

Realizing the potentials of a National Spinal Cord Injury Registry – 10 years of experiences

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ABSTRACT

The Norwegian Spinal Cord Injury Registry is a national quality registry that just celebrated its 10-year anniversary. The registry contributes to quality improvement in spinal cord injury care in Norway and other Nordic countries. The continuous improvement in clinical practice goes hand-in-hand with the further registry development. Data from the registry are furthermore used in different kinds of research projects. This article aims to provide an overview of how the Norwegian Spinal Cord Injury Registry was established, to share our experiences, insights, lessons learned during its development and ten years in operation, and to highlight its potential.

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BACKGROUND

Spinal cord injury (SCI) is a rare but severe medical condition that may cause life-long impairment that affects various aspects of life (1). Spinal cord injuries often cause permanent changes in muscle strength, sensation, and other body functions such as breathing, bowel and bladder control, and sexual function. Additionally, the secondary complications following SCI, such as pressure ulcers, pain, and cardiovascular complications, increase morbidity and decrease community participation and health-related quality of life (2). Therefore, the healthcare needs are multifaceted and must be managed with a multidisciplinary approach across several phases, from pre-hospital and acute medical care to post-acute rehabilitation, to lifelong follow-up (1).

The post-acute rehabilitation and follow-up of SCI patients in Norway is centralized in three specialized centers: Haukeland University Hospital in Bergen, St. Olav's University Hospital in Trondheim, and Sunnaas Rehabilitation Hospital in Oslo/Nesodden (3). A description of the Norwegian SCI care was previously published (4). The Norwegian SCI registry (NorSCIR) is a national quality registry that provides a unique opportunity to monitor the quality of the provided SCI care. NorSCIR contains individualized data concerning patient problems, medical interventions, and outcomes after treatment (including patient-reported outcomes).

This article aims to provide an overview of how NorSCIR was established, to share our experiences, insights, lessons learned during its further development and ten years in operation, and to highlight its potential.

THE ESTABLISHMENT OF THE NORWEGIAN SPINAL CORD INJURY REGISTRY

The initiative of launching a national SCI registry came from the three specialized SCI units, in cooperation with the National Spinal Cord Injuries Association (www.lars.no) in 2009, intending to improve and nationally compare the quality of care, establish and monitor clinical practice, and serve as a resource for research by providing comprehensive data on SCI care. There was an early consensus to develop the Norwegian SCI registry based on the International SCI (ISCI) Data Sets (5), which are freely available for SCI registries (www.iscos.org.uk). The consensus ensures an internationally recognized uniform data collection.

The registration is electronic and runs on the Medical Registry System (MRS) developed by the Central Norway Regional Health Authority IT department (Hemit IT). Data are transferred via the Norwegian Health Network (NHN), providing an efficient, secure electronic exchange of patient information. The data controller is St. Olav's University Hospital, Trondheim, Norway. All SCI patients (traumatic and non-traumatic) admitted for primary rehabilitation, and later follow-up to one of the three specialized SCI units are included. Registration in the registry is voluntary, and written informed consent must be obtained before registration occurs. NorSCIR has been in operation since 2011 and was approved as a national medical quality registry by the Ministry of Health and Care Services in 2012. Since 2012, the further development of NorSCIR has been a continuous process that has been gradual and cumulative.

