



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 insci.network/au. Please login with your InSCI-ID and your personal password:

Your InSCI-ID is: #####

Your personal password is: #####

Date survey completed: Day _____ Month _____ Year _____

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@aus.insci.network or contact our toll-free InSCI-helpline at (02) 9926 4772.

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. A. In which country were you born?



B. Are you of Aboriginal and/or Torres Strait Islander origin?

- Yes
- No

C. Do you speak a language other than English at home?

- Yes
- No



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 or paid assistants

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

- Primary
- Lower secondary (Year 10 High school)
- Higher secondary (Year 12 High school)
- Post-secondary (e.g. vocational education and training, certificate, tertiary preparation)
- Short tertiary (e.g. diploma)
- Bachelor or equivalent (3-4 year degree)
- Master or equivalent (Post-graduate or long first degree i.e. 5 years)
- 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] tax on average per week?

- Less than \$455 AUD per week (i.e. \$23,660 per annum)
- \$456 AUD per week (i.e. \$23,712 pa) - \$686 AUD per week (i.e. \$35,672 pa)
- \$687 AUD per week (i.e. \$35,724 pa) - \$909 AUD per week (i.e. \$47,268 pa)
- \$910 AUD per week (i.e. \$47,320 pa) - \$1,203 AUD per week (i.e. \$62,556 pa)
- \$1,204 AUD per week (i.e. \$62,608 pa) - \$1,548 AUD per week (i.e. \$80,496 pa)
- \$1,549 AUD per week (i.e. \$80,548 pa) - \$1,931 AUD per week (i.e. \$100,412 pa)
- \$1,932 AUD per week (i.e. \$100,464 pa) - \$2,374 AUD per week (i.e. \$123,448 pa)
- \$2,375 AUD per week (i.e. \$123,500 pa) - \$2,969 AUD per week (i.e. \$154,388 pa)
- \$2,970 AUD per week (i.e. \$154,440 pa) - \$3,979 AUD per week (i.e. \$206,908 pa)
- \$3,980 AUD or more per week (i.e. \$206,960 pa)

[Please note that the ranges listed above for median gross household income are the most recent available from the Australian Bureau of Statistics in 2013-14]

10. Think of this ladder as representing where people stand in Australia.

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 Australia



Lesion characteristics

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

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

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; if you were injured playing sport, please also specify what sport and how you were injured.

- Accident during sports 
- Accident during leisure activity
- Accident during work
- Transport-related accident
- Injury due to violence *e.g., assault, gunshot wound*
- Fall from less than 1 metre
- Fall from more than 1 metre
- 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., lack of blood supply, bleeding,, 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"/>

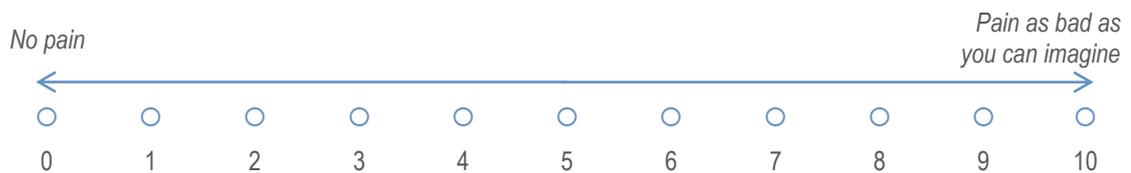
Health problems

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"/> Yes <input type="radio"/> No				
25. Bowel dysfunction <i>e.g., diarrhea, stool incontinence ('accidents') and constipation.</i>	<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"/> 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"/> 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"/> 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"/> 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"/> Yes <input type="radio"/> No				
31. Pressure sores/ulcers <i>These develop as a skin rash or redness and may progress to a sore.</i>	<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"/> 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"/> Yes <input type="radio"/> No				
34. Circulatory problems <i>This involves the swelling (oedema) of feet, legs or hands, or the occurrence of blood clots in veins.</i>	<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"/> 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"/> Yes <input type="radio"/> No				
37. Pain <i>Having pain in your day-to-day life.</i>	<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 (e.g. diabetes, heart problems, visual problems):

No additional health problem experienced

.....

