FinSCI

Finnish Spinal Cord Injury Study

Sinikka Hiekkala, Adj.prof., PhD

Research Director

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Finnish Spinal Cord Injury Study

Purpose of the FinSCI

to identify factors related to the health and functioning of people with spinal cord injury, their challenges with accessibility, and how such factors are interconnected




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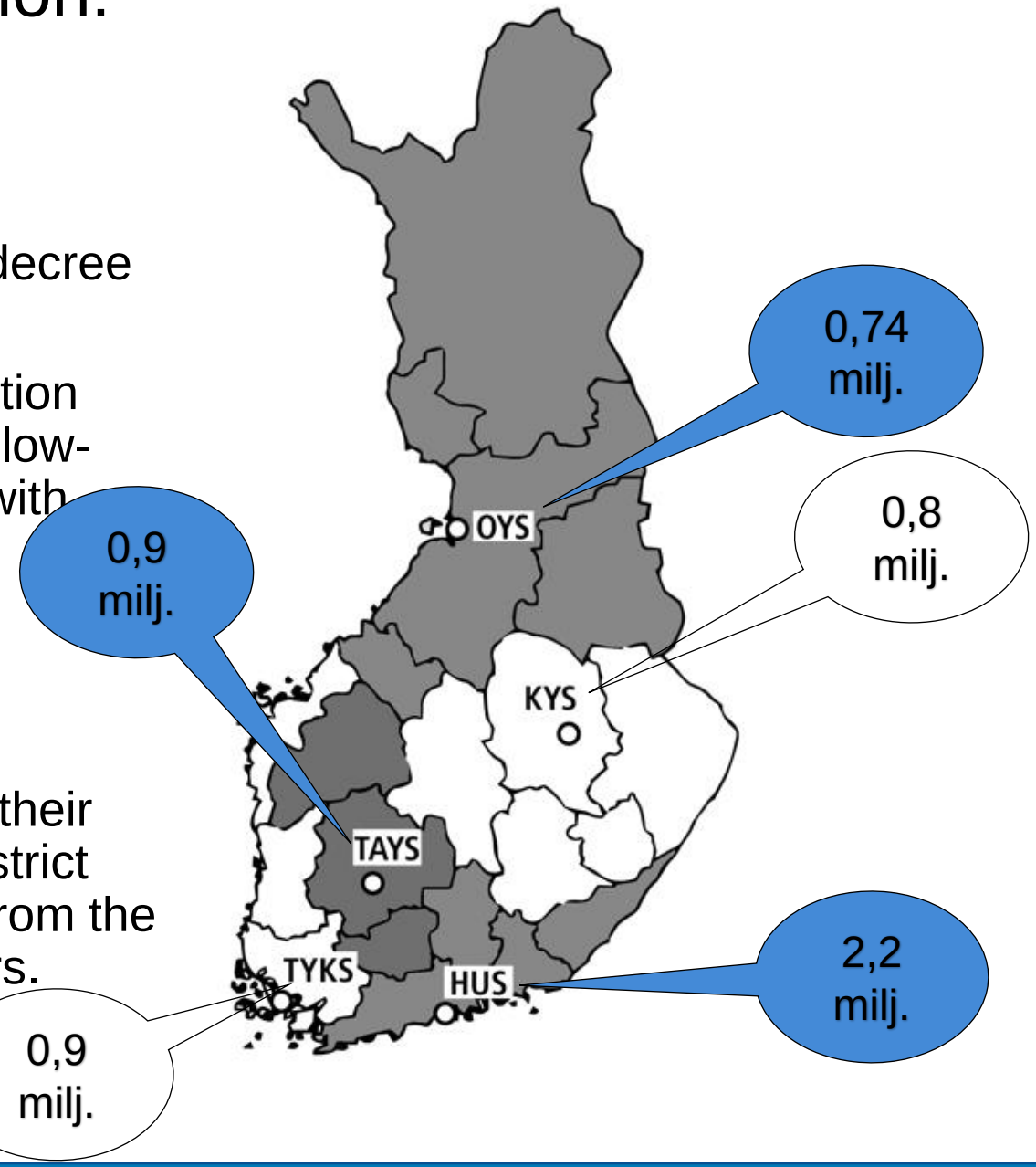
Finnish population 5.54 million: 3 SCI outpatient clinics

- 5 university hospitals in Finland
- The Health Care Act and government decree in 2011:

  acute care, immediate rehabilitation and life-long multi-professional follow-up, and rehabilitation of persons with SCI have been centralized at 3 university hospitals.
- These 3 hospitals serve the whole SCI population in Finland.
- Turku (TYKS) and Kuopio (KYS) send their persons with SCI from their hospital district areas mainly to TAYS, but depending from the resources of the services in SCI centers.



Research group

Responsible leader of the FinSCI

Sinikka Hiekkala, Adj.prof, PhD, Research Director, The Finnish Association of People with Physical Disabilities

Anni Täckman, Trad.AMK, Project Manager,

Rusetti ry

Anna-Maija Kauppila, MD, physiatrist,

The Social Insurance Institute of Finland

Mauri Kallinen, Prof., physiatrist, Chief physician, Central Finland Health Care District, Oulu University (OYS)

Eerika Koskinen, MD, neurologist, Tampere University Hospital (TAYS)

Heidi Anttila, PhD, specialist researcher, Finnish Institute for Health and Welfare

Jari Arokoski, Prof., physiatrist, Chief physician, Chief administrative physician, Helsinki University Hospital (HUS), HU (University of Helsinki)

Harri Hämäläinen, (retired) MD, physiatrist, Chief physician, Chief administrative physician, HUS, HU

Aki Vainionpää, MD, physiatrist, Chief physician, Seinäjoki Central Hospital

Susanna Tallqvist, MSc, PT
Doctoral student, HU

Paula Bergman, MSc, biostatistician, Biostatistics Unit, Department of Public Health, HU,HUS

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Students

Susanna Tallqvist, MSc in health sciences, PT
Doctoral student in population health/HU

Kirsi Majamäki, PT
Master student/graduated in health sciences/JYU

Joonas Poutanen, MSc in health sciences, PT
Doctoral student in clinical research/HU

