

Brukermedvirkning i Norsk ryggmargsskadereregister og i forskning

6.11.2023

Seminar for brukerrepresentanter- og pasientorganisasjoner

Annette Halvorsen, Ingrid Njerve og Anders Nupen Hansen

Hvem er vi?



Bilde: Pixabay

Vi ønsker å dele våre erfaringer med dere

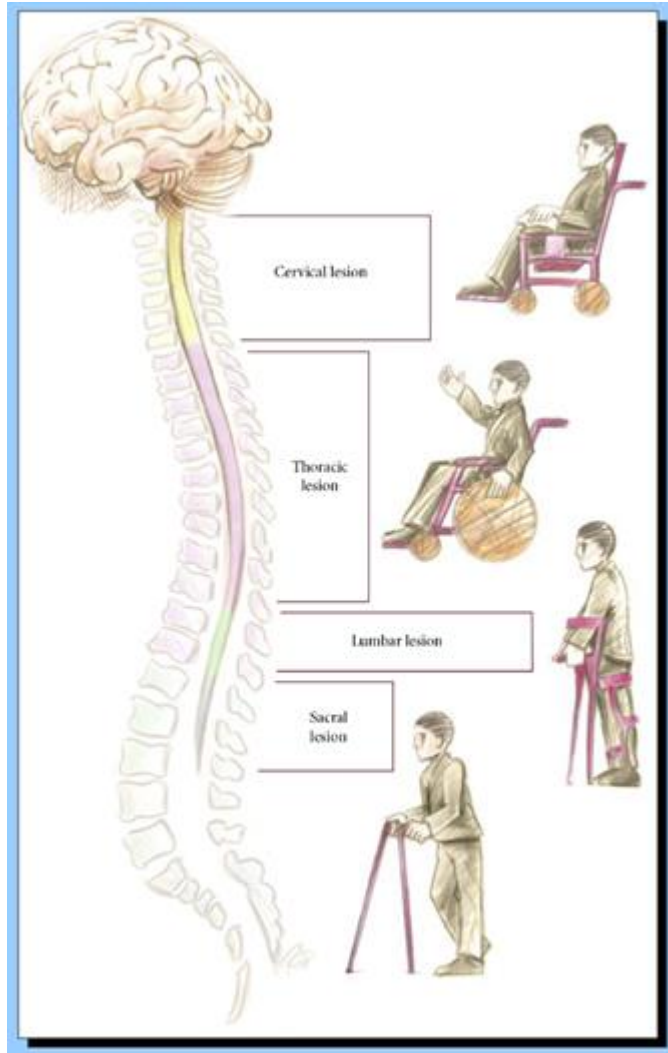


Agenda



1. Ryggmargsskade
2. Brukermedvirkning i ryggmargsskaderegister
3. Brukermedvirkning i forskingsprosjekt

Følgetilstand etter skade på ryggmargen



- Motorisk utfall (Lammelser)
- Sensorisk utfall (Hudfølelse)
- Kroppsfunksjoner er påvirket (Bant annet Blære, tarm, lunge)
- Autonome nervesystem er påvirket

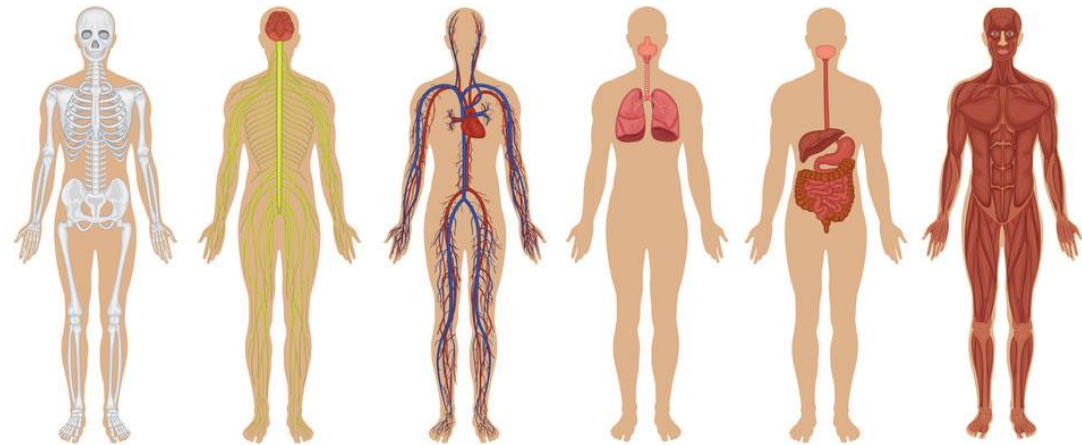


Illustration from: https://libguides.gen.vic.edu.au/sciences/body_systems

Halvorsen 2023

Individuelle forskjeller



Bilde: New Dawn ~ New Day ~ New Life: Life Support (newdawnforus.blogspot.com)



Bilde: Store norske leksikon
Birgit Skarstein Av Caroline Dokken Wendelborg/Norges idrettsforbund og olympiske og paralympiske komité.
Halvorsen 2023



Bilde FlintRehab: www.flintrehab.com

Innvirkning



Bilde: Pixabay

Ryggmargsskadeomsorgen i Norge

- Sentralisert til 3 sykehus
- Livslang oppfølging
- Landsforeningen for ryggmargsskadde
- Norsk ryggmargskaderegister (NorSCIR)

COUNTRY REPORT

People with Spinal Cord Injury in Norway

Vegard Strøm, PhD, Grethe Månun, PhD, Annelie Leulfsrud, MA, Pia Wedege, MSc, Tina Rekdal, PhD, Annette Halvorsen, MD, Leif Arild Fjellheim, and Johan K. Stanghelle, PhD