.....

.....

.....

.....

40. Please indicate your current smoking status:

- Never smoked
- Former smoker
- Current smoker (including occasional smoker); please specify:

Type of cigarette (e.g., "vape", tobacco, etc.):

Amount smoked per day:

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"/>				
42. ... handling stress?	<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"/>				
44. ... getting where you want to go?	<input type="radio"/>				
45. ... using public transportation?	<input type="radio"/>				
46. ... using private transportation?	<input type="radio"/>				
47. ... looking after your health, eating well, exercising or taking your medicine?	<input type="radio"/>				
48. ... getting your household tasks done?	<input type="radio"/>				
49. ... providing care or support for others?	<input type="radio"/>				
50. ... interacting with people?	<input type="radio"/>				
51. ... with intimate relationships?	<input type="radio"/>				
52. ... doing things for relaxation or pleasure?	<input type="radio"/>				
53. ... with shortness of breath during physical exertion?	<input type="radio"/>				
54. Are you able to sit without assistance? <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"/>				
55. Are you able to stand without assistance? <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"/>				

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?	<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

includes soaping and drying, and turning a water tap on and off.

- 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

includes soaping and drying, and turning a water tap on and off.

- 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

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

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. Faecal 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 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 metres)

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

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, a great deal
- Yes, to some extent
- Yes, to a small extent
- No, not at all
- I didn't need any vocational assistance

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 (not looking for work)
- Unemployed (but actively looking for work)
- 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 <i>No problem</i>	2	3	4	5 <i>Extreme problem</i>	
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"/>	
	<i>Completely</i>	<i>To a large extent</i>	<i>To some extent</i>	<i>To a small extent</i>	<i>Not at all</i>	<i>I do not have such a need</i>
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.

	<i>Strongly agree</i>	<i>Agree</i>	<i>Disagree</i>	<i>Strongly disagree</i>
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.

	<i>Not applicable</i>	<i>No influence</i>	<i>Made my life a little harder</i>	<i>Made my life a lot harder</i>
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**
e.g., disability insurance or other benefits

Health care services

101. **Who were the health care providers you visited in the community or hospital, 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, gynaecologist, psychiatrist, ophthalmologist*)
- Nurse or midwife
- Dentist
- Physiotherapist
- Chiropractor
- Occupational therapist
- Social Worker
- Psychologist
- Dietitian
- 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"/>				
104.	...how clearly health care providers explained things to you?	<input type="radio"/>				
105.	...your experience of being involved in making decisions for your treatment?	<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 transport

- 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: 

	<i>Very satisfied</i>	<i>Satisfied</i>	<i>Neither satisfied nor dissatisfied</i>	<i>Dissatisfied</i>	<i>Very dissatisfied</i>
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.

	<i>Not at all</i> 1	2	3	4	<i>Completely</i> 5
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?

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 last 14 days ...	<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"/>
In the last 14 days ...	<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! You have now completed
the questions for all countries.

The following questions are specifically for people living in
Australia - Please continue or take a break before completing
last part of survey.

Access to spinal cord injury services

126. Which state do you live in?

- Australian Capital Territory
- New South Wales
- Northern Territory
- Queensland
- South Australia
- Tasmania
- Victoria
- Western Australia

127. Where do you live?

- Capital city
- Other metropolitan centres (urban centre population > 100,000)
- Large rural centres (urban centre population 25,000-99,999)
- Small rural centres (urban centre population 10,000-24,999)
- Other rural areas (urban centre population < 10,000)
- Remote areas (urban centre population < 5,000)

128. Who is your main contact for spinal cord injury specific problems?

- General practitioner
- Local specialist (e.g. rehabilitation physician, urologist, neurologist)
- Spinal specialist working in a specialist spinal cord injury service/unit
- Others, namely: 

