

Australian arm of the International Spinal Cord Injury Community Survey

(Aus-InSCI Community Survey)

National Report

March 2021

This document is submitted to the National Steering Committee at the completion of the Aus-InSCI Community Survey project (2017 - 2019).

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Key Partner Organisations

New South Wales



THE UNIVERSITY OF
SYDNEY

icareTM
Insurance and Care NSW



Health
Northern Sydney
Local Health District



Health
South Eastern Sydney
Local Health District



Royal Rehab
The Rehabilitation & Disability
Support Network

scia
Spinal Cord Injuries Australia

ParaQuad
Paraplegic & Quadriplegic Association of NSW

Queensland



Queensland
Government

**Princess Alexandra
Hospital**
BRISBANE • AUSTRALIA

Victoria



Austin Health

South Australia



**Government
of South Australia**
SA Health

PQSA
PARAQUAD SOUTH AUSTRALIA
Living your potential



Lifeline
SUPPORT

Western Australia



Curtin University

Australian Capital Territory



Australian Government
**Australian Institute of
Health and Welfare**

Project Team

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Acknowledgements

National Level

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International Level

The project team would like to acknowledge the Swiss Paraplegic Research Centre for their most helpful advice and ongoing support throughout the study. This study is based on data from the International Spinal Cord Injury (InSCI) Community Survey. (Ref. Am J Phys Med Rehabil 2017;96(Suppl):S23–S34). The members of the InSCI Steering Committee are: J. Middleton, J Patrick Engkasan, G Stucki, M Brach, J Bickenbach, C Fekete, C Thyrian, L Battistella, J Li, B Perrouin-Verbe, C Gutenbrunner, C Rapidi, LK Wahyuni, M Zampolini, E Saitoh, BS Lee, A Juocevicius, N Hasnan, A Hajjioui, MWM Post, JK Stanghelle, P Tederko, D Popa, C Joseph, M Avellanet, M Baumberger, A Kovindha, R Escorpizo.

Funding sources

National level

The project sites in the four Australian states that participated in the Aus-InSCI Community Survey project received funding from the following sources:

- ✓ The coordinating National study centre in New South Wales based at John Walsh Centre for Rehabilitation Research at the University of Sydney received funding from Insurance and Care NSW (icare NSW).
- ✓ The site in Queensland had internal departmental funding.
- ✓ The site in Victoria received funding from the Australasian Spinal Cord Injury Network Ltd (SCIN) and the Spinal Research Institute (SRI).
- ✓ The site in South Australia received funding from Lifetime Support Authority South Australia.

National Steering Committee

A membership list of the National Steering Committee for the Aus-InSCI study is presented in **Table 1** below:

Table 1 Membership of National Steering Committee

#	Name	Member role
1	James Middleton	Chief Investigator - Australia
2	Mohit Arora	Postdoctoral Fellow and Manager
3	Ian Cameron	Principal Investigator - New South Wales
4	Ashley Craig	Consultant - New South Wales
5	Tim Geraghty	Principal Investigator – Queensland
6	Andrew Nunn	Principal Investigator – Victoria
7	Ruth Marshall	Principal Investigator - South Australia
8	John Walsh	Peer Reviewer and Consultant
9	Suzanne Lulham	Funder representative
10	Garry Kent / Jacqueline Scott	Funder representative
11	Dianne Lucas / Peter Perry	Consumer organisation representative
12	Kylie Wicks	Consumer organisation representative
13	Peter Stewart	Consumer organisation representative

National Scientific Advisory Committee

A sub-committee of the Aus-InSCI Steering Committee comprised the Scientific Advisory Committee, consisting of:

- Four state-wide Principal Investigators
 - a. **James Middleton**, NSW
 - b. **Timothy Geraghty**, QLD
 - c. **Ruth Marshall**, SA
 - d. **Andrew Nunn**, VIC
- **Mohit Arora**: Postdoctoral Fellow and Manager
- **John Walsh**: Consumer representative
- **Ashley Craig**: Expert Advisor
- **Annette Kifley**: Consultant Statistician Advisor

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Section 1 Background and rationale

Australia participated in a world first survey, which aimed to describe the lived experience of people with spinal cord injury (SCI) in Australia. The study identified key factors that determine different levels of functioning and independence, health, community participation and quality of life. There was a need for better information from people with a SCI about the most important problems and needs that they experience across their lifespan. This forms part of a new global 'learning systems' initiative to improve the lived experience of people living with SCI that is linked to implementation of the World Health Organisation (WHO) Global Disability Action Plan 2014-2021 Better health for all people with disability. The study was affiliated with the WHO, the International Spinal Cord Society and the International Society of Physical Rehabilitation Medicine.

The John Walsh Centre for Rehabilitation Research based at the University of Sydney, funded by icare NSW was the Australian coordinating and research centre for the study supporting nine data custodians within Australia. Swiss Paraplegic Research in Nottwil, Switzerland was the international coordinating and research centre supporting 22 participating WHO member countries.

Ultimately, the goal of this research is to identify targets for effective interventions at various levels of government policy-making (in relation to evidence and rights), health and service delivery systems and to participate in and contribute to society, and to have a say in their own future. In addition to providing reliable and detailed information about the personal lived experience, the survey results will also reveal best practices and strategies that are working in other countries that we can learn from, explore for better solutions and adapt to the Australian context. This would provide a baseline for future comparison within Australia, as well as international benchmarking across level of functioning, social and economic participation, and social support. The data may also complement future data collection on performance and outcomes by the National Disability Insurance Authority and the National Injury Insurance Scheme, as well as other schemes (e.g., for Motor Vehicle and Workers Compensation).

Section 2 Project methodology

2.1 Study objectives

The overall objective of the InSCI survey was to describe and identify the determinants of levels of functioning, health and wellbeing of persons living with SCI within and across countries. The guiding hypotheses for the analysis of the InSCI survey are the following:

- Functioning, health and wellbeing vary between countries and WHO regions.
- Variation in functioning, health and wellbeing is related to variation in self-reported environmental factors.
- Variation in functioning, health and wellbeing is related to variation in self-reported personal factors.
- Variation in functioning, health and wellbeing between countries and WHO regions are partly attributable to macro-level differences in health systems and policies and general socioeconomic characteristics.

2.2 Study design

Aus-InSCI was part of a cross-sectional, multi-national community survey based on the International Classification of Functioning, Disability and Health Core Sets for spinal cord injury (SCI). The study was implemented in 2017, in parallel to the WHO *Model Disability Survey*, and planned to be repeated at 5-year intervals to obtain longitudinal and contemporary information about the lived experience of persons with SCI across nations, as well as evidence of improvements with implementation efforts. In addition to Australia, 21 other countries also participated in the InSCI survey from all of the six WHO regions, representing different stages of economic development and health care systems, allowing for comparative analysis.

2.3 Study procedure

Sampling: The prevalent SCI population in Australia is estimated and beyond the scope of this project to determine definitively. As such, it was not possible to use a simple approach of random sampling to recruit a representative sample of people with both traumatic (TSCI) and non-traumatic SCI (NTSCI). Notwithstanding this limitation, much is known about the demographic and injury characteristics of the population, especially those with TSCI. To ensure comprehensive coverage is achieved, four Australian states were involved to achieve a target of a minimum of 1000 people. Periodic monitoring by the coordinating centre was undertaken to ensure a balanced sample with TSCI and NTSCI with the following characteristics: living in metropolitan and regional/rural settings (70%, 30%); with paraplegia and tetraplegia (50%, 50%); complete and incomplete impairment (40%, 60%); aged <40 years, 40-60 years and >60 years (40%, 30%, 30%), time post-injury <10 years, 10-20 years, >20 years (33%, 33%, 33%), and compensable or no insurance (30%, 70%). These strata mirror the best current understanding of the demographics of the prevalent TSCI and NTSCI population in Australia.

It was planned that the survey will target New South Wales, Queensland, Victoria and South Australia. Eligible people with SCI for whom survival status is known were identified through three main sources involving custodians from four states:

- 1) State SCI Service / Unit databases (i.e., Spinal Cord Injury Directorate, Spinal Outreach and Rural SCI Service databases in NSW; Spinal Care database in Victoria; the Queensland SCI Unit database; and the South Australian / Northern Territory Spinal Cord Injury Service data-base);
- 2) State-wide health organisation ?? RR
- 3) Not-for-profit, member-based SCI Consumer organizations (e.g., Paraplegic and Quadriplegic Association of NSW, Paraplegic and Quadriplegic Association of SA, also known as PQSA, and Spinal Cord Injuries Australia); and

- 4) Motor Vehicle Third Party Insurers / Lifetime Care and Support Agencies, such as NSW Lifetime Care and Support Authority (LTCSA) and SA Lifetime Support Authority (LSA).

Inclusion Criteria:

- Adults (aged 18 years or older) with an established traumatic SCI (including cauda equina syndrome) or non-traumatic SCI (due to non-progressive aetiologies, such as due to vascular accidents, infection and primary neurological tumours) at least 12 months post-injury.
- Eligible subjects were Australian residents living in the community with SCI, who are able to fill in questionnaire in one of the available translated language (English and others possible languages included Chinese, Italian, Greek and Arabic).