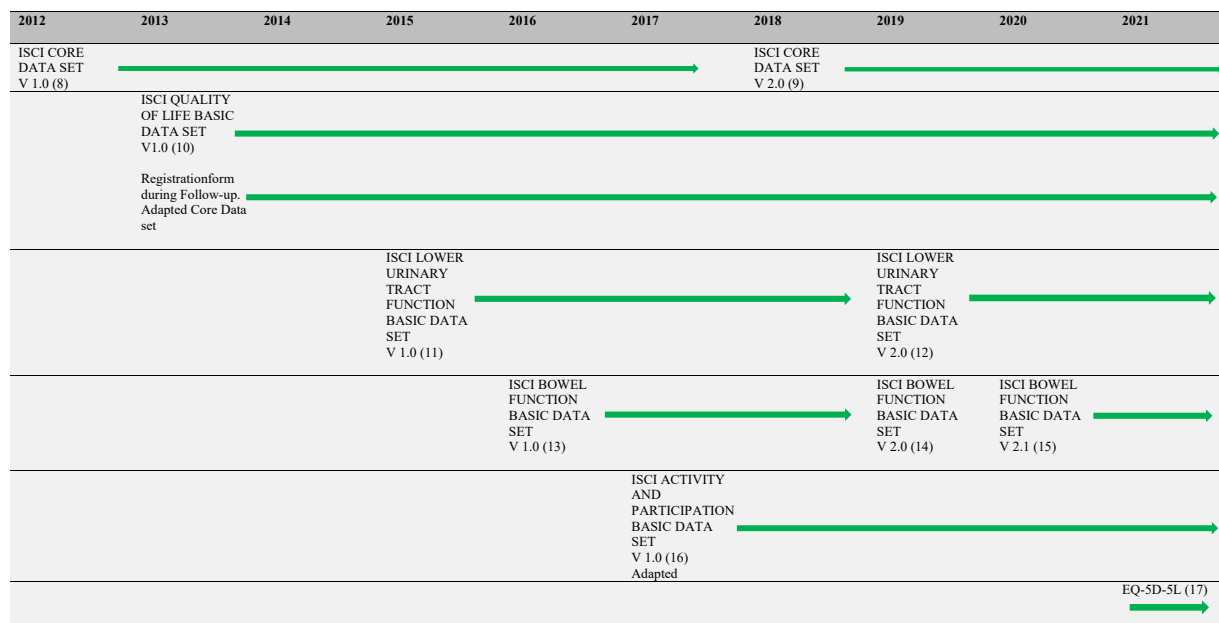


Figure 1. Timeline implementation of datasets in the Norwegian spinal cord injury registry. Abbreviations: ISCI, International Spinal Cord Injury. V, Version. EQ-5D-5L, EuroQol-5 Dimension- 5 levels.

THE FURTHER DEVELOPMENT OF NORSCIR – A CONTINUOUS PROCESS

The International Classification of Functioning, Disability and Health (ICF) is an internationally accepted standard to describe and measure health and disability in persons with all kinds of diseases or conditions, including SCI (6). The ICF conceptualizes a person's level of functioning as a dynamic interaction between her or his health conditions, environmental factors, and personal factors (6). The international SCI (ISCI) Data Sets are based on the ICF framework and provide a common language among SCI centers worldwide (7). The ISCI Data Sets cover important areas encountered along the continuum from the acute situation to rehabilitation and throughout the lifetime of persons with SCI living in the community.

The first ISCI data set was published in 2006 (8). The purpose of the ISCI Core Data Set is to standardize the collection and reporting of a minimal amount of information necessary to evaluate and compare the results of published studies (8). Since then, twenty-five ISCI Data Sets have been developed and published by various working groups of topic-specific experts (www.iscos.org.uk). All data sets are created according to an established consensus and approval process, which includes receiving comments from all relevant and interested organizations and individuals in an open, iterative process (5). Several ISCI Data Sets have been revised after some years of experiences, to improve their clinical and research use.

During the last ten years, the advisory board in NorSCIR has made a list of priority of ISCI data sets to be implemented in the NorSCIR. It was considered important to keep the data collection manageable to ensure

complete data. The following five ISCI datasets have been implemented over the years, of which two are Patient Reported Outcome Measures (PROM): ISCI Core Data Set (8,9), ISCI Quality of Life Data Basic Set (PROM) (10), ISCI Lower urinary tract function Basic Data Set (11,12), ISCI Bowel function Basic Data Set (13-15), and an adapted version of the ISCI Activity and participation data set (participation part is PROM) (16). In 2021 it was decided to implement a non-specific SCI PROM instrument to describe and value health EuroQol-5 Dimension-5 levels (EQ-5D-5L) (17). EQ-5D-5L comprises five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. The EQ VAS also measures the patient's self-assessed health using a visual analog scale (VAS scale). Figure 1 shows an overview of the datasets in use in NorSCIR. The figure illustrates that NorSCIR strives to implement the latest version of ISCI Data Sets, when updates are made. It is relevant in this case to mention that inconsistencies in the ISCI Bowel Data Set version 2.0 were recognized by NorSCIR and that was corrected and clarified in version 2.1 (15).

Registration of the ISCI Core Data Set is mandatory and a prerequisite to register other forms. This ensures that all included patients have main characteristics of spinal cord injury recorded. The coverage (completeness) of the registry was > 90 % in 2012-2021.

