



International Spinal Cord Injury Survey (InSCI)

*The first worldwide survey
on community-dwelling persons with spinal cord injury.*

*Countries all over the world take part in this initiative to capture the
experience of living with spinal cord injury by asking those who know best:
persons with spinal cord injury.*

A collaboration of





Dear participant

Welcome to the InSCI survey, we are very happy to have you on board!

InSCI is the first worldwide survey on community-dwelling persons with spinal cord injury. Countries all over the world take part in this initiative to capture the experience of living with spinal cord injury by asking those who know best: persons with spinal cord injury.

Please fill in the questionnaire as completely as possible and don't leave any questions unanswered. There is no right or wrong and no good or bad answer. It is important that you answer spontaneously and decide which response best applies to your personal situation.

You can also complete the questionnaire online at [www.insci.com]. Please login with your InSCI-ID and your personal password:

Your InSCI-ID is: #####

Your personal password is: #####

We guarantee that your data is protected with the highest security standards. No personal data will be handed out to third persons outside the study center. All questionnaires are anonymized by a unique identification number (InSCI-ID) and there is no personal information such as name or address on the paper or online questionnaire.

In case you have any question or need support in questionnaire completion, we are happy to help. Please send us an email at contact@en.insci.network or contact our toll-free InSCI-helpline at 0700 523 696 631.

Thank you again for your commitment!

Your InSCI-Team

Personal information

1. Please indicate your gender:

- Male
- Female

2. What day, month and year were you born?

DD / MM / YYYY

/ /

3. In which country were you born?







4. What is your current marital status?

- Single
- Married
- Cohabiting or in a partnership
- Separated or divorced
- Widowed

5. Who lives in your household with you?


Check all that apply

- I live alone
- Children under 14 years of age, number: 
- Youth between 14 and 18 years of age, number: 
- Persons between 18 and 64 years of age, number: 
- Persons over 64 years of age, number: 
- I live in an institution e.g. *home for the elderly, nursing home*


6. Do you get assistance with your day-to-day activities at home or outside?


- No
- Yes, by the following persons:
Check all that apply
 - Family
 - Friends
 - Professionals / paid assistants

7. What is the highest level of education that you have completed?

- Primary
- Lower secondary
- Higher secondary
- Post-secondary
- Short tertiary
- Bachelor or equivalent
- Master or equivalent
- Other, namely: 

8. How many years of education or training have you completed?

Years of education or training before your spinal cord injury:  (Number of years)

Years of education or training after your spinal cord injury:  (Number of years)

9. Taking into account all persons living in your household who work for a salary or wage: what is the total household income **[before, after]** taxes on average per month?

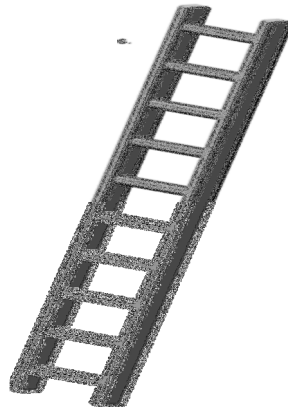
- Less than xx per month
- xx - xx per month
- xx - xx per month
- xx - xx per month
- xx - xx per month
- xx - xx per month
- xx - xx per month
- xx - xx per month
- xx - xx per month
- xx - xx per month
- xx or more per month

10. Think of this ladder as representing where people stand in **[country]**.

At the top of the ladder are the people who are the best off - those who have the most money, the most education and the most respected jobs. At the bottom are the people who are the worst off – who have the least money, least education, and the least respected jobs or no job. The higher up you are on this ladder, the closer you are to the people at the very top; the lower you are, the closer you are to the people at the very bottom.

Where would you place yourself on this ladder?

Please place a large **X** on the rung where you would place yourself at this time in your life, relative to other people in **[your country]**



Lesion characteristics

11. Please describe the level of your spinal cord injury:

- Paraplegia (normal movement and feeling in the upper limbs)
- Tetraplegia (absent or abnormal movement or feeling in the upper and lower limbs)

12. Is your injury complete or incomplete?

- Complete (unable to feel and move any part of your body below injury level)
- Incomplete (able to feel or move some part/s of your body below injury level)

13. Please indicate the cause of your spinal cord injury:

Caused by injury:

Check all that apply

For example if you check the box 'accident during work', please also specify if it was a fall or another cause of injury.

