Basic N° 49	InSCI N° 60
58.	Washing your lower body <i>This includes soaping and drying, and using a water tap</i>	<p>I need total assistance (1)</p> <p>I need partial assistance</p> <p>I am independent but need adaptive devices or specific equipment e.g., bars, chair</p> <p>I am independent and do not need adaptive devices or specific equipment (4)</p>	SCIM-SR	d510	Basic N° 50	InSCI N° 61
59.	Dressing your upper body <i>This includes putting on and taking off clothes like t-shirts, blouses, shirts, bras, shawls, or orthoses (e.g., arm splint, neck brace, corset).</i> <i>Easy-to-dress clothes are those without buttons, zippers or laces</i> <i>Difficult-to-dress clothes are those with buttons, zippers or laces</i>	<p>I need total assistance (1)</p> <p>I need partial assistance, even with easy-to-dress clothes</p> <p>I do not need assistance with easy-to-dress clothes, but I need adaptive devices or specific equipment</p> <p>I am independent with easy-to-dress clothes and only need assistance or adaptive devices or a specific setting with difficult-to-dress clothes</p> <p>I am completely independent (5)</p>	SCIM-SR	d540	Basic N° 51	InSCI N° 62
60.	Dressing your lower body <i>This includes putting on and taking off clothes like shorts, trousers, shoes, socks, belts, or orthoses (e.g., leg splint).</i> <i>Easy-to-dress clothes are those without buttons, zippers or laces</i> <i>Difficult-to-dress clothes are those with buttons, zippers or laces</i>	<p>I need total assistance (1)</p> <p>I need partial assistance, even with easy-to-dress clothes</p> <p>I do not need assistance with easy-to-dress clothes, but I need adaptive devices or specific equipment</p> <p>I am independent with easy-to-dress clothes and only need assistance or adaptive devices or a specific setting with difficult-to-dress clothes</p> <p>I am completely independent (5)</p>	SCIM-SR	d540	Basic N° 52	InSCI N° 63

61.	Grooming <i>e.g., activities such as washing hands and face, brushing teeth, combing hair, shaving, or applying make-up.</i>	I need total assistance (1) I need partial assistance I am independent with adaptive devices I am independent without adaptive devices (4)	SCIM-SR	d5100, d520	Basic N° 53	InSCI N° 64	
62.	Breathing I need a respiratory (tracheal) tube ... I do not need a respiratory (tracheal) tube...	and permanent or assisted ventilation from time to time. (1) and extra oxygen and much assistance in coughing or respiratory (tracheal) tube management. and little assistance in coughing or respiration (tracheal) tube management. (3) but I need extra oxygen or much assistance in coughing or a mask (e.g. PEEP) or assisted ventilation from time to time (e.g. BIPAP). (4) and only little assistance or stimulation for coughing. and can breathe and cough independently without assistance or device. (6)	SCIM-SR	b440	Basic N° 54	n/a	
63.	Bladder management <i>Please think about the way you empty your bladder</i> a) Use of an indwelling catheter	Yes >> Please go to question 64 No	SCIM-SR	d5300	Basic N° 55	InSCI N° 65	
	b) Intermittent catheterization	I need total assistance (1) I do it myself with assistance (self-catheterization) I do it myself without assistance (self-catheterization) I do not use it (4)	SCIM-SR	d5300	Basic N° 55	InSCI N° 65	
	c) Use of external drainage instruments <i>e.g., condom catheter, diapers, sanitary napkins</i>	I need total assistance for using them (1) I need partial assistance for using them I use them without assistance I am continent with urine and do not use external drainage instruments (4)	SCIM-SR	d5300	Basic N° 55	InSCI N° 65	