EPIDEMIOLOGY OF SPINAL CORD INJURY IN NORWAY

In 2014, 122 new cases of spinal cord injury (SCI) were registered in the Norwegian Spinal Cord Injury Registry (NorSCIR), of which 80 were traumatic and 42 were non-traumatic.¹ Written consent is obtained from the participants before entering data into the registry, and permission is only requested from SCI patients submitted to a specialized SCI unit in Norway. Such permissions are obtained from 91% to 93% of the relevant patients. Data from 419 individuals are included for the period 2011–2014: 250 with a traumatic SCI and 169 with a nontraumatic SCI. Historical data on incidence and prevalence of SCI in Norway are relatively sparse. In 1974–1975, the incidence of traumatic SCI was reported to be 16.5.² For the period 1952–2001, it was found to be 13.9 in western Norway.³ Thus, a relatively stable trend is found during the past 50 to 60 years. The etiology of SCI, based on the 2014 data from NorSCIR,¹ are nontraumatic causes, 34.4%; traumatic causes due to falls, 29.5%; sports, 13.9%; transport, 13.1%; other traumatic, 8.2%; and assault, 0.8%. The main causes of traumatic SCIs have been unchanged for the past 50 years,⁴ except for an increasing trend toward higher incidence of fall-induced SCI among persons older than 50 years.³ People with traumatic SCI have an increased mortality rate (1.85) compared with the Norwegian population.⁵ Women with SCI have a significant higher mortality rate than men.^{5,6}

THE PATIENTS' JOURNEY THROUGH THE CHAIN OF CARE

The Norwegian emergency medical service system consists of specialized rescue teams for acute medicine and traumatology including SCI and provides assistance regardless of time, place, and insurance by a uniform alert and response system. A dedicated toll-free phone number, 113, routes calls to emergency medical dispatch centers (EMDCs). Ground ambulances, boats, and/or helicopters are dispatched with

specialized teams including medical doctors based on criteria in the Norwegian Index for Medical Emergencies,⁷ a decision tool to secure appropriate responses to medical emergencies. Each call is classified as either "acute" (highest priority), "urgent" (high, but lower priority), or "not urgent" (lowest priority). When "acute," both ambulances and the medical staff on call are alerted. Together with the emergency medical dispatch centers and increasing competence of ambulance personnel, the emergency medical service of serious accidents and/or illnesses has improved.⁶

In cases of accidents where a traumatic SCI cannot be excluded, the patient is assessed and stabilized as soon as possible by specialized emergency medical staff and, with some exceptions, transported to 1 of 4 specialized trauma hospitals. These hospitals are located in the cities of Oslo, Bergen, Trondheim, and Tromsø and cover 20 emergency regions.⁸ In 6 of the emergency regions, the transport time is less than 2 hours. In northern Norway, it is more than 4 hours in 2 of 5 regions.⁸ If transport time is more than 45 minutes to a trauma hospital, the patient will be transported to the nearest acute care hospital.

In Norway, there are 3 specialized SCI rehabilitation units; these are located at Sunnaas Rehabilitation Hospital, Haukeland University Hospital, and St. Olav's University Hospital. Each SCI unit covers a designated part of Norway: Sunnaas Rehabilitation Hospital the southeastern part, Haukeland University Hospital the western part, and St. Olav's University Hospital the mid- and northern part of Norway.

LIVING WITH SCI

Norway has a number of laws and regulations aiming to reintegrate people with disability back to employment. Important regulations are the Disability Discrimination Act,⁹ The Working Environment Act,¹⁰ and the Agreement on Inclusive Working Conditions between the government, the labor unions, and the Norwegian Federation of Employers.¹¹ The UN Convention on Disability from 2006 was implemented into the Norwegian legal system in 2008.¹² Norway is among the top spenders on publicly sponsored reeducation and back-to-work programs in Europe.¹³

Studies of the Norwegian SCI population show that approximately 65% to 70% is employed at some time after injury (Leulfsrud A, Solheim E, submitted for publication, 2015).¹⁵ Important factors predicting employment after injury are levels of education and the opportunity to continue working in the same organization as before the SCI (Leulfsrud A, Solheim E, submitted for publication, 2015), and also age and severity of the injury.¹⁵ Women have been reported to have significant lower employment odds in the past,¹⁵ but more recent data

From the Sunnaas Rehabilitation Hospital, Nessøkdalangen, Norway (VS, GM, PW, RK); Spinal Cord Unit, St. Olav's University Hospital, Trondheim, Norway (AL); Department of Neurology, Haukeland University Hospital, Bergen, Norway (TR); Institute for Neuroscience and Physiology, Sahlgrenska Academy, University of Gothenburg, Sweden (TB); Norwegian Spinal Cord Injury Registry, St. Olav's University Hospital, Trondheim, Norway (AH); The Norwegian Spinal Cord Injury Association, Gjøvik, Oslo, Norway (LAF); and Faculty of Medicine, University of Oslo, Oslo, Norway (GM, RK).
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Agenda



1. Ryggmargsskade

2. Brukermedvirkning i ryggmargsskadereregister

3. Brukermedvirkning i forskingsprosjekt

Norsk ryggmargsskaderegister



A	Neurologisk klassifisering ved innkomst og utreise
B	Andel pasienter som har fått kartlagt og vurdert blærefunksjon
C	Blæretømmingsregime for pasienter med paraplegitilstand
D	Lavest mulig andel pasienter skrevet ut til sykehjem
E	Andel pasienter som har fått kartlagt og vurdert tarmfunksjon.
F	Andel pasienter med selvrappoert livskvalitet (PROM) under primæropphold.
G	Aktualitet av data i registeret
H	Andel pasienter som har fått kartlagt og vurdert funksjon relatert til aktivitet og deltakelse
I	Andel pasienter med selvrappoert tilfredshet relatert til aktivitet og deltakelse
J	Andel gjennomførte kontrollopphold etter sykehusets egen anbefaling

Fagrådet NorSCIR



Årsrapport 2022

Skade på ryggmargen

Skadeårsak:

Traumatisk ryggmargsskade 44 %, vanligst fall



Ikke-traumatisk ryggmargsskade 56 %, vanligst degenerativ etiologi



Sammensetting av pasientgruppen:

