

Supplementary material to article by C. Fekete et al. et al. "Inception cohort of the swiss spinal cohort injury study: design, participant characteristics, response rates and non-response"

Table S1. Specification on the Swiss Spinal Cord Injury Cohort Study (SwiSCI) inception cohort measures by measurement time-points T1-T5

Assessment mode	Assessed construct	Measures; classification system; clinical assessment	Number of items/measurement time-points					
			T1 Week 4	T2 Week 12	T3 Week 24	T4 Discharge	T5 Outpatient	
Medical record data	Demographic characteristics ^a	ISCoS core data-set	9	-	-	1	-	
	Dates (injury, diagnosis, admittance, discharge, death) ^a	ISCoS core data-set	4	-	-	2	-	
	Previous hospitalization ^a	Newly developed	4	-	-	-	-	
	Lesion characteristics and aetiology ^a	ISCoS core data-set/ICECI/ISCoS NT-SCI data-set	2/2/7	-	-	-	-	
	Associated injuries in addition to SCI ^a	ISCoS core data-set	6	-	-	-	-	
	Health complications ^a	CIRS*	14 ^b , 14	-	-	28	-	
	Cardiovascular function ^a	ISCoS cardiovascular BDS	1 ^b , 1	1	1	1	-	
	Neurological status (also via clinical assessment)	ISNSCI	10	10	10	10	6	
	Surgical interventions and corticosteroid ^a	ISCoS spinal intervention and spinal procedures BDS/ISCoS core data-set	1/1	-	-	-	-	
	Health services ^a	Newly developed	-	-	-	9	-	
	Pulmonary function	ISCoS pulmonary function BDS; selected items	1 ^b , 4	4	4	4	-	
	Bowel function ^a	ISCoS bowel function BDS	7	7	7	8	-	
	Functional independence in activities of daily living ^a	SCIM-III	19	19	19	19	-	
	Medication ^a	ATC	1	1	1	1	-	
	Participation goals ^a	ANQ goal attainment scale	3	-	-	3	-	
Clinical assessment	Spasticity	MAS/WMTS	4/0	-	-	4/0	0/2	
	Urinary tract function	ISCoS Lower urinary tract function BDS	6	-	-	7	-	
	Urinary tract infection ^a	Urinary tract infection BDS	6	6	6	6	-	
	Sexual function	ISCoS Male sexual function BDS/ ISCoS Female sexual function BDS	-	-	5 (males)/ 6 (females)	-	-	
	Pulmonary function (spirometry)	ISCoS Pulmonary function BDS	4	4	4	4	3	
	Anthropometrics	ISCoS Cardiovascular function BDS/ISCoS Endocrine and metabolic function BDS	7/2	7/1	7/1	7/1	7/1	
	Skin function ^a	ISCoS Skin function BDS	1	1	1	1	-	
	Blood sample	ISCoS Endocrine and metabolic function BDS	6	-	-	6	9	
	Arm-hand function	GRASSP (tetraplegics only)/ISNSCI (key muscles UE, tetraplegics only)/Hand dynamometry	1/1/1	-	-	1/1/1	-	
	Joint range of motion	Goniometry	3	-	-	3	-	
	Questionnaire	Demographic characteristics	SwiSCI community survey	1 ^b , 3	-	-	-	-
		Employment status, education and income	SwiSCI community survey	4 ^b	-	-	9	9
		Basic information on health service use	SwiSCI community survey	-	-	-	-	2
		Psychological strain	Distress thermometer	1	1/1	1	1	-
		Quality of life	ISCoS quality of life BDS/WHOQoL BREF	3/0	3/0	3/0	3/5	3/0
Self-esteem		RSES	4	4	4	10	-	
General self-efficacy		GSES	5	-	-	5	5	
Post-traumatic growth and depreciation		PTGI	-	-	-	20	-	
Social support		SHP	6	-	6	-	-	
Physical activity		PASIPD	-	4 ^b	-	-	-	
Nutrition		SHS*	-	5 ^b	-	-	3	
Smoking status		ISCoS Pulmonary function BDS	-	5 ^b	-	2	-	
Alcohol consumption		SHS*	-	3	-	-	2	
Appraisals		ALES (subscales threat, loss and challenge)	-	16	-	-	-	
Anxiety and depression		HADS (T5: only subscale Depression)	14	-	14	14	7	
Post-traumatic stress		IES-6	6	-	6	-	-	
Coping behaviour		COPE	-	24	-	-	-	
Vitality and mental health		SF-36 subscales vitality and mental health/IMPACT-S	9/0	-	9/0	-	1/3	
Optimism		LOT/SHP	6/1	-	6/1	6/1	-	
Drug and medication use		SHS	-	2	2	-	1	
Participation	USER-P	-	11 ^b	-	-	32		
Environmental factors	NEFI-S	-	-	-	3	16*		
Pain	BPI	8	8	8	8	8		
Purpose in life	PIL/ESS	4/1	-	-	4/1	4/0		
Computer-assisted telephone interview	Demographic information, main reason for visit	SwiSCI community survey	-	-	-	-	5	
	Medication	ATC	-	-	-	-	1	
	Social support	SwiSCI community survey	-	-	-	-	1	
	Employment status, occupational rehabilitation, education	SwiSCI community survey	-	-	-	-	4	
	General health perception	SF-36, subscale general health	-	-	-	-	2	
	Health complications	SCI-SCS*/SCQ*/SHS	-	-	-	-	16/15/4	
	Smoking status	ISCoS Pulmonary function BDS*	-	-	-	-	2	
	Functional independence in activities of daily living	SCIM-SR/IMPACT-S	-	-	-	-	19/1	
	Physical activity	PASIPD	-	-	-	-	4	
Critical life events	Newly developed	-	-	-	-	2		
Bio-sampling for biobank	Blood sample	Processed and cryopreserved as of serum, plasma, 55 ml DNA, RNA (all at -80°C) and PBMC (at -150°C),	-	-	-	55 ml	-	
	Urine sample	Processed and cryopreserved as urine sediment and 30 ml urine supernatant (liquid fraction) (all at -80°C)	-	-	-	30 ml	-	