64.	Bowel management a) Do you need assistance with bowel management? e.g., for applying suppositories	Yes No	SCIM-SR	d5301	Basic N° 56	InSCI N° 66	
	b) My bowel movements are...	irregular or seldom (less than once in 3 days) regular (once in 3 days or more)	SCIM-SR	d5301	Basic N° 56	InSCI N° 66	
	c) Fecal incontinence (“accidents”) happens ...	Daily (1) 1-6 times per week 1-4 times every month Less than once per month Never (5)	SCIM-SR modified response options	d5301	Basic N° 56	InSCI N° 66	
65.	Using the toilet <i>Please think about the use of the toilet, cleaning your genital area and hands, putting on and taking off clothes, and the use of sanitary napkins or diapers.</i>	I need total assistance (1) I need partial assistance and cannot clean myself I need partial assistance but can clean myself I do not need assistance but I need adaptive devices (e.g., bars) or a special setting (e.g., wheelchair accessible toilet) I do not need any assistance, adaptive devices or a special setting (5)	SCIM-SR	d530	Basic N° 57	InSCI N° 67	
66.	Which of the following activities can you perform without assistance or electrical aids?	<i>Check all that apply</i> Turning your upper body in bed Turning your lower body in bed Sitting up in bed Doing push-ups in in a chair or wheelchair None, I need assistance in all these activities	SCIM-SR modified	d410	Basic N° 58	InSCI N° 68	
67.	Transfers from the bed to the wheelchair	I need total assistance (1) I need partial assistance, supervision or adaptive devices e.g., sliding board I do not need any assistance or adaptive devices I do not use a wheelchair (4)	SCIM-SR	d410, d420	Basic N° 59	InSCI N° 69	
68.	Transfers from the wheelchair to the toilet / in the tub <i>These transfers also include transfers from the wheelchair or bed to a toilet wheelchair.</i>	I need total assistance (1) I need assistance, supervision or adaptive devices (e.g. sliding board) I do not need assistance or adaptive devices I do not use a wheelchair. (4)	SCIM-SR	d420	Basic N° 60	n/a	

69.	<p>Moving around in the house/in the apartment I use a wheelchair. To move around I need...</p> <p>In the house/in the apartment I walk and ...</p>	<p>total assistance (1) need an electric wheelchair or partial assistance in a manual wheelchair. no assistance in a manual wheelchair.</p> <p>need supervision while walking (with or without devices). walk with a walking frame or crutches, swinging forward with both feet at a time. walk with crutches or two canes, setting one foot before the other. walk with one cane. walk with leg orthosis (e.g. leg splint) only. walk without walking aids. (9)</p>	SCIM-SR	dd4500, d465	Basic N° 61	n/a	
70.	<p>Moving around moderate distances (10 to 100 meters) I use a wheelchair. To move around...</p> <p>I walk moderate distances and I ...</p>	<p>I need total assistance (1) I need an electric wheelchair or partial assistance to operate a manual wheelchair I am independent in a manual wheelchair</p> <p>need supervision while walking (with or without walking aids) walk with a walking frame or crutches, swinging forward with both feet at a time walk with crutches or two canes, setting one foot before the other walk with one cane walk with a leg orthosis(es) only e.g., leg splint walk without walking aids (9)</p>	SCIM-SR	d4500, d465	Basic N° 62	InSCI N° 70	

71.	<p>Moving around outdoors for <u>more than 100 meters</u> I use a wheelchair. To move around I need...</p> <p>I walk <u>more than 100 meters</u> and ...</p>	<p>total assistance. (1) an electric wheelchair or partial assistance in a manual wheelchair. no assistance in a manual wheelchair.</p> <p>need supervision while walking (with or without devices). walk with a walking frame or crutches, swinging forward with both feet at a time. walk with crutches or two canes, setting one foot before the other. walk with one cane. walk with leg orthosis (e.g. leg splint) only. walk without walking aids. (9)</p>	SCIM-SR	d450, d465	Basic N°63	n/a	
72.	<p>Ascending or descending stairs</p> <p>I can ascend and descend at least 3 steps...</p>	<p>I am unable to ascend or descend stairs. (1)</p> <p>but only with support or supervision. but only with devices (e.g. handrail, crutch or cane). without any support, supervision or devices. (4)</p>	SCIM-SR	d4551	Basic N°64	n/a	
73.	<p>Transfers from the wheelchair into the car <i>This transfer also includes the loading and unloading of the wheelchair into and out of the car.</i></p>	<p>I need total assistance.(1) I need assistance, supervision or adaptive devices (e.g. sliding board). I do not need assistance or adaptive devices. I do not use a wheelchair.(4)</p>	SCIM-SR	d420	Basic N°65	n/a	
74.	<p>Transfers from the floor to the wheelchair</p>	<p>I need assistance.(1) I do not need assistance. I do not use a wheelchair. (3)</p>	SCIM-SR	d420	Basic N°66	n/a	
Hand cycle							
75.	<p>Do you use a hand cycle?</p>	<p>Yes, an everyday hand cycle (attachable to the wheelchair) (1) Yes, a sports hand cycle (recumbent or sitting position) Yes, a sports hand cycle (kneeling position) (3) No >> continue with question 77 (0)</p>	Item based on SwiSCI Community Survey 2012 , developed by Shoulder Health & Mobility Group		Basic N° 71 modified	n/a	
76.	<p>How often do you use the hand cycle during the hand cycling season?</p>	<p>Less than once a month (1) 1-3 times a month 1-6 times a week Daily (4)</p>	New item developed by Shoulder Health & Mobility Group		n/a	n/a	

