

# Brukermanual NordicSCIR, gyldig fra 2024 (5.0)



## Innlogget som Pasientansvarlig:

## Hovedside IceSCIR

På startside til registeret finnes fanene: **Create patient** og **Patients**. Nyttige lenker til benyttelse i registerarbeidet ligger lett tilgjengelig på startside. Ved innlogging vil islandsk språk automatisk velges. På nordisk nettside [www.nordicscir.no](http://www.nordicscir.no) legges aktuelle papirskjema til benyttelse i registerarbeidet.

The screenshot shows the IceSCIR web application interface. At the top, it displays "Innlogget som Ola Testersen" with a Norwegian flag icon and a "Logg ut" button. Below this is a search bar labeled "Pasientsøk" with a search icon and a dropdown arrow. A language selection dropdown menu is open, showing options: "English language", "Norsk språk", "Dansk sprog", "Íslenska tungumál", and "Svenska språk". The main content area is titled "IceSCIR (Icelandic Spinal Cord Injury Registry)" and includes a navigation menu with "Home", "Create patient", and "Patients". A search bar for patients is also present. The main content is divided into two columns. The left column contains the "IceSCIR (Icelandic Spinal Cord Injury Registry)" title, a description of SCI, the registry's purpose, main objectives, and participating SCI units. The right column contains a "News" section with two entries: "Version 3.1" (dated 19.01.2018) and "Version 3.0" (dated 01.12.2017), each with a list of updates.

**IceSCIR (Icelandic Spinal Cord Injury Registry)**

A spinal cord injury (SCI) may cause life-long impairment with various late complications that requires management and follow up. NordicSCIR was established in 2016 as a result of a project for a Nordic cooperation on highly specialized treatments, initiated by The Nordic council of ministers.

NordicSCIR is based on variables from the international SCI Data Sets. The registry runs on an electronic platform and registration is performed through secured web. Written informed consent is obtained from the participants before entering data into the registry. Data from the Nordic registry will be stored and processed in Norway, the data controller is St Olavs hospital.

**NordicSCIR main objectives:**

- To ensure and improve care for individuals with SCI.
- To facilitate comparisons regarding injuries, treatment, and outcomes between patients, centers and countries.
- To provide information regarding prevention; primary, secondary and tertiary.

**Participating SCI units:**

- Denmark
  - Spinal Cord Injury Center of Western Denmark, Department of Neurology, Regional Hospital of Viborg
  - Clinic for Spinal Cord Injuries, NeuroScience Centre, Rigshospitalet, University of Copenhagen
- Iceland
  - Landsþítali University Hospital, Department of Rehabilitation Medicine at Grensas, Álmgardi, Reykjavík
- Sweden
  - Rehabiliteringsmedicinska kliniken, US i Linköping, Region Östergötland
- Norway
  - Sunnaas Sykehus (Helseregion Sør-Øst)
  - Haukeland Universitetssykehus Bergen (Helseregion Vest)
  - St. Olavs Universitetssykehus Trondheim (Helseregion Mitt og Nord)

**Documents - Norway**

[Brukermanual](#)

**Current links**

[International Spinal Cord Society](#)

**News**

**Version 3.1** Date: 19.01.2018

- Updated documents
- Upgraded MRS core to v7.3.1

**Version 3.0** Date: 01.12.2017

- New variable on all forms: "FirstTimeClosed". Will contain the date for the first time (after this version) the form was closed
- New variable on Spinal Cord Injury Core form: "Non-traumatic spinal cord dysfunction"
- New variable on Spinal Cord Injury Core form: "Death during rehabilitation"
- New variable on Control Form: "Control form number"
- New option in variable "Ventilatory Assistance"
- Sacral option S04 and S05 merged into one: S04-05
- Enabled swedish language and added Linköping hospital
- Updated and added documentation on front page
- Changed texts in code book for Lower urinary tract function form
- Upgraded MRS core to v7.2.1

## Finn pasient

For å opprette en ny pasient trykker man på fanen Create patient. Her legges alle pasientopplysninger inn. Benytt pasientens personnummer i feltet Identity number.

The screenshot shows the 'Stofna sjúkling' (Create patient) form in the IceSCIR web application. The form includes the following fields and options:

- Identity number:
- Date of birth:  (with a calendar icon)
- First name:
- Last name:
- Gender:  Male,  Female
- Address:
- Postal code:
- Postal city:

A blue 'Create patient' button is located at the bottom of the form.

Man kommer da direkte til **Create a new registration of a SCI injury**.

The screenshot shows the 'Create a new registration of a SCI injury' button in the IceSCIR web application. The button is blue and located below a table with the following columns: Form title, Form date, Last saved, and Status. The table is currently empty.

Her registreres innleggelsesdato akutt sykehus. Denne dato spesifiserer første akuttinnleggelse på sykehus etter ryggmargskaden (AdmitDt). Opplasting av samtlige skjema er knyttet til AdmitDt. Det betyr at AdmitDt i 2023 generer skjema for 2023. Mens AdmitDt tidligere år generer opplasting av tilhørende skjema for dette året. Da vi omtrent har årlige oppdateringer, vil det være små endringer inne i skjema, og derfor denne strukturen.

Hovedskjema skal registreres kun en gang, ved første opphold til primærrehabilitering. Alle variabler registreres etter ISCoS variabelbeskrivelse. Beskrivelsen ligger inne i den elektroniske løsningen som hjelpetekst til hver enkelt variabel. Du får den opp ved å klikke på spørsmålstegnet utenfor den enkelte variabel.

Det er valideringsregler som skal hindre logiske feilregistreringer. Reglene vil komme opp ved ferdigstilling av skjema. Skjema mellomlagres kontinuerlig. Men må ferdigstilles.

Personalia kommer opp når man klikker på pasientens navn.

Ved senere søk på pasienten vil alle tidligere registrerte skjema bli synlig i pasientoversikten.

**Vis mine pasienter** her vises en oversikt over de pasienter som tidligere er innregistrert.

**Skjema** Under finn skjema kan du søke fram tidligere registrerte skjema. Velg Fra/til dato, status på skjema (alle/kladd/ferdigstilt/returnert). Du kan også velge om du ønsker å kun se på dine egne skjema eller hele sykehuset. Skjema mellomlagres kontinuerlig. Men må ferdigstilles.

## 1. Upplýst samþykki

Upplýst samþykki:


Dagsetning upplýsts samþykkis:

- 0 No
- 1 (Not in use)
- 2 Register in NordicSCIR (Nordic consent required)

Registrering i NordicSCIR krever samtykke fra pasienten. Velg dato for innhenting av samtykke. Skjemaet kan ikke lukkes uten samtykke.

## 2. Dagsetningar

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Slysadagur óþekktur:  

Slysadagur:   

Dagsetning innlagnar:   

Dagsetning innlagnar á endurhæfingardeild:   


Dagsetning útskriftar:   

Heildarfjöldi daga utan spítala fyrir  
endurhæfingu

Heildarfjöldi daga utan spítala á  
endurhæfingartímabilinu

Fjöldi legudaga á sjúkrahúsi fyrir innlögn á  
endurhæfingardeild

Heildarfjöldi daga á endurhæfingardeild

Heildarfjöldi daga á spítala:  

Dánardagur:  

**Variable:**

Slysadagur óþekktur (InjuryDateUnknown)

**Description:**

This variable is used when injury date is unknown. Occurs for example when a non-traumatic injury has occurred gradually

**Notes:**

Mark when Injury date is unknown

**Variable:**

Slysadagur (InjuryDt)

**Description:**

This variable specifies the date the spinal cord injury occurred.

**Notes:**

Record the year, month, and day of injury. For non-traumatic cases, date of injury should be coded as the approximate date of the first physician visit for symptoms related to spinal cord dysfunction.

**Variable:**

Dagsetning innlagnar (AdmitDt)

**Description:**

This variable specifies the date of admission to the first acute care hospital after the spinal cord injury occurred.

**Notes:**

Record the year, month, and day of first acute care hospital admission.

