The Incidence and Prevalence of Spinal Cord Injury in Canada

Overview and estimates based on current evidence

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Executive Summary

This report was prepared to provide a review of the current measures of the incidence and prevalence of spinal cord injury (SCI) in Canada. It is to be considered within the context of a strategic discussion concerning the need for, and direction of, further formal research into the extent of spinal cord injury in the country. The report commences with consideration of definitions relating to spinal cord injury, followed by a review of methodology used in the measurement of its incidence (annual number of new cases) and prevalence (total number of people living with SCI, the cumulative net result of past SCI), and of the major Canadian publications, and selected international ones, that are concerned with this measurement. On this basis, estimates of the current levels of incidence and prevalence of spinal cord injury in Canada are presented, before concluding with recommendations concerning these estimates and possible directions for further research.

The terms of reference for this research were to produce estimates of the incidence and prevalence of spinal cord injury in Canada based on currently published evidence. It is important to note that no such measures currently exist: very little has been published about the extent of spinal cord injury in Canada, and what has is limited to the incidence of traumatic spinal cord injury, with the literature silent on its prevalence, and most strikingly, on both the incidence and prevalence of non-traumatic spinal cord injury. The absence of estimates of incidence and prevalence is of significant concern, as it limits a wide range of research and policy, ranging from the determination of the most effective prevention strategies through the delivery of health and medical care to the consideration of the financial impact of SCI and funding of prevention and care programmes.

Given the information provided in the reviewed publications, and data on the current and historical demography of Canada, the report presents three distinct measures concerning the current extent of SCI. The first is an estimate of the **initial incidence of SCI**, which includes all new occurrences of SCI during a year, including persons dying of spinal cord injury before reaching hospital, those dying before hospital discharge, and those discharged from hospital: this is estimated to be 4,259 new cases per year of SCI in Canada today. Of this total, an estimated 42 percent (1,785 cases) are the result of traumatic spinal cord injury and 58 percent are from non-traumatic causes. The second measure of the extent of SCI is the **discharge incidence of SCI**, or the total number of people discharged from hospital after a spinal cord injury each year: this is estimated to currently be 3,675 persons, 1,389 as a result of traumatic causes and 2,286 from non-traumatic causes. The third measure of the extent of SCI is its overall prevalence, or the total number of people who have incurred a spinal cord injury and who are currently living in Canada: it is estimated that there are currently 85,556 persons living with spinal cord injury in Canada. Of this total, 51 percent (43,974 people) were the result of traumatic, and 49 percent from non-traumatic causes.

These aggregate estimates are built up from single year of age and sex specific estimates of initial and discharge incidence and prevalence for both traumatic and non-traumatic spinal cord injury at both the tetraplegic and paraplegic levels of injury. These detailed estimates are summarized by major age groups on the following table and by five year age groups in Appendix IV of this report.

Table 1

Estimated Extent of Spinal Cord Injury in Canada, 2010								
Age	Incidence				Prevalence			
	Traumatic		Non-traumatic		Traumatic		Non-traumatic	
	Initial	Discharge	Initial	Discharge	Paraplegia	Tetraplegia	Paraplegia	Tetraplegia
0-19	243	189	53	49	459	601	181	80
20-39	646	502	285	263	3,923	5,134	2,114	941
40-59	501	390	757	700	7,782	10,154	8,598	3,818
60-79	290	226	974	900	5,502	7,048	12,214	5,354
80+	105	82	405	374	1,567	1,805	5,904	2,377
Total	**1,785**	**1,389**	**2,474**	**2,286**	**19,232**	**24,742**	**29,011**	**12,570**

Acknowledgment that these estimates are based on the best currently available evidence also requires acknowledgement that this evidence is far from the best that there could be, particularly with respect to non-traumatic spinal cord injury. As the terms of reference for this research required the preparation of these estimates, use of the available evidence in turn required the development and documentation of a number of assumptions; in these cases, the assumptions were intentionally conservative. This means that the estimates of incidence and prevalence may be biased downward, particularly in the case of non-traumatic spinal cord injury, from the actual levels that prevail in Canada.