Kaarina Eskola, MSc in social sciences, social worker
Doctoral student in social sciences/HU

Kristiina Puranen, PT
Master student in health sciences/JYU

Sanna-Mari Saarimäki, PT
Master student in health sciences/JYU

Marketta Rajavaara, prof.
in social sciences, HU

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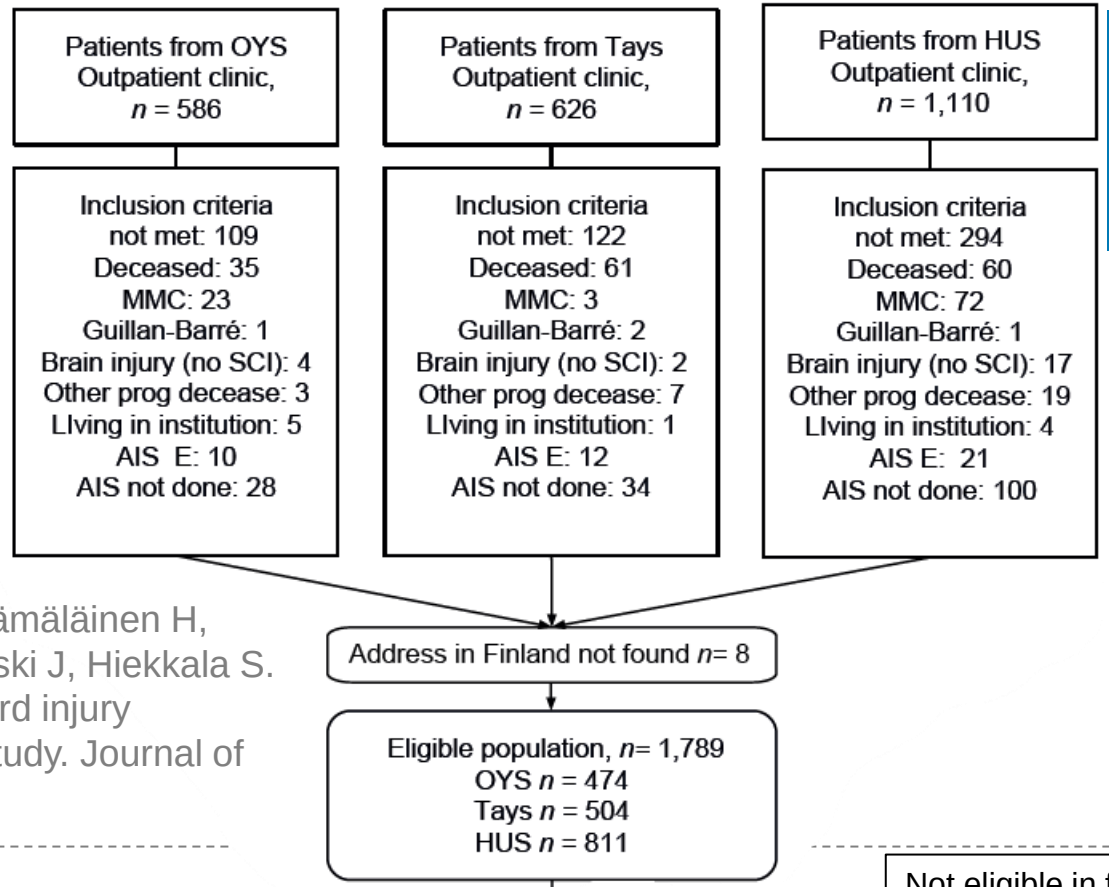
1. Registration study

OYS 1/2012 - 12/2017

TAYS 5/2011 – 12/2017

HUS 8/2013 – 6/2018



Tallqvist S, Anttila H, Kallinen M, Koskinen E, Hämäläinen H, Kauppila A-M, Täckman A, Vainionpää A, Arokoski J, Hiekkala S. Health, functioning and accessibility of spinal cord injury population in Finland - Protocol for the FinSCI study. Journal of Rehabilitation Medicine 2019 : 51;273-280.

Not eligible in final checkout, n = 17

Eligible population, n = 1772

2. Survey: February - July 2019

Non-respondents, n = 888

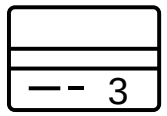
Participants, n = 884 (response rate 49,9)

n = 1772

Paper survey, possiblity for Web-based response

n = 1772

Paper survey, possiblity for Web-based response



n = 950

Post card and link for Web-based response

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Content of the FinSCI-survey

Arviointimenetelmä	Käyttötarkoitus
Spinal Cord Injury Secondary Condition Scale, SCI-SCS	Self-assessment of Health
The Spinal Cord Independence Measure, SCIM-SR	Self-assessment of Functioning
Nottwil Environmental Factors Inventory Short Form, NEFI-SF	Self-assessment of Environmental factors
Patient-Reported Outcomes Measurement Information System, PROMIS®	Self-assessment of wide aspect of generic functioning
Kansallinen terveys-, hyvinvointi- ja palvelututkimus, FinSOTE	Diseases and self-assessment of social and health services

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Comparisons of respondents and non-respondents

Tallqvist S, Kauppila AM, Vainionpää A, Koskinen E, Bergman P, Anttila H, Hämäläinen H, Täckman A, Kallinen M, Arokoski J, Hiekkala S.
Prevalence of comorbidities and secondary health conditions among the Finnish population with spinal cord injury.
Spinal Cord (2021)

Majamäki K, Tallqvist S, Vainionpää A, Koskinen E, Kauppila A-M, Bergman P, Anttila H, Hämäläinen H, Täckman A, Kallinen M, Arokoski J, Hiekkala S.
Functional independence in the Finnish spinal cord injury population.
Spinal Cord (2021)