- Accident during sports
- Accident during leisure activity
- Accident during work
- Traffic accident
- Injury due to violence *e.g., gunshot wound*
- Fall from less than 1 meter
- Fall from more than 1 meter
- Other cause of injury: *✎*

Caused by disease:

Check all that apply

- Degeneration of the spinal column
- Tumor – benign
- Tumor – malignant (cancer)
- Vascular problem *e.g., ischemia, hemorrhage, malformations*
- Infection *e.g., bacterial, viral*
- Other disease: *✎*

14. Please indicate as precisely as possible the date on which your spinal cord injury occurred:

DD / MM / YYYY

□□/□□/□□□□

Energy and feelings

These questions are about how you have felt and how things have been with you during the last 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the <u>last 4 weeks</u> ...	<i>All of the time</i>	<i>Most of the time</i>	<i>Some of the time</i>	<i>A little of the time</i>	<i>None of the time</i>
15. Did you feel full of life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. Have you been very nervous?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. Have you felt so down in the dumps that nothing could cheer you up?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. Have you felt calm and peaceful?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. Did you have a lot of energy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. Have you felt downhearted and depressed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. Did you feel worn out?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. Have you been happy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. Did you feel tired?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Health problems

For the following health problems please rate how much of a problem it was for you in the last 3 months. If you have experienced the health problem please indicate whether you have received treatment or not (e.g., taking a medication or getting treatment by doctors or other health professionals).

	1 No problem	2	3	4	5 Extreme problem	Do/did you receive treatment for it?
24. Sleep problems <i>e.g., problems falling asleep or sleeping through the night and waking up early.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes <input type="radio"/> No
25. Bowel dysfunction <i>e.g., diarrhea, stool incontinence ('accidents') and constipation.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes <input type="radio"/> No
26. Urinary tract infections <i>e.g., kidney or bladder infection.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes <input type="radio"/> No
27. Bladder dysfunction <i>e.g., incontinence ('accidents'), bladder or kidney stones, kidney problems, urine leakage and urine back up.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes <input type="radio"/> No
28. Sexual dysfunction <i>e.g., difficulty with sexual arousal, erection, lubrication, and reaching orgasm.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes <input type="radio"/> No
29. Contractures <i>This is a limitation in the range of motion of a joint.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes <input type="radio"/> No
30. Muscle spasms, spasticity <i>This refers to uncontrolled, jerky muscle movements, such as uncontrolled muscle twitches or spasms.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes <input type="radio"/> No
31. Pressure sores, decubitus <i>These develop as a skin rash or redness and may progress to an infected sore.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes <input type="radio"/> No
32. Respiratory problems <i>Symptoms of respiratory infections or problems include difficulty in breathing and increased secretions.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes <input type="radio"/> No
33. Injury caused by loss of sensation <i>e.g., burns from carrying hot liquids in the lap or sitting too close to a heater or fire.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes <input type="radio"/> No
34. Circulatory problems <i>This involves the swelling of veins, feet, legs or hands, or the occurrence of blood clots.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes <input type="radio"/> No

	1 No problem	2	3	4	5 Extreme problem	Do/did you receive treatment for it?
35. Autonomic dysreflexia <i>Symptoms are sudden rises in blood pressure and sweating, skin blotches, goose bumps, pupil dilation and headache.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes <input type="radio"/> No
36. Postural hypotension <i>This involves a strong sensation of lightheadedness following a change in position. It is caused by a sudden drop in blood pressure.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes <input type="radio"/> No
37. Pain <i>Having pain in your day-to-day life.</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/> Yes <input type="radio"/> No

38. Please rate your pain by circling the number that best describes your pain at its worst in the last week.



39. Please name up to five additional health problems that also bother you:

No additional health problem experienced

.....

.....

.....

.....

.....

40. Please indicate your current smoking status:

- Never smoked
- Former smoker
- Current smoker (including occasional smoker)

Activity and participation

The following section is about problems you experience in your life. Please take both good and bad days into account.

In the last 4 weeks , how much of a problem have you had...	1 No problem	2	3	4	5 Extreme problem
41. ... carrying out daily routine?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
42. ... handling stress?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
43. ... doing things that require the use of your hands and fingers, such as picking up small objects or opening a container?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
44. ... getting where you want to go?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
45. ... using public transportation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
46. ... using private transportation?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
47. ... looking after your health, eating well, exercising or taking your medicine?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
48. ... getting your household tasks done?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
49. ... providing care or support for others?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
50. ... interacting with people?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
51. ... with intimate relationships?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
52. ... doing things for relaxation or pleasure?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
53. ... with shortness of breath during physical exertion?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
54. Are you able to sit unsupported? <input type="radio"/> No <input type="radio"/> Yes → How much of a problem is sitting for long periods such as 30 minutes?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
55. Are you able to stand unsupported? <input type="radio"/> No <input type="radio"/> Yes → How much of a problem is standing for long periods such as 30 minutes?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

These questions ask about your ability to do activities that involve mobility. Select the response that best describes your ability to do the activity without help from another person but using the equipment or devices you normally use (e.g., transfer boards lifts, hospital bed).