Exclusion Criteria:

- Persons with spinal cord damage due to congenital aetiologies, such as spina bifida, or because of progressive disease, such as secondary tumours with metastatic cancer or neurodegenerative disorders, such as multiple sclerosis.
- Persons with an acute SCI more than 12 months and were still receiving acute care or subacute rehabilitation as an inpatient in hospital.
- People unable to complete the survey due to cognitive impairment (i.e. severe TBI, major mental health condition or dementia).

Recruitment: Participants with SCI were identified from databases held by the state Spinal Cord Injury Units / Services, not-for-profit member-based SCI Associations and Third Party Insurers/Lifetime Care & Support Agencies in New South Wales, Queensland, South Australia and Victoria. Each of the nine data custodians (shown in **Table 2** below) then extracted data for all potential participants containing minimum socio-demographic and injury-related variables. These data were securely transferred to a third-party data linkage services, Population Health Research Network - Centre for Data Linkage (PHRN-CDL) based at the Centre for Population Health Research at the Curtin University. Data transfer agreements (DTA) were executed between each data custodian and PHRN-CDL. The PHRN-CDL also ensured that the privacy of individuals during the linkage process was protected by creating a “linkage key” for each participant.

Table 2 Nine data custodians participated in the Aus-InSCI Community Survey

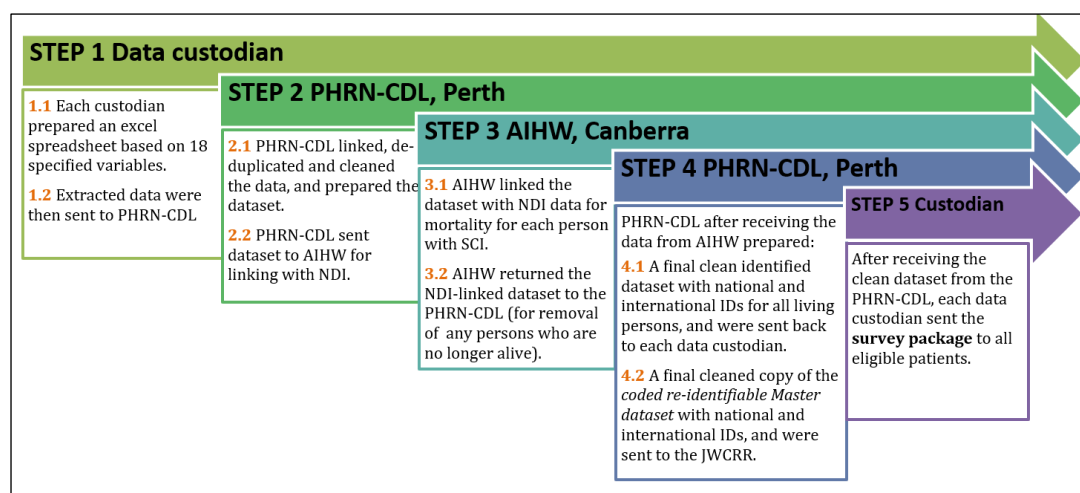
DATA CUSTODIANS		
NSW	1	NSW Agency for Clinical Innovation (Spinal Cord Injury Database)
	2	Royal Rehab (Rural Spinal Cord Injury Services and Spinal Outreach Services Datasets)
	3	Spinal Cord Injuries Australia
	4	ParaQuad NSW
	5	icare NSW
QLD	6	Metro South Hospital and Health Service, Queensland Spinal Cord Injuries Services, Princess Alexandra Hospital
VIC	7	Victorian Spinal Cord Service, Austin Health
SA	8	Central Adelaide Local Health Network Incorporated, South Australia Spinal Cord Injury Service, Hampstead Rehabilitation Centre
	9	The Paraplegic and Quadriplegic Association of South Australia

Rigorous processes and protocols had been developed to protect the privacy and confidentiality of individuals during the record linkage process. These include strict data governance procedures covering people, processes and information technology, role separation and restricted data flows. Combinations of these are used to mitigate

risks to privacy by limiting access to certain information. Ultimately, an integrated master dataset containing the minimum socio-demographic and injury-related variables (allowing for correction of non-response bias in sampling) was created using Linkage Services (including Privacy-Preserved Record Linkage via Bloom Filter Method) by PHRN-CDL. PHRN-CDL sent the master dataset to the AIHW for linkage with the National Death Index to ascertain survival status (alive or dead) for each participant to minimise the possibility of approaching relatives or family members of deceased individuals that data custodians were not aware of.

The secure mechanism and processes for transferring and linking information from the separate databases released with permission from the host organisations, in compliance with ethical requirements, are shown below in **Figure 1**.

Figure 1 Data linkage process



Abbreviations: PHRN-CDL, Population Health Research Network- Centre for Data Linkage (Perth); AIHW, Australian Institute of Health and Welfare (Canberra); NDI, National Death Index; JWCRR, John Walsh Centre for Rehabilitation Research (Sydney);

A letter of invitation to participate, printed questionnaire and a pre-paid response envelope, along with a Participant Information Sheet, were mailed out independently from the research team (JWCRR) by the relevant organisation (SCI Association, SCI Service / Unit or Third-Party Insurer/Lifetime Care & Support Agency). Consent is implied by survey completion. All responses were treated as anonymous by including a unique ID code and a password for accessing/completing the online questionnaire and/or a reference study ID for other modes of completion (see section below on different completion modes).

Participation in this survey was entirely voluntary and participants were not under any obligation to complete the survey questionnaire. Participation (response) rates were monitored using the unique ID provided so that reminders can be sent only to those who have not responded.

Sample size: A minimum of 1,000 participants (200-300 from >1,000 potential participants invited from each state).

Survey completion modes: A participant was given three possible ways to complete the survey, namely “online via password-secured web-based entry form”, “pen and paper version” or “by telephone interview”. For each mode, a single unique InSCI ID and password was allocated to each participant. For those who did not wish to complete the survey by any of the ways, they were asked to send the blank questionnaire in the stamped, return addressed envelope provided, to the John Walsh Centre for Rehabilitation Research, The University of Sydney.

Study duration: Letters of invitation were sent in February 2018 with two follow-up reminders sent to all non-responders in July 2018 and November 2018, respectively. The study recruitment was closed on 15 January 2019.

Support for nine data custodians: Regular support and coordination of the study and its activities was provided by the John Walsh Centre for Rehabilitation Research at the University of Sydney to each of the sites on a fortnightly/monthly basis or when required. The unidentifiable data collected for 1579 participants for all nine custodians was closely monitored and quality checked by the Coordinating centre on regular basis. After data collection was completed, the final cleaned version of the data was migrated from the international secure platform to a secure platform, REDCap hosted by the University of Sydney.

In addition, the following procedure or standard were developed:

- Three standardised practical guides (Volume 1 to 3) were developed by the Study Centre, which were provided to all custodians to support the quality process of sending invitations to potential participants and reminders to all non-responders.
- Data sharing policy, authorship guidelines and publication review procedures were developed.
- The following templates were developed to support each lead author for disseminating the results of the Aus-InSCI Community survey in an appropriate and consistent way:
 - Template for acknowledgement, funding source and information related to ethical approvals.
 - A template and guidance related to *Companion document* (which is a one-page lay summary or infographic of their study findings) that each lead author needs to provide the coordinating centre for dissemination purpose.
 - Template for writing the study proposal to be considered by the Scientific Advisory Committee for their approval.

Section 3 Governance

3.1 National Ethical and Scientific approvals

The Aus-InSCI study, as part of the International Spinal Cord Injury (InSCI) Community Survey, was approved by the Northern Sydney Local Health District HREC (HREC/16/HAWKE/495) and Australian Institute of Health and Welfare Ethics Committee (EO2017/1/341). Local state-specific governance approvals were also received. All data were to be retained for 7 years (1st February 2025). The proposed record linkage process was undertaken without the specific written consent of individual with SCI, whose data are believed to be in the public interest and at low risk (under Section 95A of Commonwealth Privacy Act 1988/2014).

- Original Application submitted: November 2016
- Approved original HREC: dated 10 March 2017
- Approved HREC amendment #1: dated 23 June 2017
- Approved HREC amendment #2: dated 2 August 2017

3.2 National Death Linkage (NDI) approvals from Australian Institute of Health and Welfare (AIHW)

The project was approved by the AIHW Ethics Committee at its meeting on 21 February 2017 subject to the receipt and consideration of approval by the Northern District Local Health District HREC and the project approved. Approval is valid until 30 June 2018 with data retention to 30 June 2025 as well as approval was granted for a waiver of consent pursuant to s.95 of the Privacy Act 1988.

- Approved original application: dated 21 February 2017
- Approved amendment #1: dated 18 July 2017

3.3 Site specific Authorisations dates for participating SCI Units in four Australian states.

- NSW- Royal North Shore Hospital: approved 21 August 2017
- VIC- Austin Health: approved 13 November 2017
- QLD- Princess Alexandra Hospital: approved 18 September 2017
- SA- Hampstead Rehabilitation Centre: approved November 2017

3.4 National Steering Committee

A National Steering Committee for the Aus-InSCI community survey was established. A total of six Steering committee meetings were held over the course of the study, with following aims and objectives:

- ✓ providing oversight and advice to achieve the project outcomes
- ✓ monitoring progress against timelines
- ✓ monitoring the quality of the project and identifying any potential risks
- ✓ reviewing study results, and
- ✓ providing advice about further steps and implementation strategies.