Participation in activities						
Frequency Scale						
<p>A. How many hours per week do you spend on the following activities? The following questions refer to a <u>normal week</u> (holidays and possible travel times are excluded). The questions refer to the number of <u>hours per week</u>. Please tick the answer that <u>best describes</u> your situation.</p>						
77.	<p>Paid work All forms of paid work, including work for your own business</p>	0 hours (1) 1-8 hours 9-16 hours 25-35 hours 36 hours or more (6)	USER-P Subscale A	d850	Basic N°73	
78.	<p>Unpaid work Activities in an association, in a community centre, at school or any other voluntary activities</p>	"	USER-P Subscale A	d855	Basic N°74	
79.	<p>Education Only training or courses in the context of your paid work or for a possible paid work in the future</p>	"	USER-P Subscale A	d839	Basic N°75	
80.	<p>Household chores e.g. cooking, cleaning, shopping, caring for or supervising children, performing small works at home, gardening</p>	"	USER-P Subscale A	d230 d649	Basic N°76	
<p>B. How often have you performed the following activities in the last 4 weeks? For example, if you take a walk approximately twice a week, this equals eight times in four weeks. In that case you choose the category "6-10 times". Do not include any activity in more than one category. Activities concerning work, school or household are excluded. Travel times are excluded. The questions refer to the frequency in the last four weeks.</p>						
81.	<p>Sports or other physical exercise e.g. tennis, hand cycling, fitness activities, long walks. Please note: rides to work with the hand cycle or wheelchair are not considered</p>	Never (1) 1-2 times 3-5 times 6-10 times 11-18 times 19 times or more (6)	USER-P Subscale B	d920	Basic N°77	
82.	<p>Going out e.g. eating out, going to a cafe, cinema, concerts, alone or with others</p>	"	USER-P Subscale B	d920	Basic N°78	
83.	<p>Day trips and other activities away from home e.g. shopping, attending events, going to the beach, visiting churches or mosques</p>	"	USER-P Subscale B	d920	Basic N°79	

84.	Recreational activities at home <i>e.g. shopping, attending events, going to the beach, visiting churches or mosques</i>	"	USER-P Subscale B	d920	Basic N°80	
85.	Visiting family or friends	"	USER-P Subscale B	d760 d7500	Basic N°81	
86.	Visits from family or friends	"	USER-P Subscale B	d760 d7500	Basic N° 82	
87.	Contacting others by phone or computer <i>e.g. talking on the phone, texting, e-mailing</i>	"	USER-P Subscale B	d360	Basic N°83	
Restriction Scale						
<p>C. Does your spinal cord injury currently limit your everyday life?</p> <p><u>NA (not applicable):</u> You do not take part in this activity, but this is not due to your spinal cord injury.</p> <p><u>Not possible:</u> You do not take part in this activity due to your spinal cord injury.</p> <p><u>With assistance:</u> You perform this activity partly by yourself, but need assistance due to your spinal cord injury, e.g. you have a help to perform heavy household duties, family members take you by car to places. This includes paid help as well as unpaid help from family members or friends.</p> <p><u>With difficulty:</u> If you have more troubles performing the activity due to your spinal cord injury and e.g. it takes you considerably more time, you need to rest occasionally, you now do it less frequently or for a shorter time or in a less exhausting way.</p>						
88.	Paid work, unpaid work or education	NA (1) Not possible With assistance With difficulty Without difficulty (5)	USER-P Subscale C	d850	Basic N° 84	n/a
89.	Household duties <i>e.g. cooking, cleaning, shopping, taking care of or supervising children, performing small works at home, gardening</i>	"	USER-P Subscale C	d230 d649	Basic N° 85	n/a
90.	Outdoor mobility <i>e.g. driving a car, travelling by bus or train, going to work or shopping by hand cycle/wheelchair</i>	"	USER-P Subscale C	d470	Basic N° 86	n/a
91.	Sports and other physical activities <i>e.g. tennis, hand cycle cycling, fitness activities, long walks</i>	"	USER-P Subscale C	d920	Basic N° 87	n/a
92.	Going out <i>e.g. eating out, visiting a cafe, the cinema, a concert, alone or with others</i>	"	USER-P Subscale C	d920	Basic N° 88	n/a
93.	Day trips and other activities away from home <i>e.g. shopping, attending events, going to the beach, visiting churches or mosques</i>	"	USER-P Subscale C	d920	Basic N° 89	n/a