Are you able to...	<i>Without any difficulty</i>	<i>With a little difficulty</i>	<i>With some difficulty</i>	<i>With much difficulty</i>	<i>Unable to do</i>
56. ...get up off the floor from lying on your back?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
57. ...push open a heavy door?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
58. ...moving from sitting at the side of the bed to lying down on your back?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Independence in activities of daily living

For each item, please check the box next to the statement that best reflects your current situation. Please read the text carefully and only check one box in each section.

59. Eating and drinking

- I need artificial feeding or a stomach tube
- I need total assistance with eating / drinking
- I need partial assistance with eating / drinking or for putting on/taking off adaptive devices
- I eat / drink independently, but I need adaptive devices or assistance for cutting food, pouring drinks or opening containers
- I eat / drink independently without assistance or adaptive devices

60. Washing your upper body and head

This includes soaping and drying, and using a water tap.

- I need total assistance
- I need partial assistance
- I am independent but need adaptive devices or specific equipment *e.g., bars, chair*
- I am independent and do not need adaptive devices or specific equipment

61. Washing your lower body

This includes soaping and drying, and using a water tap.

- I need total assistance
- I need partial assistance
- I am independent but need adaptive devices or specific equipment *e.g., bars, chair*
- I am independent and do not need adaptive devices or specific equipment

62. Dressing your upper body

This includes putting on and taking off clothes like t-shirts, blouses, shirts, bras, shawls, or orthoses (e.g., arm splint, neck brace, corset).

- Easy-to-dress clothes are those without buttons, zippers or laces
- Difficult-to-dress clothes are those with buttons, zippers or laces

- I need total assistance
- I need partial assistance, even with easy-to-dress clothes
- I do not need assistance with easy-to-dress clothes, but I need adaptive devices or specific equipment
- I am independent with easy-to-dress clothes and only need assistance or adaptive devices or a specific setting with difficult-to-dress clothes
- I am completely independent

63. Dressing your lower body

This includes putting on and taking off clothes like shorts, trousers, shoes, socks, belts, or orthoses (e.g., leg splint).

- Easy-to-dress clothes are those without buttons, zippers or laces
- Difficult-to-dress clothes are those with buttons, zippers or laces

- I need total assistance
- I need partial assistance, even with easy-to-dress clothes
- I do not need assistance with easy-to-dress clothes, but I need adaptive devices or specific equipment
- I am independent with easy-to-dress clothes and only need assistance or adaptive devices or a specific setting with difficult-to-dress clothes
- I am completely independent

64. Grooming

e.g., activities such as washing hands and face, brushing teeth, combing hair, shaving, or applying make-up.

- I need total assistance
- I need partial assistance
- I am independent with adaptive devices
- I am independent without adaptive devices

65. Bladder management

Please think about the way you empty your bladder.

A. Use of an indwelling catheter

- Yes → *Please go to question no. 66*
- No → *Please also answer B and C.*

B. Intermittent catheterization

- I need total assistance
- I do it myself with assistance (self-catheterization)
- I do it myself without assistance (self-catheterization)
- I do not use it

C. Use of external drainage instruments *e.g., condom catheter, diapers, sanitary napkins*

- I need total assistance for using them
- I need partial assistance for using them
- I use them without assistance
- I am continent with urine and do not use external drainage instruments

66. Bowel management

A. Do you need assistance with bowel management *e.g., for applying suppositories?*

- Yes
- No

B. My bowel movements are...

- irregular or seldom (less than once in 3 days)
- regular (once in 3 days or more)

C. Fecal incontinence ("accidents") happens ...

- Daily
- 1-6 times per week
- 1-4 times every month
- Less than once per month
- Never

67. Using the toilet

Please think about the use of the toilet, cleaning your genital area and hands, putting on and taking off clothes, and the use of sanitary napkins or diapers.

- I need total assistance
- I need partial assistance and cannot clean myself
- I need partial assistance but can clean myself
- I do not need assistance but I need adaptive devices (*e.g., bars*) or a special setting (*e.g., wheelchair accessible toilet*)
- I do not need any assistance, adaptive devices or a special setting

68. Which of the following activities can you perform without assistance or electrical aids?

Check all that apply

- Turning your upper body in bed
- Turning your lower body in bed
- Sitting up in bed
- Doing push-ups in in a chair or wheelchair
- None, I need assistance in all these activities

69. Transfers from the bed to the wheelchair

- I need total assistance
- I need partial assistance, supervision or adaptive devices *e.g., sliding board*
- I do not need any assistance or adaptive devices
- I do not use a wheelchair

70. Moving around moderate distances (10 to 100 meters)

I use a wheelchair. To move around, ...