3.5 National Scientific Advisory Committee

In addition, a National Scientific Advisory Committee for the Aus-InSCI survey was also established later on during the project to provide an undergoing scientific review process for all proposals to analyse, present and publish the Aus-InSCI data. To date, four committee meetings have been held. The intention of the Scientific Committee is to contribute expertise through participation in scheduled meetings and teleconferences, as well as offline work to the research design and effective advocacy,

dissemination and implementation of the project. The Scientific Committee provides support with the following:

- ✓ Review of all research proposals to provide feedback and recommendations.
- ✓ Nomination of a member approver for each proposal.
- ✓ Identifying priorities for research and development activities related to the InSCI project.
- ✓ Building strategies for effective advocacy, dissemination and implementation of the project.

Section 4 Descriptive analyses of eligible participants

4.1 Eligibility, response status and participation rates for Aus-InSCI participants

Table 3 Eligibility, response status and participation rates for the Aus-InSCI participants

Heading	n
Total invited	6123
Eligible	5925
Not eligible	198
Moved abroad	98
Age	12
Medical exclusion criteria	21
Deceased before invitation	66
Duplicate	1
Response status	
Participation	1579
Non-participation	4346
Refusal	3783
Active refusal	327
Passive refusal	3456
Give up reminding	3446
Deceased after invitation	10
No contact	563
Participation rates	%
Absolute cooperation rate	29
Absolute contact rate	91
Absolute response rate	27

4.2 Descriptive comparison between responders and non-responders

Table 4 Comparison of demographic characteristics of participants (responders) and non-participants (non-responders)

Variables	All eligible persons (n=5925)	Participants (n=1579)	Non-participants (n=4346)
Age; mean (SD) [Range]	54 (16) [18-100*]	58 (14) [19-94]	52 (16) [18-100*]
SEIFA; mean (SD) [Range]	5.6 (3.0) [1-10]	5.7 (2.9) [1-10]	5.7 (3.0) [1-10]
Injury duration; mean (SD) [Range]	17 (13) [1-81]	17 (14) [1-73]	17 (14) [1-81]
Injury duration; median [IQR]	13 [7-24]	12 [6-25]	14 [7-24]
State of contact;	n (%)	n (%)	n (%)
New South Wales	2366 (40)	691 (44)	1675 (39)
Victoria	1079 (18)	251 (16)	828 (19)
Queensland	2000 (34)	481 (31)	1519 (35)
South Australia	471 (8)	147 (9)	324 (7)
Gender			
Male	4411 (75)	1157 (73)	3254 (76)
Female	1451 (25)	422 (27)	1029 (24)
Age group (in years)			
18 to 30	462 (8)	76 (5)	386 (9)
31 to 45	1411 (24)	246 (16)	1165 (28)
46 to 60	1863 (32)	532 (34)	1331 (31)
61 to 75	1550 (27)	590 (37)	960 (23)
>75	524 (9)	135 (9)	389 (9)
Injury level			
Paraplegia	2728 (54)	936 (60)	1792 (52)
Tetraplegia	2297 (46)	621 (40)	1676 (48)
Injury duration (in years)			
1 to 5	1103 (20)	353 (22)	750 (20)
6 to 10	1010 (19)	317 (20)	693 (18)
11 to 5	897 (17)	235 (15)	662 (17)
16 to 20	625 (12)	156 (10)	469 (12)
20 to 25	486 (9)	122 (8)	364 (9)
26 to 30	298 (6)	68 (4)	230 (6)
31 to 35	352 (7)	100 (6)	252 (7)
36 to 40	296 (6)	89 (6)	207 (5)
>40	318 (6)	131 (8)	210 (5)
Geographical remoteness (ABS)			
Major cities	2957 (52)	743 (49)	2214 (53)
Inner regional	1267 (22)	379 (25)	888 (21)
Outer regional	1138 (20)	331 (22)	807 (19)
Remote	172 (3)	31 (2)	141 (3)
Very remote	168 (3)	32 (2)	136 (3)

**Age data ranged up to 118 years in eligible nonparticipants with no obvious cut-off in frequency counts between the plausible and non-plausible values, a threshold of 100 was used as a plausible upper limit, year of birth data implying ages above this threshold was treated as missing data.*

Section 5 Descriptive analyses of the Aus-InSCI responders

5.1 Response rate by each data custodian for the Aus-InSCI eligible participants

Table 5 Response rate by each data custodian

	Eligible persons n	Participants n (%)
NSW		
Agency for Clinical Innovation	75	13 (17)
Royal Rehab Rural	252	77 (31)
Royal Rehab SOS	520	100 (19)
Spinal Cord Injuries Australia	1228	408 (33)
icare NSW	253	81 (32)
ParaQuad NSW	38	12 (32)
Total	2366	691 (29)
QLD		
Princess Alexandra Hospital	2000	481 (24)
SA		
Hampstead Rehabilitation Centre,	101	25 (25)
Paraplegic and Quadriplegic Association of SA	370	122 (33)
Total	471	147 (31)
VIC		
Austin Health	1079	251 (23)
Unknown*		9

**study id page was removed by the participant.*

5.2 Mode of response for the Aus-InSCI eligible participants

Table 6 Mode of response for completing the Aus-InSCI Community survey

Completion type	%
Completed online	32
Completed by paper or telephone	68

5.3 Overall recruitment and completion of the data collection

From the total number of 5925 surveys sent out by nine data custodians, 1906 responses were finally received, which included **1579 completed surveys** (27% completion rate) and 327 withdrawals.

It is worth noting that NSW has the highest number of completed survey responses, that is, **691 completed survey** (44% of all responders). icare NSW has **81 completed surveys** (12% of all responders in NSW).

Overall, the rates for data completion range between 71 to 98% for some of the key health and physical domains that were included in the international as well as national module (see **Table 7**).

Table 7 Summary of the rates of completion for demographics, injury, health and other domains included in the international as well as national module of the Aus-InSCI Community survey

Demographics/Questionnaire domains	Number completed	%
Age	1577	99
Gender	1579	100
Income	1376	87
Social status ladder	1512	96
SCI type and degree	1481	94
Duration of injury	1542	98
Energy and feelings	1509	96
Health problems – pain	1545	98
Health problems – sexual	1450	92
Pain intensity	1542	98
Number of activity and participation issues (allow 2 skipped)	1509	96
SCIM score based on completed data	1271	81
Job before injury	1537	97
Worked after injury	1497	95
Current paid work	1535	97
Disability pension	1528	97
Environmental factors	1432	91
Health care provider - any listed	1520	96
Personal factors section	1469	93
General QOL and subscales section	1490	94
Fatigue questions	1483	94
Social integration questions	1119	71
Social injustice questions	1463	93
Self-reported sleep problems section	1329	84

5.4 Descriptive summary of responders

5.4.1. Demographic characteristics

Participants (n=1579) were predominantly male (73%) and Australian-born (77%), with half married (50%). Average age was 57 years (range 19-94), with a median 59 years (interquartile range 48-68). Most were living with at least one other adult (69%), although 23% lived alone and a further 5% with minors only (<18 years). Only 4% were living in institutional settings.

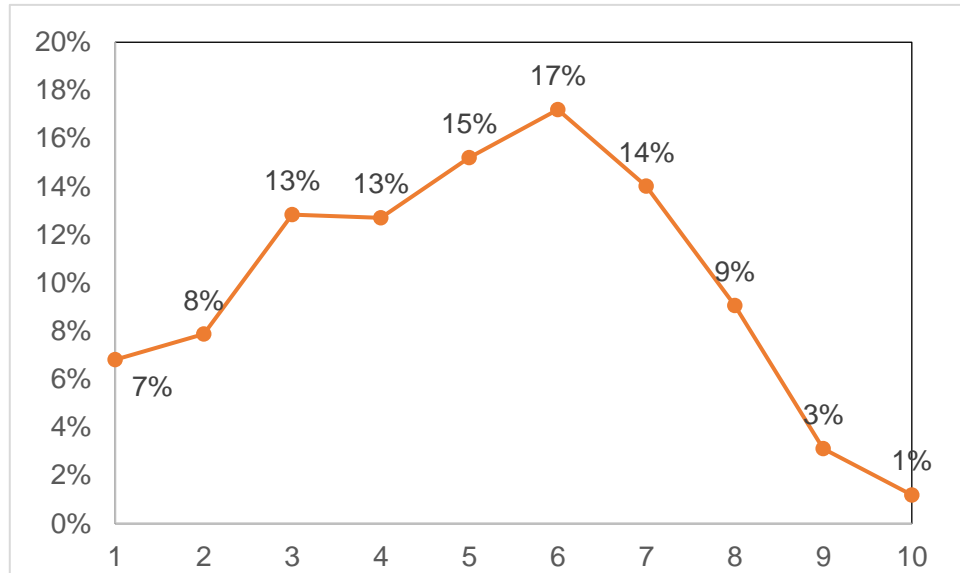
Most lived in NSW (41%), QLD (32%), VIC (15%), or SA (9%) as these were the states in which participating hospitals and organisations were primarily based, with 3.6% in total (n=55) living in TAS, ACT, NT or WA. Thirty-four per cent lived in a capital city, 23% in another metropolitan centre, 16% in a large rural centre, 18% in other rural areas, and 9% in remote areas (see **Table 8**).