	Respondents N884, *n* (%)	Non-respondents N888, *n* (%)	*p* arvo
Gender			<0.01
Female	307 (35%)	253 (29%)	
Male	577 (65%)	633 (71%)	
Age, years	(min 20, max 90, mean 61, sd 14)	(min 17, max 93, mean 54, sd 17)	<0.01
	median 63 IQR 53–71	median 55 IQR 40–68	
20–30	34 (4%)	96 (11%)	
31–45	108 (12%)	204 (23%)	
46–60	238 (27%)	243 (27 %)	
61–75	386 (44%)	243 (27%)	
≥76	118 (13%)	102 (12%)	
Aetiology			0.1
Traumatic	492 (56%)	527 (59%)	
Non-traumatic	392 (44%)	361 (41%)	
Severity of SCI			0.21
C1–4 AIS A, B, ja C	95 (12%)	107 (11%)	
C5–8 AIS A, B, ja C	55 (6%)	62 (7%)	
T1–S5 AIS A, B, ja C	184 (21%)	209 (24%)	
AIS D at any injury level	550 (62%)	510 (57%)	
Time since injury, years	(min 1, max 67, mean 11, sd 11)	(min 1, max 66, mean 10, sd 10)	0.52
	Median 7 IQR 4–14	median 6 IQR 4–14	
1–5	353 (40%)	379 (43%)	
6–10	227 (26%)	222 (25%)	
11–15	128 (14%)	111 (12%)	
≥16	176 (20%)	176 (20%)	

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ISCoS The International Spinal Cord Society

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Prevalence of comorbidities and secondary health conditions among the Finnish population with spinal cord injury

Susanna Tallqvist[1✉], Anna-Maija Kauppila[2], Aki Vainionpää[3], Eerika Koskinen[4], Paula Bergman[5], Heidi Anttila[6], Harri Hämäläinen[7], Anni Täckman[8], Mauri Kallinen[9,10], Jari Arokoski[7] and Sinikka Hiekkala[11,12]

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Diseases

12. FinSote 30 **Have you had any of the following medical conditions or illnesses treated by a doctor <u>in the last 12 months?</u>**

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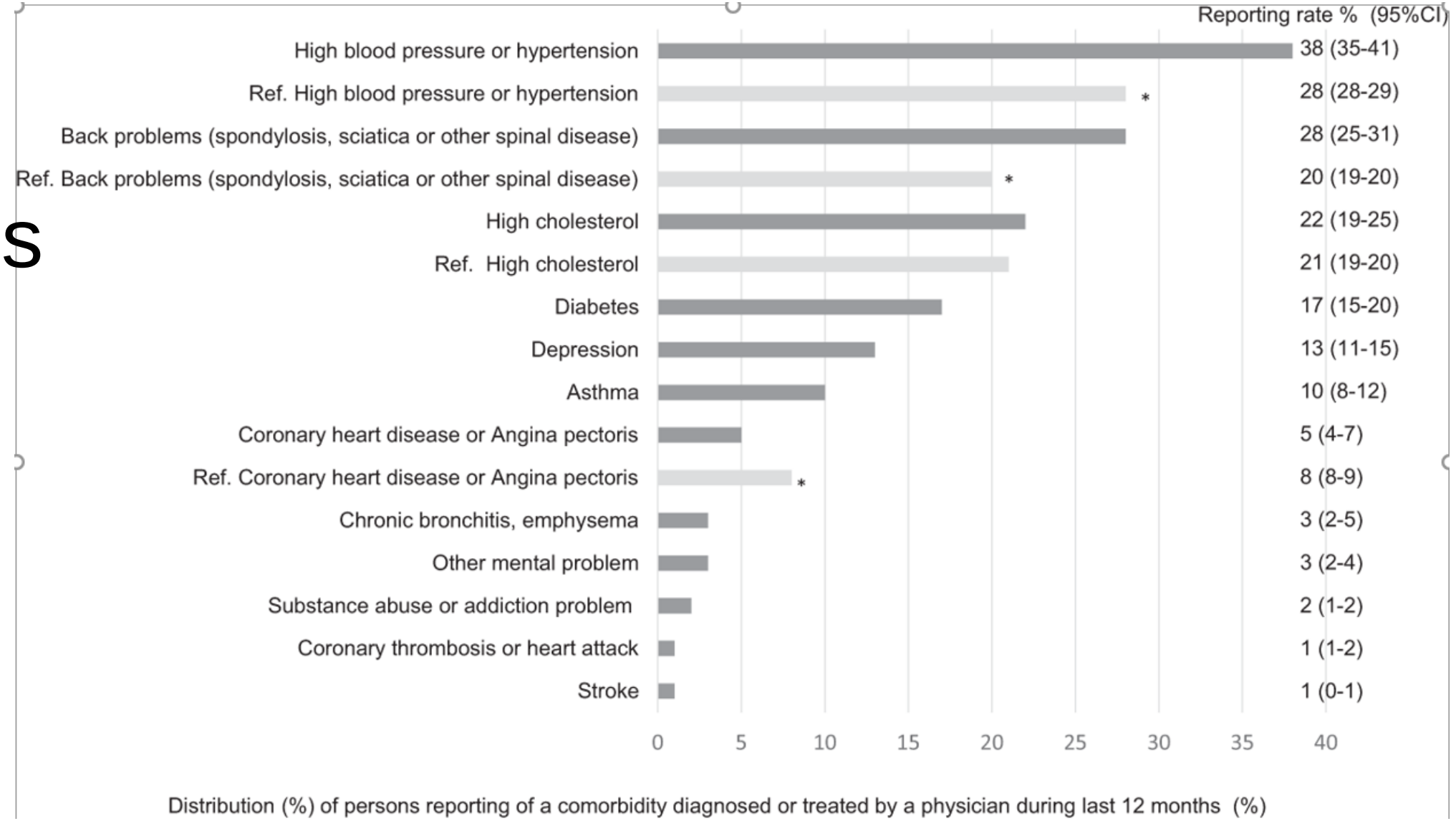
Diseases



Tallqvist S, Kauppila AM, Vainionpää A, Koskinen E, Bergman P, Anttila H, Hämäläinen H, Täckman A, Kallinen M, Arokoski J, Hiekkala S. Prevalence of comorbidities and secondary health conditions among the Finnish population with spinal cord injury. Spinal Cord (2021)

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Diseases

- More reports of back problems and asthma in females than in males
- Blood pressure/hypotension, high cholesterol, back problems, coronary heart diseases or angina pectoris, and diabetes were lowest among the youngest participants and increased in every age group
- Depression, substance abuse or addiction problems were most common in the 46–60 age group
- Other mental problems were more frequent in the youngest age group

Tallqvist S, Kauppila AM, Vainionpää A, Koskinen E, Bergman P, Anttila H, Hämäläinen H, Täckman A, Kallinen M, Arokoski J, Hiekkala S. Prevalence of comorbidities and secondary health conditions among the Finnish population with spinal cord injury. Spinal Cord (2021)

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Secondary Health Conditions

13. SCI-SCS **The following questions assess the impact of various spinal cord injury problems on your daily activities and independence over the past three months.** Answer each box by checking one box per line.