**Variable:**

Dagsetning innlagnar á endurhæfingardeild (AdmitRehDt)

**Description:**

This variable specifies the date of transmission/ admission to SCI rehabilitation unit for individuals with SCI to one of the hospitals that provide specialized care, in (Denmark, Norway, Finland, Iceland and Sweden), after finished acute treatment in another hospital ward ( Intensiv, orthopedic, neurosurgical, or other wards responsible for acute care after a SCI.

**Notes:**

Record the year, month and date of SCI rehabilitation unit

**Variable:**

Dagsetning útskriftar (DischgDt)

**Description:**

This variable specifies the date of discharge from the last inpatient hospital when all planned acute care and rehabilitation phases of treatment are completed.

**Notes:**

Record the year, month, and day of discharge from the last inpatient hospital when all planned acute care and rehabilitation phases of treatment are completed. If the month or day is unknown, it should be coded "99"; if the year is unknown, it should be coded "9999".

Numeric format is used rather than date format for computer storage of the data because the unknown codes are not valid dates. On this date, patients will typically be discharged home (with no further planned inpatient admissions) or discharged to a long-term care facility. Outpatient rehabilitation or a home rehabilitation program may continue after this date, or limited rehabilitation therapy may continue in the long-term care facility. If the patient dies during inpatient hospitalization, this will be the date of death.

If there is a planned interruption in the inpatient hospitalization and the patient is readmitted for further care, then the date of inpatient discharge is the date of discharge for the planned readmission. An example of this would be a patient who is discharged home temporarily until he is ready for further rehabilitation and then is brought back to the hospital for completion of inpatient rehabilitation. The date of inpatient discharge is the last date of discharge with no further planned hospitalizations. Subsequent admissions and discharges for treatment of unplanned secondary medical complications such as infections or pressure sores are not to be coded in this variable.

Variable:

Heildarfrjöldi daga á spítala (HosptlDy)

Description:

This variable specifies the total number of days spent in the hospital from the date of injury until discharge from the last inpatient treatment phase (the date of inpatient discharge).

Notes:

Do not count days when the patient is temporarily discharged pending readmission

Innregistreringsløsningen skiller på når i forløpet pasienten er ute av sykehuset. Det regnes da ut **Antall døgn innlagt på rehabilitering** og **Antall døgn innlagt på sykehus**. Merk at ved antall døgn ute av sykehus under rehabilitering: Legg inn de permisjoner som har en varighet på 5 dager eller mer. Det legges ikke inn helgepermisjoner, men i de tilfeller hvor pasienten har hatt en utskrivelse/permisjon som strekker seg over 5 dager.

Variable:

Dánardagur (Dead)

Description:

This variable specifies the date of death for patients who have died during primary rehabilitation

Notes:



### 3. Orsök slyss

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Orsök slyss:  ▼ ⓘ

Skaði á hryggsúlu:  ▼ ⓘ

Aðrir áverkar:  ▼ ⓘ

Skurðaðgerð á hrygg:  ▼ ⓘ

Aðstoð við öndun:  ▼ ⓘ

Útskrifast hvert:  ▼ ⓘ

**Variable:**

Orsök slyss (Scietiol)

**Description:**

This variable identifies the etiology of the SCI. SCI is impairment of the spinal cord or cauda equina function resulting from the application of an external force of any magnitude or a dysfunction or disease process.

**Notes:**

For traumatic spinal cord injuries, this variable has been adapted from the International Classification of External Causes of Injuries (ICECI). In its entirety, the ICECI provides a multi-axial description of the event that resulted in SCI. Four axes have been developed, including the External Cause of Injury Axis, the Intent of Injury Axis, the Place of Injury Axis, and the Injury Activity Axis. Use of the complete version of the ICECI (including all four axes and subcategories not included in the core data set) is recommended for injury surveillance activities or other research studies the goal of which would be to provide information useful for the development of interventions targeted at primary prevention of spinal cord injuries. Because it is possible that an injury event may be classifiable into more than one of these categories, the following prioritization has been established for assigning codes:

First coding priority for traumatic SCI is given to sports. If the injury event involved sports it should be coded as a 1 (Sports) regardless of whether it involved assault, transport or a fall. Code 1 would be appropriate whenever the ICECI Injury Activity Axis would be coded as "sports and exercise during leisure time" (ICECI Injury Activity code 4), regardless of coding on other ICECI Axes. Second priority for traumatic SCI is given to Assault. If the event did not involve sports but it did involve an assault, then the event should be coded as a 2 (Assault) regardless of whether it involved transport or a fall. Code 2 would be appropriate whenever the ICECI Intent of Injury Axis would be coded as "assault" (ICECI Intent of Injury code 3) and the ICECI Injury Activity Axis would not be coded as "sports and exercise during leisure time" (ICECI Injury Activity code 4), regardless of other ICECI Axes. Third priority for traumatic SCI is given to Transport. If the event was neither sports nor assault related but it involved transport, then the event should be coded as 3 (Transport), regardless of whether it involved a fall. Code 3 would be appropriate whenever the ICECI External Cause of Injury Axis would be coded as "transport injury event" (ICECI External Cause of Injury code 1.1) and ICECI Intent of Injury Axis would not be coded as "assault" (ICECI Intent of Injury code 3) and ICECI Injury Activity Axis would not be coded as "sports and exercise during leisure time" (ICECI Injury Activity code 4).

Fourth priority for traumatic SCI is given to Fall. If the event was neither sports-, assault- nor transport-related and it involved a fall then it should be coded as 4 (Fall). Code 4 would be appropriate whenever the ICECI External Cause of Injury Axis would be coded as "falling, stumbling, or jumping" (ICECI External Cause of Injury code 1.5) and the ICECI External Cause of Injury Axis would not be coded as "transport injury event" (ICECI External Cause of Injury code 1.1), the ICECI Intent of Injury Axis would not be coded as "assault" (ICECI Intent of Injury code 3), and the ICECI Injury Activity Axis would not be coded as "sports and exercise during leisure time" (ICECI Injury Activity code 4).

Use code 5 (other traumatic cause) for birth injuries or all other known (specified) or unknown traumatic causes whenever codes 1 through 4 of this etiology variable do not apply. Paralysis secondary to surgical procedures when the patient does not have a neurological deficit prior to surgery would be coded in this category. It is possible to specify the cause.

Use codes 6 through 12 (non-traumatic causes) if there is impairment of the spinal cord or cauda equina function that is not caused either directly or indirectly by an external event.

Codes 6-11 include the most common non-traumatic causes as classified by the non-traumatic SCI datasets classification to the second level (New and Marshall 2014).

Code 12 should be used for all other less common causes of non-traumatic spinal cord damage and cases of non-traumatic spinal cord damage where the exact etiology is unknown. It is possible to specify the cause, e.g. with International Classification of Disease (ICD) code.

#### Code:

- 1 Sports
- 2 Assault
- 3 Transport
- 4 Fall
- 5 Birth injury or other traumatic cause, specify
- 6 Congenital or genetic etiology (e.g., spina bifida)
- 7 Degenerative non-traumatic etiology
- 8 Tumor – benign
- 9 Tumor – malignant
- 10 Vascular etiology (e.g., ischemia, hemorrhage, arteriovenous malformation)
- 11 Infection (eg., bacterial, viral)
- 12 Other non-traumatic spinal cord dysfunction, specify
- 99 Unspecified or Unknown

#### Variable:

Skaði á hryggsúlu (Vrtbrlnj)

#### Description:

This variable documents whether there was a spinal fracture and/or dislocation in addition to the spinal cord injury.

#### Notes:

Spinal fracture or dislocation is defined as any break, rupture, or crack through or between any part(s) of the vertebral column from the occiput to the coccyx.

**Variable:**

Aðrir áverkar (AssocInj)

**Description:**

This variable documents whether any of the following pre-specified major injuries occurred at the same time as the spinal cord injury: moderate to severe traumatic brain injury (Glasgow Coma Scale 12 or below at discharge), non-vertebral fractures requiring surgery, severe facial injuries affecting sense organs, major chest injury requiring chest-tube or mechanical ventilation, traumatic amputations of an arm or leg (or injuries severe enough to require surgical amputation), severe hemorrhaging, or damage to any internal organ requiring surgery.

**Notes:**

Do not include other associated injuries not listed above, negative findings from exploratory surgery, and do not include injuries that pre-date the spinal cord injury.