129. How satisfied are you with the services provided by your General Practitioner?

- Very satisfied
- Satisfied
- Neither satisfied nor dissatisfied
- Dissatisfied
- Very dissatisfied
- I don't use this service

130. How satisfied are you with the services provided by your local general hospital/s?

- Very satisfied
- Satisfied



- Neither satisfied nor dissatisfied
- Dissatisfied
- Very dissatisfied
- I don't use this service

131. How satisfied are you with the services provided by the Spinal Cord Injury Unit/Service/s in your state?

- Very satisfied
- Satisfied
- Neither satisfied nor dissatisfied
- Dissatisfied
- Very dissatisfied
- I don't use this service

Other factors impacting on functioning

132. Compared to one year ago, how would you rate your function and independence?

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

133. Have you had any pain during the last seven days including today?

No (go to Question 144)

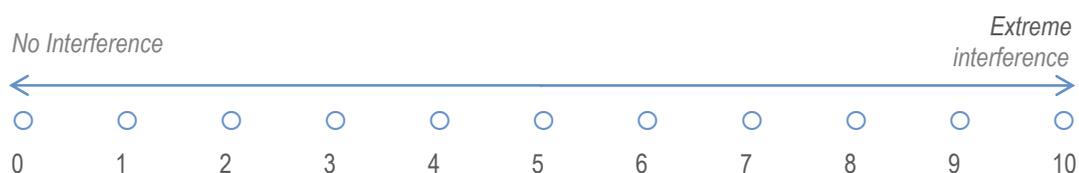
Yes If yes, please answer the following questions about the extent to which pain interferes with your life and how it is being managed:

134. How would you describe your pain?

Check all that apply

- I experience pain that is hot or burning, cold or freezing, pins and needles, tingling, electric shock-like or similar in quality.
- I experience pain that is dull, aching, cramping or tender in muscles in an area or normal sensation.
- The pain only occurs in an area of the body in which I have no feeling on the skin overlying that area.
- The skin over the area of pain is abnormally sensitive to touch and without any surgical scars, ulcers or breaks in the skin.
- The pain is usually unchanged with movement of the painful area.
- The pain is made worse by certain movements, postures or activities.
- I experience pain all the time without any breaks when I am awake (although it may vary in intensity during different times).

135. In general, how much has pain interfered with your day-to-day activities in the last week?



136. In general, how much has pain interfered with your overall mood in the last week?



137. In general, how much has pain interfered with your ability to get a good night's sleep in the last week?



138. During the last 3 months, have you experienced shoulder pain lasting for more than one day?

Shoulder pain is defined as pain in or around the shoulder area.

- No (please go to Question 141)
- Yes, I have experienced pain in the right shoulder
- Yes, I have experienced pain in the left shoulder
- Yes, I have experienced pain in both shoulders

139. For how long have you experienced shoulder pain?

- Less than 3 months
- 3 – 12 months
- 1 – 5 years
- 6 – 10 years
- 11 – 15 years
- More than 15 years

140. Over the last 3 months, has your shoulder pain prevented you from doing things in your everyday life?

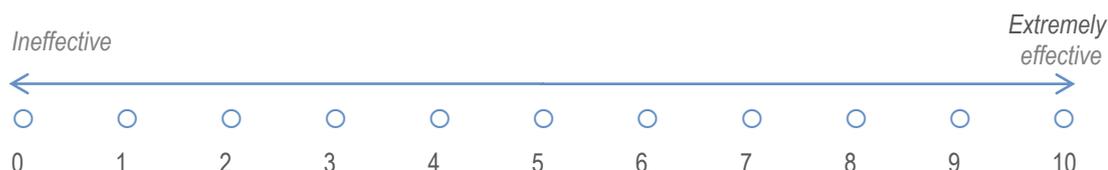
- No
- Yes, please specify:

