

The Hopkins Centre

Research for Rehabilitation and Resilience

International Spinal Cord Injury (InSCI) Survey:

Health characteristics and health service use of long-term spinal cord injury in Queensland

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Bold ideas. Better solutions.



Metro South Health



A joint initiative of the
Division of Rehabilitation, Metro South Health, and
Menzies Health Institute Queensland, Griffith University.

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Background

- Inconsistent or inadequate SCI data across countries ¹
- In 2014, *WHO Global Disability Action Plan 2014-2021*:
- *Better health for all people with disability*



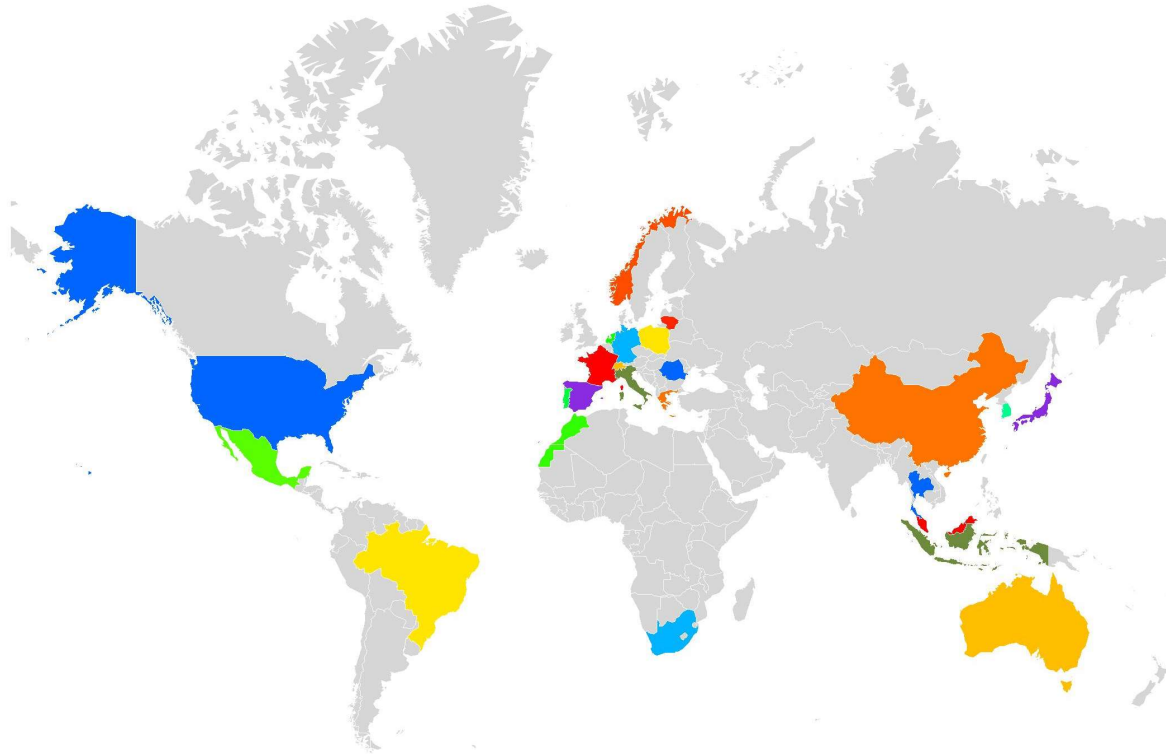
International Spinal Cord Injury Survey

Aims:

1. To capture and describe the lived experience of persons with SCI
2. To strengthen relevant data collection on an internationally comparable basis

InSCI Community Survey

28 participating countries



<https://inci.network/inci/T1/en/welcome.php>

New South Wales
Queensland
Victoria
South Australia

Aim

To provide an overview of the health and characteristics of persons with SCI in Queensland

Method

Design: Cross-sectional survey (mailed out; online or interview option)

Sample and setting: Patients of the Spinal Injuries Unit Metro South Health, Queensland, Australia.