- I need total assistance
- I need an electric wheelchair or partial assistance to operate a manual wheelchair
- I am independent in a manual wheelchair

I walk moderate distances and I ...

- need supervision while walking (with or without walking aids)
- walk with a walking frame or crutches, swinging forward with both feet at a time
- walk with crutches or two canes, setting one foot before the other
- walk with one cane
- walk with a leg orthosis(es) only *e.g., leg splint*
- walk without walking aids

Work

71. What was the name or title of your main job before your spinal cord injury?

- I did not have a job before my spinal cord injury.
- The name or title of my main job was as follows:

.....

Please be as specific as possible, e.g., not just 'clerk' but 'bank clerk'; not just 'manager' but 'sales manager'

72. Did you receive **vocational** rehabilitation services after your spinal cord injury?

e.g., vocational counseling, vocational retraining, job skills training

- Yes
- No

73. After your discharge from initial inpatient rehabilitation, how long did it take before you started or resumed paid work?

- I never worked after initial inpatient rehabilitation
- Immediately after initial rehabilitation
- I resumed work after *.....* years and *.....* months

74. Do you currently receive a disability pension or a similar disability benefit?

- Yes
- No

75. What is your current working situation?

Check all that apply

- Working for wages or salary with an employer for *.....* hours a week
- Working for wages with an employer for *.....* hours a week, but currently on sick leave for more than three months
- Self-employed, working for *.....* hours a week
- Working as unpaid family member *e.g., working in family business*
- Housewife / househusband
- Student
- Unemployed
- Retired due to the health condition
- Retired due to age
- Other, please specify: *.....*

76. Are you currently engaged in **paid** work?

- Yes
- No → *Please go to question no. 84*

77. What is the name or title of your current main job?

Please be as specific as possible, e.g., not just 'clerk' but 'bank clerk'; not just 'manager' but 'sales manager'

.....

78. Do you want to work more, less or the same amount of hours as you currently do?

- More hours
- Less hours
- The same amount

	1 No problem	2	3	4	5 Extreme problem
79. How much of a problem is getting things done as required at work?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
80. How much of a problem do you have in accessing your workplace? <i>e.g., access to the building, your office or toilets</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Completely	To a large extent	To some extent	To a small extent	Not at all	I do not have such a need
81. Do you have the assistive devices that you need for work? <i>e.g., assistive computer devices, adjustable desks or arm/hand braces or prosthetics</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The following two questions refer to your present occupation. For each of the following statements, please indicate whether you strongly agree, agree, disagree or strongly disagree.

	Strongly agree	Agree	Disagree	Strongly disagree
82. I receive the recognition I deserve for my work.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
83. Considering all my efforts and achievements, my salary is adequate. <i>→ Please go to question no. 87</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

84. Would you like to have paid work?


- Yes
- No

85. Do you feel able to perform paid work?

- Yes, for 1 – 11 hours a week
- Yes, for 12 – 20 hours a week
- Yes, for more than 20 hours a week
- No, not at all

86. What are the reasons you are not currently working?

Check all that apply

- Health condition or disability
- Still engaged in educational or vocational training
- Personal family responsibilities
- Could not find suitable work
- Do not know how or where to seek work
- Do not have the financial need
- Parents or spouse did not let me work
- Insufficient transportation services
- Lack of accessibility to potential workplaces *e.g., access to the building, your office or toilets*
- Lack of assistive devices
- Fear of losing disability benefits *e.g., pension payments, health insurance coverage*
- I do not want to work
- Other, please specify: 

Environmental factors

In daily life, we are exposed to various external influences or environmental factors. These can make daily life easier or more difficult. Thinking about the last 4 weeks, please rate how much these environmental factors have influenced your participation in society.