Table 8 Demographic characteristics of responders

Demographic characteristics	%
Gender	
Male	73
Female	27
Age group (in years)	
18 to 30	5
31 to 45	16
46 to 60	34
61 to 75	37
More than 75	9
Country of birth	
Australia	77
Other	23
Marital status	
Single	25
Married	50
Cohabiting or in a partnership	9
Separated or divorced	12
Widowed	4
Living area	
Australian Capital Territory	1
New South Wales	41
Northern Territory	<1
Queensland	32
South Australia	9
Tasmania	2
Victoria	15
Western Australia	1
Living place (population)	
Capital city	34
Other metropolitan centre (>100,000)	23
Large rural centres (25,000-99,999)	16
Small rural centre (10,000-24,999)	10
Other rural area (<10,000)	8
Remote area (<5000)	9
Geographical remoteness (ABS)	
Major cities	49
Inner regional	25
Outer regional	22
Remote	2
Very remote	2

On a 10-point ladder for subjective social position, participant responses were centred at the midpoint (mean and median both at 5, interquartile range 3-7), see **Figure 2**.

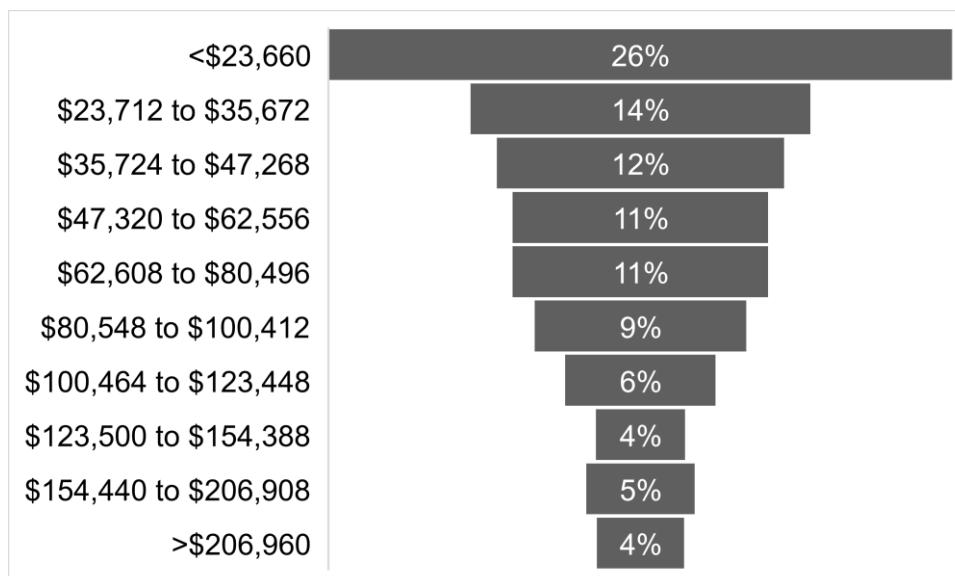
Figure 2 Self-perception of where people place themselves in Australia on a social ladder on a scale of 1 to 10, (in %)



Interpretation of ladder: Participants were asked to place themselves on the ladder where they would place themselves at this time of filling the survey relative to other people in Australia.

Just over half of the study participants (54%) had post-secondary education, including 24% with a bachelor or postgraduate degree or equivalent. Nevertheless, 26% of participants were in the lowest category for household income (less than AUD\$23,660) with a further 14% in the next lowest (to AUD\$35,672), see **Figure 3**.

Figure 3 Total household income per annum before tax, (in %)



5.4.2. Injury characteristics

Paraplegia was more common than tetraplegia, and incomplete lesions more common than complete, with 37% of participants having incomplete paraplegia, 30% incomplete tetraplegia, 24% complete paraplegia and 9% complete tetraplegia. A traumatic cause of injury was listed in 84%. The most common causes of injury were related to transport (30%), leisure activities (17%) and falls (13%), with another 9% due to sport and 7% to other work-related injuries. Traumatic injuries were much more likely to be complete than non-traumatic injuries (37% vs 12%).

Proportionately, males were more likely than females to have traumatic injuries ($p<0.0001$) and complete lesions ($p=0.0002$), and younger age groups were more likely than older groups to have traumatic injuries and tetraplegia ($p<0.0001$).

Mean age at the time of injury was 40 years (range 0-88), with median 38 years (interquartile range 24-55), and was substantially higher on average for people with non-traumatic compared with traumatic injuries. The mean age at the time of injury was 48 years, median 52, interquartile range 34-64 years for non-traumatic injuries versus mean 38 years, median 36, interquartile range 23-52 years for traumatic injuries ($p<0.0001$). Mean duration of injury was 17 years (range 1-73 years), with a median of 13 years (interquartile range 6-25 years), see **Table 9**.

Table 9 Injury characteristics of responders

Injury characteristics	%
Level and degree	
Complete paraplegia	24
Complete tetraplegia	9
Incomplete paraplegia	37
Incomplete tetraplegia	30
Cause of injury	
Traumatic	84
Non-traumatic	16
Injury duration (in years)	
1 to 5	22
6 to 10	20
11 to 15	15
16 to 20	10
20 to 25	8
26 to 30	4
31 to 35	6
36 to 40	6
>40	8
Age at time of injury (in years)	
0 to 14	3
15 to 29	37
30 to 44	23
45 to 59	22
60 to 74	16
>75	3

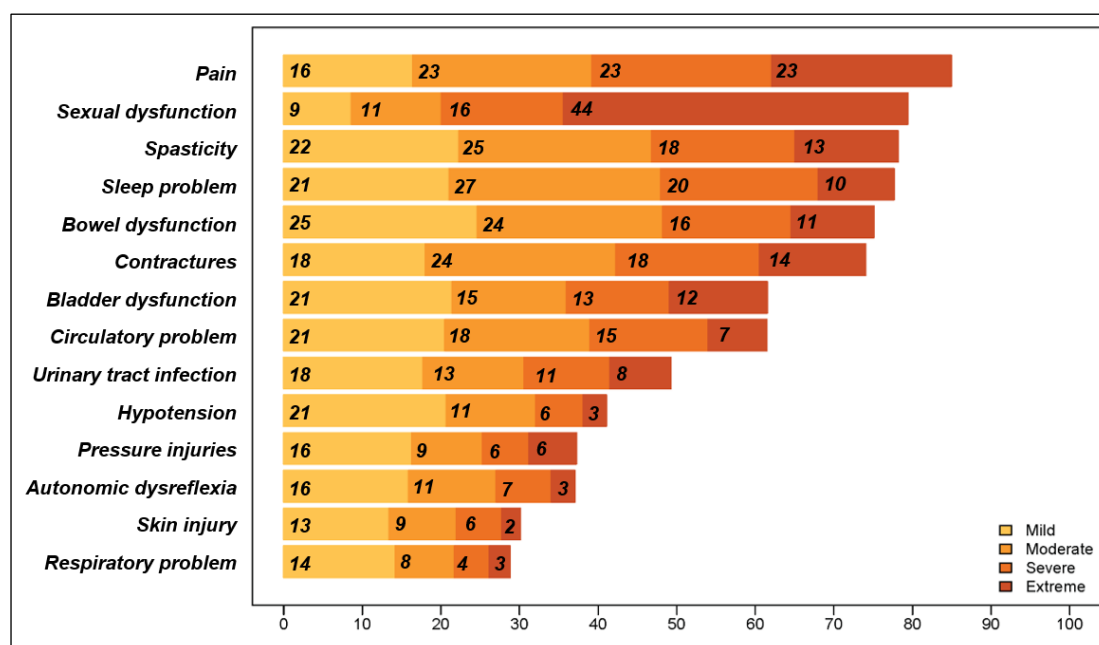
Section 6 Theme-specific analyses of the Aus-InSCI responders

6.1. Secondary health conditions

A majority of participants reported pain (85%), sexual dysfunction (79%), muscle spasms or spasticity (78%), contractures (74%), sleep problems (78%), bowel problems (75%), bladder problems (62%) and circulatory problems (61%) over the preceding 3 months. A substantial minority reported urinary tract infections (48%), postural hypotension (40%), pressure injuries (37%), autonomic dysreflexia (37%), injuries due to loss of sensation (30%), and respiratory problems (29%), see **Figure 4**.

Similarly, severe to extreme secondary health conditions most commonly involved sexual dysfunction (59%), pain (46%), contractures (32%), muscle spasms or spasticity (31%), sleep problems (30%), bowel problems (27%), bladder problems (26%), and circulatory problems (23%), followed by urinary tract infections (19%), pressure injuries (12%), autonomic dysreflexia (10%), postural hypotension (9%), injuries due to loss of sensation (8%) and respiratory problems (7%).