Data collection: March 2017 to October 2018

Eligibility criteria:

- 18+ years
- 12-months post spinal injury
- Traumatic and non-traumatic aetiologies
- Able to complete the questionnaire in English

InSCI Community Survey

3055

Identified records from PAH database

1845

Surveys mailed out

Excluding duplicates across states, invalid or overseas addresses, deceased

480

Completed surveys

26.0% participation rate

Demographics



Male 74%



Female 26%

59.1 years

22.6 years post-SCI



84%

Traumatic

16%

Non-traumatic



60%

City area

32%

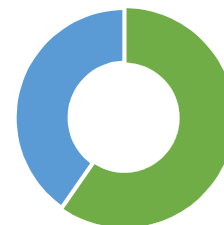
Small and large rural area

8%

Remote area

40.3%

Tetraplegia



59.7%

Paraplegia

27.5%

Complete



72.5%

Incomplete

43%

Married

26%

Single

15%

Separated, or divorced

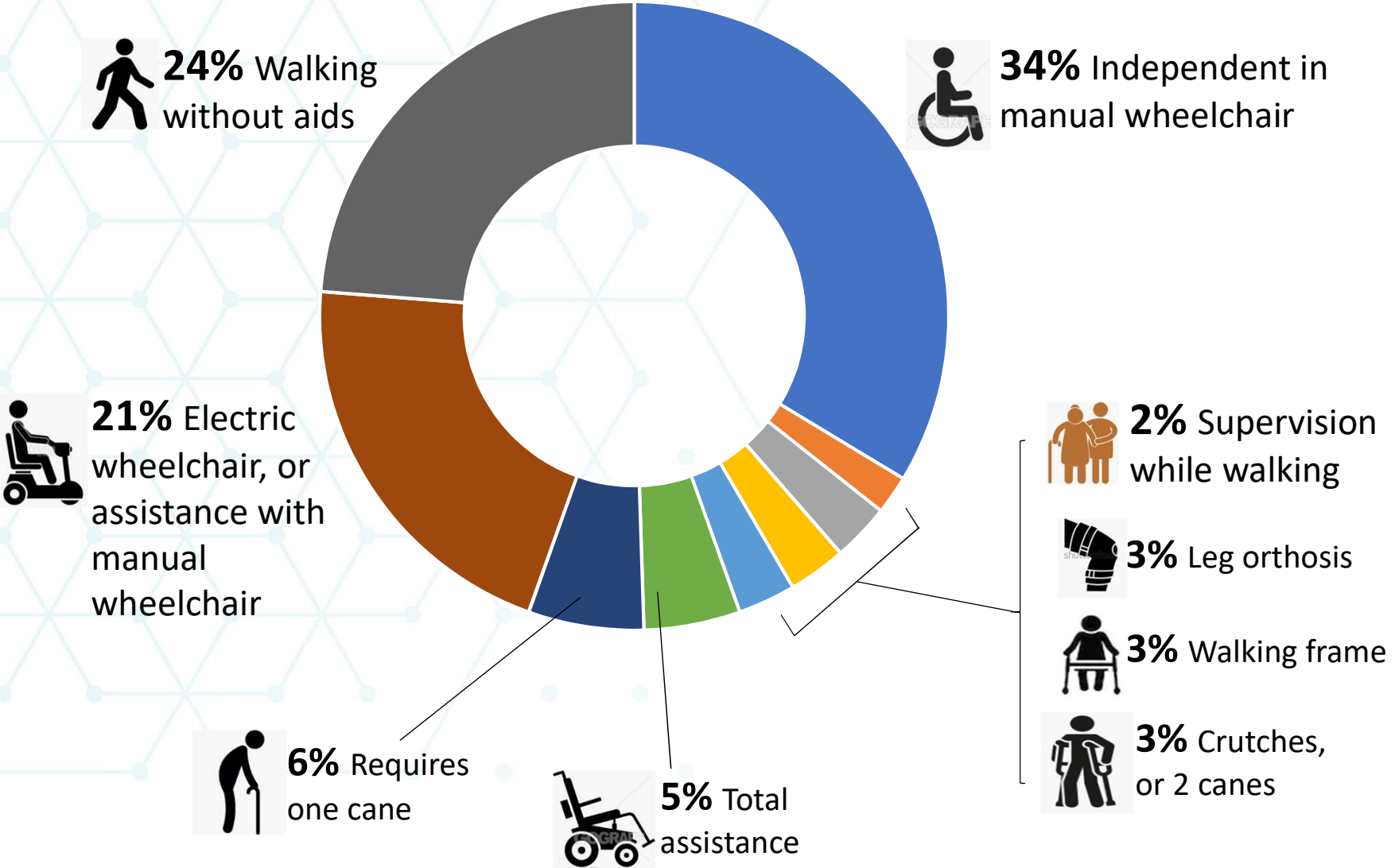
11%

Cohabiting

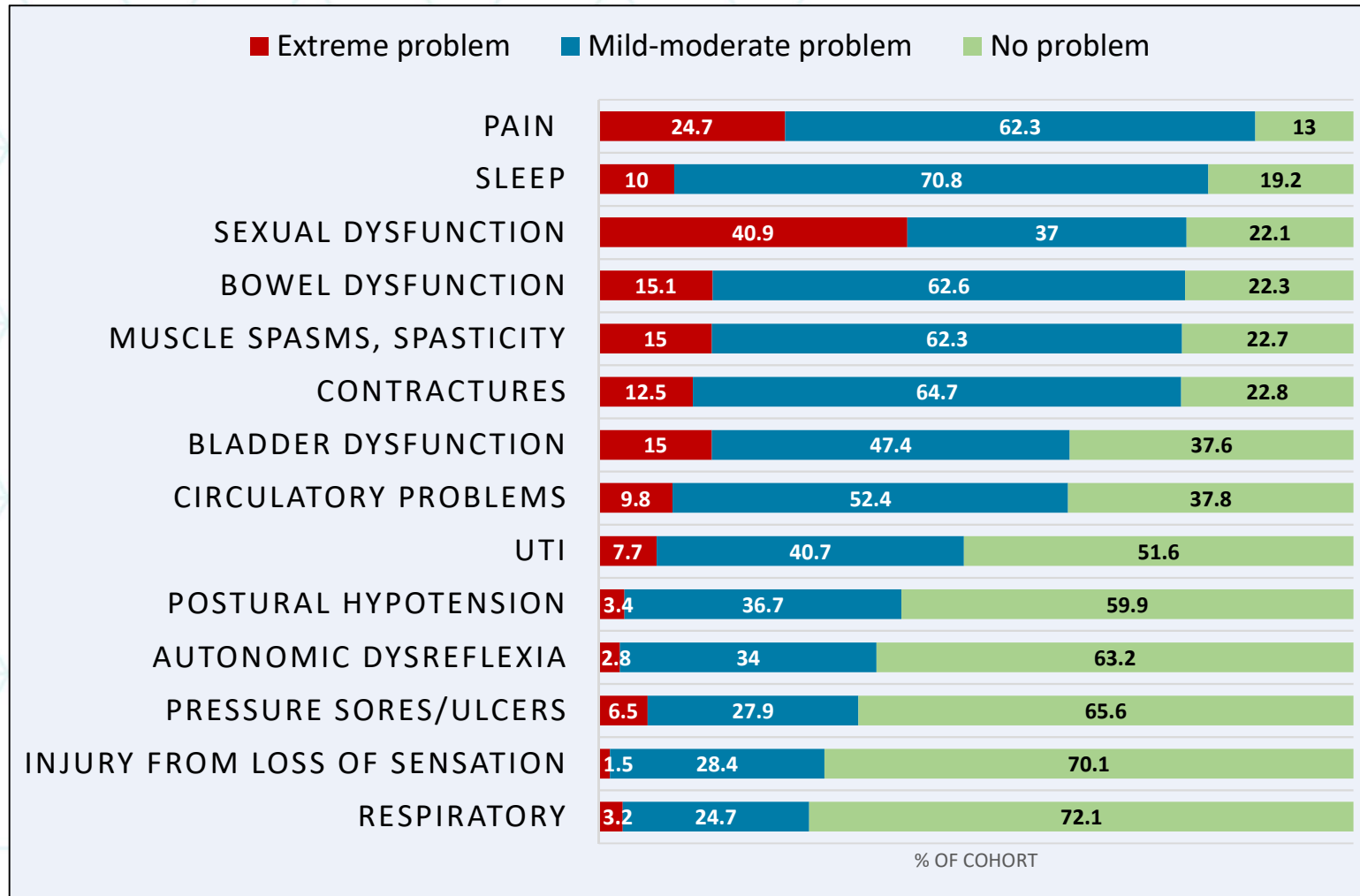
5%

Widowed

Functionality: Moving moderate distances



Secondary health problems



Australian study investigating secondary conditions: spasms and pain, sexual dysfunction, pressure areas and fatigue⁴