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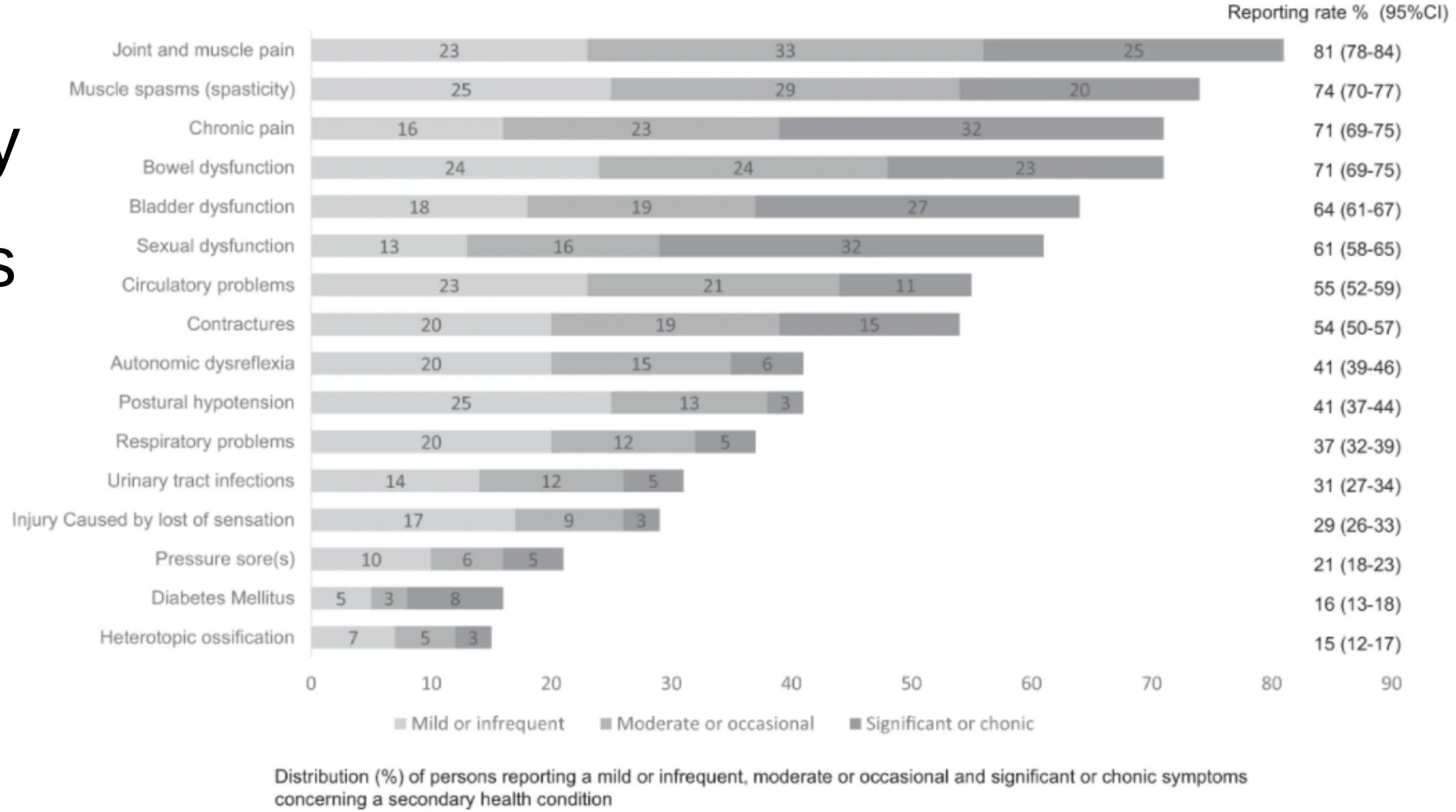
Secondary Health Conditions



Distribution (%) of persons reporting a mild or infrequent, moderate or occasional and significant or chonic symptoms concerning a secondary health condition

Tallqvist S, Kauppila AM, Vainionpää A, Koskinen E, Bergman P, Anttila H, Hämäläinen H, Täckman A, Kallinen M, Arokoski J, Hiekkala S. Prevalence of comorbidities and secondary health conditions among the Finnish population with spinal cord injury. Spinal Cord (2021)