Variable:

Skurðaðgerð á hrygg (SpnlSurg)

Description:

This variable documents whether any of the following spinal surgical procedures were performed during the inpatient hospitalization following a traumatic SCI: laminectomy, neural canal restoration, reduction, spinal fusion, or internal fixation of the spine.

Notes:

Laminectomy is defined as removal of normal intact lamina or foreign body at the site of spinal cord damage. Neural canal restoration is defined as the removal of bone or disk fragments, blood clots, or foreign bodies (such as bullet fragments) from the spinal canal.

Reduction is defined as replacement of one or more dislocated, subluxated or angulated vertebra into anatomic or near anatomic alignment.

Spinal fusion is defined as the addition of a bone graft to the vertebrae for the purpose of achieving intervertebral fusion or stability. Internal fixation of the spine is defined as attaching rods, plates, wires, staples, etc. to the spine (individually or in combination) to provide internal surgical stabilization of the vertebral column.

Variable:

Aðstoð við öndun (VentAssi)

Description:

This variable documents any use of any type of ventilatory assistance used to sustain respiration on the date of final inpatient discharge (the date of discharge from the last inpatient rehabilitation hospital or discharge from the last acute care hospital if the patient is not admitted to a rehabilitation hospital).

Notes:

Ventilatory assistance includes, but is not limited to, mechanical ventilators, phrenic nerve stimulators, diaphragmatic pacing, external negative pressure devices, and Bilevel Positive Airway Pressure (BiPAP). Do not include routine administration of oxygen or periodic Intermittent Positive Pressure Breathing (IPPB) administration

Variable:

Útskrifast hvert (PlaceDis)

Description:

This variable specifies the discharge disposition of the patient.

Notes:

If the patient's place of residence does not fit into any of the above classifications, document it as "other, unclassified".

Code:

- 01 Private residence: includes house, condominium, mobile home, apartment, or houseboat
- 02 Hospital: includes mental hospital or other acute care hospital for management of continuing medical issues after spinal cord injury-related care and/or rehabilitation is completed
- 03 Nursing home: includes skilled nursing facilities and institutions providing essentially long-term, custodial, chronic disease care
- 04 Assisted living residence: includes residential non-institutional locations in which some level of support for activities of daily living is provided
- 05 Group living situation: includes transitional living facility or any residence shared by non-family members
- 06 Correctional institution: includes prison, penitentiary, jail, correctional center, etc.
- 07 Hotel or motel
- 08 Homeless: includes cave, car, tent, etc.
- 09 Deceased
- 10 Other, unclassified
- 99 Unknown

Veljið gildi

1 Heim

11. Áætlað heim

2 Sjúkrahús

3 Hjúkrunarheimili

4 Þjónustuíbúð

5 Sambýli

6 Fangelsi

7 Hótel eða Mótél

8 Heimilislaus

9 Látinn

10 Annað, óflokkað

99 Óþekkt




**Planlagt hjem** benyttes i de tilfeller hvor pasienten er planlagt hjem, men allikevel blir utskrevet til et midlertidig opphold. Dette er midlertidig pleiehjem/avlastningsplass, midlertidig institusjon som tilbyr trening, midlertidig sykehus og midlertidig familie/slekt/venner.

## 4. Taugastarfsemi við innlögn


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Ekki framkvæmt

Dagsetning skoðunar:   

### Skynhæð

Vinstri:   

Hægri:   

### Hæð hreyfigetu

Vinstri:   

Hægri:   

ASIA Impairment Scale (AIS):   

Variable:

Dagsetning skoðunar (ANeuExmDt)

Description:

Initial acute care hospital examination

Notes:

Record the year, month, and day.

When parts of the exam are done on different dates, the date of the exam should be the day on which most parts of the exam were done.

All exams should be performed within 72 hours of the corresponding admission or discharge date; however, data for exams performed later than 72 hours after admission or more than 72 hours before discharge can be included in the database.

The complete neurologic exam consists of the sensory and motor levels and the ASIA Impairment Scale. This exam must be performed by a physician or a designated person who has been trained using the ASIA guidelines.

**Variable:**

Vinstri (ASensLvlAreaL)

**Description:**

The sensory level (which may differ by side of body) is the most caudal segment of the spinal cord with normal sensory function for pinprick and light touch on both sides of the body. Right and left levels are documented separately at initial acute care hospital examination

**Notes:**

If only the alphabetic part of the level is known, it is permissible to use code C, L, T, or S followed by numeric code '99'. Use code X99 if the level is completely unknown, the exam was not done, or there was no corresponding admission or discharge.

SOURCE: Refer to the latest published version of The International Standards for Neurological Classification of Spinal Cord Injury for complete information on the sensory examination and a listing of all key points.

**Variable:**

Hægri (ASensLvlAreaR)

**Description:**

The sensory level (which may differ by side of body) is the most caudal segment of the spinal cord with normal sensory function for pinprick and light touch on both sides of the body. Right and left levels are documented separately at initial acute care hospital examination

**Notes:**

If only the alphabetic part of the level is known, it is permissible to use code C, L, T, or S followed by numeric code '99'. Use code X99 if the level is completely unknown, the exam was not done, or there was no corresponding admission or discharge.

SOURCE: Refer to the latest published version of The International Standards for Neurological Classification of Spinal Cord Injury for complete information on the sensory examination and a listing of all key points.

**Variable:**

Vinstri (AMtrLviAreaL)

**Description:**

The motor level (the lowest normal motor segment - which may differ by side of body) is defined by the lowest key muscle that has a grade of at least 3, provided the key muscles represented by segments above that level are judged to be normal (grade 5). Right and left levels are documented separately at initial acute care hospital examination

**Notes:**

The examiner's judgment is relied upon to determine whether a muscle that tests as less than normal (grade 5) may in fact be fully innervated. This may occur when full effort from the patient is inhibited by factors such as pain, positioning and hypertonicity or when weakness is judged to be due to disuse. If any of these or other factors impeded standardized muscle testing, the muscle should be graded as not testable. However, if these factors do not prevent the patient from performing a forceful contraction and the examiner's best judgment is that the muscle would test normally (grade 5) were it not for these factors, it may be graded as 5. For those myotomes that are not clinically testable by a manual muscle exam (i.e., C1 to C4, T2 to L1 and S2 to S5), the motor level is presumed to be the same as the sensory level.

If only the alphabetic part of the level is known, it is permissible to use code C, L, T, or S followed by numeric code '99'. Use code X99 if the level is completely unknown, the exam was not done, or there was no corresponding admission or discharge.

SOURCE: Refer to the latest published version of the 'International Standards for Neurological Classification of Spinal Cord Injury' for complete information on the motor examination and a listing of all key muscles.

Variable:

Hægri (AMtrLvlAreaR)

Description:

The motor level (the lowest normal motor segment - which may differ by side of body) is defined by the lowest key muscle that has a grade of at least 3, provided the key muscles represented by segments above that level are judged to be normal (grade 5). Right and left levels are documented separately at initial acute care hospital examination

Notes:

The examiner's judgment is relied upon to determine whether a muscle that tests as less than normal (grade 5) may in fact be fully innervated. This may occur when full effort from the patient is inhibited by factors such as pain, positioning and hypertonicity or when weakness is judged to be due to disuse. If any of these or other factors impeded standardized muscle testing, the muscle should be graded as not testable. However, if these factors do not prevent the patient from performing a forceful contraction and the examiner's best judgment is that the muscle would test normally (grade 5) were it not for these factors, it may be graded as 5. For those myotomes that are not clinically testable by a manual muscle exam (i.e., C1 to C4, T2 to L1 and S2 to S5), the motor level is presumed to be the same as the sensory level.

If only the alphabetic part of the level is known, it is permissible to use code C, L, T, or S followed by numeric code '99'. Use code X99 if the level is completely unknown, the exam was not done, or there was no corresponding admission or discharge.

SOURCE: Refer to the latest published version of the 'International Standards for Neurological Classification of Spinal Cord Injury' for complete information on the motor examination and a listing of all key muscles.