This work should be viewed as the starting point in the development of robust evidence based and documented measurements of the incidence and prevalence of spinal cord injury in Canada. Further direct primary research in Canada will both increase the precision of the estimates presented here and, more fundamentally, increase our knowledge about the extent and characteristics of the population living with spinal cord injury. Of particular importance will be research on non-traumatic spinal cord injury and on the survivorship of persons living with spinal cord injury, as the unique characteristics of Canada's population, geography and health care system suggest that these may be different from other countries. Given the importance of continuing to expand our knowledge about spinal cord injury, this report closes with a discussion of the some of the avenues further research may follow.

The Incidence and Prevalence of Spinal Cord Injury in Canada

Overview and estimates based on current evidence

I. Terminology

A. Overview of Spinal Cord Injury (SCI)

The spinal cord is the major bundle of nerves connected to the brain that extends down the spinal canal formed by the vertebrae of the spinal column. When damage occurs to the spinal cord, sensory input, movement of certain parts of the body, and involuntary functions such as breathing can be lost or greatly impacted. When temporary or permanent impairment occurs due to damage to the spinal cord, it is classified as a spinal cord injury (Blackwell, 2001).

There are two general classes of SCI:

> **Traumatic SCI (tSCI)** occurs when an external physical impact, such as that resulting from a motor vehicle accident, a fall, or from violence, damages the spinal cord. Hagen *et al*, 2009 defined traumatic SCI as an acute, traumatic lesion of the spinal cord with varying degrees of motor and/or sensory deficit or paralysis. In this definition, injuries of the cauda equina, the most caudal part of the spinal cord, were included. According to the American Board of Physical Medicine and Rehabilitation Examination Outline for Spinal Cord Injury Medicine, traumatic SCI includes fractures, dislocations and contusions of the vertebral column (Kirshblum *et al,* 2002).
>
> **Non-traumatic SCI (ntSCI)** occurs when a health condition, such as disease, infection, or a tumour damages the spinal cord; that is, when damage is done to the spinal cord by means other than an external physical force. The causal factors involved in non-traumatic SCI include motor neuron diseases, spondylotic myelopathies, infectious and inflammatory diseases, neoplastic diseases, vascular diseases, toxic and metabolic conditions, and congenital and developmental disorders (Kirshblum *et al,* 2002).

The consequence of SCI is generally classified as either:

> **Tetraplegia** (or quadriplegia) which involves impairment of function in the arms as well as in the trunk (the body excluding the head and limbs), legs and pelvic organs but does not include brachial plexus lesions or injury to peripheral nerves outside neural canal; or
>
> **Paraplegia**, which involves impairment of the trunk, legs and pelvic organs, but with arm function not impaired; cauda equina and conus medullaris injuries are included but lumbosacral plexus lesions or injury to peripheral nerves outside neural canal are excluded (International Standards for Neurological Classification of Spinal Cord Injury, ISNCSCI).

Classification of SCI into traumatic and non-traumatic and by the severity of the injury are particularly important for the treatment, recovery and rehabilitation of the patient. When a SCI occurs, there can be complete or incomplete lesion(s) of the spinal cord, which, in turn, alters whether there is partial or total motor and/or sensory deficit. The neurological extent of the injury, or how much motor or sensory function is left intact after the SCI, is measured by a neurological examination specified by ISNCSCI. This examination determines the level of impairment of the patient, reported with an American Spinal Injury Association (ASIA) Impairment Scale grade.

The standard approach to the identification of SCI occurs within the hospital context, where hospital record coders assign the relevant International Classification of Diseases (ICD) codes to patients. The ICD diagnosis codes in themselves indicate the level and severity of SCI but not the etiology, morphology, or exact location of SCI, and hence are necessary but not sufficient for the measurement of SCI. In order to determine the causal mechanism, details of SCI, and extent of impairment that results, it is necessary to additionally obtain ICD External Cause of Injury Code (E-codes) for causation in tSCI, existing health conditions in cases of ntSCI, and ISNCSCI results for research purposes.

