

Patient outcomes and needs after initial spinal cord injury rehabilitation in Sweden – study design and experiences

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- Limited use of SCI-specific outcome measures (accurate picture?)
- Lack of multi-centre research studies on SCI rehabilitation (holistic picture? equity? pooling?)
- Lack of internationally comparable data (pooling? international benchmarking?)
- Limited understanding of patient perceived outcomes and experiences (person-centeredness?)
- ❖ **NHV is finally a reality!** (that will need to be calibrated to changing demographics and to maturing clinical processes)
- ❖ We need accurate and timely evidence to design future adaptations, benchmarking to aim for even higher quality, and inform the focus of secondary rehabilitation and follow-up programs



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Aim

1. Establish patient outcomes and unmet rehabilitation needs at discharge from initial inpatient rehabilitation for SCI.
2. Describe the trajectories of patient outcomes during the first year after SCI.
3. Identify the unmet rehabilitation needs between discharge from initial inpatient rehabilitation and one year after SCI.
4. Explore predictors of patient outcomes, changes in outcomes, and unmet rehabilitation needs.



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Project composition

- PI & co-PI: Anestis Divanoglou (Linköping), Sophie Jörgensen (Lund)
- Project group: Peter Flank (Umeå), Emelie Butler Forslund (Rehab Station), Wolfram Antepohl (Linköping), Johanna Wangdell (CARE), Richard Levi (Linköping)
- Advisory group: Claes Hultling (Spinalis), Erik Berndtsson (RG Aktiv Rehab), Tomasz Tasiemski (Poland), Nora Sandholt (Linköping), Gunilla Åhrén (Ryggmärgsskadecentrum)
- Scientific committee: Jan Lexell (Lund), Kerstin Wahman (Rehab Station), Britt-Marie Stålnacke (Umeå), Elisabet Åkesson (Stockholmssjukhem); Xiaolei Hu (Umeå); Nada Andelic (Oslo)
- Collaborators: Anna Granström (Jönköping), Lisa Holmlund (Karolinska Inst.), Ulrica Lundström (Linköping)

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Method

- Longitudinal multi-centre cohort study, currently ongoing pilot phase
- Data collection
 - T0: admission to primary in-patient rehabilitation
 - T1: discharge from primary in-patient rehabilitation
 - T2: 1 year after SCI
- A study coordinator in each participating centre
- Self-report: **SCIM-SR**, **MSES**, ISCoS Quality of Life and Participation Datasets, HADS, EQ5D-5L, LiSat, **NPCS**
- Profession: **SCIM-IV**, **NPCS**, demographic and injury-related data incl. complications
- Pseudonymised data from paper forms are registered in REDCap

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Outcome measures

SCIM-IV (profession)	}	Project specific data
SCIM-SR (self-report)		
MSES (self-report)		
IntSCI QoL dataset (self-report)		
IntSCI Participation Dataset (self-report)		
Needs and Provision Complexity scale (profession/self-report)		
HADS (self-report)	}	Also collected for SveReh
LiSat-11 (self-report)		
EQ5D (self-report)		
ISNCSCI (profession)	}	Medical record
Demographic and injury-related data (profession/self-report)		

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Participating clinics in the pilot

- Department of Rehabilitation Medicine, Skåne University Hospital
- Neuro 5, Karolinska University Hospital, Region Stockholm
- Rehab Station Stockholm, Aleris, Stockholm
- Stockholmssjukhem, Stockholm
- Department of Rehabilitation Medicine, Norrland University Hospital
- Department of Rehabilitation Medicine, Linköping University Hospital
- Department of Rehabilitation Medicine, Sunderby Hospital, Luleå
- Frykcenter Rehabilitering
- Department of Rehabilitation Medicine, Ryhov Regional Hospital, Jönköping
- Department of Rehabilitation Medicine, Region Halland, Halmstad

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EPM & GDPR processes

Roles

- ❖ Ansvarig forskningshuvudman: Region Östergötland
- ❖ Medverkande forskningshuvudmän: all partners
- ❖ Personuppgiftsansvar (Gemensamt): Region Östergötland, Region Skåne
- ❖ Personuppgiftsbiträde: all other partners

Challenges

- Interpretation of legislation and procedures varies between regions and partners
- Dataskyddsombud and consultancies have different level of experience
- Clinicians have limited interest, patience and time for these

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Figure 1. Work plan for each quartile (Q) during Pilot phase (2022-2023) and Main Study (2023-2025)

Status	Milestones	2022	2023 (pilot)				2024				2025				2026			
			Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4	Q1	Q2	Q3	Q4
C	Ethical approval	█																
O	Networking	█	█	█	█	█	█	█	█									
C	Finalize SCIM-IV translation	█																
C	Workshop development	█																
O	Workshop delivery	█	█		█				█	█								
C	GDPR forms and agreements	█	█	█				█	█									
O	Pilot data collection	█	█	█														
P	Data Analysis – Psychometrics				█													
P	Amendment of ethical approval based on findings from the pilot				█													
	Launch of centralization process		█															
S	Data collection (inception)					█	█	█	█									
S	Data collection 1 year follow-up									█	█	█	█					
S	S1 Analysis & Writing										█	█	█	█				
S	S2 Analysis & Writing													█	█	█	█	
S	S3 Analysis & Writing																	█
S	S4 Analysis & Writing																	█
	Dissemination					SciPub +Conf +LayPub		SciPub + Conf						SciPubs +Conf +LayPub	SciPubs +LayPub		SciPubs +Conf +Report	

Q: Quartile; SCIM: Spinal Cord Independence Measure; Lay Pub: Publication in a lay person's magazine; Sci Pub: publication in an Open Access peer-reviewed journal; Conf: conference presentation; P: Planning; O: Ongoing; C: Completed; S: Scheduled.

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Other considerations

- Networking
 - NHV partners
 - Non-NHV partners that may provide primary and secondary rehabilitation
 - Providers of lifelong follow-up
 - NHV steering committee
- Funding
 - Compensation for data collection
 - Compensation for participating researchers
- Implementation of SCI-specific measures in routine clinical process
- Interplay with Quality Registries (SveReh, Nordic SCIR)
- Authorship agreement, data ownership and intellectual rights

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Contact us if you want to know more or get involved

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- Sophie Jörgensen, MD, PhD; Skåne University Hospital;
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Key pubs

Moschovou, M., Antepohl, W., Halvorsen, A. Pettersen AL, & Divanoglou A. (2022). Temporal changes in demographic and injury characteristics of traumatic spinal cord injuries in Nordic countries - a systematic review with meta-analysis. *Spinal Cord*.

Jörgensen, S., Butler Forslund, E., Lundström, U., Nilsson, E., Levi, R., Berndtsson, E., & Divanoglou, A. (2021). Sound psychometric properties of the Swedish version of the Spinal Cord Independence Measure Self-Report. *Journal of rehabilitation medicine*, 53(5), jrm00197. <https://doi.org/10.2340/16501977-2839>

Mangold J, Divanoglou A, James W Middleton, & Sophie Jörgensen. The Swedish Version Of The Moorong Self-Efficacy Scale (S-MSES) – Translation Process And Psychometric Properties In A Community Setting" (Submitted November 2022)

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