Respiratory: top cause of death; and problem including during chronic stages^{5,6}

Pain



78%

Pain, past week

41%

Pain Intensity $\geq 7/10$, past week

61%

Pain in one or both shoulders

23%

Shoulder pain for more than 11 years

Sleep disturbances



73%

Pain

60%

Twitching or jerking legs

51%

Feeling too hot

48%

Feeling too cold

Causes of sleep disturbances: pain, spasticity, immobility and restless leg syndrome⁷

Pressure injuries



29%

Pressure injury, past year

12%

Skin breakdown, never healed

3%

Surgically treated

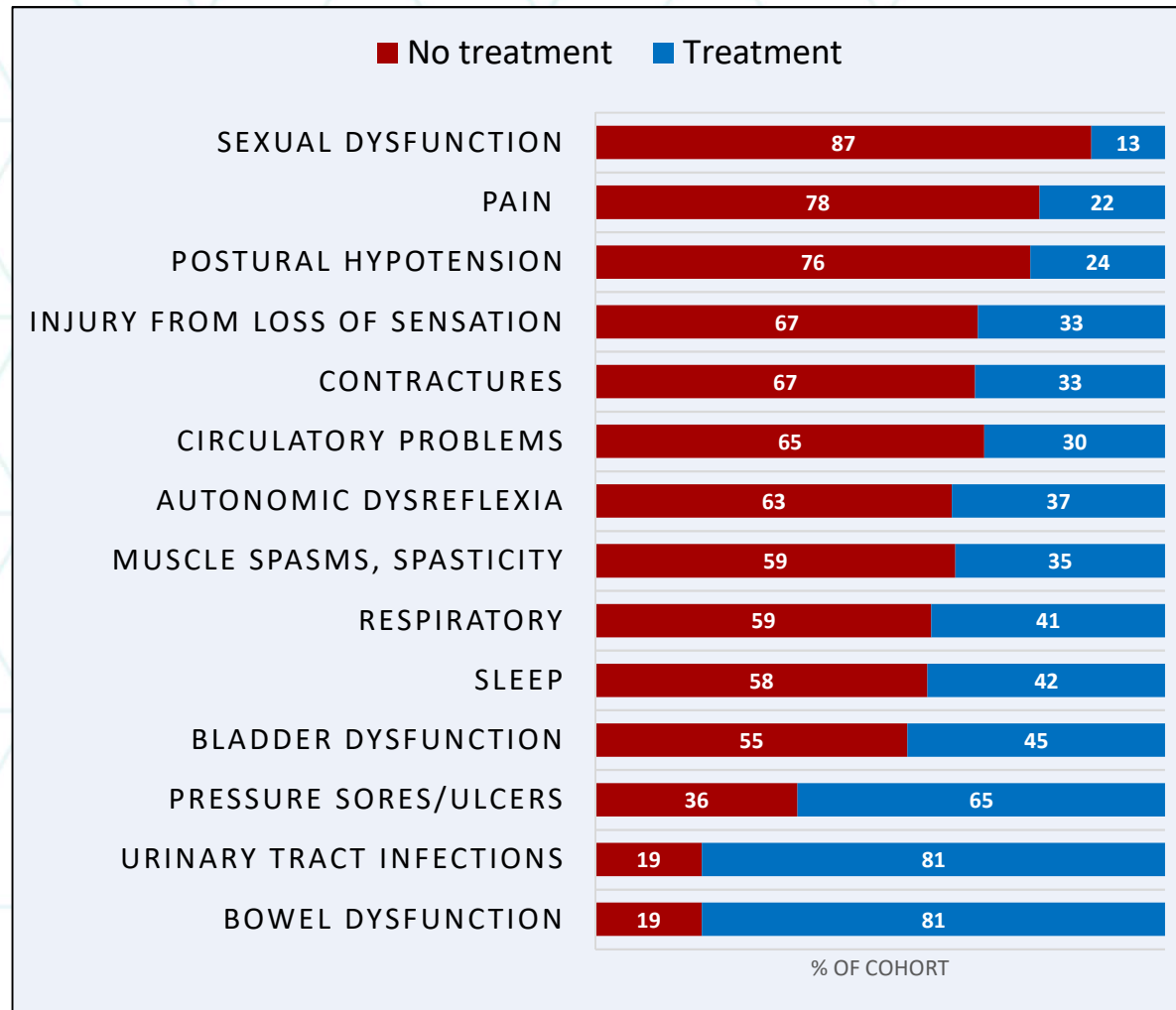
Location

34% Sacrum
30% Ankle

Similar between para and tetra

Higher incidence rate of pressure injuries in paraplegia vs. tetraplegia (47.4 vs. 33.9%)⁸