B. Incidence and Prevalence

The incidence of SCI is defined as the number of new cases that occur each year (generally reported as a number of new SCI cases per million population per year); its prevalence is defined as the number of persons with SCI who are alive at a point in time, the cumulative result of past incidence of SCI net of mortality and potential cures measured as a number per million population (Lin, 2003).

The hospital based process for the identification of SCI imposes significant limitations on the measurement of its incidence and prevalence, for while the assignment of ICD codes routinely occurs, the administration of ISNCSCI tests on SCI patients is not entirely inclusive (oftentimes non-traumatic SCI patients are not administered the ISNCSCI), and ISNCSCI results are not routinely well reported. Another concern is the accuracy of the translation of diagnosis from a clinician's examination to the most appropriate ICD code by hospital record coders. Although there is general agreement within the medical community on the definition of tSCI, there is no specified standard of ICD codes that are to be included. Further, there is no consensus, general or specific, on what constitutes ntSCI cases or which ICD codes apply. There is no standard reporting of people living with SCI, either within or outside the hospital context, and hence both procedures and codes must be developed in order to ensure effective and comparable measurement of this population group. In this context, a number of recent studies have called for a standard definition for traumatic and non-traumatic SCI and a uniform data collection methodology (Ackery *et al*, 2004; New & Sundararajan, 2008; Wyndaele & Wyndaele, 2006).

The absence of routine reporting has meant that measurement of incidence and prevalence has occurred on a project by project basis, leading to research using a wide range of measures and methodologies, and hence a wide range of estimated levels. The resultant findings are quite localized, as the research shows that SCI is not only age specific (with the highest rates for traumatic SCI found in the young adult stage of the life cycle and non-traumatic SCI demonstrating a steadily increasing incidence rate with increasing age), but also specific to the economic, social, and cultural structure of communities. This means that comparison of overall incidence and prevalence levels must acknowledge not only different behavioural patterns with respect to SCI but also different underlying demographic and community factors.

As the general review of major published articles summarized in Section III of the body of this report (based on the more detailed review in Appendix I 'Summary of Major Articles Concerning SCI') shows, a number of researchers have provided significant insights into the measurement of incidence and prevalence, but the results fall within a wide range. There have been two general methodological approaches used in published research. The first approach, most commonly used in studies of SCI incidence, has been a case-based approach, using reported ICD codes to identify cases of SCI from databases such as the National Trauma Registry (NTR) or Discharge Abstract Database (DAD) and in some cases supplementing findings by reviewing hospital charts. On the basis of this measurement of annual incidence, population age compositions and life expectancies are then used to estimate prevalence.

In using this approach to estimate prevalence, it is necessary to consider historical changes in incidence and duration (life expectancy of those with SCI), in the age-specific pattern of incidence, and the underlying demography. It is also important to consider the stage in the medical process that measurement occurs, as some incidence studies focus on initial incidence which includes SCI that results in death before and during hospitalization. While this metric is an important consideration in the context of prevention, when using incidence to estimate prevalence, it is appropriate to include only those persons who survive to reach hospital discharge.

The second approach is to measure both incidence and prevalence through a survey of the general population by using standard sampling and survey techniques. This approach provides a direct measurement, and can measure traumatic and non-traumatic injury by level of injury. It has a number of limitations, ranging from self-reporting bias to the problems of obtaining a statistically representative number of respondents, particularly when any degree of cross-tabulation is to be pursued.

As the following Section II discusses, accurate and standardized measurement of the incidence and prevalence of SCI is essential to evaluation and improvement of programs relating to the prevention and treatment of SCI. Such measurement does not currently occur, with existing studies, while valuable in their own right, using different definitions and measures of both incidence and prevalence.

II. Relevance of Measuring the Incidence and Prevalence of SCI

There are profound reasons for having good measures of the incidence and prevalence of spinal cord injury by cause, severity, age group, and geographical location. These reasons range from determining the most effective prevention strategies, through the delivery of services and treatment across the continuum of care, to consideration of the financial impact of SCI and funding of prevention and care programmes. In this section, a brief review of importance of these measurements from an institutional perspective is presented.