31 % kvinner og 69 % menn

Gjennomsnittsalder 53 år

Yngste pasient 11 år og eldste 82 år



Av 142 pasienter som var innlagt til spesialisert rehabilitering av sin ryggmargsskade er 128 inkludert i registeret. (Dekningsgrad 90 %)

Årsrapport 2022

Utreise spesialisert ryggmargsskade rehabilitering

Graden av selvstendighet i ulike daglige aktiviteter ved utreise:

- Forflytter seg selvstendig med eller uten hjelpemidler: 91 %
- Selvstendig i av-/påkledning underkropp 72 %
- Selvstendig i spising/matsituasjon: 86 %
- Selvstendig i toalettsituasjon: 74 %

Gjennomsnitt livskvalitet skår (range fra 0 til 10) ved utreise:

- Generelt (overall well-being) 6.7
- Fysisk helse 6.1
- Psykisk helse 7.2

Naturlige funksjoner:

1 av 3 personer har moderat eller alvorlig nevrogen tarmdysfunksjon.

1 av 3 personer opplever inkontinens for urin.

Det er kun 4 % av personer med en ryggmargsskade i yrkesaktiv alder som skrives ut til sykehjem i Norge

Bruk av registerdata

- Konkret klinisk forbedringsarbeid:
 - Nevrogen tarmfunksjon
 - Livslang oppfølging
 - Nevrologisk klassifikasjon
 - Smerter
- Ledelse/administrasjon/styring
- Forskning



Brukermedvirking i registeret...Ingrid forteller

- Erfaringsbasert kunnskap blir brukt i fagrådet, for eks valg av nye variabler.
- Resultater fra registeret blir brukt i arbeidet til Landsforening for ryggmargsskadde (LARS).
- Resultater fra registeret blir formidlet til medlemmer i LARS

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Bakgrunn

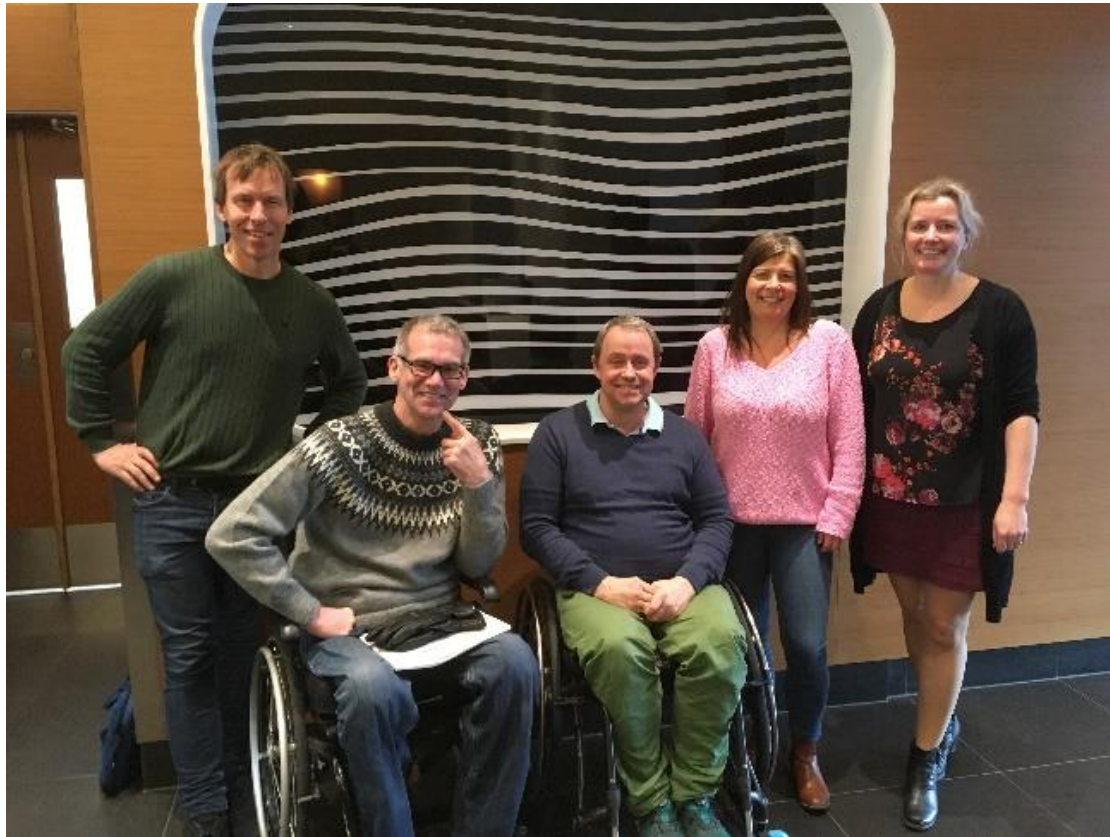
- Motivasjon
 - Klinisk erfaring
 - Ubesvarte spørsmål
 - NorSCIR
- Unik mulighet med kobling av ulike registerdata

Mål forskningsprosjekt

- Ny kunnskap om å leve med ryggmargsskade
- Spesifikk på: **Deltakelse - livskvalitet og -omsorg**
- Blant **personer med ryggmargsskade og deres pårørende**