**Variable:**

ASIA Impairment Scale (AIS) (AAis)

**Description:**

This variable attempts to quantitate the degree of impairment

- 1) at initial acute care hospital examination
- 2) at discharge from the last inpatient hospital

**Notes:**

When an associated injury (e.g., traumatic brain injury) or certain non-neurologic impairments interfere with the performance of a complete neurological examination, the ASIA Impairment Scale should be coded Unknown.

For an individual to receive a grade of B, C, or D, he/she must be incomplete, that is, have sensory or motor function in the sacral segments S4-S5. Any sensation felt in the anal area during this part of the exam signifies that the patient is sensory incomplete (at least grade B). In addition, for an individual to receive a grade of C or D, the individual must have either (1) voluntary anal sphincter contraction or (2) sparing of motor function more than three levels below the motor level. Refer to the latest published version of the International Standards for Neurological Classification of Spinal Cord Injury

**Code:**

- A Complete Injury. No sensory or motor function is preserved in the sacral segments S4-S5.
- B Incomplete. Sensory but not motor function is preserved below the neurological level and includes the sacral segments S4-S5.
- C Incomplete. Motor function is preserved below the neurological level, and more than half of the key muscles below the neurological level have a muscle grade less than 3.
- D Incomplete. Motor function is preserved below the neurological level, and at least half of key muscles below the neurological level have a muscle grade greater than or equal to 3.
- E Normal. Sensory and motor function are normal.
- U Unknown or not applicable.

## 5. Taugastarfsemi við útskrift

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Ekki framkvæmt

Dagsetning skoðunar:   

### Skynhæð

Vinstri:   

Hægri:   

### Hæð hreyfigetu

Vinstri:   

Hægri:   

ASIA Impairment Scale (AIS):   

Variable:

Dagsetning skoðunar (FNeuExmDt)

Description:

Discharge from the last inpatient hospital

Notes:

Record the year, month, and day.

When parts of the exam are done on different dates, the date of the exam should be the day on which most parts of the exam were done.

All exams should be performed within 72 hours of the corresponding admission or discharge date; however, data for exams performed later than 72 hours after admission or more than 72 hours before discharge can be included in the database.

The complete neurologic exam consists of the sensory and motor levels and the ASIA Impairment Scale. This exam must be performed by a physician or a designated person who has been trained using the ASIA guidelines. (The International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI) - e-learning InSTeP).



**Variable:**

Vinstri (FSensLvlAreaL)

**Description:**

The sensory level (which may differ by side of body) is the most caudal segment of the spinal cord with normal sensory function for pinprick and light touch on both sides of the body. Right and left levels are documented separately at discharge from the last inpatient hospital

**Notes:**

If only the alphabetic part of the level is known, it is permissible to use code C, L, T, or S followed by numeric code '99'. Use code X99 if the level is completely unknown, the exam was not done, or there was no corresponding admission or discharge.

SOURCE: Refer to the latest published version of The International Standards for Neurological Classification of Spinal Cord Injury for complete information on the sensory examination and a listing of all key points.

**Variable:**

Hægri (FSensLvlAreaR)

**Description:**

The sensory level (which may differ by side of body) is the most caudal segment of the spinal cord with normal sensory function for pinprick and light touch on both sides of the body. Right and left levels are documented separately at discharge from the last inpatient hospital

**Notes:**

If only the alphabetic part of the level is known, it is permissible to use code C, L, T, or S followed by numeric code '99'. Use code X99 if the level is completely unknown, the exam was not done, or there was no corresponding admission or discharge.

SOURCE: Refer to the latest published version of The International Standards for Neurological Classification of Spinal Cord Injury for complete information on the sensory examination and a listing of all key points.

**Variable:**

Vinstri (FMtrLvlAreaL)

**Description:**

The motor level (the lowest normal motor segment - which may differ by side of body) is defined by the lowest key muscle that has a grade of at least 3, provided the key muscles represented by segments above that level are judged to be normal (grade 5). Right and left levels are documented separately at discharge from the last inpatient hospital

**Notes:**

The examiner's judgment is relied upon to determine whether a muscle that tests as less than normal (grade 5) may in fact be fully innervated. This may occur when full effort from the patient is inhibited by factors such as pain, positioning and hypertonicity or when weakness is judged to be due to disuse. If any of these or other factors impeded standardized muscle testing, the muscle should be graded as not testable. However, if these factors do not prevent the patient from performing a forceful contraction and the examiner's best judgment is that the muscle would test normally (grade 5) were it not for these factors, it may be graded as 5. For those myotomes that are not clinically testable by a manual muscle exam (i.e., C1 to C4, T2 to L1 and S2 to S5), the motor level is presumed to be the same as the sensory level.

If only the alphabetic part of the level is known, it is permissible to use code C, L, T, or S followed by numeric code '99'. Use code X99 if the level is completely unknown, the exam was not done, or there was no corresponding admission or discharge.

SOURCE: Refer to the latest published version of the 'International Standards for Neurological Classification of Spinal Cord Injury' for complete information on the motor examination and a listing of all key muscles.

#### Variable:

Hægri (FMtrLvlAreaR)

#### Description:

The motor level (the lowest normal motor segment - which may differ by side of body) is defined by the lowest key muscle that has a grade of at least 3, provided the key muscles represented by segments above that level are judged to be normal (grade 5). Right and left levels are documented separately at discharge from the last inpatient hospital

#### Notes:

The examiner's judgment is relied upon to determine whether a muscle that tests as less than normal (grade 5) may in fact be fully innervated. This may occur when full effort from the patient is inhibited by factors such as pain, positioning and hypertonicity or when weakness is judged to be due to disuse. If any of these or other factors impeded standardized muscle testing, the muscle should be graded as not testable. However, if these factors do not prevent the patient from performing a forceful contraction and the examiner's best judgment is that the muscle would test normally (grade 5) were it not for these factors, it may be graded as 5. For those myotomes that are not clinically testable by a manual muscle exam (i.e., C1 to C4, T2 to L1 and S2 to S5), the motor level is presumed to be the same as the sensory level.

If only the alphabetic part of the level is known, it is permissible to use code C, L, T, or S followed by numeric code '99'. Use code X99 if the level is completely unknown, the exam was not done, or there was no corresponding admission or discharge.

SOURCE: Refer to the latest published version of the 'International Standards for Neurological Classification of Spinal Cord Injury' for complete information on the motor examination and a listing of all key muscles.

**Variable:**

ASIA Impairment Scale (AIS) (FAIs)

**Description:**

This variable attempts to quantitate the degree of impairment

- 1) at initial acute care hospital examination
- 2) at discharge from the last inpatient hospital

**Notes:**

When an associated injury (e.g., traumatic brain injury) or certain non-neurologic impairments interfere with the performance of a complete neurological examination, the ASIA Impairment Scale should be coded Unknown.

For an individual to receive a grade of B, C, or D, he/she must be incomplete, that is, have sensory or motor function in the sacral segments S4-S5. Any sensation felt in the anal area during this part of the exam signifies that the patient is sensory incomplete (at least grade B). In addition, for an individual to receive a grade of C or D, the individual must have either (1) voluntary anal sphincter contraction or (2) sparing of motor function more than three levels below the motor level. Refer to the latest published version of the International Standards for Neurological Classification of Spinal Cord Injury

**Code:**

A Complete Injury. No sensory or motor function is preserved in the sacral segments S4-S5.

B Incomplete. Sensory but not motor function is preserved below the neurological level and includes the sacral segments S4-S5.

C Incomplete. Motor function is preserved below the neurological level, and more than half of the key muscles below the neurological level have a muscle grade less than 3.

D Incomplete. Motor function is preserved below the neurological level, and at least half of key muscles below the neurological level have a muscle grade greater than or equal to 3.

E Normal. Sensory and motor function are normal.

U Unknown or not applicable.

## 6. Annað

Mælt með eftirfylgd

Veljið gildi

Innan árs

Innan 2ja ára

Innan 3ja ára

Innan 4ra ára

Innan 5 ára

Ekki tímabært

Ekki búið að bóka tíma fyrir næstu eftirfylgd

Á ekki við

Variable:

Mælt með eftirfylgd (RecCtrl)

Description:

Denne variabelen dokumenterer anbefalt tidspunkt for kontroll i ryggmargsskadeavdelingen.