Data collection occurs at various time points during the first rehabilitation admission and all check-ups, resulting in longitudinal data. The centralized SCI care in Norway contributes to highly experienced SCI professionals performing consistent clinical evaluations and data collection. High data quality is considered one of the registry's most essential elements. NorSCIR ensures high data quality through regular data assessments

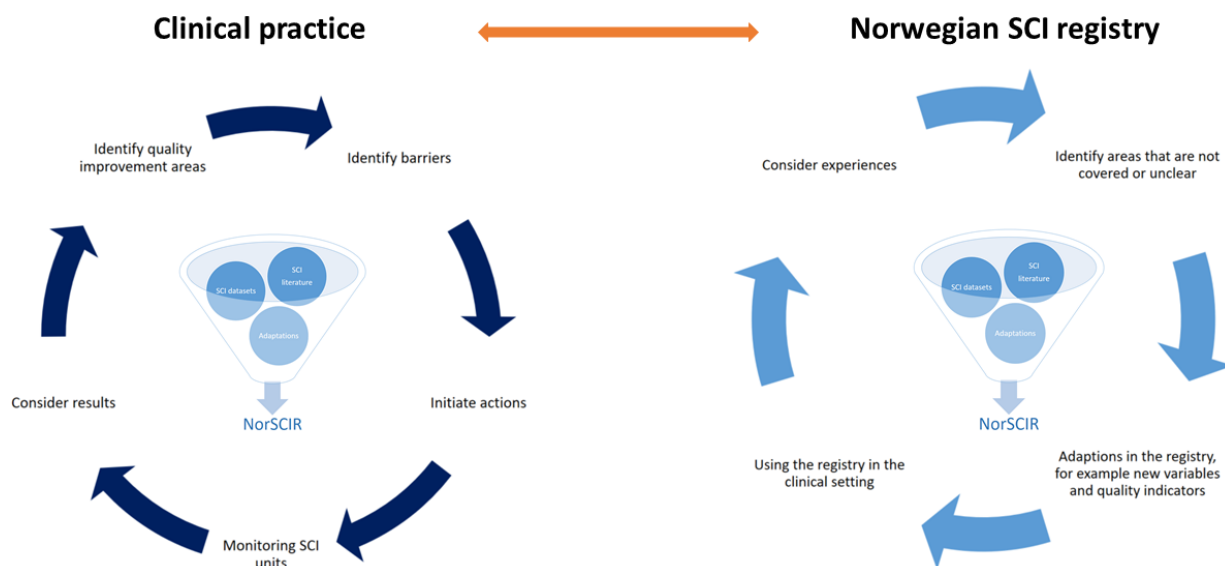


Figure 2. Continuous improvement in clinical practice and the registry.

(18). Thus, due to carefully selected measurement instruments and high data quality, NorSCIR is able to provide insights about the impact of an SCI on important areas in a person's life and the given SCI care in Norway.

THE RESULTS AND POTENTIALS OF A NATIONAL SPINAL CORD INJURY REGISTRY

NorSCIR provide information and feedback to health-care professionals on a continuous basis. The hospitals have electronic access to updated data, not only from their own hospital, but also in comparison with national data in NorSCIR. Additionally, NorSCIR provides monthly and annual reports (18). Feedback and data from the registry may provide health care professionals insight into their own performance, and this may lead to a motivation for changes and quality improvement activities (19).

In collaboration with the advisory board and SCI professionals in the field, ten quality indicators have been created during the last decade that measures the hospitals' compliance with the existing professional guidelines. Low achievement on a quality indicator often leads to actions in order to achieve a better result. Discussions across the hospitals and the registry have often contributed to ideas for improvement. Data from the registry are used to evaluate the results of the initiated actions. Thus, structured data from registries plays a central role in planning improvement activities and studying if these activities have been effective. On the other hand, is the feedback from the hospitals about their experience of using NorSCIR in the clinical setting crucial for further development of the registry. Examples of feedback may be areas that need to be covered or that need to be clarified. Figure 2 shows that continuous improvement in clinical practice goes hand-in-hand with the further registry development.

An example of a quality improvement project in NorSCIR, called "Neurological classification," has been described earlier and is summarized here (19). During the rehabilitation period, an examination and classification of the spinal cord injury should be performed in accordance with the established international ISNCSCI (International Standards for Neurological Classification of Spinal Cord Injury) guidelines (20). The registry revealed that a neurological classification had not been performed in many cases, and this area was therefore selected as a relevant quality improvement project. The project's objective was to establish common routines for performing neurological classification of spinal cord injuries. An interdisciplinary network that included all three hospitals treating patients with spinal cord injuries was established. This learning network agreed on a common procedure for the neurological classification of injuries. The purpose of the procedure is to ensure high quality in the examination process, including documentation. It also encompasses a training package for recently employed healthcare personnel.

Results from the registry show a clear increase in the number of examinations performed. Table 1 shows the characteristics and outcomes of all persons registered in NorSCIR in a ten-year period, categorized in two groups (persons with SCI 2012-2016 and persons with SCI 2017-2021). In the period 2012-2016 91 % patients were examined at admission, whereas in 2017-2021 97 %.

