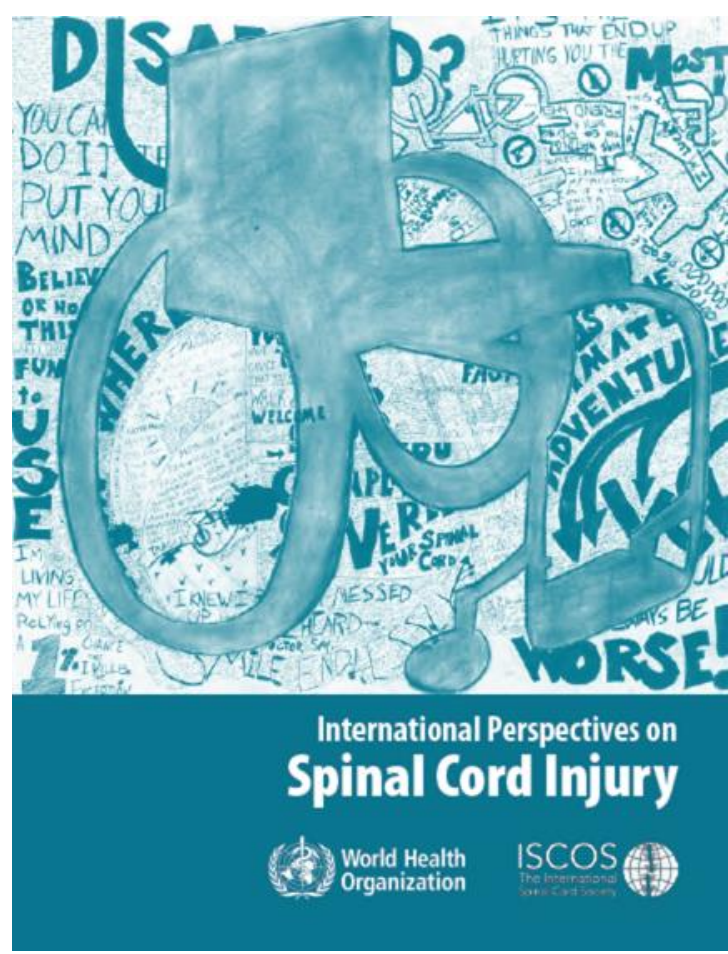


Establishment of a Nordic Spinal Cord Injury Registry

NordicSCIR

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 On behalf of the Steering Committee NorSCIR and the project group NordicSCIR



The WHO IPSCI report concluded that *“there is a serious need to collect more data on a worldwide basis. There is also a need to improve the quality of data. Reliable data and evidence are essential for describing the numbers of people affected and the impact on their lives, assessing causes, developing and evaluating interventions, providing information for policy-makers and decision makers, and raising awareness.*



A spinal cord injury (SCI) may cause life-long impairment with various late complications that requires management, and follow up.



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 for SCI registries.

The main objectives of a SCI Registry:

- to improve care for individuals with SCI
- to facilitate comparisons regarding injuries, treatment, and outcomes between patients, centres and countries
- to provide important data for prevention, both primary, secondary and tertiary



Illustration ISCoS



The Norwegian Directorate of Health contacted NorSCIR spring 2013, to initiate a pilot project for the establishment of a Nordic SCI quality registry. There was established a Nordic cooperation on highly specialized treatments, by the Nordic council of ministers. Several pilot projects were launched with the aim of improving co-operation. The NordicSCIR project is coordinated by the Norwegian Directorate of Health. In the NordicSCIR project are Central Norway regional Health authority IT department (Hemit) and Center for clinical documentation and evaluation (SKDE) important contributors. Hemit is responsible for the IT system and database infrastructure. SKDE provides statistical and legal assistance.



The Norwegian Spinal Cord Injury Registry (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.