Notes:

Et kontrollopphold er tidligere definert som følgende: Oppholdet er kort og har først og fremst en forebyggende hensikt. Her gjøres en gjennomgang av nevrologisk status, urinveiene undersøkes, lungefunksjonen sjekkes, hjelpemidler vurderes og en får en mulighet til samtale med ulike fagpersoner fra det tverrfaglige team (ref 2) ABC om ryggmargsskade for helsepersonell, 2012)

Sykehusene som rehabiliterer personer med ryggmargsskade har ansvar for å følge opp disse i et livslangt perspektiv. I statens helsetilsyn veiledningsserie om behandling av ryggmargsskadde i Norge (ref 1) er det skrevet at medisinsk kontroll og oppfølging skal være planlagt og dokumentert i forbindelse med utskrivning etter primærrehabiliteringen. Fagmiljøet ved de ulike avdelinger bestemmer selv utfra pasientens behov når pasienten skal komme til kontrollopphold. Ved utreise fra primær rehabilitering skal pasienten informeres om plan for videre oppfølging.

Referanser: 1) "Statens helsetilsyn veiledningsserie 4-98", behandling av ryggmargsskadde i Norge. 2) ABC om ryggmargsskade for helsepersonell, 2012. Heftene er tilgjengelig på [www.lars.no](http://www.lars.no)

## Nyttige tips:

- Ved å klikke på ønsket variabel i menyen til venstre kan man manøvrere seg raskere inne i skjema.

[← Back to patient page](#)

### MÆNUSKAÐI

**1. Upplýst samþykki** >

2. Dagsetningar >

3. Orsök slyss >

4. Taugastarfsemi við innlögn >


5. Taugastarfsemi við útskrift >

Last saved í gær kl. 15:28

[Complete form](#)

## Livskvalitetsskjema

For å registrere tilknyttede skjema velger man først pasienten, som allerede ligger inne i registeret. Du får da et valg **Opprett nytt koblet skjema**.

 Fru Test

Form title	Create attached form
Mænuskaði	<a href="#">New attached form...</a>

## Koblet skjema

Velg det skjema du ønsker å knytte opp til hovedskjema

## Select attached form

---

Eftirfylgdarskrá

Skráning á gögnum um lífsgæði

Starfsemi neðri þvaggæra

Starfsemi þarma

Etterhvert som man knytter koblede skjema til hovedskjema, vil de forsvinne fra listen

### Livskvalitetsskjema

Registrering av **livskvalitetsdata** utføres i løpet av den siste uka av primæroppholdet, og ved senere kontrollopphold. Pasienten fyller selv ut papirskjema. Dette legges inn elektronisk av helsepersonell. Svarene oppgis på en skala fra 0 til 10, hvor 0 er svært misfornøyd og 10 er svært fornøyd.

### 1. Gögn um lífsgæði

---

Dagsetning framkvæmdar:

Hversu ánægð(ur) ert þú með líf þitt og persónulegar aðstæður síðustu fjórar vikur, þegar á heildina er litið?

Veljið gildi 

Hversu ánægð(ur) ert þú með líkamlega heilsu þína síðustu fjórar vikur?

Veljið gildi 

Hversu ánægð(ur) ert þú með andlega heilsu þína, tilfinningar og skap síðustu fjórar vikur?

Veljið gildi 

## Skjema for Nedre urinveier

Registrering utføres i løpet av den siste uka av primæroppholdet.

### 1. Starfsemi neðri þvagfæra

Dagsetning skráningar

5.2.2019



Skerðing á starfsemi þvagfæra ótengd  
mænuskaða

Veljið gildi



Tilfinning fyrir þvaglátsþörf

Veljið gildi



Variable:

Dagsetning skráningar (LutfxnDt)

Description:

This variable documents the date of data collection

Notes:

This collection of data on lower urinary tract function may be carried out at any time after the spinal cord lesion.

Therefore the date of data collection is imperative to be able to identify the data collected in relation to other data collected on the same individual at various time points. In addition, the date is likewise important to calculate the time interval from date of birth (age), and time interval from date of lesion (time since lesion).



Variable:

Skerðing á starfsemi þvagfæra ótengd mænuskaða (Utimprun)

Description:

This variable documents any type of urinary tract impairment unrelated to spinal cord lesion on the date of data collection.

Notes:

To be able to evaluate the lower urinary tract function in an individual with spinal cord lesion it is necessary to know if there are any other urinary tract impairments unrelated to the spinal cord lesion.

If there have been any urinary tract impairments unrelated to the spinal cord lesion this/these is/are recommended to be written in a text-field, from which it will be possible to retrieve more detailed data when necessary. Because many possible urinary tract impairments exist, it is not practical to give an exact list of impairments.

If this information has been documented once and no additional urinary tract impairments unrelated to the spinal cord lesion have been identified it is only necessary fill in this item once, to avoid redundant data.

This variable is appropriate for all pediatric age groups 0-5, 6-12, 13-14, and 15-17. If collecting information from pediatric patients, self-report will be primarily collected from parents for age groups 0-5; and primarily from the child for age groups 6-12 (parent report, secondary), 13-14 (parent report, supplemental), and 15 and older (parent report, optional)

Variable:

Tilfinning fyrir þvaglátsþörf (Awarblad)

Description:

This variable documents awareness of the need to empty the bladder on the date of data collection.

Notes:

Awareness of the need to empty the bladder indicates any kind of bladder sensation as defined by International Continence Society (Abrams et al. 2002), i.e. normal (the individual is aware of bladder filling and increasing sensation up to a strong desire to void), increased (the individual feels an early and persistent desire to void), reduced (the individual is aware of bladder filling but does not feel a definite desire to void) or non-specific bladder sensation (the individual reports no specific bladder sensation, but may perceive bladder filling as abdominal fullness, vegetative symptoms like sweating or spasticity). No awareness of the need to empty the bladder should be noted as "no". Absent bladder sensation according to the definition of bladder sensation by the International Continence Society (the individual reports no sensation of bladder filling or desire to void) (Abrams et al. 2002) is not exactly the same as filling sensation and desire to void can be absent while temperature sensation or electrosensation can be present. "Not applicable" is to be used when the individual with spinal cord lesion has for example an unclamped indwelling catheter or non-continent urinary diversion.

This variable is appropriate for all pediatric age groups older than 3 years. If collecting information from pediatric patients, parents are the primary source of report for 3-5; and self-report primarily from the child for age groups 6-12 (parent report, secondary), 13-14 (parent report, supplemental), and 15 and older (parent report, optional)." However, for very young children (birth- to 3 years) this variable is "Not applicable".

## 2. Blöðrutæming

---

Óþekkt  ?

Eðlileg þvaglát:  Aðalaðferð  Viðbótaraðferð

### Viljastýrð örvun blöðrutæmingarviðbragðs

↳ Viljastýrð (bank, klór, endaþarmsörvun o.s.frv.):  Aðalaðferð  Viðbótaraðferð

↳ Ósjálfráð:  Aðalaðferð  Viðbótaraðferð

### Ytri þrýstingur á blöðru (Credé aðferð)

↳ Rembast eða þrýstingur á kvið (Valsalva aðferð):  Aðalaðferð  Viðbótaraðferð

↳ Ytri þrýstingur á blöðru (Credé aðferð):  Aðalaðferð  Viðbótaraðferð

### Reglubundin Hrein Blöðrutæming

↳ Tæmir blöðru sjálf/ur með legg:  Aðalaðferð  Viðbótaraðferð

↳ Aðstoðarmaður tæmir blöðru með legg:  Aðalaðferð  Viðbótaraðferð

### Inniliggjandi þvagleggur

↳ Um þvagrás:  Aðalaðferð  Viðbótaraðferð

↳ Um kviðvegg (suprapubisleggur):  Aðalaðferð  Viðbótaraðferð

Hjáveita fyrir þvagleiðara (Brickers blaðra):  Aðalaðferð  Viðbótaraðferð

Önnur aðferð, tilgreinið:  Aðalaðferð  Viðbótaraðferð

Variable:

Óþekkt (EmbladUn)

Description:

This variable documents the method(s) used by the spinal cord injured individual to empty the bladder on the date of data collection.