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Secondary Health Conditions

Secondary health condition	Gender		Age groups					Severity of SCI						
	Male	Female	*p*	20–30	31–45	46–60	61–75	≥ 76	*p*	C1-4 AIS A, B, and C	C5-8 AIS A, B, and C	T1-S5 AIS A, B, and C	AIS D at any injury level	*p*
	% (95%CI)	% (95%CI)		% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)		% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	
Joint and muscle pain	79 (76–83)	84 (80–89)	0.03	79 (64–94)	78 (70–87)	83 (78–88)	82 (78–86)	76 (68–85)	0.48	77 (68–87)	84 (73–94)	85 (80–91)	80 (76–83)	0.48
Muscle spasms (spasticity)	75 (72–79)	70 (65–76)	0.12	73 (57–89)	73 (65–82)	75 (70–81)	74 (70–79)	69 (61–78)	0.82	87 (80–94)	80 (69–91)	67 (60–74)	73 (69–77)	<0.01
Chronic pain	70 (66–74)	73(68–79)	0.16	64 (46–81)	63 (53–72)	78 (73–84)	70 (65–75)	68 (58–77)	<0.01	68 (58–78)	67 (54–81)	68 (61–75)	73 (69–77)	0.61
Bowel dysfunction	69 (65-73)	77 (72–82)	0.01	73 (57–89)	77 (69–86)	73 (67–79)	70 (65–75)	68 (58–77)	0.54	71 (62–81)	80 (68–91)	84 (78–90)	67 (63–71)	<0.01
Bladder dysfunction	60 (55–64)	72 (67–78)	<0.01	64 (46–81)	70 (61–79)	60 (53–66)	64 (59–69)	69 (59–78)	0.23	68 (58–78)	65 (51–79)	73 (66–80)	60 (56–64)	0.03
Sexual dysfunction	70 (66–74)	45 (39–51)	<0.01	55 (37–72)	69 (59–78)	66 (59–72)	60 (55–65)	53 (42–63)	0.07	69 (59–79)	61 (47–75)	70 (63–77)	58 (53–62)	<0.01
Circulatory problems	53 (49–58)	60 (55–66)	0.03	39 (22–57)	47 (37–57)	57 (51–64)	57 (52–63)	61 (51–71)	0.03	60 (49–70)	65 (51–79)	68 (61–75)	50 (46–54)	<0.01
Contractures	56 (52–60)	48 (42–54)	0.08	24 (9–40)	40 (31–50)	53 (46–59)	58 (53–63)	61 (51–71)	<0.01	61 (51–73)	45 (30–59)	47 (39–55)	54 (50–59)	0.04
Autonomic dysreflexia	44 (40–48)	38 (32–44)	0.12	48 (30–66)	48 (38–58)	48 (41–55)	40 (35–45)	27 (18–36)	<0.01	63 (53–74)	63 (49–77)	43 (35–50)	36 (32–40)	<0.01
Postural hypotension	39 (37–49)	43 (37–49)	0.05	33 (16–50)	42 (32–52)	38 (31–44)	39 (34–45)	52 (41–62)	0.12	60 (49–70)	49 (34–63)	32 (25–40)	39 (35–43)	<0.01
Respiratory problems	36 (32–40)	36 (30–41)	0.49	21 (6–36)	26 (18–35)	33 (26–39)	39 (34–45)	46 (36–57)	<0.01	45 (34–56)	45 (30–59)	25 (18–32)	37 (33–41)	<0.01
Urinary tract infections	30 (26–34)	32 (26–37)	0.51	33 (16–50)	39 (30–49)	31 (25–37)	28 (24–33)	27 (18–36)	0.39	55 (44–66)	51 (37–66)	43 (36–51)	20 (17–24)	<0.01
Injury caused by loss of sensation	31 (27–35)	27 (21–32)	0.22	30 (14-47)	33 (24–43)	41 (35–48)	24 (19–28)	19 (11–28)	<0.01	31 (21–41)	27 (14-39)	30 (23-37)	30 (26–34)	0.98
Pressure sore(s)	24 (20–28)	14 (10–18)	<0.01	27 (11–43)	30 (21–39)	19 (14–24)	19 (15–23)	17 (9–25)	0.13	48 (37–59)	33 (19–46)	35 (27–42)	10 (7–13)	<0.01
Diabetes Mellitus	16 (12–19)	15 (11–20)	0.68	0 (0–0)	5 (1–9)	15 (10–19)	19 (15–24)	20 (12–29)	<0.01	14 (7–22)	18 (7–30)	12 (7–17)	17 (13–20)	0.66
Heterotopic ossification	15 (12–18)	14 (10–18)	0.94	0 (0–0)	12 (5–18)	12 (8–17)	17 (13–21)	22 (13–30)	.01	18 (9–26)	10 (1–19)	18 (12–24)	14 (11–17)	0.34

Tallqvist S, Kauppila AM, Vainionpää A, Koskinen E, Bergman P, Anttila H, Hämäläinen H, Täckman A, Kallinen M, Arokoski J, Hiekkala S. Prevalence of comorbidities and secondary health conditions among the Finnish population with spinal cord injury. Spinal Cord (2021)

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Multimorbidity

- The mean number of reported diseases varied 0-12
- The mean was lowest in the 20–30 years age group (0.48)
- The mean was highest among the participants aged 76 years or older (2.0)
- Persons with NTSCI had a 27% higher expected number of comorbidities than persons with TSCI
- The scale range for the secondary health conditions was 0-16
- For the SHCs, the lowest mean was also observed among the youngest participants (6.4), but the highest mean was observed in the SCI severity group C1-4 AIS A, B, and C (8.9)

Tallqvist S, Kauppila AM, Vainionpää A, Koskinen E, Bergman P, Anttila H, Hämäläinen H, Täckman A, Kallinen M, Arokoski J, Hiekkala S. Prevalence of comorbidities and secondary health conditions among the Finnish population with spinal cord injury. Spinal Cord (2021)

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Functional independence in the Finnish spinal cord injury population

Kirsi Majamäki[1,14], Susanna Tallqvist[2,14]✉, Aki Vainionpää[3], Eerika Koskinen[4], Anna-Maija Kauppila[5], Paula Bergman[6], Heidi Anttila[7], Harri Hämäläinen[8], Anni Täckman[9], Mauri Kallinen[10,11], Jari Arokoski[8] and Sinikka Hiekkala[12,13]

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Functional Independency

14. SCIM-SR **The Spinal Cord Independence Measure-Self Report evaluates a wide range of everyday physical functions.** For each item, please thick the box next to the statement that best reflect your current situation. Please, refer your answers to the present situation also if you currently face health problems that limit you in your current independence. Please read the text carefully and only check one box in each section.