*Modified from original measurement instrument or clinical assessment. ^aIncluded in the minimal data-set. ^bAssessment on the status before the occurrence of the spinal cord injury. A: clinical assessment; CATI: computer-assisted telephone interview; MR: medical record; Q: questionnaire; ALES: Appraisal of Life Events Scale; ANQ: Association Nationale pour le développement de la Qualité dans les hôpitaux et les cliniques; ATC: Anatomical Therapeutic Chemical Classification System; BDS: Basic Data-set; BPI: Brief Pain Inventory; CIRS: Cumulative Illness Rating Scale; COPE: Brief COPE Inventory; DNA: Deoxyribonucleic acid; ESS: European Social Survey; GRASSP: Graded Redefined Assessment of Strength, Sensibility and Prehension; GSES: General Self-Efficacy Scale; HADS: Hospital Anxiety and Depression Scale; ICECI: International Classification of External Causes of Injury; IES-6: Impact of Event Scale-6; IMPACT-S: ICF Measure of Participation and Activities; ISCoS: International Spinal Cord Society; ISNSCI: International Standards for Neurological Classification of Spinal Cord Injury; LOT: Life Orientation Test - Revised; MAS: Modified Ashworth Scale; NEFI-S: Nottwil Environmental Factors Inventory - Short Form; PASIPD: Physical Activity Scale for Individuals with Physical Disabilities; PBMC: Peripheral Blood Mononucleated Cells; PIL: Purpose in Life Test-Short Form; PTGI: Post-Traumatic Growth Inventory; RNA: ribonucleic acid; RSES: Rosenberg Self-Esteem Scale; SCIM-III: Spinal Cord Independence Measure, Version 3; SCIM-SR: Spinal Cord Independence Measure for Self-Report; SCI-SCS: Spinal Cord Injury - Secondary Conditions Scale; SF-36: Short Form Health Survey, 36 Item Version; SHP: Swiss Household Panel; SHS: Swiss Health Survey; SwiSCI: Swiss Spinal Cord Injury Cohort Study; USER-P: Utrecht Scale for Evaluation of Rehabilitation Participation; WHOQoL BREF: World Health Organization Quality of Life BREF; WMTS: Walker Muscle Tone Scale.