A. The Rick Hansen Institute

Effective measurement of the incidence, number, and characteristics of people living with SCI is fundamental to a range of interests at the Rick Hansen Institute (RHI). In the context of its objective to increase the independence and improve the quality of life of people living with SCI, the RHI must know both the scale and the scope of SCI in Canada in order to ensure that it is reaching this community; to facilitate discovery, development and implementation of relevant solutions to improve their quality of life; and to compare the impact or success of such interventions and innovations.

In addition to this core focus on people living with SCI, the RHI must also know the extent of SCI in order to broaden public knowledge of SCI, to encourage the implementation of the most effective prevention programmes, and to increase public support for the Institute and for the funding of its activities. In the very specific context of funding for the RHI, it is important to note that Health Canada, the federal department responsible for helping Canadians maintain and improve their health, provides primary funding for RHI, with secondary funding supplied by the Western Economic Diversification (WED) and from other provincial governments. To sustain and obtain further funding from these constituencies, and to support and evaluate research currently underway, a baseline of information on incidence and prevalence will assist to both measure performance value and to document progress and accountability.

While a separate interest in its own right, there are strong connections between the measurement interest and the Rick Hansen Spinal Cord Injury Registry (RHSCIR, rickhansenregistry.org). The objectives of this registry are to create a digital connection and meeting place for people living with SCI, as well as for researchers, clinicians, and health care professionals. The Registry will include information on those living with tSCI, including new incidences, and clinical, social, geographic, and demographic characteristics. It will facilitate the monitoring of specific outcome measures and will aid in the discovery, validation and translation of relevant treatments and practices that will increase independence and improve quality of life for people living with SCI. It will provide access for people with tSCI to new and reliable information about SCI and clinical, rehabilitation, and community options.

In order to ensure that the Registry is reaching the communities of interest, it will be essential to know the prevalence of SCI in Canada, by both geography and demography. As the registry develops, it will provide a valuable calibration of the estimates of incidence and prevalence calculated using non-registry methods.

B. The Researcher Community

To conduct clinical trials and studies, researchers must ensure that the participants are representative of both the scale and characteristics of SCI, which in turn necessitates knowledge of the incidence and prevalence of SCI. These research activities are diverse in nature, including prevention, acute post-injury care, timing and type of intervention, rehabilitation, need, and outcome trials and studies. The more researchers understand about the epidemiology of SCI, such as the specific type of SCI or level of injury, the more applicable and valuable this information becomes. Furthermore, this knowledge aids in the verification of value of treatments by allowing the researchers to estimate the number of people who would benefit from new therapeutic strategies. Allocation of funding and resources to identify those strategies that would be most beneficial is essential for moving forward in SCI research.

The incidence and prevalence knowledge is also fundamental in the determination of the strategic focus on different populations at risk or living with SCI, and in the comparisons of SCI epidemiology with other nations which may identify potential issues, such as an unusually high national or regional SCI incidence rate in the Canadian context.

C. The Canadian Public

The consequences of SCI are overwhelmingly borne by persons living with SCI and their family and friends, and hence they, and the rest of the public, have profound interest in the prevention of, and care for, spinal cord injury. Prevention is the foundation of health policy: effective prevention strategies can be implemented only with an understanding of the extent and socio-demographic characteristics of the incidence of SCI, an understanding that must be shared by researchers and the Canadian public as a whole. Understanding the extent of SCI is also fundamental to the evaluation of the wider consequences of SCI that are the foundation of public efforts to provide facilities, services, and care that increase independence and improve the quality of life of people living with SCI.

It is essential to demonstrate to the Canadian public the full cost of SCI, to both individuals and communities, and to demonstrate the benefits of programs that will either reduce incidence or improve the lives of those with SCI so that the wider public will give their support, both in spirit and in funding, of these programmes. The foundation for both of these efforts is an effective measurement of the incidence and prevalence of SCI in Canada.