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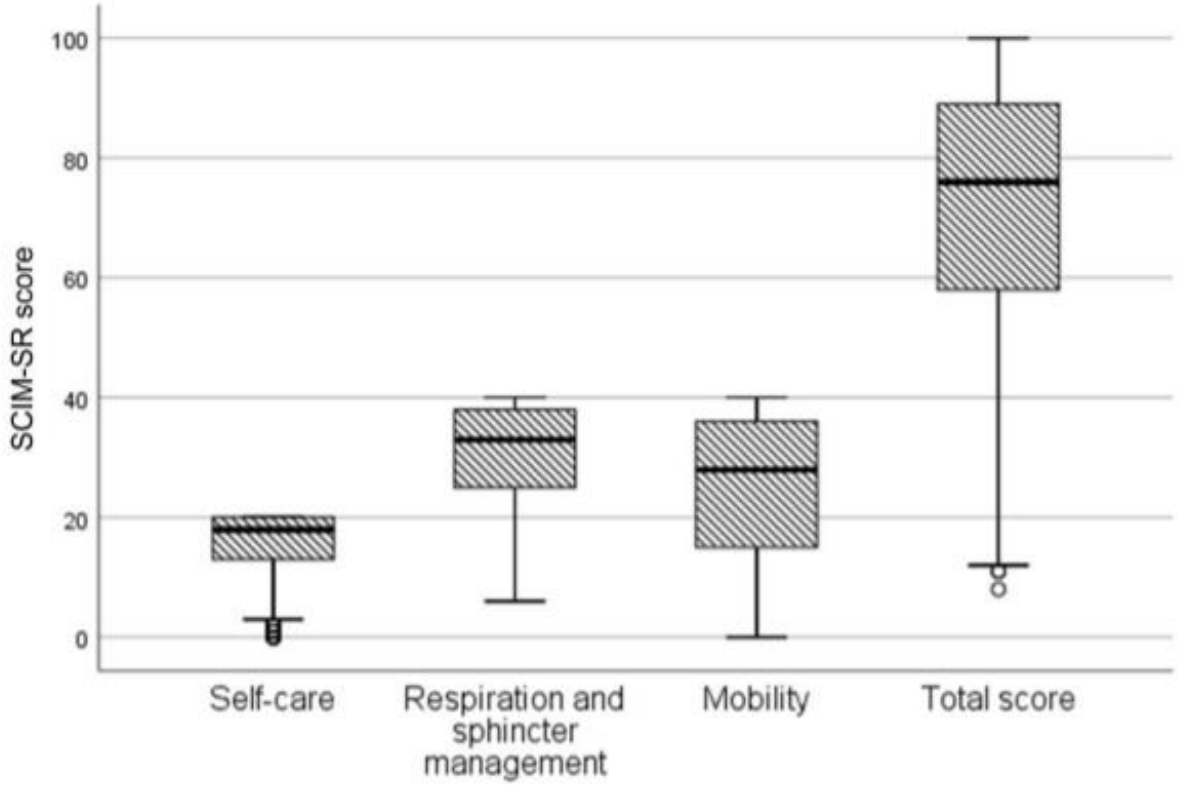
Functional Independency



Majamäki K, Tallqvist S, Vainionpää A, Koskinen E, Kauppila A-M, Bergman P, Anttila H, Hämäläinen H, Täckman A, Kallinen M, Arokoski J, Hiekkala S. Functional independence in the Finnish spinal cord injury population. Spinal Cord (2021)

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Functional Independency

- The females had higher scores than the males.
- The scores decreased with the number of years since injury
- AIS D at any injury level scored highest
- The NTSCI group had higher scores than did the TSCI group.

Majamäki K, Tallqvist S, Vainionpää A, Koskinen E, Kauppila A-M, Bergman P, Anttila H, Hämäläinen H, Täckman A, Kallinen M, Arokoski J, Hiekkala S. Functional independence in the Finnish spinal cord injury population. Spinal Cord (2021)

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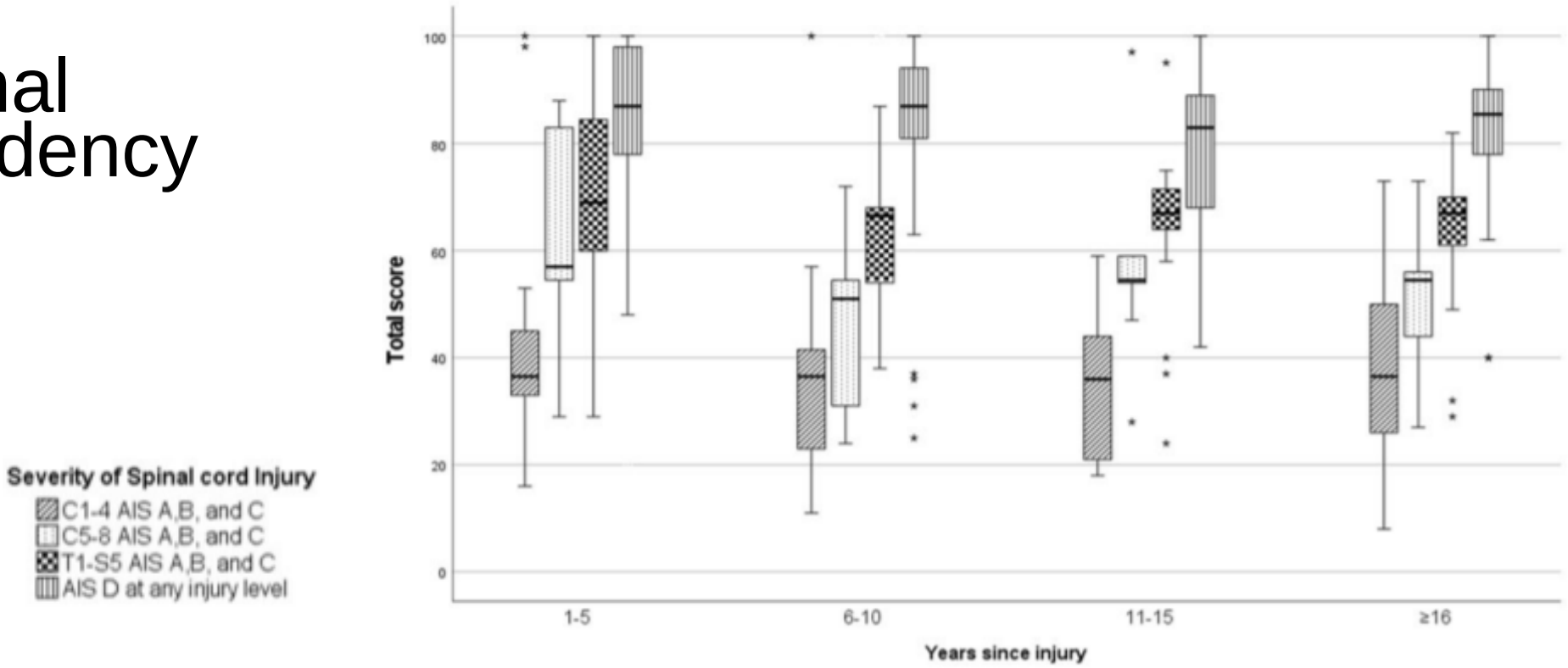
Functional Independency