141. Which of these treatments/strategies do you use to help manage your pain – *select all that apply*?

Check all that apply

- Take over the counter medicines (e.g. Paracetamol, Ibuprofen)
- Take prescribed nerve pain medications (e.g. Lyrica, Neurontin)
- Take prescribed opioid medications (e.g. Endone, Oxycodone, Fentanyl patch)
- Take non-prescribed medications (e.g. marijuana)
- Use alcohol to dull the pain
- Attend physiotherapy
- Seek emotional or psychological support
- Attend peer support groups
- Keep physically active (e.g. walking, fitness programs, daily chores)
- Try to get enough sleep
- Practice relaxation / meditation (e.g. mindfulness) techniques regularly
- Try to eat a healthy diet and keep to a healthy weight
- Attend manual therapies (e.g. massage, acupuncture, osteopathy, chiropractic)
- Receive other complementary therapies or treatments (e.g. homeopathy, naturopathy, Chinese herbalism)
- Others, namely:

142. Please rate how effective you find the treatments you use for managing your pain?



143. Where do you receive advice and help to manage your pain – select all that apply?

Check all that apply

- General Practitioner
- Spinal Medical Specialist
- Pain Specialist
- Physical therapist (eg: physiotherapist, exercise physiologist, occupational therapist)
- Psychologist / Counsellor
- Hospital (including Emergency Department)
- Chronic Pain Clinic (which provides multi-disciplinary care)
- Online Pain Management Courses (e.g. e-centre clinic)
- Complementary therapist (e.g. acupuncturist, homeopath, naturopath, Chinese herbalist)
- Website (e.g. ACI Pain Management Network - SCI Pain pages)
- Other, please specify:

The next four questions ask about the impact of fatigue on your functioning. Please choose a number for each statement from 1 to 7 that indicates your level of agreement with each statement, where 1 indicates “Strongly disagree” and 7 indicates “Strongly agree”

Statement	1 <i>Strongly disagree</i>	2 <i>Disagree</i>	3 <i>Slightly disagree</i>	4 <i>Neither agree nor disagree</i>	5 <i>Slightly agree</i>	6 <i>Agree</i>	7 <i>Strongly agree</i>
144. I am easily fatigued.	○	○	○	○	○	○	○
145. Fatigue interferes with my physical functioning.	○	○	○	○	○	○	○
146. Fatigue causes me frequent problems.	○	○	○	○	○	○	○
147. Fatigue interferes with my work, family or social life.	○	○	○	○	○	○	○

The next few questions ask about problems with skin breakdown that may affect your health, function and participation.

148. In the last 12 months, have you had an area of skin breakdown / ulcer / pressure injury?

- No (please go to Question 153)
- Yes, I have experienced one pressure injury / ulcer
- Yes, I have experienced two or more pressure injuries / ulcers
- Yes, I have experienced skin breakdown, but it was not caused by pressure (eg. burn)
- Other, please specify:

If Yes, please indicate the location of pressure ulcer/s over last 12 months:

Please fill in the following diagram ***with one tick for each ulcer***:

	Right	Mid-line	Left
Occiput (back of head)			
Scapula (shoulder blade)			
Elbow			
Ribs			
Spinous processes (bony prominences over vertebra)			
Sacrum (triangular bone at base of spine) & Coccyx (tail bone)			
Ischial tuberosity (buttock, where we sit)			
Trochanter (area over hip joint when lying on side)			
Genitals			
Knee			
Ankle over malleolus (bony prominence)			
Heel			
Other location			

149. How long did the area of skin breakdown / ulcer / pressure injury take to heal completely?

- Less than 1 week
- 1-4 weeks
- 1-3 months
- 3-6months
- 6-12 months
- More than 12 months

150. Did the skin breakdown / ulcer / pressure injury require an admission/s to hospital?

- No
- Yes, I spentdays in hospital

If Yes, was the area of skin breakdown / ulcer treated surgically

- No
- Yes

151. Were you referred to a Spinal Plastics Service / Spinal Pressure Care Clinic based in your capital city?

- No
- Yes

152. Do you have a skin breakdown / ulcer / pressure injury that has never completely healed or that breaks down frequently?