Notes:

For each method of bladder emptying, indicate whether this is a main or a supplementary method. Two main and one or more supplementary methods may be indicated (adopted from Levi and Ertzgaard 1998).

Normal voiding: Voluntary initiation of micturition without reflex stimulation or compression of the bladder. This does not presume entirely normal function (Levi and Ertzgaard 1998).

Bladder reflex triggering comprises various manoeuvres performed by the individual with spinal cord lesion or an attendant in order to elicit reflex detrusor contraction by exteroceptive stimuli. The most commonly used manoeuvres are suprapubic tapping, thigh scratching and anal/rectal manipulation (Abrams et al. 2002).

Voluntary bladder reflex triggering indicates that the bladder reflex is triggered by the individual with spinal cord lesion him/herself or by the attendant.

Involuntary bladder reflex triggering implies that there is no voluntary triggering of the voiding, but the individual with spinal cord lesion allows the urine to pass by itself when the reflex detrusor contraction occurs.

Bladder expression comprises various manoeuvres aimed at increasing intravesical pressure in order to facilitate bladder emptying. The most commonly used manoeuvres are abdominal straining, Valsalva's manoeuvre and external manual suprapubic pressure (Credé manoeuvre) (Abrams et al. 2002, Gajewski et al. 2018).

Straining includes abdominal straining, Valsalva's manoeuvre.

External compression includes Credé manoeuvre.

Catheterisation is a technique for bladder emptying employing a catheter to drain the bladder or urinary reservoir (Abrams et al. 2002).

Intermittent catheterisation is by the International Continence Society defined as drainage of the bladder or a urinary reservoir with subsequent removal of the catheter mostly at regular intervals (Gajewski et al. 2018).

In the International SCI LUT Function Basic Data Set the following types of intermittent catheterisation can be reported:

Intermittent self-catheterisation is performed by the individual himself/herself.

Intermittent catheterisation can also be performed by an attendant (e.g. family member or personal aid).

This means there will not be distinguished between the techniques used and defined by the International Continence Society, i.e. Clean, Aseptic, Sterile or No-touch technique intermittent catheterization (Gajewski et al. 2018).

Indwelling catheterisation: an indwelling catheter remains in the bladder, urinary reservoir or urinary conduit for a period longer than one emptying (Abrams et al. 2002, Gajewski et al. 2018).

In the International SCI LUT Function Basic Data Set the following types of indwelling catheterisation can be reported:

Transurethral indwelling catheterisation indicates that the urine is drained through a catheter placed in the urethra.

Suprapubic indwelling catheterisation indicates that the urine is drained through a catheter via the abdominal wall.

Non-continent urinary diversion/ostomy: This includes ureteroileocutaneostomy (ileoureterostomy, ileal loop, Bricker conduit, ileal conduit), ileovesicostomy, vesicostomy.

Other method, specify \_\_\_\_\_

If any other method is used for bladder emptying it is recommended to be written in a text-field, from which it will be possible to retrieve more detailed data when necessary. Because other methods of bladder emptying, including sacral anterior root stimulators, are generally rare, it is not practical to give an inclusive list of bladder emptying methods.

This variable is appropriate for all pediatric age groups 0-5, 6-12, 13-14, and 15-17. If collecting information from pediatric patients, self-report will be primarily collected from parents for age groups 0-5; and primarily from the child for age groups 6-12 (parent report, secondary), 13-14 (parent report, supplemental), and 15 and older (parent report, optional).

Fjöldi viljastýrðra blöðrutæminga á sólarhring að jafnaði síðustu viku

Veljið gildi  

#### Variable:

Fjöldi viljastýrðra blöðrutæminga á sólarhring að jafnaði síðustu viku (Avbladem)

#### Description:

This variable documents the average number of voluntary bladder emptyings per 24 hours during the last week

#### Notes:

The average number of voluntary bladder emptying per day during the last week is given separately. This number refers to the number of voluntary bladder emptyings irrespective of the method. Any of the following methods may be used separate or in combination: normal voiding, voluntary bladder reflex triggering, bladder expression, intermittent catheterization, or sacral anterior root stimulation. If a combination of methods is used during the same bladder emptying it should only be counted as one bladder emptying. The number is given as an average for the last week only, as the individual is not expected to remember this for a longer period of time. The number is given as the nearest integer number.

This variable is appropriate for all pediatric age groups 0-5, 6-12, 13-14, and 15-17. If collecting information from pediatric patients, self-report will be primarily collected from parents for age groups 0-5; and primarily from the child for age groups 6-12 (parent report, secondary), 13-14 (parent report, supplemental), and 15 and older (parent report, optional). "Not applicable" is to be used for individuals using an indwelling catheter. "Unknown" may be used if someone such as a child or an adult who wears diapers/nappies/incontinence briefs is not aware of the number of bladder emptyings.

### 3. Þvagleki

Þvagleki síðustu fjórar vikur

Veljið gildi



Notkun hjálpartækja vegna þvagleka

Veljið gildi



#### Variable:

Þvagleki síðustu fjórar vikur (Incontnc2)

#### Description:

This variable documents the average involuntary urine leakage (urinary incontinence) within the last four weeks prior to the date of data collection.

#### Notes:

Urinary incontinence is defined by the International Continence Society (Abrams et al. 2002, Gajewski et al. 2018) as the complaint of involuntary loss of urine. In each specific circumstance the urinary incontinence should be further described by specifying relevant factors such as type (Stress, Urgency, Mixed incontinence or Enuresis), frequency, severity, precipitating factors, social impact, effect on hygiene and quality of life, etc. (Abrams et al. 2002, Gajewski et al. 2018). In the International SCI LUT Function Basic Data Set only a simple indication of severity and collection of urine is given.

Bladder reflex triggering including into a collection system, e.g. condom catheter may be voluntary and thus not considered as incontinence.

However, if the condom or ostomy bag falls off and the individual complains of incontinence then it should be recorded as "Yes".

Involuntary urine leakage (urinary incontinence) within the last four weeks implies leakage of urine outside the urinary tract or a closed urinary collection system.

"Not applicable" may be used when the individual has, for example, a non-continent urinary diversion.

This variable is appropriate for all pediatric age groups 0-5, 6-12, 13-14, and 15-17. If collecting information from pediatric patients, self-report will be primarily collected from parents for age groups 0-5; and primarily from the child for age groups 6-12 (parent report, secondary), 13-14 (parent report, supplemental), and 15 and older (parent report, optional).

Variable:

Notkun hjálpertækja vegna þvagleka (Collect)

Description:

This variable documents use of any collecting appliances for urinary incontinence on the date of data collection.

Notes:

Collecting appliances are any externally applied aids to avoid urinary leakage, or devices for collection of urine. Regular use of one or more collecting appliances is to be recorded. Individuals that use such appliances less than once a month, "for the sake of safety", and who have no more than exceptional episodes of leakage during a year should be coded as "No" (adapted from Levi and Ertzgaard 1998).

This variable is appropriate for all pediatric age groups 0-5, 6-12, 13-14, and 15-17. If collecting information from pediatric patients, self-report will be collected primarily from parents for age groups 0-5; and primarily from the child for age groups 6-12 (parent report, secondary), 13-14 (parent report, supplemental), and 15 and older (parent report, optional).



## 4. Lyf

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Lyf sem gæti haft áhrif á þvagfæri innan  
síðustu fjögurra vikna

Veljið gildi



### Variable:

Lyf sem gæti haft áhrif á þvagfæri innan síðustu fjögurra vikna  
(AnyDrugs2)

### Description:

This variable documents use of any drugs, systemic or intravesical, with possible influence on the urinary tract within the last four weeks on the date of data collection.

### Notes:

Bladder relaxant drugs, i.e. drugs causing relaxation of the detrusor, include antimuscarinics, anticholinergics, tricyclic antidepressant, etc. These drugs may also be delivered intravesically. This does not include treatment with injections into the detrusor.

Sphincter and bladder neck relaxant drugs include alpha adrenergic blockers, etc. This does not include treatment with injections into the sphincter.