Furthermore, temporal changes in injury and treatment characteristics by comparing the two groups are shown in Table 1. For example regarding completeness of injury, where we observed an increased number of patients with AIS D, meaning less severe incomplete SCI. Another important result is the difference in length of stay at the hospital, which was significantly shorter in the period 2017-2021 compared with the period

Table 1. Demographics and outcomes for persons with spinal cord injury 2012-2016 compared with persons with spinal cord injury 2017-2021.

Characteristics	SCI 2012-2016 (N = 573)		SCI 2017-2021 (N = 614)		P Value
Mean age (SD)	50,1 (18,5)		51,3 (19,4)		
Median age	53		55		
Age					
0-14	9	(1,6)	23	(3,7)	
15-29	96	(16,8)	87	(14,2)	
30-44	101	(17,6)	93	(15,1)	
45-59	149	(26,0)	158	(25,7)	
60-74	184	(32,1)	204	(33,2)	
75+	34	(5,9)	49	(8,0)	
Gender (%)					
Male	398	(69,5)	424	(69,1)	
Female	175	(30,5)	190	(30,9)	
Cause of injury					0,042**
Sports	73	(12,7)	87	(14,2)	
Assault	5	(0,9)	13	(2,1)	
Transport	65	(11,3)	61	(9,9)	
Fall	162	(28,3)	168	(27,4)	
Other traumatic cause	44	(7,7)	25	(4,1)	
Non-traumatic cause	224	(39,1)	260	(42,3)	
Total length of stay in days					<0,001*
Mean (SD)	112,7 (60,8)		97,7 (57,7)		
Median	105		89		
AIS at admission					<0,001**
A	102	(17,8)	88	(14,3)	
B	57	(9,9)	30	(4,9)	
C	81	(14,1)	104	(16,9)	
D and E	282	(49,2)	371	(60,4)	
Unknown or not applicable	51	(8,9)	21	(3,4)	
Neurological level of injury					
Tetraplegia	217	(37,9)	301	(49,0)	
Paraplegia	302	(52,7)	294	(47,9)	
Unknown or not applicable	54	(9,4)	19	(3,1)	
Place of discharge					
Home	406	(70,9)	446	(72,6)	
Other location	167	(29,1)	168	(27,4)	

Abbreviations: SCI, spinal cord injury. AIS, American Spinal Injury Association Impairment Scale.

AIS A motor–sensory complete, AIS B motor complete–sensory incomplete, AIS C–D motor–sensory incomplete, AIS E normal examination.

P value: Independent sample T test * and Pearson Chi-square test **

2012-2016. A change regarding cause of injury is as well observed, however this was less significant than the other findings. Summarized may the observed changes indicate the need for adapting the SCI care, prevention strategies, and possible research focus.

Besides the important role of NorSCIR in quality improvement projects to improve healthcare, the registry is as well a source for research.

Systematic and epidemiologic registry data based on internationally provided data sets has been published in international peer-reviewed journals (20,21). In Norway, we have the unique opportunity to link data from different registers. Combining data from NorSCIR with other registry data has been effective to find answers to other research questions, for example regarding labour market participation and, the use of sickness and disability benefits in the SCI population (22). Thus, through

research on data from the registry, one can examine both epidemiology, and study associations between the impact of SCI and the provided care, and different short- and long-term outcomes.

A Nordic cooperation on highly specialized treatments was established by the Nordic council of ministers in 2013 (23). Several pilot projects were launched with the aim of improving co-operation. The Norwegian Directorate of Health in Norway requested NorSCIR to initiate a pilot project, to establish a common Nordic SCI quality registry (NordicSCIR). The development of NordicSCIR is similar to the development of NorSCIR as described in this article. NordicSCIR includes all patients with SCI, hospitalized in one of the seven SCI units in Denmark, Norway, Iceland or in Linköping, Sweden. The other SCI units in Sweden are planned to be included in near future,

towards the ongoing centralization process. Currently Finland is not included. Since 2017, NordicSCIR collects data and facilitates comparisons regarding injuries, treatments, and outcomes between patients, hospitals, and countries. Annual reports have been published (www.nordicscir.no) and data from NordicSCIR have been used in research (24).

CONCLUSION

There are numerous benefits to developing an SCI registry, some of which include the possibility of quality improvement in clinical practice and research. Implementing, maintaining and running a registry requires substantial effort. However, this effort results in continuous improvement, both in clinical practice

and in the registry. These benefits have been realized in Norway and other Nordic countries. The acknowledged international SCI data sets have contributed to the success. Experiences from NorSCIR may be helpful for other registry initiatives.

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