- No
- Yes

153. What do you do when you discover you have a red mark, skin breakdown, ulcer or pressure injury on an area you sit on?

Check all that apply

- Maintain complete 24 hour per day lying in bed (I do **not** get up to go to the toilet or have a shower)
- Stay in bed (but I do get up to go to the toilet and have a shower)
- Reduce time sitting
- Seek advice from an Occupational Therapist or Seating Therapist

- Contact local medical or nursing services
- Contact the Spinal Unit or Spinal Plastics Service / Spinal Pressure Care Clinic for advice
- I am able to increase the amount of care I receive
- I am able to upgrade my equipment if required (e.g. mattress, wheelchair cushion, commode)
- Other, please specify: 

154. Please name any barriers (up to five) that make it difficult to heal a skin breakdown, ulcer or pressure injury:

- No barriers experienced











Physical Activity

This section is about your current level of physical activity and exercise. Please remember there are no right or wrong answers. We simply need to assess your current level of activity.

155. During the past 7 days, how many days did you walk, wheel, (hand) cycle outside your home other than specifically for exercise. For example, getting to work or class, walking the dog, shopping, or other errands?

_____ days per week [score options: 0 – 7] *If 0 days → Go to question 156.*

On average, how many minutes per day did you spend walking, wheeling or (hand) cycling outside your home?

_____ minutes per day.

156. During the past 7 days, how many days did you engage in light sport or recreational activities such as bowling, golf with a cart, hunting or fishing, darts, billiards or pool, therapeutic exercise (physical or occupational therapy, stretching, use of a standing frame) or other similar activities?

Note: Light sport or recreational activities require very light physical effort; these activities make you feel like you are working a little bit, but you can keep doing them for a long time without getting tired.

_____ days per week [score options: 0 – 7] *If 0 days → Go to question 157.*

On average, how many minutes per day did you spend in these light sport or recreational activities?

_____ minutes per day.

157. During the past 7 days, how many days did you engage in moderate sport and recreational activities such as doubles tennis, softball, golf without a cart, ballroom dancing, wheeling or pushing for pleasure or other similar activities?

Note: Moderate sport and recreational activities require some physical effort; these activities make you feel like you are working somewhat hard, but you can keep doing them for a while without getting tired.

_____ days per week [score options: 0 – 7] *If 0 days → Go to question 158.*

On average, how many minutes per day did you spend in these moderate sport and recreational activities?

_____ minutes per day.

158. During the past 7 days, how many days did you engage in *strenuous sport and recreational* activities such as jogging, wheelchair racing (training), off-road pushing, swimming, aerobic dance, arm cranking, cycling (hand or leg), singles tennis, rugby, basketball, walking with crutches and braces, or other similar activities?

Note: Strenuous sport and recreational activities require a lot of physical effort; these activities make you feel like you are working really hard, almost at your maximum. You cannot do these activities for very long without getting tired. These activities may be exhausting.

_____ days per week [score options: 0 – 7] *If 0 days → Go to question 159.*

On average, how many minutes per day did you spend in these strenuous sport or recreational activities?

_____ minutes per day.

159. During the past 7 days, how many days did you do any exercise specifically to increase muscle strength and endurance, such as lifting weights, push-ups, pull-ups, dips, or wheelchair push-ups, etc?

_____ days per week [score options: 0 – 7] *If 0 days → Go to question 160.*

On average, how many minutes per day did you spend in these exercises to increase muscle strength and endurance?