	Not applicable	No influence	Made my life a little harder	Made my life a lot harder
87. Missing or insufficient accessibility of public places <i>e.g., inaccessible public buildings, parks</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
88. Missing or insufficient accessibility to the homes of friends and relatives	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
89. Unfavorable climatic conditions <i>e.g., weather, season, temperature, humidity</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
90. Negative societal attitudes toward persons with disability <i>e.g., prejudice, stigma, ignorance</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
91. Negative attitudes of your family and relatives with regards to your disability <i>e.g., prejudice, lack of support, overprotective behavior</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
92. Negative attitudes of your friends with regards to your disability <i>e.g., prejudice, lack of support, overprotective behavior</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
93. Negative attitudes of neighbors, acquaintances and work colleagues with regards to your disability <i>e.g., prejudice, lack of support, overprotective behavior</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
94. Lack of or insufficient adapted assistive technology for moving around over short distances <i>e.g., stair lift, walking aids or wheelchair</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
95. Lack of or inadequate adapted means of transportation for long distances <i>e.g., lack of adapted car or hard to use public transportation</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
96. Lack of or insufficient nursing care and support services <i>e.g., home health care or personal assistance</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
97. Lack of or insufficient medication and medical aids and supplies <i>e.g., catheters, disinfectants, splints, pillows</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
98. Problematic financial situation <i>e.g., shortage of money</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
99. Lack of or insufficient communication devices <i>e.g., lack of or insufficient writing devices, computer, telephone, mouse</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
100. Lack of or insufficient state services <i>e.g., disability insurance or other benefits</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Health care services

101. Who were the health care providers you visited, or who visited you in your home, in the last 12 months?

Check all that apply

- Primary care physician / general practitioner
- Rehabilitation physician / spinal cord injury physician
- Other specialist physician *e.g., surgeon, gynecologist, psychiatrist, ophthalmologist*
- Nurse or midwife
- Dentist
- Physiotherapist
- Chiropractor
- Occupational therapist
- Psychologist
- Alternative medicine practitioner *e.g., naturopath, acupuncturist*
- Pharmacist
- Home health care worker
- Others, please specify: *.....*
- I did not visit any health care provider in the last 12 months

102. Over the last 12 months, how many times were you a patient in a hospital, rehabilitation facility or another care facility for at least one night?

..... (times)

For your last visit to a health care provider, how would you rate the following:		Very good	Good	Neither good nor bad	Bad	Very bad
103. ...your experience of being treated respectfully?		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
104. ...how clearly health care providers explained things to you?		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
105. ...your experience of being involved in making decisions for your treatment?		<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

106. In the last 12 months, have you needed health care but did not get it?

- No
- Yes. Which reasons best explain why you did not get the health care you needed?

Check all that apply

- Could not afford the cost of the visit
- There was no service
- No transport available
- Could not afford the cost of transportation
- You were previously badly treated
- Could not take time off work or had other commitments
- The health care provider's drugs or equipment were inadequate
- The health care provider's skills were inadequate
- You did not know where to go
- You tried but were denied health care
- You thought you were not sick enough
- Other, please specify: *.....*

	Very satisfied	Satisfied	Neither satisfied nor dissatisfied	Dissatisfied	Very dissatisfied
107. In general, how satisfied are you with how the health care services are run in your area?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Personal factors

The following questions are about how you see yourself.

	1 Not at all	2	3	4	5 Completely
108. How confident are you that you can find the means and ways to get what you want if someone opposes you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
109. How confident are you that you could deal efficiently with unexpected events?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
110. How confident are you that you can maintain contact with people who are important to you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
111. How confident are you that you can maintain good health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
112. Do you think that living with your spinal cord injury has made you a stronger person?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
113. Do you worry about what might happen to you in the future? <i>e.g., thinking about not being able to look after yourself, or being a burden to others in the future</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
114. Do you feel that you will be able to achieve your dreams, hopes, and wishes?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
115. Do you get to make the big decisions in your life? <i>e.g., deciding where to live, or who to live with, how to spend your money</i>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
116. Do you feel included when you are with other people?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

117. In the **last 12 months**, have you experienced any major adverse life event?

e.g., a serious health condition or accident, a serious conflict with other persons, divorce or death of a loved one.

No

Yes, please specify: 



Quality of life and general health

The next questions are about how you rate your quality of life over the last 14 days. Please keep in mind your standards, hopes, pleasures and concerns.

In the <u>last 14 days</u> ...	<i>Very poor</i>	<i>Poor</i>	<i>Neither poor nor good</i>	<i>Good</i>	<i>Very good</i>
118. How would you rate your quality of life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	<i>Very dissatisfied</i>	<i>Dissatisfied</i>	<i>Neither satisfied nor dissatisfied</i>	<i>Satisfied</i>	<i>Very satisfied</i>
119. How satisfied are you with your health?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
120. How satisfied are you with your ability to perform your daily living activities?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
121. How satisfied are you with yourself?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
122. How satisfied are you with your personal relationships?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
123. How satisfied are you with your living conditions?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

124. In general, would you say your health is:

- Excellent
- Very good
- Good
- Fair
- Poor

125. Compared to one year ago, how would you rate your health in general now?

- Much better
- Somewhat better
- About the same
- Somewhat worse
- Much worse

**We thank you very much
for participating in the InSCI survey!**