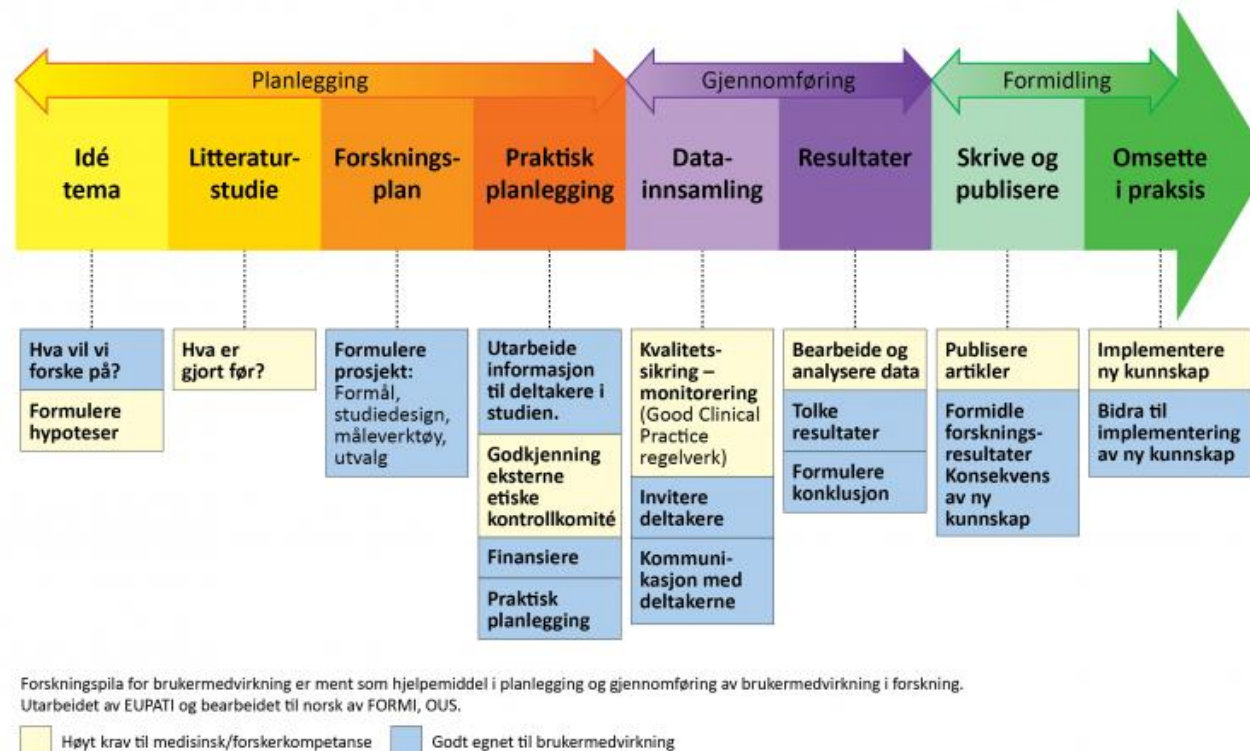


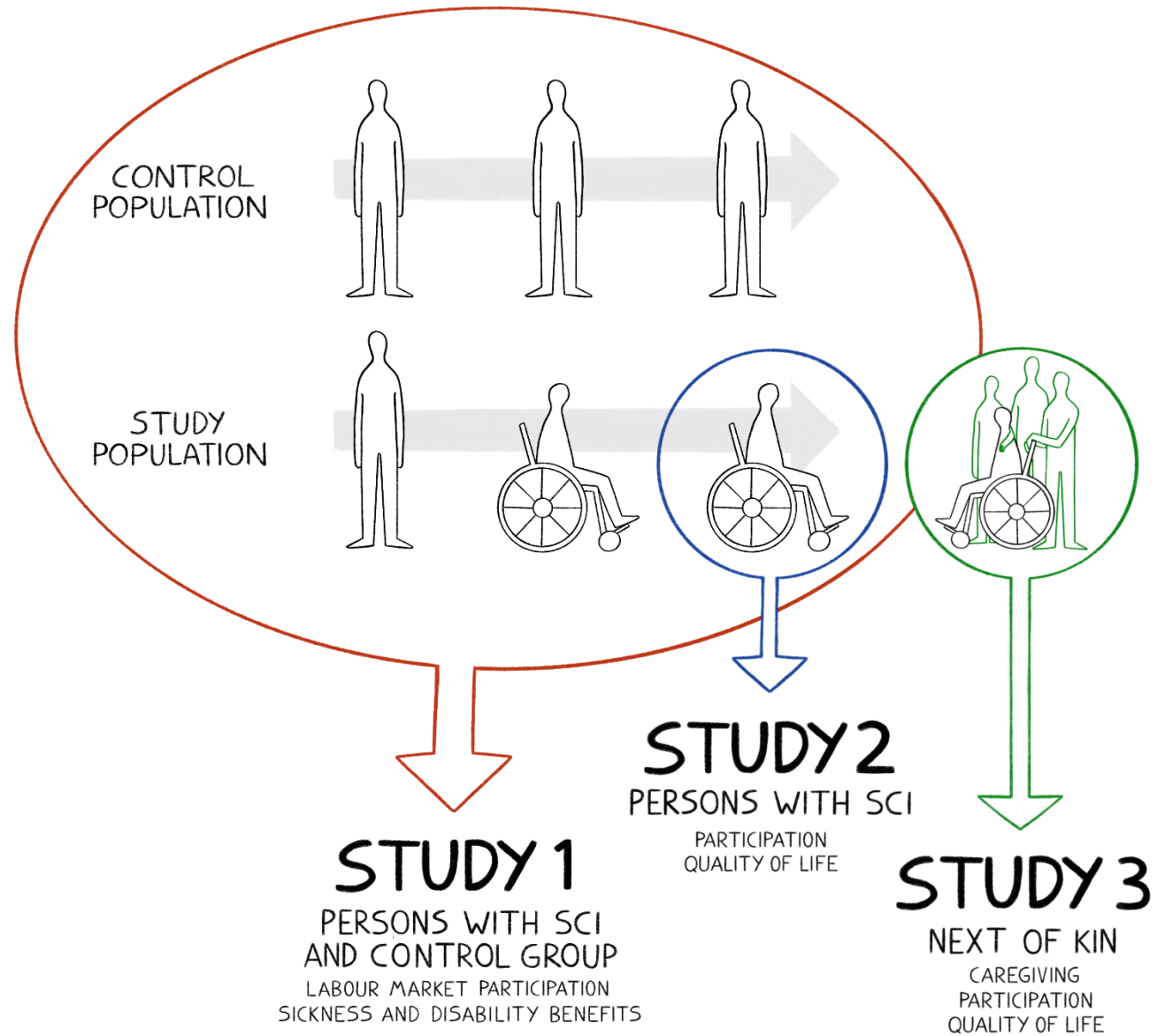
Brukerrepresentanter - medforskere



Brukermedvirkning

Brukermedvirkning i forskning







Landsforeningen for Ryggmargsskade
Schweigaardsgt. 12, Postboks 9217 Grønland, 0134 Oslo

Til Extrastiftelsen

Dato: 19.05.2017

EGENERKLÆRING FRA LANDSFORENINGEN FOR RYGGMARGSSKADDE

Erklæring samarbeidspartner til forskningsprosjektet: «Register research in combination with health surveys and patient data, to assess work participation and quality of life among persons with spinal cord injury and their caregivers».

