

ESTIMATING THE UK POPULATION OF PEOPLE LIVING WITH SCI

Andrew Coxon – NHS England, Shajia Shahid – Spinal Research

AIMS

The current stated number of people living with SCI in the UK is 50,000, with an estimated 2,500 new injuries per year. The aim of this project is to provide an updated conservative estimate of the number people currently living in the UK with a Spinal Cord Injury (SCI)

METHODS

Prevalence = (Incidence) x (Disease Duration)

To calculate the prevalence of SCI in the UK we will need to calculate the annual incidence of new SCI in the UK, and the duration of the condition. As SCI is a lifelong duration this will be the expected life expectancy of people newly injured with SCI.

INCIDENCE

Health Services in the UK are devolved to England, Scotland, Wales and Northern Ireland. Each region was approached to provide what information they had available.

ENGLAND

In 23/24 there were 3,343 referrals to Spinal Cord Injury Centres (SCICs) of people with an acute neurological impairment associated with SCI made through the National Spinal Cord Injury Database (NSCID). The latest figures from the UK-ROC database, covering Neurological Rehabilitation Centres in England, showed that 469 people with newly diagnosed SCI were admitted to those facilities in a year.

Whilst it is possible that some of those admitted into a Neuro Rehab facility were also referred to an SCIC, it is also well understood that a significant number of acute SCI cases in England are not referred to an SCIC at all, especially paediatric SCI and those with comorbid cancer. Additionally a comorbid brain injury always precludes admission into an SCIC, as a Neuro Rehab facility is more appropriate in these cases and as such it would be expected that referring clinicians being aware of this, should not refer these patients.

As a conservative estimate is the goal of this project, the decision was made to add the above two numbers together for the English annual incidence. Whilst it is possible that some double counting occurred with patients initially referred to an SCIC then being admitted into a Neuro Rehab facility, the numbers of acute SCI patients not referred at all would be much higher than this. We should also take into account that the SCI Service Specification specifically excludes those with comorbid brain injury.

SCOTLAND

The latest annual report from the SCIC in Glasgow showed that they received 342 referrals and admitted 130 patients. The Scottish SCI Service Specification varies from the English version in that it also excludes SCI acquired by non-traumatic means whereas these patients can access the SCIC pathway in England.

Detailed breakdowns of the referral data are not available in the annual report but we can note the admission of 130 patients with acute traumatic SCI. In this period in England there were 1,243 referrals to the SCI Service of patients with acute traumatic SCI and given the population of England is roughly ten times that of Scotland, it correlates.

The above comparison is comparing English referrals to Scottish admissions, however as the Scottish system has a much greater capacity and ability to admit patients rapidly, we are assuming that far fewer SCI patients get turned away in that system.

WALES

No data were made available from the Welsh NHS.

NORTHERN IRELAND

The data from Northern Ireland showed very low patient numbers, and it was considered by the reporting body that the cost of expanding this data collection would be above the 'Appropriate Limit' as defined by the Freedom of Information Act under Section 12.

FINAL FIGURE

As we had detailed referral data from England, data that indicated similar annual incidence rates in Scotland, and nothing useable from Wales and Northern Ireland the method used was to take the incidence rate in England and scale it up to match the UK population, giving a final conservative estimate of 4,461.

DURATION

In 2012 Middleton et al. described a method for providing an adjustment of the life expectancy of a newly injured SCI patient based on the severity of their injury. The NSCID provides information sufficient to map this algorithm onto newly injured SCI patients who were referred using that system. For each patient referred in 23/24 their life expectancy was calculated based on their age at injury, their gender and the UK life expectancy figures. This figure was then modified based on their injury severity using the scaling algorithm described by Middleton et al. Finally the average of these adjusted life expectancies was taken, giving a final number of 25.9 years.

SCALING

The final figures will be dependent on the population they are taken out of, and as there is a long duration, these will be artificially inflated, as patients injured in the past when the population was smaller will be taken into account. To adjust for this the final values will be scaled to 92% of their original value (the population size difference between 2024 and 2011 – chosen as 2011 is half the above duration ago).

RESULTS

These results are aimed to be conservative and will be updated annually to take into account anticipated improvements in data capture and collection.

The final results are that there are 4,400 new cases of SCI in the UK each year, and 105,000 people currently living with SCI in the UK. This gives us an incidence of 65 new cases per million people and 1544 people living with SCI per million people.

REFERENCES

Tenny S, Hoffman MR. Prevalence. [Updated 2023 May 22]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2024 Jan-. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK430867/>

Middleton JW, Dayton A, Walsh J, Rutkowski SB, Leong G, Duong S. Life expectancy after spinal cord injury: a 50-year study. *Spinal Cord*. 2012 Nov;50(11):803-11. doi: 10.1038/sc.2012.55. Epub 2012 May 15. PMID: 22584284.