Treatment for secondary problems



Health professional use:

Utilised in the past year

75% GP

34% Allied health

33% Other medical specialist

22% Rehabilitation specialist

Main contact:

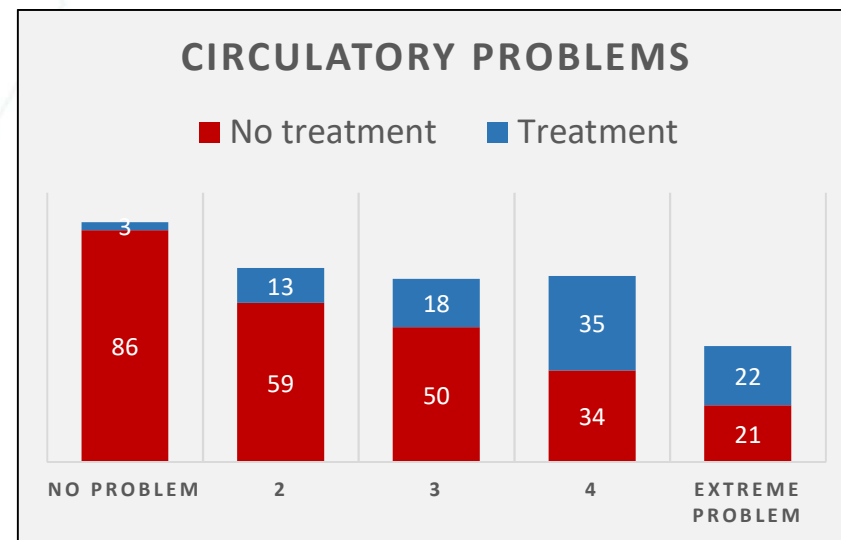
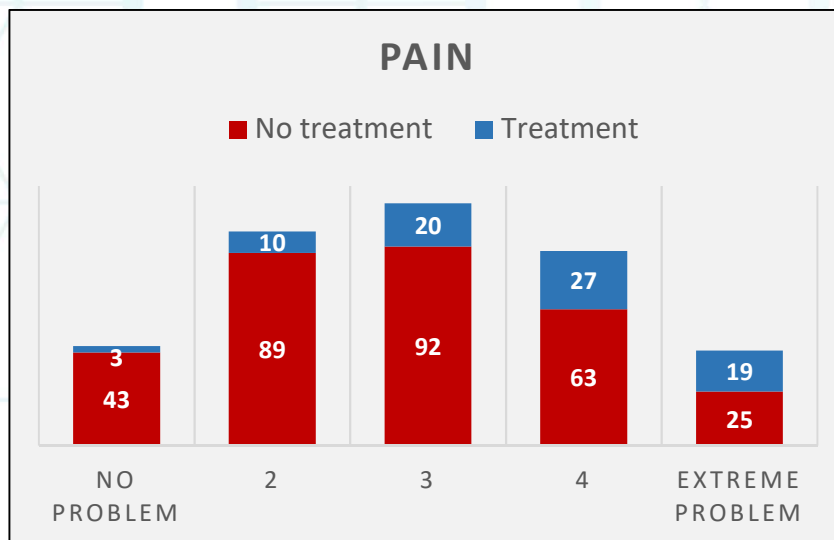
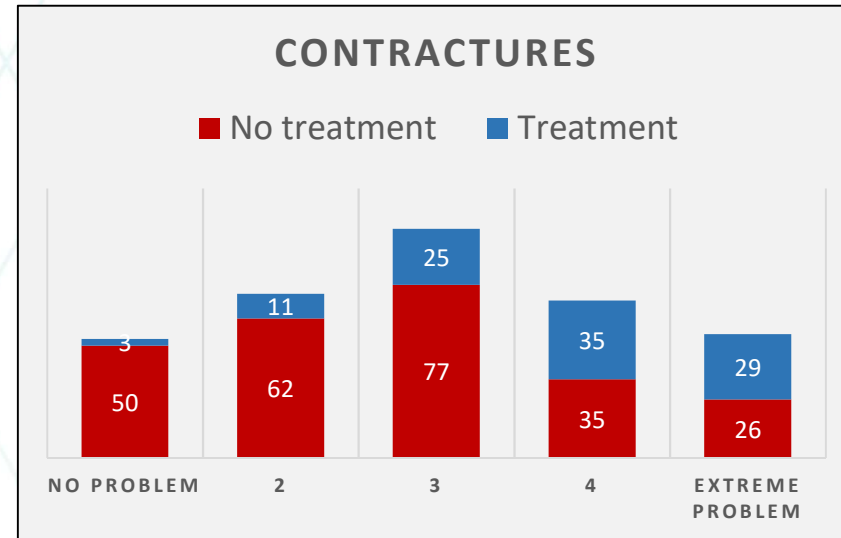
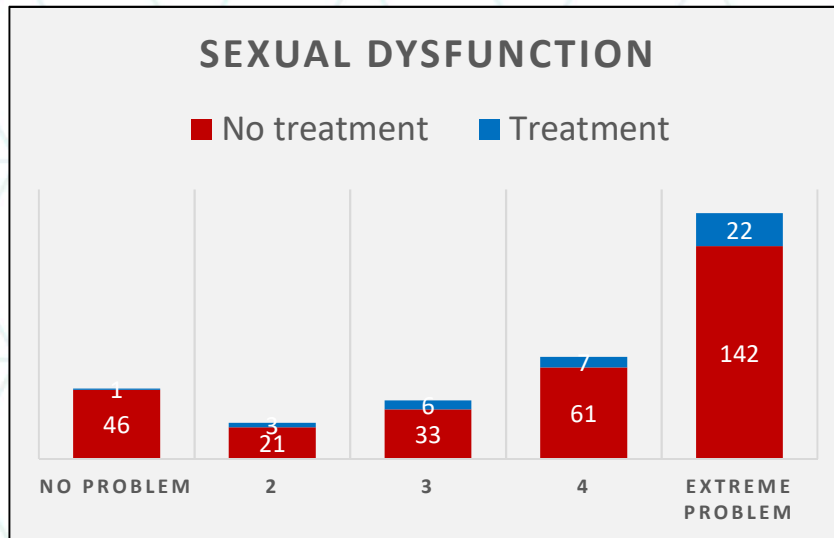
65% GP