Majamäki K, Tallqvist S, Vainionpää A, Koskinen E, Kauppila A-M, Bergman P, Anttila H, Hämäläinen H, Täckman A, Kallinen M, Arokoski J, Hiekkala S. Functional independence in the Finnish spinal cord injury population. Spinal Cord (2021)

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Conclusions

→SCIM-SR for use in SCI outpatient clinics

→SCI consumes more health than ageing alone does

→The time since injury had a negative impact on functional independence as early as 6–10 years after SCI, and the scores decreased between all the time-since-injury groups

→the needs of elderly persons with SCI should be carefully evaluated and supported

Majamäki K, Tallqvist S, Vainionpää A, Koskinen E, Kauppila A-M, Bergman P, Anttila H, Hämäläinen H, Täckman A, Kallinen M, Arokoski J, Hiekkala S. Functional independence in the Finnish spinal cord injury population. Spinal Cord (2021)

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In press for the Journal of Spinal Cord Medicine

Physical Health Among the Finnish Spinal Cord Injury Population According to the Patient Reported Outcome Measurement Information System (PROMIS®)

Joonas Poutanen, Heidi Anttila, Susanna Tallqvist, Mauri Kallinen, Eerika Koskinen, Harri Hämäläinen, Anna-Maija Kauppila, Anni Täckman, Aki Vainionpää, Jari Arokoski, Sinikka Hiekkala

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PROMIS® Adult Self-Reported Health

Global Health

	Physical Health		Mental Health	Social Health
PROMIS Profile Domains	Fatigue	6	Anxiety	Ability to Participate in Social Roles & Activities
	Pain Intensity	1	Depression	
	Pain Interference	4		
	Physical Function	28		
	Sleep Disturbance	4		
PROMIS Additional Domains	Dyspnea		Alcohol	Companionship
	Gastrointestinal Symptoms		Anger	Satisfaction with Social Roles & Activities
	Itch		Cognitive Function	Social Isolation
	Pain Behavior		Life Satisfaction	Social Support
	Pain Quality		Meaning & Purpose	
	Sexual Function		Positive Affect	
	Sleep-related Impairment		Psychosocial Illness Impact	
			Self-efficacy for Managing Chronic Conditions	
			Smoking	
			Substance Use	

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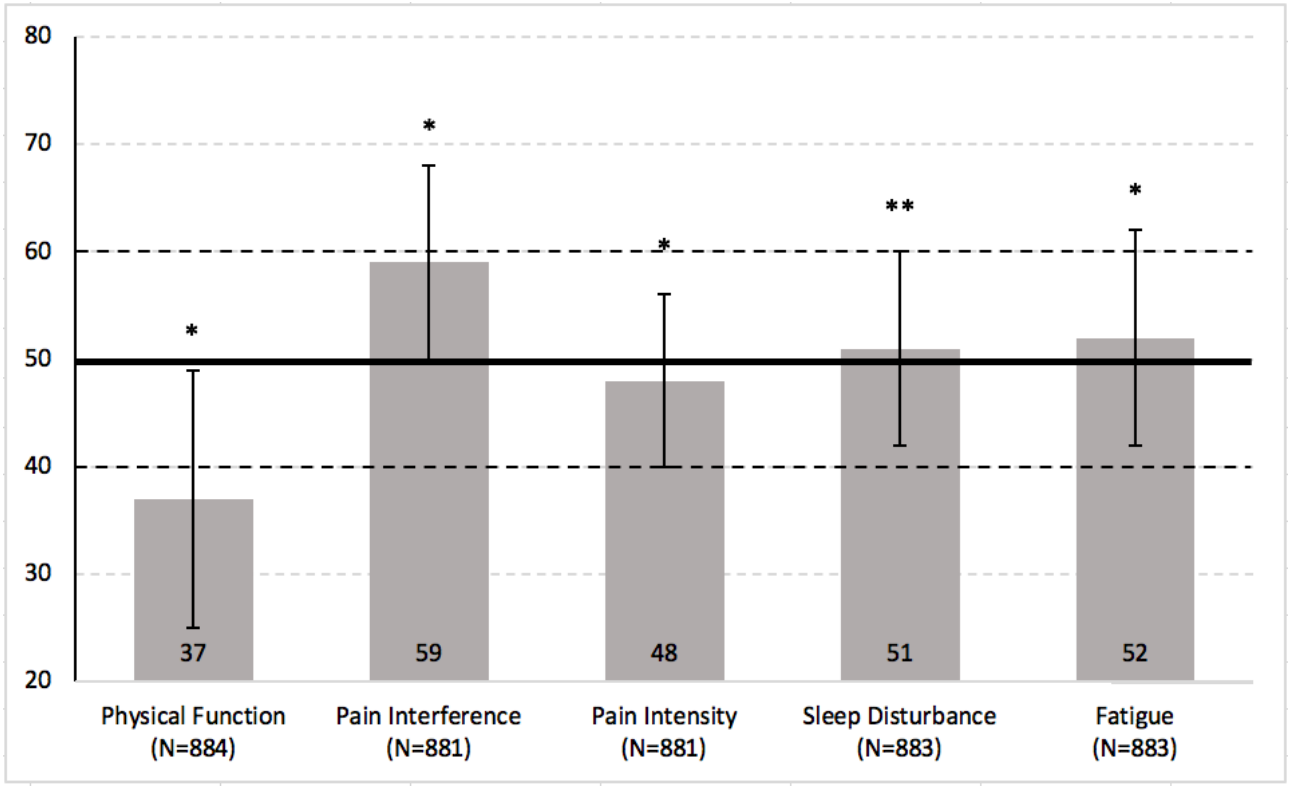
Physical Health