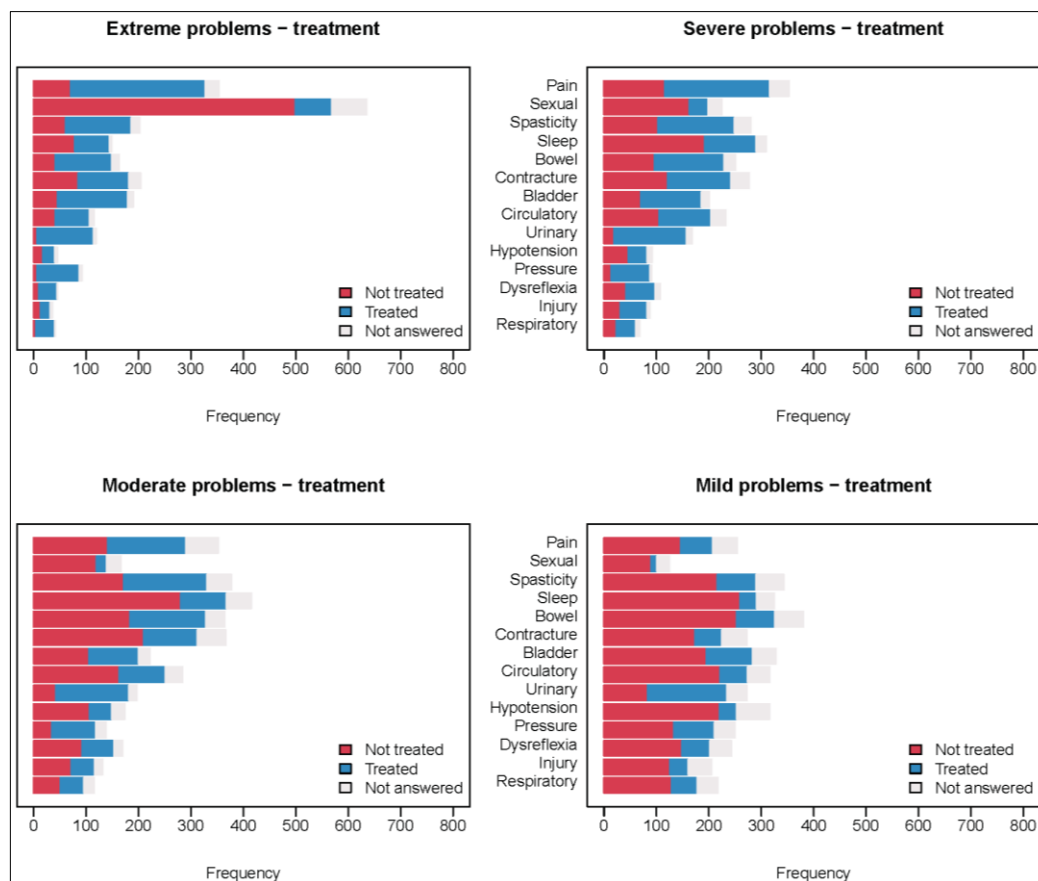
Figure 4 Secondary health conditions and levels of severity, (in %)



Pressure injuries were reported by 27% of participants, while a further 8% reported some other type of skin breakdown or problem. Where any pressure injuries were reported, 45% indicated that they had two or more ulcers or pressure injuries, and 38% reported a pressure injury that has never completely healed or that breaks down frequently. The most common sites were the sacrum (30%), heel (28%), ischial tuberosity (25%), ankle (24%), knee (10%), genitals (8%), and trochanter (7%).

The typical number of health problems was 8 for both mean and median for problems of any severity (interquartile range 6-10), and 3 for severe to extreme problems (interquartile range 1-5). A notably high proportion of extreme or severe conditions did not receive treatment (see **Figure 5**); in particular, sexual dysfunction (88-82%), sleep problems (53-66%), postural hypotension (43-56%), contractures (47-50%), circulatory problems (39-51%), injuries due to loss of sensation (42-38%), muscle spasms or spasticity (33-41%), bowel problems (27-42%), autonomic dysreflexia (22-43%), bladder problems (26-), pain (22-37%), and respiratory problems (10-38%). By contrast, for pressure injuries (7-16%) and urinary tract infections (6-12%) participants reported mostly having received some form of treatment.

Figure 5 Treatment status of the secondary health condition by severity, (n)

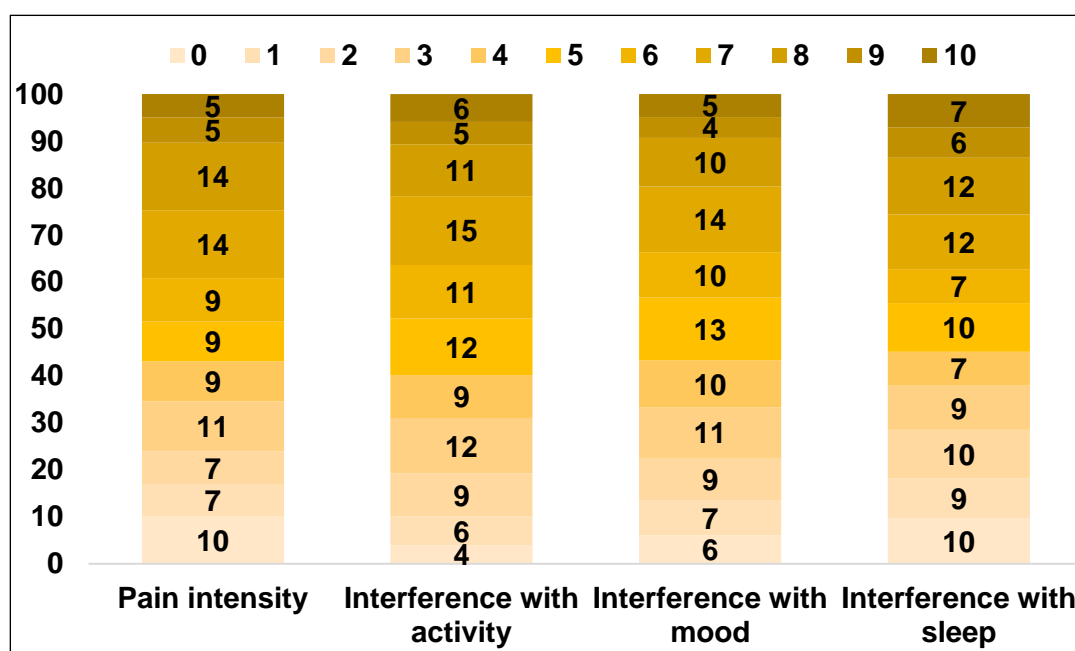


6.2. Pain

Most participants (78%) had experienced pain during the past week. Notably, most had also experienced at least some level of pain interference with either day-to-day activities, mood or sleep (76%) and almost half (46%) said they experienced pain all the time without any breaks while awake. Almost half of participants (49%) reported shoulder pain lasting more than one day during the preceding 3-month period and, among these, shoulder pain had prevented doing things in everyday life in 50% of cases.

When asked to rate the severity of the worst pain experienced during the past week on a scale of 0 (no pain) to 10 (worst pain imaginable), responses centered around the midpoint (mean and median both 5, interquartile range 3-7). Among those reporting any pain interference, the reported severity of interference on a scale of 0 (lowest) to 10 (highest) was centred around the midpoint of 5 for interference with day-to-day activities (interquartile range 3-7), interference with overall mood (interquartile range 3-7), and interference with sleep (interquartile range 2-8), see **Figure 6**.

Figure 6 Pain intensity (in the last 7 days) and its interference with day-to-day activities, mood and sleep (VAS scale 0 to 10)



The most common treatment strategies for managing pain were over the counter medication (55%), trying to eat a healthy diet and keep a healthy weight (53%), prescribed nerve pain medication (45%), keeping physically active (43%), trying to get enough sleep (41%), attending manual therapies such as massage, acupuncture, osteopathy or chiropractic (29%), attending physiotherapy (27%) and prescribed opioid medication (25%). Most participants (70%) used three or more treatment strategies for pain. Ratings for the effectiveness of pain management strategies were centred just above the midpoint of a scale from 0 (ineffective) to 10 (extremely effective) (mean 5.5, median 6, interquartile range 4-7).

Advice about pain management was most commonly sought from general practitioners (74%), followed by spinal medical specialists (30%) and therapists, including physiotherapists, exercise physiologists or occupational therapists (29%).

6.3. Activities and participation

Most participants received day-to-day assistance (73%), including 21% from professional or paid assistants only, 23% from family or friends only, 29% from both. Based on ability to move over moderate distances (10-100 metres), 596 participants (41%) were ambulant with or without assistance while walking, 516 (36%) used a manual wheelchair, and 384 (27%) required used an electric wheelchair or required some assistance to operate a manual wheelchair. On raw proportions, gender was not associated with these mobility categories. Older persons were more likely to be ambulant and less likely to have manual wheelchairs than younger age groups, while at the same time, groups with longer duration of injury were less likely to be ambulant and more likely to have manual wheelchairs than those with relatively recent injuries.

The ambulant group almost entirely comprised individuals with incomplete lesions, either paraplegia or tetraplegia. Complete paraplegia was strongly associated with the use of a manual wheelchair and complete tetraplegia with the use of a motorised or assisted manual wheelchair ($p < 0.0001$), however, individuals from all four lesion subtypes were represented in both groups of wheelchair users (see **Table 10**).