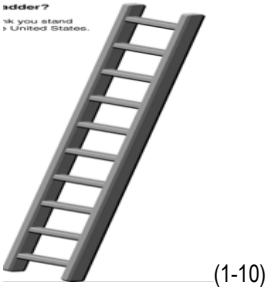
94.	Recreational activities at home <i>e.g. shopping, attending events, going to the beach, visiting churches or mosques</i>	"	USER-P Subscale C	d920	Basic N° 90	n/a	
95.	Relationship with your partner <i>e.g. communication, sexuality</i>	"	USER-P Subscale C	d770	Basic N° 91	n/a	
96.	Visiting family or friends	"	USER-P Subscale C	d7500 d760	Basic N° 92	n/a	
97.	Visits from family or friends	"	USER-P Subscale C	d7500 d760	Basic N° 93	n/a	
98.	Contacting others by phone or computer <i>e.g. talking on the phone, texting, e-mailing</i>	"	USER-P Subscale C	d360	Basic N° 94	n/a	
Satisfaction Scale							
D. How satisfied are you with your current everyday life? <i>NA (not applicable): only choose this option if you neither have work nor participate in any (further) education (question 99) or if you do not have a partner (question 106)</i>							
99.	Paid work, unpaid work or education	Very dissatisfied (1) Dissatisfied Neither satisfied nor dissatisfied Satisfied Very satisfied NA (6)	USER-P Subscale D	d850	Basic N° 95	n/a	
100.	Household duties <i>e.g. cooking, cleaning, shopping, taking care of or supervising children, performing small works at home, gardening</i>	"	USER-P Subscale D	d230 d649	Basic N° 96	n/a	
101.	Outdoor mobility <i>e.g. driving a car, travelling by bus or train, going to work or shopping by hand cycle/wheelchair</i>	"	USER-P Subscale D	d470	Basic N° 97	n/a	
102.	Sports or other physical exercise <i>e.g. tennis, hand cycle cycling, fitness activities, long walks. Please note: rides to work with the hand cycle or wheelchair are not considered</i>	"	USER-P Subscale D	d920	Basic N° 98	n/a	
103.	Going out <i>e.g. eating out, going to a cafe, cinema, concerts, alone or with others</i>	"	USER-P Subscale D	d920	Basic N° 99	n/a	
104.	Day trips and other activities away from home <i>e.g. shopping, attending events, going to the beach, visiting churches or mosques</i>	"	USER-P Subscale D	d920	Basic N° 100	n/a	

105.	Recreational activities at home <i>e.g. shopping, attending events, going to the beach, visiting churches or mosques</i>	"	USER-P Subscale D	d920	Basic N° 101		
106.	Relationship with your partner <i>e.g. communication, sexuality</i>	"	USER-P Subscale D	d770	Basic N° 102	n/a	
107.	Relationship with your family and relatives	"	USER-P Subscale D	d760 d7500	Basic N° 103	n/a	
108.	Contacts with friends and acquaintances	"	USER-P Subscale D	d7500	Basic N° 104	n/a	
Environmental factors							
109.	Missing or insufficient accessibility of public places <i>e.g., inaccessible public buildings, parks</i>	Not applicable (1) No influence Made my life a little harder Made my life a lot harder (4)	NEFI-S	e150	Basic N° 105	InSCI N° 87	
110.	Unfavorable climatic conditions <i>e.g., weather, season, temperature, humidity</i>	"	NEFI-S	e225	Basic N° 106	InSCI N° 89	
111.	Negative societal attitudes toward persons with disability <i>e.g., prejudice, stigma, ignorance</i>	"	NEFI-S	e445, e460, e465	Basic N° 107	InSCI N° 90	
112.	Negative attitudes of your family and relatives with regards to your disability <i>e.g., prejudice, lack of support, overprotective behavior</i>	"	NEFI-S	e410, e310, e315, e415	Basic N° 108	InSCI N° 91	
113.	Negative attitudes of your friends with regards to your disability <i>e.g., prejudice, lack of support, overprotective behavior</i>	"	NEFI-S	e420, e320	Basic N° 109	InSCI N° 92	
114.	Negative attitudes of neighbors, acquaintances and work colleagues with regards to your disability <i>e.g., prejudice, lack of support, overprotective behavior</i>	"	NEFI-S	e425, e325	Basic N° 110	InSCI N°93	
115.	Lack of or insufficient adapted assistive technology for moving around over short distances <i>e.g., stair lift, walking aids or wheelchair</i>	"	NEFI-S	e120	Basic N° 111	InSCI N° 94	