Poutanen J, Anttila H, Tallqvist S, Kallinen M, Koskinen E, Hämäläinen H, Kauppila A-M, Täckman A, Vainionpää A, Arokoski J, Hiekkala S. Physical health in Finnish spinal cord injury population accor-ding to Patient Reported Outcome Measurement Information System (PROMIS®). In press for Journal of Spinal Cord Medicine

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Conclusions

Physical health

- Persons with older age and higher lesion levels indicated more severe physical function impairments
- Older persons tended to have more pain interference symptoms compared to the younger participants
- The most significant association observed between pain interference and physical function highlight the substantiality of pain management in people with SCI in terms of improving physical function

Poutanen J, Anttila H, Tallqvist S, Kallinen M, Koskinen E, Hämäläinen H, Kauppila A-M, Täckman A, Vainionpää A, Arokoski J, Hiekkala S. Physical health in Finnish spinal cord injury population accor-ding to Patient Reported Outcome Measurement Information System (PROMIS®). In press for Journal of Spinal Cord Medicine

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Under preparation

Health-related factors for work participation of persons with Spinal Cord Injury in Finland

Kaarina Eskola et al.

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Työssä vs. ei työssä

		Full-time employed	Part-time employed	Work aged not at work	P-value
	n	87 (19.2%)	33 (7.3%)	332 (73.5%)	
Gender					0.587*
	Male	64 (20.5%)	22 (7.1%)	226 (72.4%)	
	Women	23 (16.4%)	11 (7.9%)	106 (75.7%)	
Age, Mean		46.8 (SD 11)	49.8 (SD 13)	50.7 (SD 11)	
	Minimum	24	23	20	
	Maximum	70	74	66	
Age group, years	20-53 224 (49.6%)	58 (12.8%)	15 (3.3%)	151 (33.4%)	0.002*
	54-74 228 (50.4%)	29 (6.4%)	18 (4.0%)	181 (40.0%)	

26,5 % employed vs the overall level of employment in the general Finnish population ~69%

Disability pension 81,6%

Gender, family relations, aetiology, cause of the injury, years since injury or severity of SCI did not differed statistically significantly between the groups.

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PROMIS® Adult Self-Reported Health

Global Health — 10

	Physical Health	Mental Health	Social Health	
PROMIS Profile Domains	Fatigue Pain Intensity Pain Interference Physical Function Sleep Disturbance	Anxiety Depression	Ability to Participate in Social Roles & Activities	2
PROMIS Additional Domains	Dyspnea Gastrointestinal Symptoms Itch Pain Behavior Pain Quality Sexual Function Sleep-related Impairment	Alcohol Anger Cognitive Function Life Satisfaction Meaning & Purpose Positive Affect Psychosocial Illness Impact Self-efficacy for Managing Chronic Conditions Smoking Substance Use	Companionship Satisfaction with Social Roles & Activities Social Isolation Social Support Satisfaction with Participation in Discretionary Social Activities	3 2

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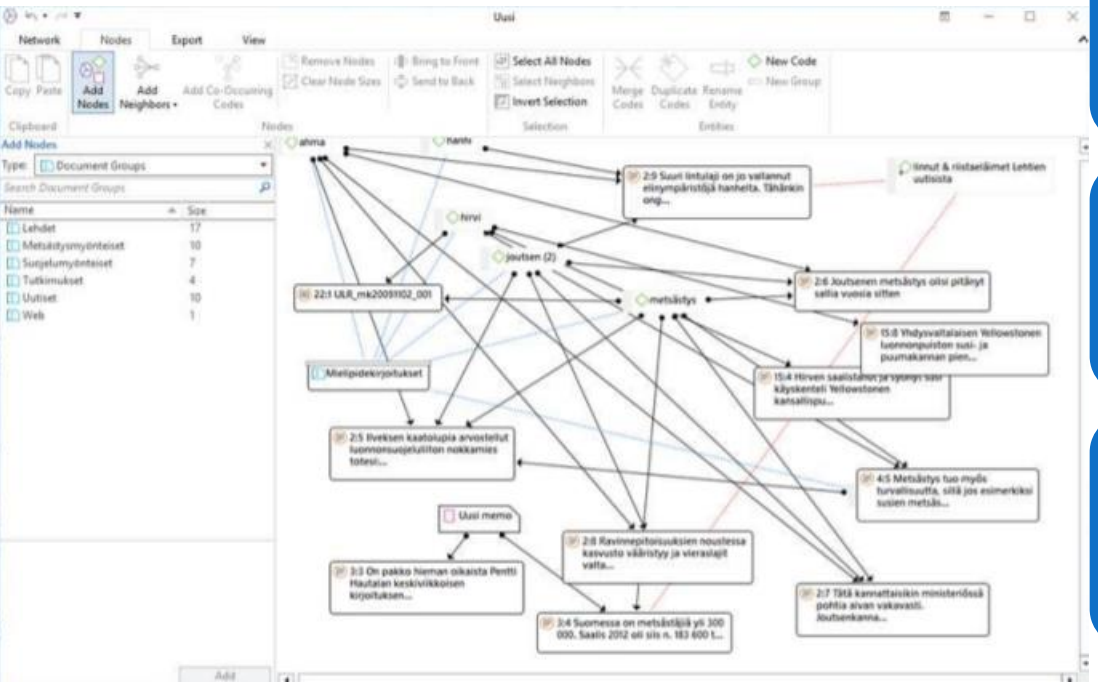
Next steps

Seuraavat stepit



Some result of the survey are still under work

Analyses of interviews (n45, 50 hours, 1500 pages) are under work

Participation of InSCI II = FinSCI II in 2023

Thank you !

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