III. The Current State of Knowledge Concerning the Incidence and Prevalence of SCI in Canada

PubMed Central Canada (an online digital archive of full-text, peer-reviewed Canadian research publications in health and life sciences, pubmedcentralcanada.ca) was searched for studies, and reviews of studies, of the incidence and prevalence of SCI published over the past decade, with a focus on studies conducted in Canada and that specifically gave an incidence rate of SCI. Four Canadian studies were found, which form the basis of the literature review presented here. Two studies from Australia relating to ntSCI were also included. Finally, two other studies were included: a literature review of all published literature that related to incidence to provide the global context and a recently published U.S. prevalence of paralysis survey initiated by the Christopher & Dana Reeve Foundation (not indexed in PUBMED).

Appendix I to this Report, 'Summary of Major Articles Concerning SCI', presents a summary of these articles highlighting the findings relevant to the measurement of incidence and prevalence. A number of general observations may be made concerning these publications. First, each uses a different methodology and different definition of SCI. Even those studies which use ICD codes to identify the potential incidence of spinal cord injury rely on different sets of codes, as is indicated in the "Comparison of ICD Codes Used in SCI Research" presented in Appendix II. Second, given the small sample sizes in each study, variance should be anticipated between measured and actual levels. Third, and more significantly, researchers have raised a significant concern about under-reporting of non-catastrophic injury for both traumatic and non-traumatic SCI.

To the extent that these publications present estimates for incidence or prevalence, the corresponding rates were tabulated and then applied to the appropriate demographic variable for the Canadian population to demonstrate what the incidence and prevalence of SCI in Canada would be should the research be directly applicable in the Canadian context. In the following section, the contents of these three Appendices are summarized (Section III. A.) and then conclusions with respect to the calculations of incidence and prevalence are presented (Section III. B.). The details of these calculations are presented in Appendix III, 'Preliminary Estimates of Prevalence of Spinal Cord Injury in Canada Using Published Incidence Rates'. In each case, incidence rates are number of new cases of SCI per million population for 2010 and prevalence rates are number of people living with SCI per million population in 2010, with incidence defined as the number of new cases in a year and prevalence as the total number of people living with spinal cord injury during the year.

A. Summary of Articles and Implied Canadian Prevalence

1. Couris *et al,* 2010 (Canada)

Gender-specific incidence rate of tSCI: 36.3 (male) and 12.1 (female).
Implied tSCI prevalence in Canada: 18,438 (male), 6,378 (female); 24,816 total.

Data source - identified 936 incident tSCI cases in southern Ontario by ICD codes from hospital Discharge Abstract Database (DAD). DAD collects information on admission, transfers and deaths of in-patients, hence this rate would include deaths during hospitalization but not before admission. Excluded cases under the age of 18 years. Sensitivity and specificity of identification of tSCI was not evaluated. Trauma patients for whom the SCI diagnosis is delayed or missed would not be counted.

2. Pickett *et al,* 2006 (Canada)

Age specific incidence rates for tSCI: 0-14 years, 3.37; 15-64 years, 41.79; 65 plus, 50.87.
Implied tSCI prevalence in Canada: 42,939 cases.

Data source - Identified 151 tSCI cases in south-western Ontario by ICD codes of medical records database. Does not specify whether data include cases of death before hospital discharge. Collection bias: no use of a trauma registry, did not include multiple sources of data.

3. Dryden *et al,* 2003 (Canada)

Gender-specific incidence rates of tSCI: detailed for ten-year age groups (see Appendix III.A.4).
Implied tSCI prevalence in Canada: 49,982 (male), 18,934 (female); 68,916 (total).

Data source - Identified 450 tSCI cases in Alberta by ICD codes from the Alberta Trauma Registry and Office of the Medical Examiner with subsequent review of charts from the Alberta Ministry of Health and Wellness. Included deaths before hospitalization and discharge, hence initial incidence rates. Validity test of approach and inclusion criteria resulted in positive predictive value of 94.4% and a sensitivity of 100%. Rapidly resolving neurological deficits would have been missed as well as pre-hospital deaths that included multiple severe injuries.