Å få en ryggmargsskade er en stor påkjenning og fører til store endringer i livet for personen selv, men også for pårørende. Det er et stort behov for å samle informasjon og kunnskap om hvordan en ryggmargsskade påvirker hverdagen og livskvaliteten for personen med skaden selv og for omsorgspersonene rundt. Landsforeningen for Ryggmargsskade (LARS) ser på denne studien som et viktig og nødvendig arbeid på veien med å kartlegge omsorgsbelastning, forbedre livskvaliteten og øke deltagelsen i samfunnet for personer med en ryggmargsskade og pårørende.

Annette Halvorsen har gjennom sitt arbeid som ryggmargsskadelege, leder for Norsk ryggmargsskaderegister og leder for prosjektet for etablering av et Nordisk Ryggmargsskaderegister hatt et nært og godt samarbeid med LARS.

LARS støtter prosjektet og stiller som samarbeidspartner. Vi ser fram til å bidra med vårt brukerperspektiv for økt fokus på konsekvensene etter alvorlig funksjonstap for personen som får en ryggmargsskade og deres pårørende.

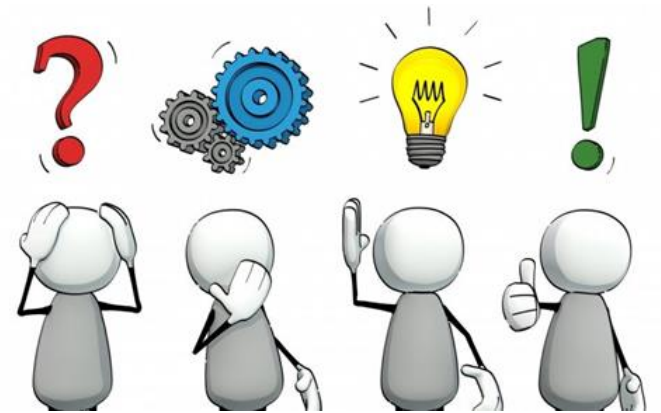
LARS støtter dette prosjektet og stiller som samarbeidspartner.

Med Vennlig hilsen


Anders Nupen Hansen
Leder for LARS

Første møte - gjensidige forventninger

- Roller
- Ulike faser
- Behov for tilrettelegging/opplæring
- Honorar
- Møteform og språk



Bilder fra: <https://www.inc.com>

Utforming og testing av spørreskjemaer

Svarsendingstjenesten
Svarsending 4689
0093 OSLO

WORK **NorSCIR** **ST. OLAVS HOSPITAL** **NTNU**

Å leve med en ryggmargsskad(d)e - Mestringsstudien

Forespørsel om deltakelse i forskningsprosjekt

Bakgrunn og hensikt
Du mottar denne forespørselen fordi du tidligere har samtykket til registrering i Norsk ryggmargsskaderregister og at vi kan kontakte deg. Nå vil vi spørre om du vil delta i et forskningsprosjekt om mestrings i hverdagen for personer med en ryggmargsskade. Kunnskap fra studien kan brukes til å forbedre ryggmargsskadeomsorgen, både for personer med en ryggmargsskade og deres pårørende. Studien gjennomføres ved Sek sjon for medisinske kvalitetsregistre, St. Olavs Hospital og Institutt for samfunnsmedisin og sykepleie, NTNU. Studien er finansiert av ExtraStiftelsen gjennom Landsforeningen for Ryggmargsskadede (LARS). Prosjektet er godkjent av Regional komite for medisinsk og helsefaglig forskningsetikk, saksnummer 2018/294/REK Midt

Hva innebærer deltakelse i studien?
Studien innebærer at du fyller ut et spørreskjema om din livskvalitet, deltakelse, mestrings, funksjon og arbeid. Ved å fylle ut dette spørreskjemaet samtykker du til deltakelse i studien. Det tar ca. 25-35 min å besvare skjemaet. Spørreskjemaet fylles ut elektronisk gjennom Helsenorge eller Digipost. De som ikke har en bruker her, får automatisk et papirskjema i posten. Hvis du ikke vil fylle ut elektronisk, kontakt prosjektet for å svare på annen måte (kontaktinformasjon finner du nederst i dette brevet).

I prosjektet vil vi benytte allerede innsamlende opplysninger om deg fra Norsk ryggmargsskaderregister, som for eksempel kjønn, alder og informasjon om din ryggmargsskade. Vi vil også innhente opplysninger om utdanning, deltakelse i arbeid og bruk av ulike trygdeytelser i tiden før og etter ryggmargsskaden fra offentlige registre. Dette har du allerede gitt samtykke til.

SCICA WORK pasientskjema - side 1 av 20

FORSK Forskningsprosjektet "Å leve med ryggmargsskad(d)e"

Startside Skjema ePROM Forskningsobjekter Verktøy Administrasjon

Administrasjon / Skjematyper / SCICA WORK pasientskjema / V1

SCICA WORK pasientskjema: V1 ePROM Publisert

Skjemabygger ePROM oppsett Forhåndsvis: Skjema i eFORSK Tekstlig visning Verdier Skjema i ePROM

SCICA WORK pasientskjema

Vennligst fyll ut spørreskjemaet så fullstendig som mulig.

Hvis du fyller ut skjemaet elektronisk, blir svarene først registrert når du har svart på alt og trykket på "Levere".