Table 10 Mobility level by type and cause of injury

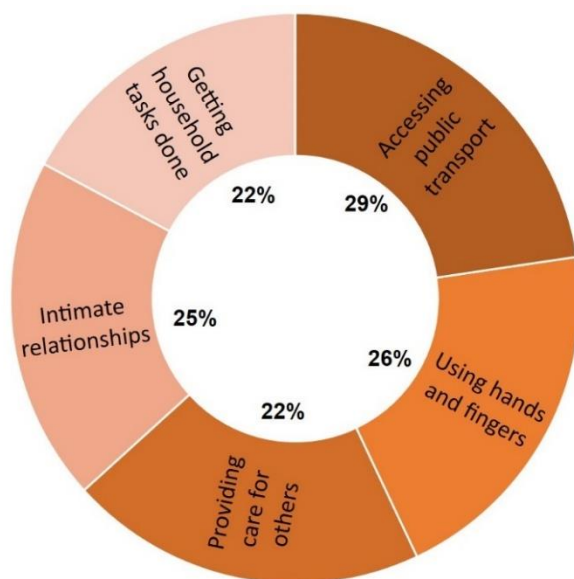
Characteristics, (in %)	Motorised WC or manual WC with assistance	Manual WC	Ambulant
Type of injury			
Complete tetraplegia	71	27	3
Complete paraplegia	23	75	3
Incomplete tetraplegia	34	15	51
Incomplete paraplegia	12	29	59
Cause of injury			
Traumatic SCI	27	36	38
Non-traumatic SCI	21	28	50
Abbreviation: WC, wheelchair			

Most participants were able to achieve a level of independence in eating and drinking, washing, dressing, grooming and using the toilet, either on their own or through the use of assistive devices. The great majority (85%) were able to sit without assistance, although of these 26% found it a moderate to extreme problem to do so, but less than half (40%) were able to stand unassisted and 64% of these found it a moderate to extreme problem to do so. The InSCI questionnaire included many but not all of the questions from a self-report version of the SCIM questionnaire on activities of daily living. On calculating a total score and scaling it to range from 0 to 100, responses centred around a mean of 61 with median 68 (interquartile range 40-83).

Almost all participants had at least some problems with activities and participation (96%). Many had a number of moderate, severe or extreme problems; in particular, for intimate relationships (49%), carrying out daily routine (45%), getting household tasks done (43%), using hands and fingers (41%), providing care or support for others (41%), handling stress (39%), doing things for relaxation or pleasure (38%), getting where want to go (37%), using public transportation (38%), using private transportation (21%), looking after health, eating well, exercising or taking medication (24%), and interacting with people (23%).

The typical number of moderate, severe or extreme problems was 4 for both the mean and median, with interquartile range from 1-7, based on a count which allowed participants to skip up to 2 of the 12 activity items. The top five severe to extreme problems are presented in **Figure 7**.

Figure 7 Top five most common severe to extreme problems experienced by survey participants



6.4. Work participation

Eighty-four per cent of participants had a job before their spinal cord injury. Fifty per cent worked after their initial rehabilitation, representing 54% of those who worked before their injury and 27% of those who did not. Just under half (48%) returned to work in less than one year, a further 19% in less than 2 years, a further 20% in less than 5 years, and the remaining 14% after 5 years. Vocational rehabilitation services were received after the initial injury in 35% of cases and not received in 39%, while 25% indicated they had not needed the services. Of those who received vocational rehabilitation, 48% received a little, 27% received some and 25% received a lot of services.

Among all participants, 47% were receiving the disability pension, 29% (n=450) were currently in paid work at the time of interview, and with multiple overlapping answers permitted, 45% flagged that they were retired, 11% that they did unpaid, voluntary or house work, 14% that they were unemployed and 3% that they were students. Most participants in current paid work were happy with the number of hours they worked (60%), while 17% would have preferred more and 24% less hours of work. Of the participants not in current paid work (n=1085), 42% of them wanted to work and among those, 83% felt able to undertake at least some paid work.

For participants of working-age (18-65 years, n=1078), 39% were currently in paid work at the time of interview and 50% were receiving the disability pension. Current paid work was less likely among those who needed but did not receive vocational counselling (29% versus 43% of those who received vocational counselling and 52% who did not need it, $p<0.0001$). Reasons for not currently working are presented in **Table 11**.

Table 11 Reasons for not working after a spinal cord injury, (%)

Reasons for not working	%
Health condition or disability	74
Could not find suitable work	26
Lack of accessibility to possible workplaces	13
Fear of losing disability benefits	12
No financial need	11
Do not want to work	11
Family responsibilities	10
Don't know how or where to seek work	9
Insufficient transportation services	8
Engaged in education or training	5
Lack of assistive devices	5
Parents or spouse did not let me work	<1

6.5. Personal factors

Participants positively rated their sense of autonomy (74% of responses above the midpoint for ability to make the big decisions in their life), ability to maintain important relationships (75% above midpoint), sense of belonging (64% above midpoint for being included when around other people), and to a lesser degree other aspects of self-efficacy (58% and 55% above midpoint for confidence in being able to overcome opposition and deal with unexpected events).

Participants were less certain that they would be able to maintain their health (50% above midpoint) and most were worried about their future (60% above midpoint). Only a minority believed they would be able to fulfil their hopes and dreams (31% above midpoint). For many participants (40%), it was somewhat of a problem or a very big problem to keep up enough enthusiasm to get things done. Just over one-third (38%) had experienced a major adverse life event within the previous 12 months.

6.6. Environmental factors

6.6.1. Nottwil Environmental Factors Inventory (NEFI)

Environmental barriers made life more difficult for participants, most commonly related to accessing public places or homes (51-55% for any more difficult, 15-23% for a lot more difficult), unfavourable climactic conditions (56% any, 17% a lot), problematic financial situation (40% any, 16% a lot), lack of or inadequate means of transportation over long distances (33% any, 14% a lot), lack of or insufficient state services (30% any, 11% a lot), lack of or insufficient assistive technologies for moving around over short distances (29% any, 6% a lot), negative societal attitudes (28% for any, 6% a lot), and lack of or insufficient nursing care or support services (22% any, 5% a lot).

The NEFI total score centred around a mean of 34 (range 0-100), with median 36 (interquartile range 12-50).

6.6.2. Workplace environment

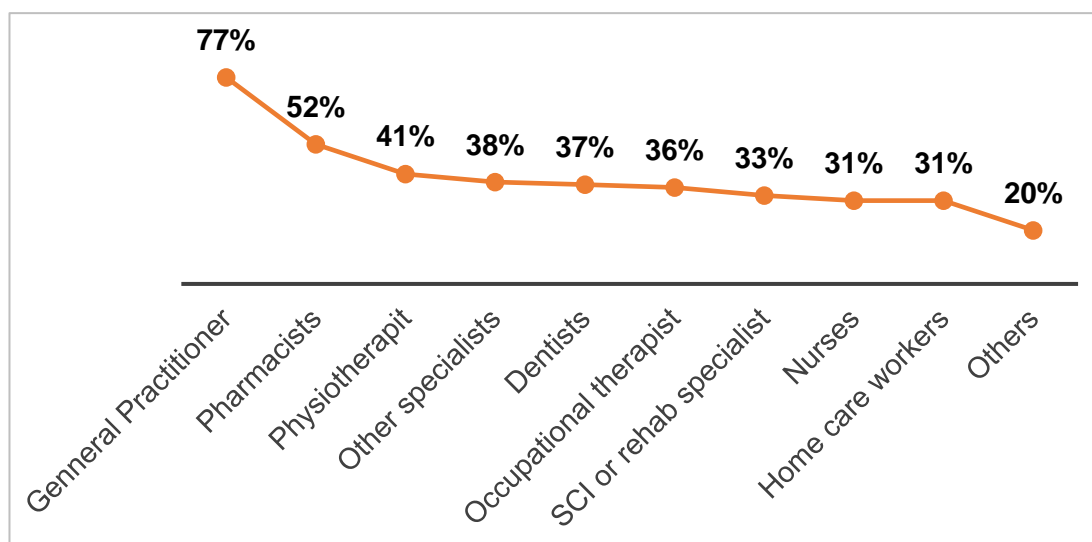
Participants in paid work mostly had little or no problem in getting things done as required at work (70%) or in accessing their workplace (88%). Most agreed or strongly agreed that they received the recognition they deserved at work (83%) and were paid appropriately for their efforts and achievements (76%). However, of 450 individuals in paid work, 291 (66%) needed assistive devices, and of these 21% did not have the devices they needed at all, a further 21% only to a small extent, and a further 16% to some extent but not largely or completely.

6.7. Health service utilisation

The main health provider contact listed for spinal cord injury specific problems was usually a GP (58%), spinal specialist from a specialised spinal cord injury unit or service (31%) or other local specialist (8%).

Almost all participants had seen a health care provider within the previous 12 months, and most had seen multiple providers during that time (see **Figure 8**).