4. Guilcher *et al*, 2010 (Canada)

No incidence or prevalence rates reported. Presents a comparison of selected characteristics of ntSCI and tSCI rehabilitation patients aged 18-plus in the province of Ontario. Initial admission for inpatient rehabilitation was 1,623 ntSCI and 842 tSCI: the exclusion criteria reduced the sample to 1,002 ntSCI cases and 560 tSCI cases, a 38 percent and 33 percent reduction, respectively.

In considering Guilcher et al, 2010, the authors of this report noted that the use of rehabilitation clinics as a setting for research on SCI potentially introduces limitations to the identification of the relative incidence of ntSCI as compared to tSCI. In discussions conducted with spinal cord injury researchers during the preparation of this report, it was occasionally remarked that individuals with ntSCI may not be as likely to be referred to rehabilitation clinics as those with tSCI. This anecdotal evidence suggests that the population with spinal cord injury in rehabilitation is not necessarily the total population with spinal cord injury as younger and middle aged persons with catastrophic tSCI are perhaps more likely to be referred to rehabilitation than the elderly, those with non-catastrophic injury, and those with ntSCI. A number of reasons for this were suggested, ranging from complications due to the causal disease or medical condition to a perception that, given their generally older age, individuals with ntSCI may not have as strong a commitment to rehabilitation as younger individuals with tSCI. At this juncture there are no data to corroborate these anecdotal comments, which are raised here only by way of establishing a context for the use of relative magnitude estimates derived from the rehabilitation context.

5. New *et al,* 2010 (Australia)

No incidence rates reported. A ratio of 1,361 to 2,241 of traumatic to non-traumatic SCI rehab cases presented. The sampling base was persons in rehabilitation programmes in Australia.

6. New & Sundararajan, 2008 (Australia)

Gender-specific incidence rates of ntSCI in Australian context: adults 15 years and older, 30.5 (male) and 22.9 (female); 0-14 years: 0.7 for both genders. Implied ntSCI prevalence in Canada using these rates: 17,045 (male), 13,216 (female); 30,261 (total). Incidence rates for ntSCI from a review of selected international publications: a range from 5.1 to 80 cases per million population per year. Implied ntSCI prevalence in Canada using these rates: a range from 6,883 to 107,967 cases

Data source for Australian study: identified 631 ntSCI cases in Australia by ICD codes from a state-wide hospital discharge database; reviewed eleven publications from eight countries. Victorian Admitted Episodes Dataset (for Australian data) includes cases on every admitted episode of care occurring in Victorian acute hospitals. Publication does not specify if it includes deaths before hospital discharge. Excluded congenital, motor neurone disease, multiple sclerosis and cases under 15 years of age. Identification of ntSCI may have not been totally inclusive and coding guidelines used in this study may not be applicable to other countries.

7. Wyndaele & Wyndaele, 2006 (Belgium – worldwide literature review)

Incidence rates for SCI (cause and incidence measure unspecified): Range 10.4 - 83.0.
Implied prevalence in Canada: from 13,334 to 106,416 cases of SCI.

This study also presented results from two post-1985 studies of prevalence of SCI in North America, citing estimates for SCI (unspecified as to type) of 681 and 755 cases per million. Applying these rates to Canada's current demography results in 22,976 and 25,473 cases of unspecified SCI.

Data Source - Review of existing literature on SCI incidence, prevalence and epidemiology. No specification of each study's inclusion and exclusion criteria or whether the studies were on traumatic or non-traumatic SCI. Demography and economy of regions of study often different than that of Canada.

8. Cahill *et al,* 2008 (Christopher & Dana Reeve Foundation Paralysis Study, USA)

Prevalence (Percent of population with paralysis due to SCI): 0.4%.
Implied SCI prevalence in Canada: 134,959 cases.

Data source: Telephone survey of households in the United States. Self-reported incidence and prevalence without clinical data. Results were generalized to the population of the United States although only households with listed telephone numbers were surveyed. Survey response management implicitly directed non-traumatic cases away from spinal cord injury category. No clinical verification that spinal cord injury was cause of paralysis (defined as difficulty moving arms or legs).

