



# A common SCI Medical Quality Registry for the Nordic Countries, “The challenges and opportunities”

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A Nordic cooperation on highly specialized treatments was established by the Nordic council of ministers in 2013. Several pilot projects were launched with the aim of improving co-operation. The Norwegian SCI Registry (NorSCIR) was requested by the Norwegian Directorate of Health to initiate a pilot project, to establish a Nordic SCI quality registry (NordicSCIR). Below the experiences of this project so far, including opportunities, challenges, solutions and status of the project.

## Opportunities

- ✓ The International Spinal Cord Injury Society (ISCOs) promotes the highest standard of care in the practice of SCI for men, women and children throughout the world. The international SCI Data Sets developed by ISCoS, are recommended and freely available for SCI registries.



- ✓ The main objectives of a SCI registry are:
  1. to improve care for individuals with SCI
  2. to facilitate comparisons regarding injuries, treatment, and outcomes between patients, centers and countries
  3. to provide important data for prevention, both primary, secondary and tertiary
- ✓ NorSCIR was established in 2009 as a result of a collaboration between all three SCI units in Norway and the Spinal Cord Injuries Association (LARS). NorSCIR includes individuals with a spinal cord injury, both traumatic and non-traumatic, or with a Cauda Equina lesion. NorSCIR is based on variables from the international SCI Data Sets.
- ✓ It is a benefit that the Nordic countries have similar healthcare systems and robust administrative routines.

## Challenges

- ✓ IT Technical:
  - The need for a multilingual websolution
  - How to manage different national personal ID numbers?
  - Possibility for import of data is requested
  - How to manage access to the registry from abroad?
  - Data security
- ✓ Sustainability and ongoing funding. Time and resources to establish and run the registry.



- ✓ Communication between several SCI units, disciplines and countries.
- ✓ Differences in legal terms and conditions in the Nordic countries.
- ✓ Need for translations of the SCI Data Sets.
- ✓ Different “patient pathways” at the hospitals in the Nordic countries.
- ✓ Need for data sharing agreement.
- ✓ Training how to use the registry.

## Solutions

- ✓ IT Technical:
  - The registration is electronic, web based on Medical Registry System (MRS)
  - The MRS platform is adapted to multilingual use
  - Information is sent through the Norwegian Health Network, providing efficient, secure electronic exchange of patient information
- ✓ Frequent meetings with representatives from participating countries and continuously dialogue with all involved SCI units. Involvement and support of the management at all hospitals.
- ✓ Multidisciplinary meetings with attendance of health care professionals, representatives from Central Norway regional Health authority IT department (HEMIT) and Center for clinical documentation and evaluation (SKDE), and hospital management.
- ✓ Due to Norwegian law, written informed consent must be obtained before entering data into the NordicSCIR.



More information about Nordic cooperation, published by Nordic Council of Ministers, february 2016. Editor «Mandag Morgen, Velfærd».

## Status

- ✓ A license for processing personal health data in NordicSCIR is granted by the Norwegian Data Protection Authority.
- ✓ There are signed agreements for cooperation in NordicSCIR between Denmark, Iceland and Norway, covering funding to operate the registry in the future.
- ✓ Finland will sign the agreement when juridical doubts are clarified.
- ✓ The SCI units in Stockholm and Linköping will be included as a pilot.
- ✓ Funding by Central Norway Regional Health Authority and the participating hospitals.
- ✓ Data controller is St. Olavs Hospital, Trondheim, Norway.
- ✓ The Nordic consumer organizations support collaboration and the establishment of a Nordic SCI registry.



- ✓ The NordicSCIR will be in operation from January 2017.

## Conclusion:

It is possible to develop a Nordic quality registry, despite the differences in legal terms and conditions The NordicSCIR will provide representative longitudinal data essential for identifying incident trends, important for prevention programs and improvement of SCI care in the Nordic countries, with population of 26.6 million.

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