Figure 8 Most healthcare providers seen in the previous 12 months



Overall, most participants were satisfied or very satisfied with health care services in their area (74%). Eighty-one per cent were satisfied or very satisfied with the service provided by their GP and 72-73% were satisfied with the services provided by their local hospital and the spinal cord unit or service in their state. The great majority rated the interaction at their most recent health-related visit as good or very good (85% or more for being treated with respect, having things clearly explained, and being involved in treatment decisions).

Nonetheless, 17% (n=254) had needed health care in the previous 12 months, which they did not receive, most commonly because they were unable to afford the cost of the visit (30%). The next most common reasons were that there was no service (19%), health care provider with inadequate skills (19%), thought not to be sick enough (18%), health care provider with inadequate drugs or equipment (15%), having been previously treated badly (13%), did not know where to go (12%), and tried but were denied health care (12%).

6.8. Overall quality of life and health

Most participants rated overall quality of life as good or very good (62%) and general health as good, very good or excellent (66%). While only 13% rated their overall quality of life as poor or very poor, dissatisfaction with specific subdomains of life quality was more common: 27% were dissatisfied or very dissatisfied with health, 25% with ability to perform activities of daily living, 23% with oneself, 16% with personal relationships and 9% with living conditions, see **Figures 9 to 11**.

Figure 9 Self-reported overall quality of life

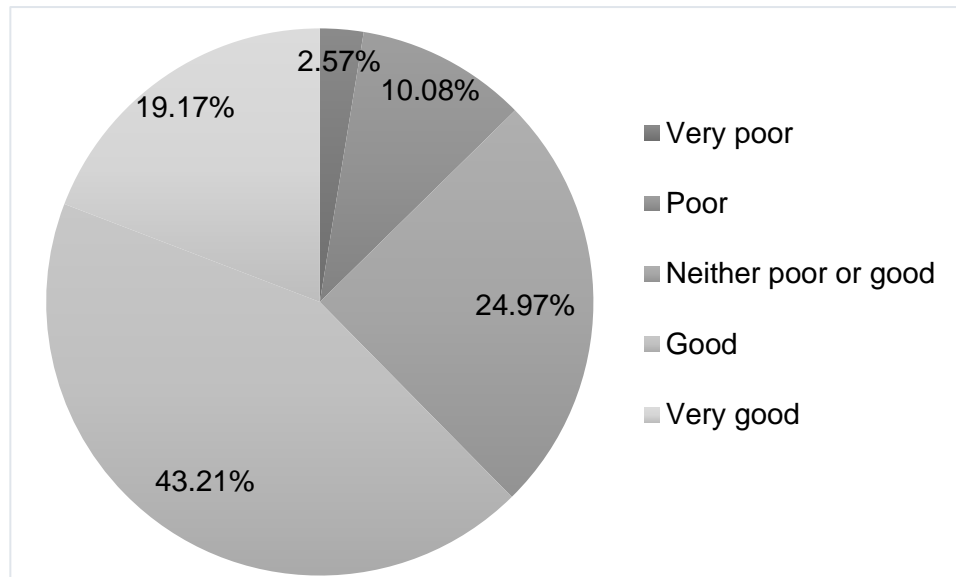


Figure 10 Self-reported overall general health

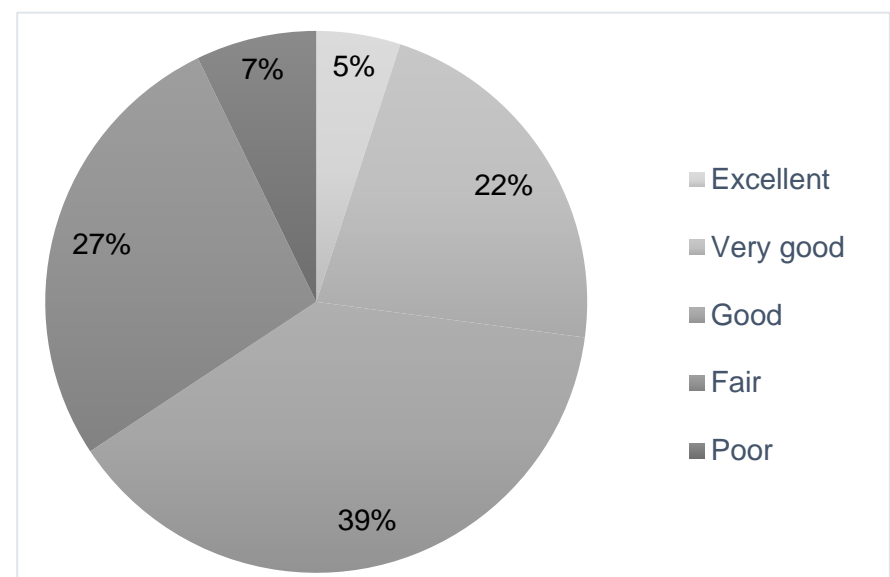
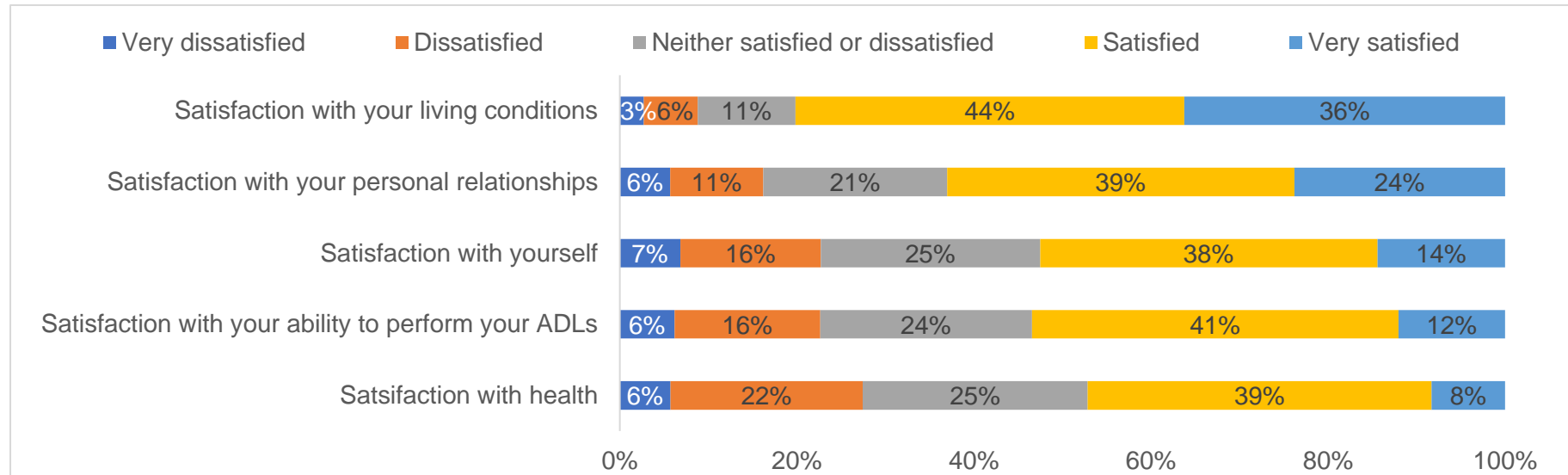


Figure 11 Satisfaction with life in last 2 weeks on five key quality of life domains



6.9. Other important findings from the Aus-InSCI community survey

6.9.1. Mental health

Feeling persistently tired or worn out were more common than feeling persistently nervous, down in the dumps or depressed (35% and 26% versus 9%, 8% and 12% respectively for usually or always having these feelings). Just over half of participants (54%) usually or always felt happy and 45% usually felt calm and peaceful, whereas 37% usually felt full of life and 26% usually felt full of energy.

On average, SF-36 mental health and vitality scores were lower than those of a general Australian population: median mental health score 48 (interquartile range 38-55) and median vitality score 43 (interquartile range 32-51).

6.9.2. Social support and social integration

Most participants positively rated the respect they received from others (80% of responses above the midpoint) and said that they received help and support from people close to them when they needed it (86% of responses above the midpoint). A substantial minority felt close to people in their local area (46% agreed or strongly agreed, most others were neutral). However, almost one-quarter of participants felt they had very little chance to show their capabilities fully (23% agreed or strongly agreed), and only one-third felt they had co-workers or supervisors who actively helped them overcome major hurdles at work or in attempting to return to work (35% of 1127 respondents to this question agreed or strongly agreed, most others were neutral).

6.9.3. Perceived social injustice

Sixty per cent of participants frequently or always felt that people did not understand the severity of their condition and roughly half frequently or always felt they just wanted their life back. Most did not attribute their suffering to the negligence of others (62% not at all), although most found it all so unfair at least some of the time (33% frequently or always, and a further 36% sometimes).

6.9.4. Physical activity

During the past week, 75% of participants reported at least some physical activity outside the home that was not specifically for the purpose of exercise (30% on a daily basis), while 46% reported at least some light sport or recreational activity (9% daily). Only a minority reported any moderate sport or recreational activity (23%) or strenuous sport or recreational activity (20%).