116.	Lack of or inadequate adapted means of transportation for long distances <i>e.g., lack of adapted car or hard to use public transportation</i>	"	NEFI-S	e120	Basic N° 112	InSCI N° 95	
117.	Lack of or insufficient nursing care and support services <i>e.g., home health care or personal assistance</i>	"	NEFI-S	e340, e580, e575	Basic N° 113	InSCI N° 96	
118.	Lack of or insufficient medication and medical aids and supplies <i>e.g., catheters, disinfectants, splints, pillows</i>	"	NEFI-S	e110, e115	Basic N° 114	InSCI N° 97	
119.	Problematic financial situation <i>e.g., shortage of money</i>	"	NEFI-S	e165	Basic N° 115	InSCI N° 98	
120.	Lack of or insufficient communication devices <i>e.g., lack of or insufficient writing devices, computer, telephone, mouse</i>	"	NEFI-S	e125	Basic N° 116	InSCI N° 99	
121.	Missing or insufficient accessibility to the homes of friends and relatives	"	NEFI-S	e155	Basic N° 117	InSCI N° 88	
122.	Insufficient national and cantonal political decisions and State services <i>e.g. problems with the disability insurance, lacking support of equal rights</i>	"	NEFI-S	e570, e580, e590, e575	Basic N° 118	InSCI N°100	

Education and income situation						
123.	<p>What is the highest level of education that you have completed?</p>	<p>Compulsory school time Primary school and 3 years of high school</p> <p>1-year education e.g. 10th school year, career choice year, preliminary apprenticeship, household apprenticeship year</p> <p>2-year vocational education e.g. Swiss Federal Vocational Certificate (EBA), 1 to 2-year vocational training time</p> <p>2-year full-time vocational school, commercial school</p> <p>2 to 3-year education: general education school e.g. qualified middle school, professional middle school</p> <p>3 to 4-year vocational education e.g. Swiss Federal Vocational Education and Training Diploma (EFZ)</p> <p>Teachers' seminary former teachers' college</p> <p>Academic high school degree</p> <p>Swiss Federal Vocational Baccalaureate</p> <p>Higher vocational education with Swiss Federal and Advanced Federal Diploma of Higher Education or Master Diploma</p> <p>College of Higher Education</p> <p>University of Applied Sciences (FH), University of Education (PH)</p> <p>University, Swiss Federal Technical University (ETH)</p> <p>Others, namely</p>	<p>MDS I1014; categorization according to UNESCO guidelines, primary, secondary and tertiary education</p>	d810-d839	Starter N°7	InSCI N°7
124.	<p>How many years of education or training have you completed in total?</p> <p><i>A vocational retraining (i.e. a new vocational education or a new study) you may have started after the onset of your spinal cord injury should also be counted here.</i></p> <p><i>e.g.: 6 (primary school) + 3 (secondary school) + 4 (apprenticeship) = 13 years.</i></p> <p><i>e.g.: 6 (primary school) + 7 (high school) + 4 (college with university degree) = 17 years.</i></p>	<p><i>..... (years)</i></p>	<p>MDS I1015</p>	d810-d839	Starter N°6	InSCI N° 8