Om deg

1. Hvilken utdanning er den høyeste du har fullført?

Grunnskole (barne- og ungdomsskole, framhaldsskole, folkehøgskole)
 1-2 Årig videregående skole (realskole, middelskole, yrkesskole)
 3 år i videregående skole (Artium, økonomisk gymnas, allmennfaglig retning i videregående skole)
 Fagbrev eller svennebrev
 Høgskole/universitet, mindre enn 4 år
 Høgskole/universitet, 4 år eller mer

2. Hvilke av følgende alternativer er mest dekkende for din hovedaktivitet?

I jobb (ansatt eller selvstendig næringsdrivende)
 Alderspensjonist (inkl AFP)
 Uføretrygd, annen pensjon/trygd
 Hjemmeværende
 Student
 Arbeidsledig / arbeidsøker

3. Hvor mange timer per uke utfører du betalt arbeid?

timer per uke

Formidling facebook og medlemsblad LARS

One Call VPN 21:06 47%

LARS - Landsforeninge...

Anders Nupen Hansen Administrator · 20. juni · 🌐

Alle invitasjoner for deltakelse i Norges første forskningsprosjekt som inkluderer både personer med en ryggmargsskade og pårørende har nå blitt sendt ut.

En stor takk til alle som har allerede svart!

Har du/dere allerede svart?

Informasjon om studien vises på denne videoen. Ved eventuelle spørsmål kan man ta kontakt med prosjektleder overlege Annette Halvorsen. (Annette.Halvorsen@stolav.no)

PROSJEKTET HAR SOM MÅL Å FRAMBRINGE NY KUNNSKAP OM

Du og 7 andre 4 kommentarer

WOSICA STØTTET AV I SPRIEISEN DAG

Stort engasjement i prosjektet for og av personer med en ryggmargsskade og deres pårørende!!

Stor engasjement

Alle personer som har tidligere samtykket til registrering i Norsk ryggmargsskaderregister i perioden 2011-2017 har fått tilsendt en invitasjon til å delta i forskningsprosjektet «Å leve med ryggmargsskad(e)». Det er fantastisk at hele 342 personer med en ryggmargsskade har svart på dette spørreskjemaet. Selve spørreskjemaet inneholder spørsmål om daglig livet, funksjon, arbeid, livskvalitet, mestring og psykisk helse.

Deltagerne ble også spurt om de har en pårørende som ønsker å delta i en pårørendestudie. Hensikten med den er å frembringe ny kunnskap om hvordan det er å være pårørende til en person med en ryggmargsskade, og betydningen for mestring, livskvalitet og arbeidsdeltakelse. Veldig gledelige at det er det 101 personer som har svart ja og oppgitt kontaktinformasjon til sin nærmeste pårørende. Så langt har 71 av de pårørende sendt inn sine svar! Tusen takk for god og nyttig respons! Hvis du som pårørende har blitt invitert og ikke svart ennå: Det er ikke for sent! Bare fyll ut skjemaet du har fått og send inn.

Neste fase

Prosjektet har nå kommet i en ny fase hvor vi skal bearbeide og analysere alle data fra spørreskjemaer, Norsk ryggmargsskaderregister og offentlige registre som vi har fått samtykke til. I tillegg til norske og internasjonale forskere bidrar også brukerrepresentanter i prosjektet og analysene. Tre brukerrepresentanter er medforskere i prosjektet og bidrar med egen erfaringskunnskap. Dette er viktig for å sikre en høy grad av relevans og nytteverdi for personer med en ryggmargsskade og deres pårørende. Selve studieresultatene vil i tillegg til internasjonale publikasjoner også bli offentliggjort i Patetra!

Medforsker Anders Nupen Hansen sier følgende om prosjektet:

«Som medforsker i dette prosjektet får vi godt innblikk i selve prosjektet. Vi er delaktig i utforming av spørreundersøkelsen og får ta del i alle fasene fra start til slutt i prosjektet. Vi sliter på masse egenertaring som kommer godt med i prosjektarbeidet. Prosjektet som har med mestring, livskvalitet og arbeidsdeltakelse er et utrolig viktig prosjekt. Det blir spennende å jobbe videre frem til konklusjoner om dette tema. Vi vil nok få bekreftet mange antagelser, samtidig som dette vil danne grunnlag for å jobbe videre med tematikken i vår organisasjon.»

Har du spørsmål om prosjektet?

Prosjektet har godkjenning av etisk komite og skal ivareta informasjonssikkerhet og personvern. Dersom du har spørsmål, kan du kontakte prosjektleder, overlege og doktorgradsstipendiat Annette Halvorsen, annette.halvorsen@stolav.no, eller veileder professor Aslak Steinsbekk, aslak.steinsbekk@ntnu.no

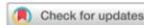
Analyser og resultater



Medforfatterskap artikler

J Rehabil Med 2021; 53: jrm00217

ORIGINAL REPORT



PARTICIPATION AND QUALITY OF LIFE IN PERSONS LIVING WITH SPINAL CORD INJURY IN NORWAY

Annette HALVORSEN, MD^{1,2,3}, Kristine PAPE, PhD¹, Marcel W. M. POST, PhD^{4,5}, Fin BIERING-SØRENSEN, PhD⁶, Steinar MIKALSEN⁷, Anders Nupen HANSEN⁸ and Aslak STEINSBEKK, PhD³
From the ¹Clinic of Physical Medicine and Rehabilitation, Department of Spinal Cord Injuries, ²Department of Medical Quality Registries, St Olavs Hospital, Trondheim University Hospital, ³Department of Public Health and Nursing, Norwegian University of Science and Technology, Trondheim, Norway, ⁴Center of Excellence for Rehabilitation Medicine, Brain Centre Rudolf Magnus, University Medical Centre Utrecht, University Utrecht and De Hoogstraat Rehabilitation, Utrecht, ⁵University of Groningen, University Medical Centre Groningen, Centre for Rehabilitation, Groningen, The Netherlands, ⁶Department for Spinal Cord Injuries, Copenhagen University Hospital, Rigshospitalet, and Institute for Clinical Medicine, University of Copenhagen, Denmark, ⁷User Representative, Skogn and ⁸User Representative, Kongsvinger, Norway

Objectives: To describe the association between sociodemographic and spinal cord injury characteristics, of people living with spinal cord injury, and participation and quality of life, and to study the association between participation and quality of life in this group of people.