Conclusions

The implied incidence and prevalence rates for the 2010 Canadian population based on these studies is an estimated annual incidence (Figure 1) of tSCI from 351 to 2,800 cases and of ntSCI from 172 to 2,699 cases; an implied prevalence (Figure 2) of tSCI from 13,334 to 106,416 and of ntSCI from 6,883 to 107,967. This implies a range of prevalence of 360 percent (from 20,217 to 214,383) of SCI in Canada. Note that there is no clustering pattern within these ranges for either incidence or prevalence.

Figure 1

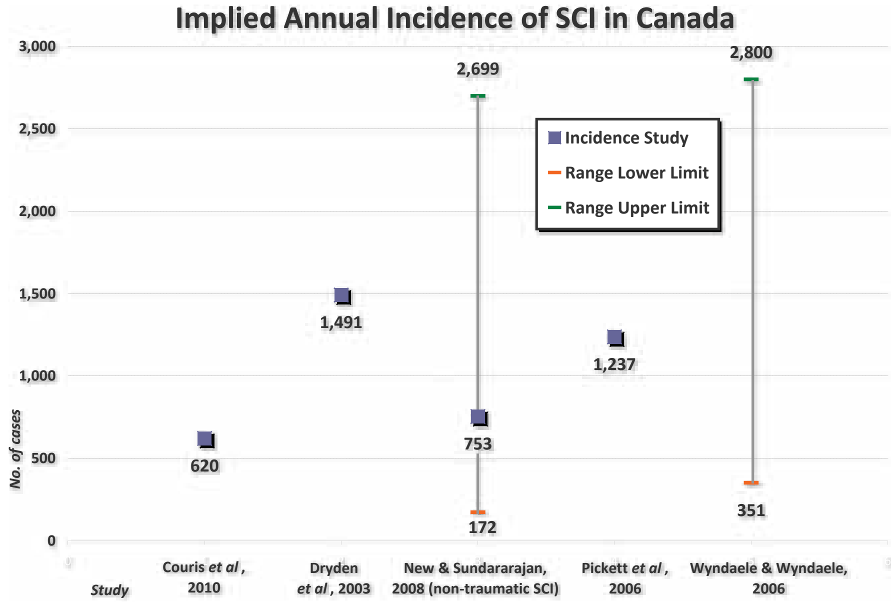
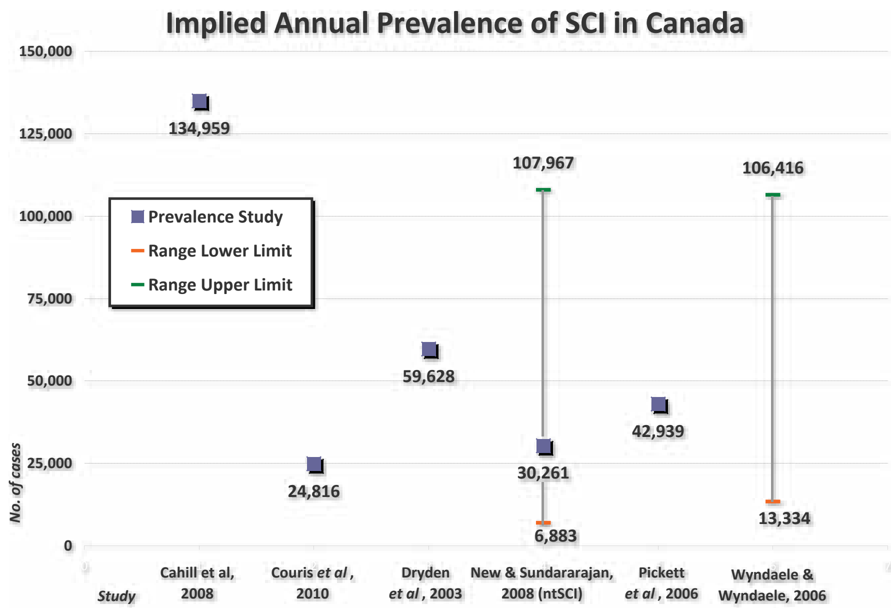