Antibiotics and antiseptics used for treatment or prophylaxis of urinary tract infections are coded separately. For prevention of urinary tract infections, drugs such as methenamine are included. For other possible drugs, it is recommended to write them in a text-field, from which it will be possible to retrieve more detailed data when necessary.

## 5. Skurðaðgerðir

---

Skurðaðgerð á þvagfærum

Veljið gildi



### Variable:

Skurðaðgerð á þvagfærum (Surgicalpr)

### Description:

This variable documents any surgical procedures on the urinary tract up to the date of data collection. If more than one procedure of the same kind has been performed only the last one is documented with date of performance.

### Notes:

Bladder stone or upper urinary tract stone removal includes any type of removal, including via endoscopy, extracorporeal shock wave lithotripsy (ESWL), or open lithotomy. The ileoureterostomy is corresponding to the formerly ileal loop or ureteroileocutaneostomy (Bricker conduit). The continent catheterizable valves, include Monte and Mitrofanoff procedures. For other possible surgical procedures it is recommended to write them in a textfield, from which it will be possible to retrieve more detailed data when necessary. If there is more than one "other" surgical procedure, this field may be duplicated or triplicated, with the latest date given when the particular procedure has been performed. If the information has been documented once and no additional surgical procedures on the urinary tract have been performed it is not necessary fill in this item again, to avoid redundant data.

This variable is appropriate for all pediatric age groups 0-5, 6-12, 13-14, and 15-17. If collecting information from pediatric patients, self-report will be collected primarily from parents for age groups 0-5; and primarily from the child for age groups 6-12 (parent report, secondary), 13-14 (parent report, supplemental), and 15 and older (parent report, optional).

## 6. Breyting

---

Breytingar á einkennum frá neðri  
þvagfærum síðastliðið ár

Veljið gildi



#### Variable:

Breytingar á einkennum frá neðri þvagfærum síðastliðið ár (Ursxchly)

#### Description:

This variable documents any change in lower urinary tract symptoms within the last year from the date of data collection

#### Notes:

Lower urinary tract symptoms are according to the International Continence Society the subjective indicator of a disease or change in conditions as perceived by the individual with spinal cord lesion, attendant or partner and may lead him/her to seek help from health care professionals (Abrams et al. 2002). Symptoms may either be volunteered or described during the data collection interview with the individual with spinal cord lesion. The information may be qualitative as well as quantitative, e.g. change in frequency, urgency, nocturia, incontinence, hesitancy, slow stream, etc. Many individuals with spinal cord lesion and bacteriuria have no associated signs or symptoms. Chills and fever are often considered to be signs of acute pyelonephritis; however, these signs do not confirm an infection in the upper urinary tract (Stover et al. 1989). Nonetheless, chills and fever may be the only symptoms reported in persons with spinal cord lesion and pyelonephritis, bacteremia, upper tract obstruction by calculi, renal abscesses, and periphrenic abscess. Other suspicious signs and symptoms may include increased sweating, abdominal discomfort, costovertebral angle pain or tenderness, and increased muscle spasticity (Stover et al. 1989). Cloudy and malodorous urine and changes in urine pH may be signs of urinary tract infection, but can also occur with colonization, changes of bacterial organisms, and various food intakes. Increased spontaneous voiding or larger residual urines including acute urinary retention may be seen with acute infection (Stover et al. 1989). 'Not applicable' is to be used when data reporting is performed within the first year after the spinal cord lesion. This variable is appropriate for all pediatric age groups 0-5, 6-12, 13-14, and 15-17. If collecting information from pediatric patients, self-report will be collected primarily from parents for age groups 0-5; and primarily from the child for age groups 6-12 (parent report, secondary), 13-14 (parent report, supplemental), and 15 and older (parent report, optional).

## Skjema for Tarmfunksjon

Registrering utføres i løpet av den siste uka av primæroppholdet.

### 1. Starfsemi þarma

---

Dagsetning framkvæmdar

Skert starfsemi meltingarfæra eða  
endaþarmsþrengis ótengd mænuskaða

Veljið gildi  

Skurðaðgerð á meltingarfærum

Veljið gildi  

Variable:

Dagsetning framkvæmdar (BfxnbaDt)

Description:

This variable documents the date of data collection

Notes:

As the collection of data on bowel function may be carried out at any time since SCI, the date of data collection is imperative to compute time since injury and to identify the data collected in relation to other data collected on the same individual at various time points.

**Variable:**

Skert starfsemi meltingarfæra eða endaparmsþrengis ótengd mænuskaða (Gifxnun)

**Description:**

This variable documents any gastrointestinal or anal sphincter dysfunction unrelated to SCI

**Notes:**

This is gastrointestinal or anal sphincter dysfunction concomitant and thus unrelated to changes in bowel function due SCI.

Functional gastrointestinal disorders, especially irritable bowel syndrome and idiopathic constipation, are very common in the general population. The prevalence depends on the exact definitions used but vary from 5% up to approximately 20% (Jones R and Lydeard S 1992). The presence of functional or other gastrointestinal disorders before SCI may affect symptoms and treatment outcome.

Anal sphincter lesions due to childbirth are common and may contribute to fecal incontinence. Many types of gastrointestinal and anal sphincter dysfunction exist and it is therefore impractical to give an exact list of such conditions.

**Variable:**

Skurðaðgerð á meltingarfærum (SurgicalIntervention)

**Description:**

This variable documents any surgical procedures on the gastrointestinal tract

**Notes:**

For the overall assessment of bowel function in individuals with SCI information about surgical procedures on the gastrointestinal tract is important. This variable covers any surgical procedure on the gastrointestinal tract before or after SCI. It also includes perianal surgery. Due to the large number of possible surgical procedures it is impractical to list more than the most important or common. Other surgical procedures on the gastrointestinal tract should be listed and specified under Other.

## 2. Aðferð til þarmalosunar (Innan síðustu fjögurra vikna)

---

Óþekkt  ③

Á ekki við

Eðlileg hægðalosun  Aðalaðferð  Viðbótaraðferð

Rembast til að tæma  Aðalaðferð  Viðbótaraðferð

Erting endaparms með fingri  Aðalaðferð  Viðbótaraðferð

Endaparmsstílar  Aðalaðferð  Viðbótaraðferð

Hægðalosun með fingri  Aðalaðferð  Viðbótaraðferð

Innhellislyf ( $\leq 150$  ml)  Aðalaðferð  Viðbótaraðferð

Innhelling ( $>150$  mL), þar með talið stólpípa um endaparm  Aðalaðferð  Viðbótaraðferð

Ristilraufun  Aðalaðferð

Raförvun á fremri sakralrótum  Aðalaðferð  Viðbótaraðferð

Önnur aðferð  Aðalaðferð  Viðbótaraðferð

Variable:

Óþekkt (DefcmthUn)

Description:

This variable documents defecation method and bowel care procedures within the last four weeks

Notes:

Individuals with SCI may use a combination of bowel emptying procedures. For practical purposes one should be defined as the Main method. This is defined as the method the individual or the doctor/nurse considers the most important. Supplementary methods should be performed at least once every week. More than one supplementary method can be used. The choice of defecation method and bowel care procedures may change with time and in the present data set they are given for the last four weeks.

Digital ano-rectal stimulation is digital triggering of rectal contractions and anal relaxation and thus rectal emptying. Digital evacuation is the need to dig out stools with a finger. Mini enema (or Clysma) contains 150 mL or less and enema contains > 150 mL.

In individuals having a colostomy, this is always considered the main method for defecation.

Not applicable is primary for children who are not of age for bowel continence.