Design: Persons registered in the Norwegian Spinal Cord Injury Registry after post-acute rehabilitation between 2011 and 2017 were invited to participate in a survey in 2019 when they were in a community setting. **Subjects:** A total of 339 people living with spinal cord injury.

Methods: The Frequency scale and Restrictions scale of the Utrecht Scale for Evaluation of Rehabilitation-Participation were used to measure participation. Quality of life was measured as life satisfaction with the World Health Organization Quality of Life assessment (WHOQoL-5) and mental health was measured using the Mental Health subscale (MHI-5).

Results: Overall, sociodemographic characteristics were more prominently associated with quality of life and participation than were spinal cord injury characteristics. Currently working as main activity and having a family income in the highest quartile were associated with higher scores on all 4 measures of participation and quality of life. There was a strong gradient between higher level of participation (frequency and restrictions) and better quality of life.

Conclusions: Participation was strongly associated with life satisfaction and mental health in people living with spinal cord injury. This indicates that participation issues should be given greater priority during post-acute rehabilitation, follow-up and subsequent care efforts provided in the community.

Key words: spinal cord injuries; participation; quality of life; Norway.

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J Rehabil Med 2021; 53: jrm00217

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Participation provides opportunities for the fulfilment of basic human needs and can be an important determinant of quality of life (QoL) (1). Persons living

LAY ABSTRACT

Having paid work, leisure-time activities and good relationships with other people is important for one's quality of life. For people living with spinal cord injury, it may be more difficult to participate in such activities than it is for people without health problems. A survey on participation problems was carried out among Norwegians living with spinal cord injury. Sociodemographic factors, such as family income and education, were found to have a greater impact on quality of life and participation, than the severity of the injury itself. Participation was strongly associated with life satisfaction and mental health. This indicates that participation issues should be given greater priority.

with spinal cord injury (SCI) may, however, experience restrictions or barriers to participation in different domains, including employment or social-recreational activities (2). Research on issues related to participation problems among persons with SCI is, however, limited. In a critical systematic review on social and community participation following SCI (3), the authors emphasized that the samples in the reviewed studies were relatively small, that the instruments used were often developed before the introduction of the International Classification of Functioning, Disability and Health (ICF), and that the use of the term "participation" varied. In addition, knowledge about the impact of injury characteristics on participation is underdeveloped (2). Furthermore, limited attention has been given in the literature to how clinical practice can be adapted to improve participation in persons with SCI. To do so, more knowledge of factors influencing participation is needed.

In the ICF, "participation" refers to the involvement of an individual in a life situation and represents the social perspective on functioning (4). To measure participation, it has been recommended to measure participation both as the so-called objective state and subjective experience (5). Objective participation can be measured as self-reported frequencies of behaviour, while subjective participation concerns self-reported experienced restrictions in participation in society. It has been commented that the ICF definition of participation does not adequately capture this (6).

J Rehabil Med 2022; 54: jrm00278

ORIGINAL REPORT

CAREGIVING, PARTICIPATION, AND QUALITY OF LIFE OF CLOSEST NEXT OF KIN OF PERSONS LIVING WITH SPINAL CORD INJURY IN NORWAY

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Objectives: To investigate how next of kin of persons with spinal cord injury (SCI) experience various life areas in terms of caregiving, participation, and quality of life, and the impact personal characteristics of next of kin and SCI characteristics.

Design: Survey of next of kin linked to data on persons with SCI in the Norwegian SCI Registry.

Participants: A total of 73 next of kin identified by persons with SCI.

Methods: Outcome measures were caregiving (4 measures), participation (1 measure), and quality of life (2 measures).

Results: Participants (73% partners, 73% female, mean age 56.4 years) gave various support to the person with SCI and considered it important to care and were happy to do so. Three-quarters of participants reported good mental health and life satisfaction, while one-quarter reported high levels of caregiver strain, especially related to emotional adjustments. Higher levels of caregiver strain were reported by participants of working age (<67 years), and by those with middle level education.

Conclusions: The majority of next of kin of persons living with SCI in Norway are doing well in most life areas. Caregiver strain may be reduced by strengthening the ability of next of kin to cope with emotional challenges.

Key words: spinal cord injury; caregiver; caregiver burden; participation; quality of life; Norway.

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Spinal cord injury (SCI) often drastically disrupts the lives of both the individuals with SCI and the people

LAY ABSTRACT

A spinal cord injury (SCI) often drastically disrupts the lives of both the individuals with SCI and the people surrounding them, such as family members. Caregiving for a loved one with SCI involves both physical and emotional investment. A survey was carried out of the caregivers of 73 persons living with SCI in Norway to assess their life situation. The study found that the majority of caregivers of persons living with SCI in Norway are doing well in most life areas. Three out of 4 caregivers reported good mental health and life satisfaction. All participants considered it important to care and most were happy to do so. Nevertheless, one-quarter reported high levels of strain, especially related to emotional adjustments. Most at risk for caregiver strain were participants of working age and those with secondary education. Caregiver strain may be reduced by strengthening the ability of the caregiver to cope with emotional challenges.

surrounding them. Many next of kin (close relatives, spouses, etc.) provide extensive support to persons with SCI (1, 2). This support is often necessary for persons with SCI to continue living at home and to maintain their well-being (3). Previous studies have reported that between 25% and 50% of partners of persons with SCI experience high levels of caregiver burden (4, 5).

The level of caregiver burden can be influenced by caregiver characteristics, such as age, sex, level of education, occupation status, and the type of relationship between caregiver and care recipient (2, 4, 6). In addition, the personal and injury characteristics of the person with SCI receiving support impacts the support provided and the perceived caregiver burden (2). However, the majority of previous studies of next of kin are based on samples that are not representative of the population of next of kin of persons with SCI and on self-reported data on injury characteristics provided by the caregiver (2). Therefore, studies using clinical register data, which

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Labour market participation after spinal cord injury. A register-based cohort study

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STUDY DESIGN: A register based cohort study.