6.9.5. Fatigue

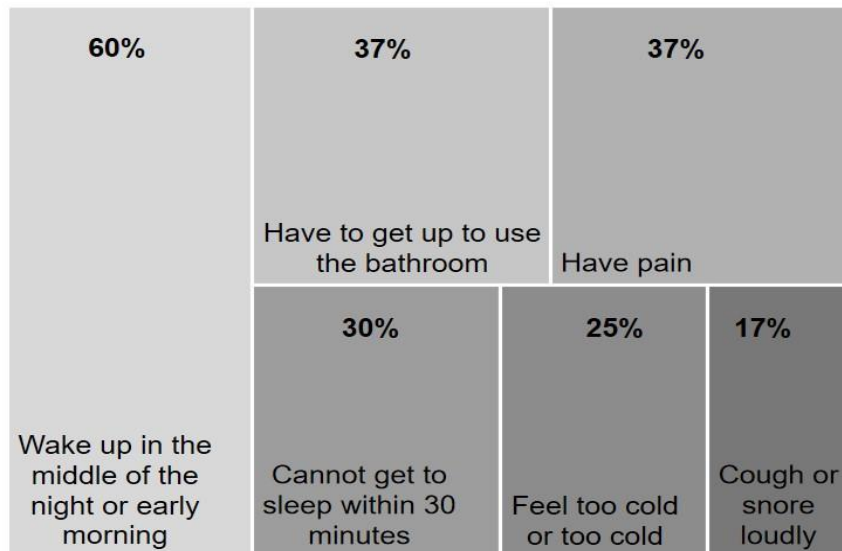
Due to a coding error, there is some ambiguity about reported fatigue levels, however, we can quantify best- and worst-case frequencies. Overall, 70-75% of participants agreed or strongly agreed that they had a problem with fatigue, including 54-65% for being easily fatigued, 53-65% for fatigue interfering with physical functioning, 42-52% for fatigue causing frequent problems, and 46-56% for fatigue interfering with work, social and family life.

6.9.6. Sleep

Sleeping difficulties were common, with 37% of participants reporting fairly bad or very bad sleep quality. Various factors were responsible for

participants have had experienced trouble sleeping in past month for more than three times a week, see **Figure 12**.

Figure 12: Some of the common factors that were responsible for trouble sleeping for more than three times a week in the last in one month



Section 7 Subgroup analysis of the Aus-InSCI responders

Raw descriptive subgroup analyses by injury characteristics, age and gender are presented below in **Table 12**. The overlaps and interactions between these factors will be an important consideration and will be examined in detail in future work.

Note: result below are presented as [*mean difference (95% CI)*]:

- Participants with poorer mobility had more health problems [1.7 (1.3, 2.2)] and environmental barriers [19 (16, 22)].
- Those requiring electric or assisted manual wheelchairs had more activity and participation problems and poorer self-reported quality of life [-0.25 (-0.38, -0.12)].
- Mental health and vitality scores were highest in the group with manual wheelchairs.
- Participants with tetraplegia and/or complete lesions displayed more health problems, activity and participation problems and environmental barriers [10.5 (6.2, 14.8)], however, self-rated overall quality of life was not meaningfully different between groups based on lesion level or completeness.
- Participants with more recent injuries displayed poorer independence scores [7.1 (2.7, 11.6)] and were struggling more on quality of life and mental health measures.
- Males reported fewer activity and participation problems and environmental barriers than females and had more positive mental health [1.5 (0.1, 3.0)] and vitality scores [2.5 (1.1, 3.8)] on average.
- Environmental barriers were less of an issue for the oldest age groups of participants, who also showed more positive mental health and vitality scores than their younger counterparts.

Table 12 subgroup analyses for different domain of the Aus-InSCI community survey

	No. of health conditions	SCIM score (range 0-100)	Number of A&P problems	NEFI score	Overall QoL (range 1 to 5)	MH score (mean 50 SD 10)	Vitality score (mean 50 SD 10)
Mobility category							
Motorised or manual assisted WC	1.7 (1.3, 2.2)	-53 (-56, -50)	1.6 (1.1, 2.1)	19 (16, 22)	-0.25 (-0.38, -0.12)	-0.5 (-2.1, 1.1)	0.3 (-1.2, 1.9)
Manual WC	0.7 (0.3, 1.2)	-19 (-21, -16)	-0.4 (-0.8, 0.02)	12 (9, 15)	0.07 (-0.05, 0.19)	1.7 (0.2, 3.2)	3.2 (1.8, 4.6)
Ambulant	Ref	ref	ref	ref	ref	ref	ref
<i>p value</i>	<0.0001	-	<0.0001	<0.0001	<0.0001	0.02	<0.0001
Lesion type							
Complete tetraplegia	1.4 (0.7, 2.0)	-46 (-52, -41)	1.3 (0.6, 2.0)	10.5 (6.2, 14.8)	-0.10 (-0.3, 0.1)	2.6 (0.2, 5.0)	2.0 (-0.3, 4.2)
Complete paraplegia	0.5 (0.02, 0.9)	-13 (-17, -8)	-0.2 (-0.7, 0.4)	5.1 (2.1, 8.1)	-0.02 (-0.15, 0.12)	1.5 (-0.2, 3.2)	1.6 (0.01, 3.1)
Incomplete tetraplegia	0.7 (0.3, 1.2)	-16 (-20, -12)	1.0 (0.5, 1.5)	1.3 (-1.5, 4.1)	-0.03 (-0.16, 0.1)	-0.2 (-1.8, 1.4)	-1.5 (-2.9, -0.03)
Incomplete paraplegia	Ref	ref	ref	ref	ref	ref	ref
<i>p value</i>	<0.0001	<0.0001	<0.0001	<0.0001	0.7	0.04	0.0006
Cause of injury							
Traumatic	0.2 (-0.3, 0.6)	-2.3 (-6.6, 2.0)	-0.4 (-1.0, 0.04)	-1.3 (-4.4, 1.8)	0.18 (0.04, 0.3)	2.2 (0.5, 3.9)	3.4 (1.8, 5.0)
Non-traumatic	Ref	ref	ref	ref	ref	ref	ref
<i>p value</i>	0.4	0.2	0.07	0.4	0.009	0.01	<0.0001
Injury duration (in years)							
Up to 5	-0.5 (-1.0, -0.03)	7.1 (2.7, 11.6)	0.4 (-0.2, 0.9)	-1.0 (-4.3, 2.4)	-0.26 (-0.41, -0.11)	-3.2 (-5.0, -1.4)	-1.9 (-3.6, -0.2)
6 to 15	-0.05 (-0.5, 0.4)	2.0 (-2.0, 6.0)	0.2 (-0.4, 0.7)	2.1 (-0.9, 5.0)	-0.09 (-0.3, 0.04)	-2.2 (-3.8, -0.6)	-1.3 (-2.9, 0.2)
16-25	0.02 (-0.5, 0.6)	3.5 (-1.2, 8.3)	0.4 (-0.2, 1.0)	1.6 (-1.9, 5.2)	-0.08 (-0.3, 0.07)	-2.0 (-3.9, -0.06)	-0.7 (-2.5, 1.2)
> 25	Ref	ref	ref	ref	ref	ref	ref
<i>p value</i>	0.1	0.01	0.4	0.2	0.005	0.003	0.14
Gender							
Male	0.2 (-0.2, 0.6)	2.9 (-0.6, 6.3)	-0.6 (-1.1, -0.3)	-3.5 (-6.1, -1.0)	-0.01 (-0.12, 0.11)	1.5 (0.1, 3.0)	2.5 (1.1, 3.8)
Female	Ref	ref	ref	ref	ref	ref	ref
<i>p value</i>	0.3	0.1	0.002	0.007	0.8	0.03	0.0002
Age group (in years)							
18 to 30	-0.07 (-1.1, 0.9)	-1.6 (-10, 8)	-0.5 (-1.6, 0.6)	15 (8, 22)	0.14 (-0.15, 0.43)	-3.5 (-7.0, 0.03)	-1.1 (-4.4, 2.3)
31 to 45	1.1 (0.3, 1.9)	4.8 (-2.1, 11.6)	0.2 (-0.6, 1.0)	13 (7, 18)	-0.12 (-0.33, 0.10)	-5.5 (-8.2, -2.9)	-3.1 (-5.6, -0.7)
46 to 60	1.1 (0.3, 1.8)	3.0 (-3.3, 9.3)	0.5 (-0.3, 1.2)	12 (7, 17)	-0.18 (-0.37, 0.02)	-4.1 (-6.5, -1.8)	-2.6 (-4.9, -0.4)
61 to 75	0.4 (-0.3, 1.2)	1.9 (-4.3, 8.1)	-0.01 (-0.7, 0.7)	8 (3, 13)	-0.13 (-0.32, 0.06)	-1.9 (-4.3, 0.4)	-0.3 (-2.5, 2.0)
> 75	ref	ref	ref	ref	ref	ref	Ref
<i>p value</i>	<0.0001	0.4	0.07	<0.0001	0.07	<0.0001	0.001

Note:

- Results are presented as **Mean difference (95% CI)**;
- "ref" is the reference group;
- All bold results for statistically significant findings (*p value* <0.0001);
- **Abbreviations:** A&P, Activity and participation; SCIM, Spinal Cord Independence Measure; NEFI, Nottwil Environmental Factor Inventory; QoL, quality of life; MH, mental health; WC, wheelchair;