_____ minutes per day.

Society / Social integration

160. **In my daily life I get very little chance to show how capable I am.**

- Agree strongly
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

161. **I feel close to the people in my local area.**

- Agree strongly
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

162. **When I hit a major problem at work or in attempting to return to work, I have co-operative co-workers or supervisors that help me overcome it.**

- Agree strongly
- Agree
- Neither agree nor disagree
- Disagree
- Strongly disagree

Please choose a number for each statement from 0 to 6 that indicates your level of agreement with each statement, where 0 indicates “Not at all” and 7 indicates “Strongly agree”

	<i>Not at all</i>						<i>A great deal</i>
	0	1	2	3	4	5	6
163. Do you feel that people treat you with respect?	<input type="radio"/>						
	<i>Not at all</i>						<i>Completely</i>
	0	1	2	3	4	5	6
164. To what extent do you receive help and support from people you are close to when you need it?	<input type="radio"/>						
	<i>No control</i>						<i>Extreme control</i>
	0	1	2	3	4	5	6
165. During the <u>past week</u> how much control do you feel that you have had over your life?	<input type="radio"/>						

When a traumatic injury or disease causes sudden spinal cord impairment, it can have profound effects on our lives. The following questions are from a scale designed to assess how your injury has affected your life. Listed below are four statements describing different thoughts and feelings that you may experience when you think about your injury.

Please indicate the degree to which you have these thoughts and feelings when you think about your injury on a 5-point scale with the endpoints where 0 indicates “not at all” and 4 indicates “all the time”.

Statement	<i>Not at all</i>				<i>All the time</i>
	0	1	2	3	4
166. Most people don’t understand how severe my condition is.	<input type="radio"/>				
167. I am suffering because of someone else’s negligence.	<input type="radio"/>				
168. I just want my life back.	<input type="radio"/>				
169. It all seems so unfair.	<input type="radio"/>				

Sleep Quality

People with a spinal cord injury commonly report problems with sleep. This final series of questions relate to your usual sleep habits during the past month only. Your answers should indicate the most accurate reply for the majority of days and nights in the past month. **Please answer all questions.**

170. During the past month, what time have you usually gone to bed at night? 

171. During the past month, how long (in minutes) has it usually taken you to fall asleep each night?


172. During the past month, what time have you usually gotten up in the morning? 

173. During the past month, how many hours of actual sleep did you get at night? (This may be different than the number of hours you spent in bed.) 

During the past month, how often have you had trouble sleeping because you...		<i>Not during the past month</i>	<i>Less than once a week</i>	<i>Once or twice a week</i>	<i>Three or more times a week</i>
174.	Cannot get to sleep within 30 minutes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
175.	Wake up in the middle of the night or early morning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
176.	Have to get up to use the bathroom	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
177.	Cannot breathe comfortably	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
178.	Cough or snore loudly	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
179.	Feel too cold	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
180.	Feel too hot	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
181.	Have bad dreams	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
182.	Have pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
183.	Other reason(s), please describe: 	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
184.	During the past month, how often have you taken medicine to help you sleep (prescribed or “over the counter”)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
185.	During the past month, how often have you had trouble staying awake while driving, eating meals, or engaging in social activity?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

186. During the past month, how much of a problem has it been for you to keep up enough enthusiasm to get things done?

- No problem at all
- Only a very slight problem
- Somewhat of a problem
- A very big problem

187. During the past month, how would you rate your sleep quality overall?

- Very good
- Fairly good
- Fairly bad
- Very bad

		<i>No bed partner or room mate</i>	<i>Partner / room mate in other room</i>	<i>Partner in same room but not same bed</i>	<i>Partner in same bed</i>
188.	Do you have a bed partner or room mate?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If you have a room mate or bed partner, ask him/her how often in the past month you have had:		<i>Not during the past month</i>	<i>Less than once a week</i>	<i>Once or twice a week</i>	<i>Three or more times a week</i>
189.	Loud snoring	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
190.	Long pauses between breaths while asleep	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
191.	Legs twitching or jerking while you sleep	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
192.	Episodes of disorientation or confusion during sleep	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
193.	Other restlessness while you sleep, please describe: 	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**Once again we thank you very much
 for participating in this survey!
 You have now completed ALL questions.**