### 3. Starfsemi

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Tími sem þarf til hægðalosunar að meðaltali  
(innan síðustu fjögurra vikna)

Veljið gildi  

Tíðni hægðalosunar (innan síðustu fjögurra  
vikna)

Veljið gildi  

Eirðarleysi, höfuverkur eða svitaköst við  
hægðalosun (innan síðustu fjögurra vikna)

Veljið gildi  

Örvun með fingri eða tæming endaparms  
(plokka) með fingri (innan síðustu fjögurra  
vikna)

Veljið gildi  

Tíðni hægðaleka (innan síðustu fjögurra  
vikna)

Veljið gildi  

Leysir vind ósjalfrátt (innan síðustu fjögurra  
vikna)

Veljið gildi  

Þörf fyrir bleyju eða endaparmstappa (innan  
síðustu fjögurra vikna)

Veljið gildi  



#### Variable:

Tími sem þarf til hægðalosunar að meðaltali (innan síðustu fjögurra vikna) (Avdefm2)

#### Description:

This variable documents average time required for each defecation within the last four weeks

#### Notes:

Time needed for defecation is clinically very important and strongly associated with impact on quality of life (Krogh et al. 2006). The time given is from first transferring to the toilet or commode until end of defecation and transfer to wheel chair or moving from the toilet. If bladder emptying, body washing, shaving etc is also performed while sitting at the toilet time for this is subtracted. For individuals performing bowel management while lying in the bed time required is from beginning to end of bowel management not including time for bladder management, body washing etc. Time needed for defecation is the assessed average time for each defecation within the last four weeks. This variable does not distinguish between spontaneous or assisted defecation. Not applicable can be used i.e. in individuals with ileo- or colostomy and in children who are not of age where fecal continence is expected.

\*The variable is included in the NBD score.

#### Variable:

Tíðni hægðalosunar (innan síðustu fjögurra vikna) (Deffrq2)

#### Description:

This variable documents the average frequency of defecation within the last four weeks

#### Notes:

The frequency of defecation is very variable. However, in the general population more than 94% defecate between three times per day and three times per week (Drossman et al. 1982). Among individuals with SCI approximately 3% defecate less than once every week. Infrequent defecation is an indicator of insufficient bowel management and associated with impact on quality of life.

\*The variable is included in the NBD score

#### Variable:

Eirðarleysi, höfuverkur eða svitaköst við hægðalosun (innan síðustu fjögurra vikna) (Defhdprs)

#### Description:

This variable documents if the individual has experienced uneasiness, headache or perspiration (or in children fussiness and irritability) during at least one defecation within the last four weeks

#### Notes:

The feelings of general uneasiness and headache and the presence of perspiration during defecation is reported by approximately 25% of individuals with SCI (Krogh K et al. 1997, Harari D et al. 1997). For children, fussiness and irritability may present (Hickey KJ et al. Spinal Cord Med 2004). The symptoms are mainly present in individuals with cervical or upper thoracic lesions and indicate that autonomic dysreflexia occurs during defecation. Digital anorectal stimulation, rectal evacuation or transanal irrigation may cause autonomic dysreflexia (Faaborg PM et al. 2014) which in some is asymptomatic.

\*The variable is included in the NBD score.

#### Variable:

Örvun með fingri eða tæming endaðarms (plokka) með fingri (innan síðustu fjögurra vikna) (Dsevacar)

#### Description:

This variable documents the frequency of digital stimulation of the anorectum to induce defecation or digital emptying of the rectum during the last four weeks

#### Notes:

Digital stimulation or evacuation is reported by approximately two thirds of individuals with SCI. In some it indicates poor emptying of the rectum and the use of digitation is associated with impaired quality of life due to NBD.

\*The variable is included in the NBD score

Variable:

Tíðni hægðaleka (innan síðustu fjögurra vikna) (Fcincfrq2)

Description:

This variable documents the average frequency of incontinence of solid or liquid stools within the last four weeks

Notes:

Fecal incontinence is defined as involuntary passage of stools. It has profound influence on quality of life and may cause severe restriction of social activities.

This variable does not distinguish between incontinence of solid or liquid stools. In individuals with ileo- or colostomy leakage of feces from the stoma bag is considered fecal incontinence. Not applicable is primary for children who are not of age for bowel continence.

\*The variable is included in the NBD score.

Variable:

Leysir vind ósjalfrátt (innan síðustu fjögurra vikna) (Flincont)

Description:

This variable documents episodes of flatus incontinence within the last four weeks

Notes:

Flatus incontinence is defined as involuntary passage of gas. In individuals with ileo- or colostomy leakage of gas from the stoma bag is considered flatus incontinence. Not applicable is primary for children who are not of age for bowel continence.

\*The variable is included in the NBD score.

**Variable:**

Þörf fyrir bleyju eða endabarmstappa (innan síðustu fjögurra vikna)  
(Wrpaplg2)

**Description:**

This variable documents the need to wear a pad or plug within the last four weeks

**Notes:**

This variable describes the need to wear a pad due to fecal incontinence or combined fecal and urinary incontinence. The need to wear a pad only for urinary incontinence is not included.

The need to wear a pad indicates insufficient bowel management. The use of anal plug is mainly relevant for individuals with conus or cauda equina lesions. Not applicable is for children who are not of age for bowel continence.

## 4. Lyf

Hægðalyf um munn (innan síðustu fjögurra vikna)

Veljið gildi



Lyf sem valda hægðatregðu/ til að hindra hægðaleka (innan síðustu fjögurra vikna)

Veljið gildi



### Variable:

Hægðalyf um munn (innan síðustu fjögurra vikna) (OralLaxatives)

### Description:

The variable documents the use of oral laxatives within the last four weeks

### Notes:

Oral laxatives are commonly used by individuals with SCI. A large number of oral laxatives exist either as drops or tablets and it is impractical to give a full list. Commonly used bulking or osmotic agents are lactulose, psyllium, magnesium and sorbitol. Commonly used irritant laxatives are bisacodyl and sodium picosulphate. The prokinetic drug Prucalopride has been evaluated in a pilot study among individuals with SCI (Krogh K et al. 2002). The guanylate cyclase-C receptor agonist Linaclotide and the chloride channel activator Lubiprostone have not yet been evaluated in individuals with SCI, but if used they should be noted here.

#### Variable:

Lyf sem valda hægðatregðu/ til að hindra hægðaleka (innan síðustu fjögurra vikna) (Fecinmed)

#### Description:

This variable documents the use of constipating medication or the use of other medication to prevent or minimize fecal incontinence within the last four weeks

#### Notes:

Fibre supplement and constipating drugs are usually first line therapy against fecal incontinence of non-neurogenic origin. The most commonly used drug is Loperamide.

In individuals with SCI this approach is, however, rarely used as it may aggravate constipation. The variable does only cover drugs given with the intent of reducing fecal incontinence. The large number of drugs given for other indications which have constipation as an side effect is not included here.

\*The variable is included in the NBD score.

## 5. Vandamál við endaparmsop

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Vandamál í kringum endaparm (innan síðustu fjögurra vikna)

Veljið gildi



### Variable:

Vandamál í kringum endaparm (innan síðustu fjögurra vikna)  
(PerianalProblems2)

### Description:

This variable documents the presence of perianal problems within the last four weeks

### Notes:

Due to straining and assisted defecation hemorrhoids, fissures, and rectal prolapse are more common among individuals with SCI than in the general population. Anal soiling may contribute to perianal sores. In the present data set, perianal sores are located within the crena ani or the perineum and not on the buttocks or lower back. For practical purposes, no distinction is made in the present data set between rectal mucosal prolapse and full-wall rectal prolapse.

Perianal problems may change with time and only those present within the last four weeks should be noted.

\*The variable is included in the NBD score.

## 6. Magaverkir og óþægindi

Magaverkir og óþægindi (innan síðustu fjögurra vikna)

Veljið gildi



### Variable:

Magaverkir og óþægindi (innan síðustu fjögurra vikna) (Abpain)

### Description:

This variable documents the presence of abdominal pain and discomfort within the last four weeks

### Notes:

Abdominal pain is commonly reported by individuals with SCI (Finnerup NB et al. Spinal Cord 2008). It may be a symptom of constipation

Total NBD Score (optional and only applicable for adult persons):\*

0

(Interpretation of the NBD score: 0-6 Very minor, 7-9 Minor, 10-13 Moderate and 14 or more Severe neurogenic bowel dysfunction).



Under **Rapporter** er ulike rapporter tilgjengelig:

## Skýrslur

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Form title	Create attached form	Form date	Last saved	Status	
Mænskafól	<a href="#">Create new form</a>	27.3.2018 00:00	23.4.2018 13:29 (icescir)	Closed	
Skráning á gögnum um lífsgæði		3.4.2018 00:00	23.4.2018 13:36 (icescir)	Closed	

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2024

Sekretariatet St. Olavs hospital