NordicSCIR

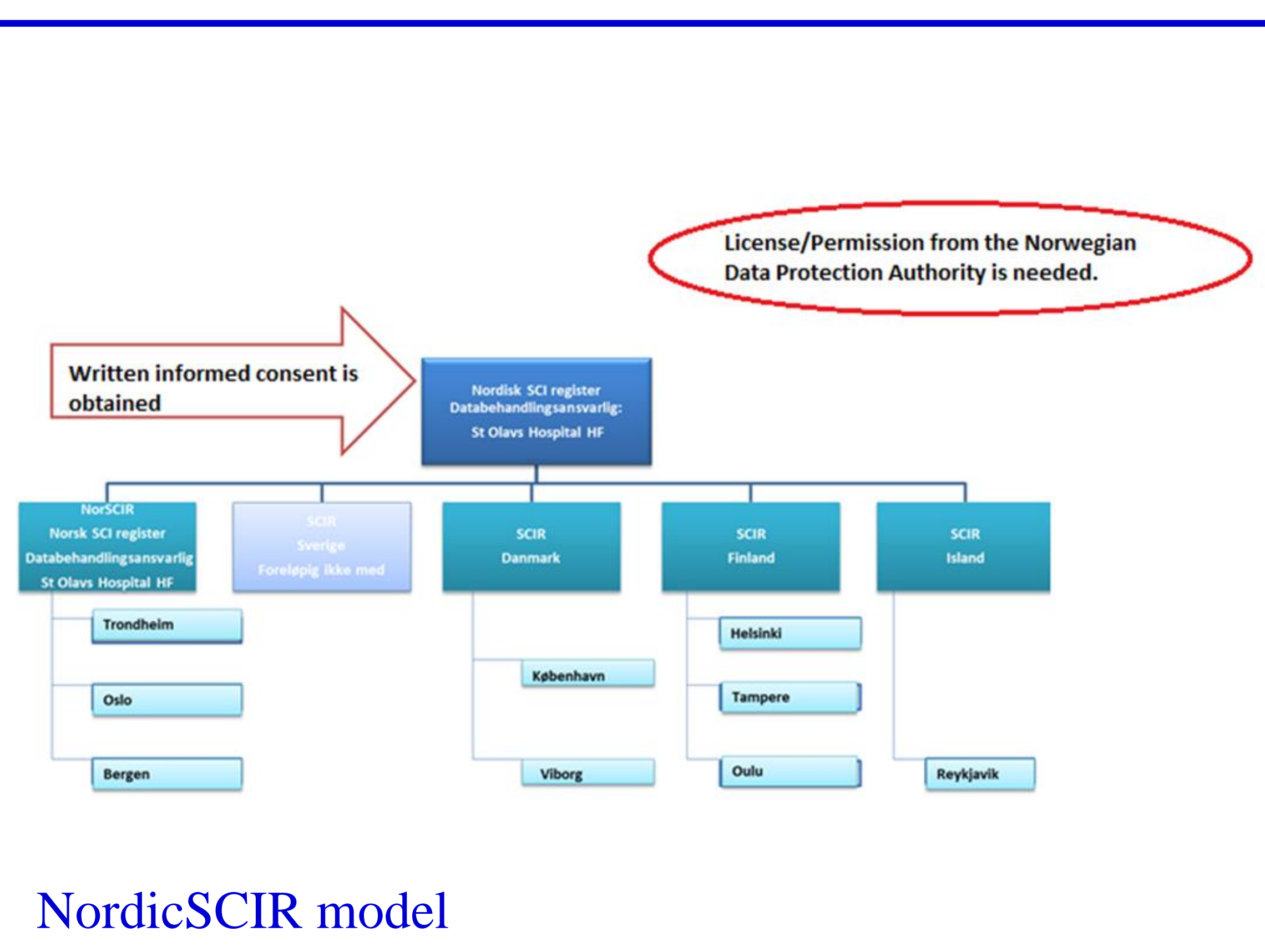
Nordic Spinal Cord Injury Registry

Project for the establishment of a Nordic Spinal Cord Injury Registry

- The registration is electronic through Norwegian health network
- Medical Registry System (MRS)
- Written informed consent is obtained from the participants before entering data into the registry
- Data controller is St. Olavs Hospital
- License has been granted by the Norwegian Data Protection Authority
- The NordicSCIR is planned to be in operation from January 2017



The Nordic consumer organizations support collaboration and the establishment of a Nordic SCI registry



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