23% Spinal specialist

7% Other (e.g. allied health)

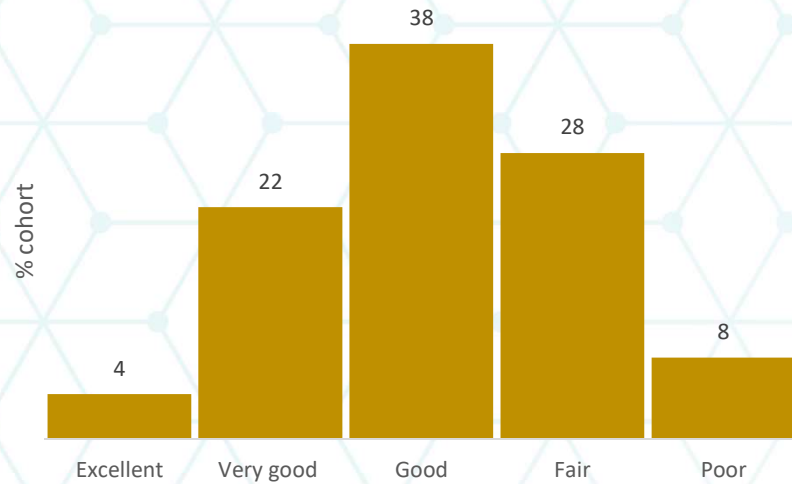
22% Local specialist

Treatment for secondary problems

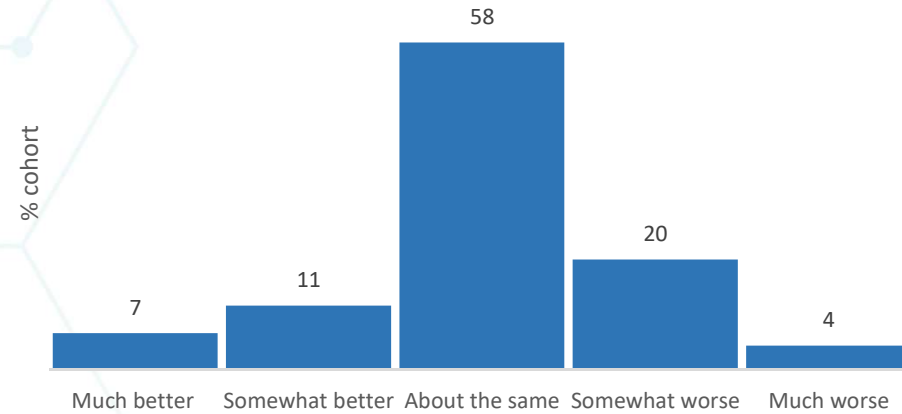


General health and QoL

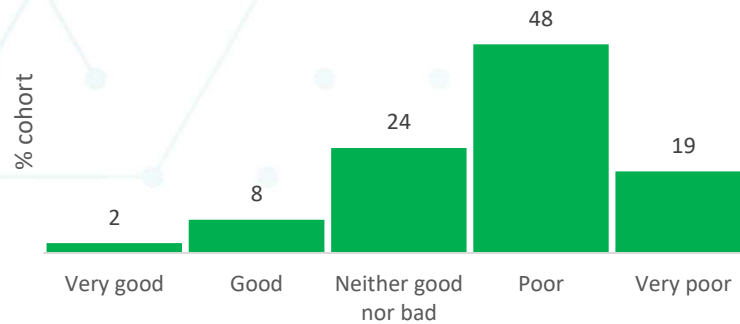
General health



Health compared to 1-year ago



Quality of life



Chronic complications heavily impact on QoL⁹

Discussion

- High prevalence of ongoing secondary health issues highlight the importance of lifelong support and treatment
 - Increase awareness of high incidence of sleep related problems
- Large numbers not being treated is concerning
 - Requires further investigation and consideration
- Self-reported health was largely good or very good, conflicting with the trend towards poorer quality of life
- Limitations
 - Responder bias
 - Self-reported data
 - Single time point

Where to next...

- Further analysis and investigations of the data
- Understanding the data at the national and international levels
- Policy and care planning implications
- InSCI round 2



References

1. Gross-Hemmi M, Post M, Ehrmann C, et al. Study Protocol of the International Spinal Cord Injury (InSCI) Community Survey. *Am J Phys Med Rehabil*, **2017**;96(Suppl):S23–S34
2. Fekete C, Boldt C, Post M, et al. How to measure what matters: development and application of guiding principles to select measurement instruments in an epidemiologic study on functioning. *Am J Phys Med Rehabil* **2011**;90(Suppl):S29-38
3. Australian Institute of Health and Welfare. Spinal cord injury, 1999-2005. April **2009**. Available from: <https://www.aihw.gov.au/getmedia/3be4ea67-7adb-42d9-846c-025627220374/injcat-124-10716.pdf.aspx?inline=true>
4. Callaway L, Barclay, L, MacDonald R, et al. Secondary health conditions experienced by people with spinal cord injury within community living: Implications for a NDIS. *Australian Occupational Therapy Journal* **2015**;62:246-254
5. Amsters DI, Pershouse KJ, Price GL, Kendal MB. Long duration spinal cord injury: Perceptions of functional change over time. *Disability and rehabilitation* **2009**; 27(9):489-97.
6. Savic G, DeVivo MJ, Frankel HL, et al. Causes of death after traumatic spinal cord injury – a 70-year British study. *Spinal Cord* **2017**; 55:891-897
7. Altindag O, Karagullu H, Gur A. Sleep disturbance in patients with spinal cord injury. *Orthopedic & Muscular System: Current Research* **2015**;3:3 DOI 10.4172/2161-0533.1000164
8. Kruger EA, Pires M, et al. Comprehensive management of pressure ulcers in spinal cord injury: Current concepts and future trends. *J Spinal Cord Med* **2013**; 36(6):572-585
9. Sezer N, Akkus S, Ugurlu FG. Chronic complications of spinal cord injury. *World Journal of Orthopedics*; **2015**;6(1):24-33

Acknowledgments

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Any questions?