125.	Have you started or completed a new education or training after the onset of your spinal cord injury?	No >> continue with question 127 Yes, namely: <i>Check all that apply</i> Vocational retraining or education - started - completed University education - started - completed Others, namely: - started - completed	New item developed by Participation, Integration & Social Epi Group				
126.	How many years of vocational or school education have you completed after the onset of your spinal cord injury?	(✍) (Years)	New item developed by Participation, Integration & Social Epi Group				
127.	What is your income currently made up of? Multiple answers possible	Income from employment Old-age pension (AHV) Disability pension (IV): ¼, ½, ¾, 100% Occupational pension (BVG) Helplessness allowance: Mild, Moderate, Severe Social benefits Accident insurance pension (e.g. SUVA, private accident insurance) Life insurance pension Unemployment pension Care compensation Family allowance/Child allowance/alimony Others, namely	Item based on SwiSCI Community Survey 2012 , developed by Rehabilitation Services & Care Unit		Starter N° 9		
128.	After the first determination of your disability pension, did you ever face a revision of your pension (i.e. an examination of your pension eligibility) by the IV, the Suva or another insurance?	Yes No >> Question 131 Pension revision is currently underway >> Question 131 I never had a pension so far >> Question 131	New item developed by Participation, Integration & Social Epi Group				
129.	In what year did your last pension revision take place?	(✍) (Year)	New item developed by Participation, Integration & Social Epi Group				

130.	<p>What was the result of your last pension revision?</p>	<p>Pension was increased (1) Pension remained the same Pension was decreased Pension was suspended (4)</p>	<p>New item developed by Participation, Integration & Social Epi Group</p>				
131.	<p>Taking into account all persons living in your household who work for a salary or wage: what is the total household net income before taxes on average per month?</p> <p><i>The net income is the sum of all incomes of all members of the household (incl. disability pension), after deduction of the compulsory contributions to social security and occupational pensions fund. The net income therefore is the amount that you are actually paid each month.</i></p> <p><i>If you receive alimony: Please add this to your net income.</i></p> <p><i>If you pay alimony: Please deduct this from your net income.</i></p>	<p>Less than 2000 Swiss Francs (1) Between 2000 and 2999 Swiss Francs Between 3000 and 3999 Swiss Francs Between 4000 and 4999 Swiss Francs Between 5000 and 5999 Swiss Francs Between 6000 and 6999 Swiss Francs Between 7000 and 7999 Swiss Francs Between 8000 and 8999 Swiss Francs Between 9000 and 9999 Swiss Francs More than 10'000 Swiss Francs (10)</p>	<p>MDS H1017 modified (categories instead of free-text); categorisation according to European Social Survey (ESS) guidelines</p>		Basic N° 123	InSCI N° 9	<p>Basic socioeconomic characteristics, pre-defined categories in order to reduce missing values</p> <p>Taking into account all persons living here who work for a salary or wage: what is the total household income after taxes on average per month?</p> <p>Original response option: Free text</p>
132.	<p>Think of this ladder as representing where people stand in Switzerland</p> <p>At the top of the ladder are the people who are the best off - those who have the most money, the most education and the most respected jobs. At the bottom are the people who are the worst off – who have the least money, least education, and the least respected jobs or no job. The higher up you are on this ladder, the closer you are to the people at the very top; the lower you are, the closer you are to the people at the very bottom.</p> <p>Where would you place yourself on this ladder?</p> <p>Please place a large X on the rung where you would place yourself at this time in your life, relative to other people in Switzerland</p>		<p>McArthur Scale of subjective social status</p>	PF		N° 10	

Abbreviations and references to measurement instruments

BPI: Brief Pain Inventory

Cleeland C, Ryan K. Pain assessment: global use of the Brief Pain Inventory. *Ann Acad Med.* 1994;23(2):129-138.

More information on the BPI via the Spinal Cord Injury Research Evidence (SCIRE) database: <http://www.scireproject.com/outcome-measures-new/brief-pain-inventory-bpi>

ILIAS: International Labour Market Integration Assessment in SCI

More information on the ILIAS survey: <https://www.ilias-survey.eu/en/index.php>

Subjective Social Status: Mc Arthur Scale of Subjective Social Status

Goodman E, Adler NE, Kawachi I, Frazier AL, Huang B, Colditz GA (2001) Adolescents' perceptions of social status: development and evaluation of a new indicator. *Pediatrics* 108:e31 <http://www.pediatrics.org/cgi/content/abstract/108/2/e31>.

Adler, N. E., Epel, E. S., Castellazzo, G., Ickovics, J. R. (2000) Relationship of subjective and objective social status with psychological and physiological functioning: preliminary data in healthy white women. *Health Psychol* 19: 586–592.