OBJECTIVES: To investigate labour market participation following spinal cord injury (SCI) and to describe the impact of personal and SCI characteristics.

SETTING: Norway.

METHODS: Persons registered with SCI in the Norwegian SCI registry 2011–2017, and matched reference individuals without SCI from the general population (named controls) were followed for up to six years after injury using national registry data on employment, education, income, and social security benefits. Main measures of labour market participation were: (1) receiving any amount of pay for work, and (2) receiving sickness and disability benefits.

RESULTS: Among the 451 persons with SCI (aged 16–66 years and working before injury), the estimated percentages receiving pay for work and sickness and disability benefits in the six years after injury were 63% (95% CI 57–69) and 67% (95% CI 61–72). Corresponding percentages for the controls (n = 1791) were 91% (95% CI 90–93) for receiving pay for work and 13% (95% CI 12–15) for receiving sickness and disability benefits. Among persons with SCI, less severe neurological outcome, higher level of education, younger age at injury, and a stronger pre-injury attachment to employment (higher employment income, having an employer, less receipt of benefits), were associated with higher labour market participation.

CONCLUSION: SCI substantially decreased labour market participation up to six years after injury compared to matched controls. Even if a relatively large proportion of persons with SCI remained in some degree of work activity, more than half did so in combination with receiving benefits.

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INTRODUCTION

Employment is a key rehabilitation outcome for people with spinal cord injury (SCI), and it tends to be positively associated with adjustment to SCI, life satisfaction, a sense of purpose, mental stimulation, social contact and well-being (1). The level of employment among people with SCI is positively influenced by a number of factors, such as personal factors (younger age at time of injury, higher level of education, higher motivation), SCI-related characteristics (less severe neurological outcome) and employment-related factors (support from the employer, possibility to continue working in the same organisation) (2–6). Most people with SCI can potentially be in employment if they get access to appropriate work accommodations (1). However, the average employment rate among 9875 persons with SCI in 22 countries across the world was 38% (ranging from 10% to 61%), which was considerably lower than in the respective general

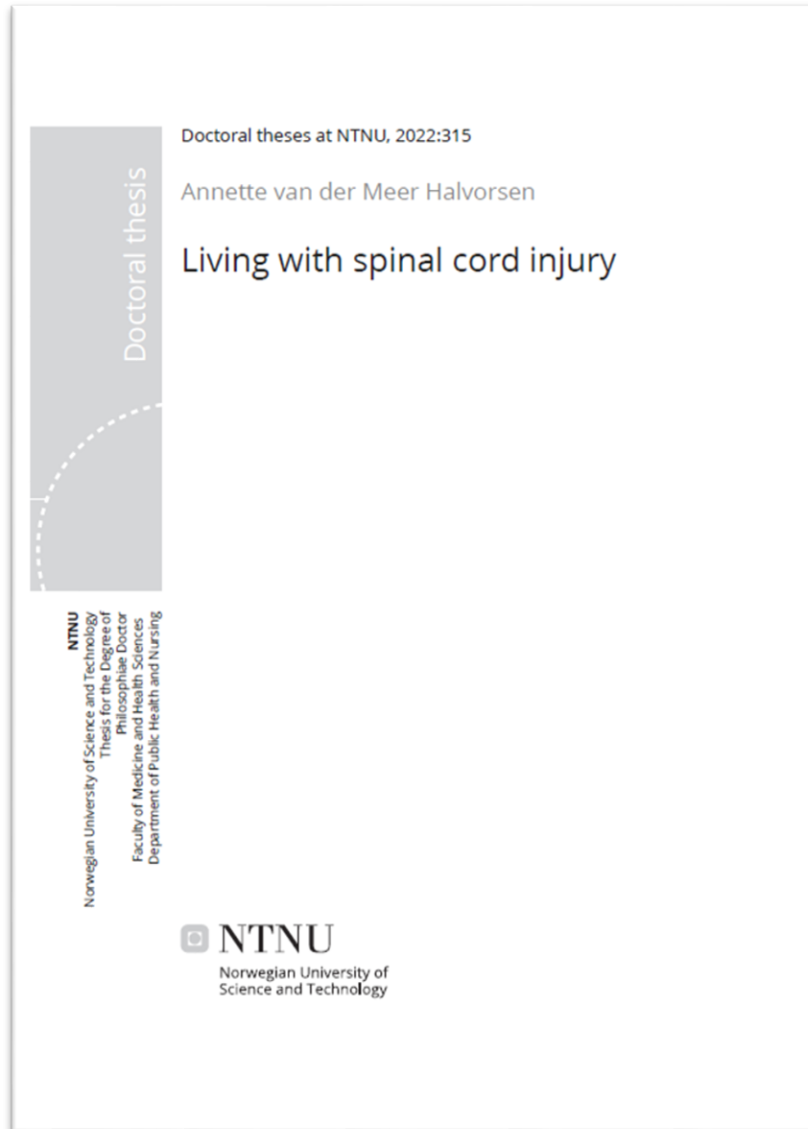
working populations (7). Contextual country-level factors, such as labour market systems and policies with respect to social security, vocational rehabilitation and employment, may explain some of the differences in employment levels across countries (8).

Norway has a well-developed welfare and health care system with universal rights to health and welfare provisions, a strong policy emphasis on high employment, and high expenditure on return to employment measures after sickness or injury. Compared with other European countries, a large portion of the Norwegian population is on sickness and disability benefits (9); 17% in the 18–66 age group (10). Still, in the last quartile of 2021, 72.3% of the population aged 15–74 was part of the workforce (11). The proportion employed following SCI in Norway have been reported to range from 35% to 52% in different studies (4, 5, 7, 12), which shows that there is considerable employment gap between persons with SCI and the general population.

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