MDS: Model Disability Survey

The MDS is launched by the World Health Organization and the World Bank by October 2015

NEFI-S: Nottwil Environmental Factors Inventory Short Form

Ballert CS, Post MWM, Brinkhof MWG, Reinhardt JD. Psychometric properties of the Nottwil Environmental Factors Inventory Short Form. *Archi Phys Med Rehabil.* 2015; 96:233-240.

Juvalta S, Post MW, Charlifue S, et al. Development and cognitive testing of the Nottwil Environmental Factors Inventory in Canada, Switzerland, and the USA. *J Rehabil Med.* 2015 doi: 10.2340/16501977-1982.

PIL-SF: Purpose in Life Scale – Short Form

Schulenberg S, Schnetzer LW, Buchanan E. The Purpose in Life Test-Short Form: Development and psychometric support. *J Happiness Studies*, 12(5):861-876.

RSES: Rosenberg Self-Esteem Scale

Rosenberg M. Society and the adolescent self-image. Princeton University Press: Princeton, NJ, 1965.

SCIM-SR: Spinal Cord Independence Measure for Self-Report

Fekete C, Eriks-Hoogland I, Baumberger M, et al. Development and validation of a self-report version of the Spinal Cord Independence Measure (SCIM III). *Spinal Cord*. 2013;51(1):40-47.

SCI-SCS: Spinal Cord Injury Secondary Health Conditions Scale

Kalpakjian CZ, Scelza WM, Forchheimer MB, Toussaint LL. Preliminary reliability and validity of a Spinal Cord Injury Secondary Conditions Scale. *J Spinal Cord Med*. 2007;30(2):131-139.

SHP: Swiss Household Panel

Individual questionnaire Wave 18; available on <http://forscenter.ch/en/our-surveys/swiss-household-panel/documentationfaq-2/questionnaires-pdf/>

SCQ: Self-Administered Comorbidity Questionnaire

Sangha O, Stucki G, Liang MH, Fossel AH, Katz JN. The Self-Administered Comorbidity Questionnaire: a new method to assess comorbidity for clinical and health services research. *Arthritis Rheum*. 2003;49(2):156-163.

SF-36 V2: The Short Form 36, Version 2

Ware JE, Sherbourne CD. The MOS 36-item Short-form Health Survey (SF-36). A Conceptual Framework and Item Selection. *Med Care*. 1992;30:473-483. (Reference for initial version 1.0)

Ware J.E., Kosinski M., Dewey J.E. *How to Score Version Two of the SF-36 Health Survey*. Lincoln, RI: QualityMetric, Incorporated, 2000.

More information on the SF-36 via the Spinal Cord Injury Research Evidence (SCIRE) database: <http://www.scireproject.com/outcome-measures-new/short-form-36-sf-36>

or via the official SF-36 website: <http://www.sf-36.org/>

SwiSCI: Swiss Spinal Cord Injury Cohort Study

Post M, Brinkhof M, von Elm E, et al. Swiss Spinal Cord Injury Cohort Study (SwiSCI): Design of an ICF-based cohort study. *Am J Phys Med Rehab.* 2011;90(11 Suppl 2):S5-16.

Cieza A, Boldt C, Ballert C, Eriks-Hoogland I, Bickenbach J, Stucki G. Setting up of a cohort study on functioning: deciding what to measure. *Am J Phys Med Rehab.* 2011;90(11 Suppl 2):S17-28.

Fekete C, Boldt C, Post M, Eriks-Hoogland I, Cieza A, Stucki G. How to measure what matters: development and application of guiding principles to select measurement instruments in an epidemiologic study on functioning. *Am J Phys Med Rehab.* 2011;90(11 Suppl 2):S29-38.

More information on the SwiSCI Cohort Study: <http://www.swisci.ch>

WHOQoL: World Health Organization Quality of Life Assessment

World Health Organization. *The World Health Organization Quality of Life (WHOQoL)-BREF.* Geneva: WHO;2004.

5 item selection validated for SCI: Geyh S, Fellinghauer BA, Kirchberger I, Post MW. Cross-cultural validity of four quality of life scales in persons with spinal cord injury. *Health Qual Life Outcomes.* 2010;8:94.

More information via the Spinal Cord Injury Research Evidence (SCIRE) database: <http://www.scireproject.com/outcome-measures-new/world-health-organization-quality-of-life-bref-whoqol-bref>