Figure 2



The wide ranges of implied incidence and prevalence are the results of the differences in definitions, inclusions, and methodology used in the published research, as well as of underlying demographic and community characteristics. **The reality that published research generates such ranges and differences when applied to Canada means that there is not an existing measure or estimate of either the incidence or prevalence of spinal cord injury in Canada that will meet the needs of the Rick Hansen Institute, researchers, or the public and its agencies.**

B. Implications for Measurement in Canada

A number of important elements of SCI that will influence the effective measurement of incidence and prevalence are discussed in these published articles:

1. The incidence of SCI is age specific

The distribution of tSCI age specific initial incidence rates (Figure 3, derived from Dryden, 2003) is bimodal, demonstrating a peak in the adolescent and younger adult stage of the life cycle primarily as a result of motor vehicle and sporting accidents and violence. A second peak in the older adult stage (70 years and older) is also seen, primarily as a result of falls (Pickett *et al,* 2006; Dryden *et al,* 2003). Age specific ntSCI initial incidence rates (Figure 4, derived from New & Sundararajan, 2008) increase steadily with age (New & Sundararajan, 2008). The mean age of incidence of ntSCI is significantly higher than that of tSCI (New *et al,* 2010; Guilcher *et al*, 2010).

The lifecycle pattern of the incidence of SCI has significant measurement implications, as it will be essential to use age-specific rates to separate the effects of demographic differences in underlying populations from those of incidence patterns. It will also have significant implications for both prevention and treatment policy, as the aging of Canada's population will shift the incidence population into the older age groups. Further, the age-specific nature of incidence will affect both the extent and the composition of prevalence. Recent studies have shown an increase in the age at injury and shifts in the mechanism of injury. Generally, the shift may be represented as being from young males injured in MVA to older people falling (Couris *et al*, 2010; Pickett *et al*, 2006), a change that will have significant impacts on the extent of SCI, on the characteristics of persons living with SCI and on the entire clinical care pathway in the future given the aging of the Canadian population that will occur in the coming decades.

Figure 3

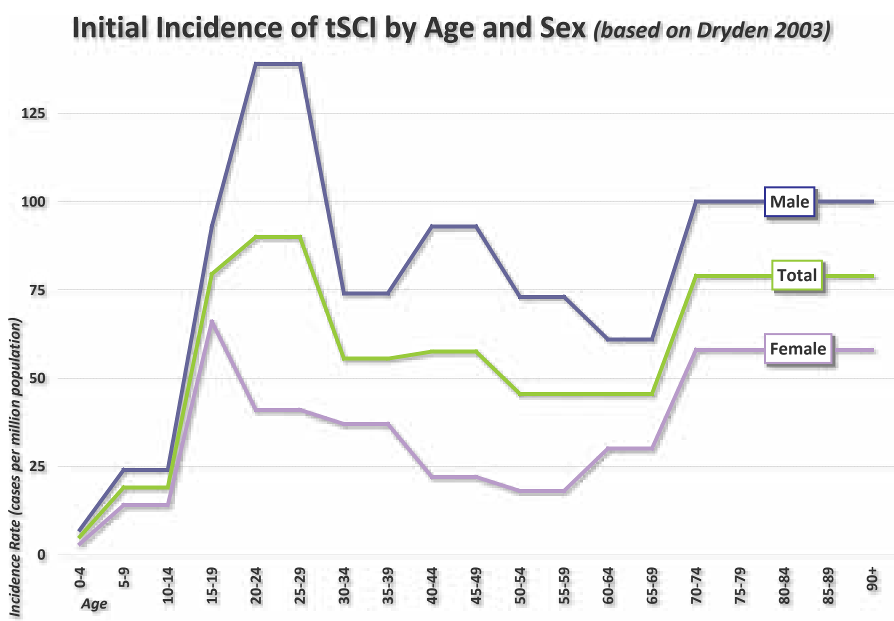
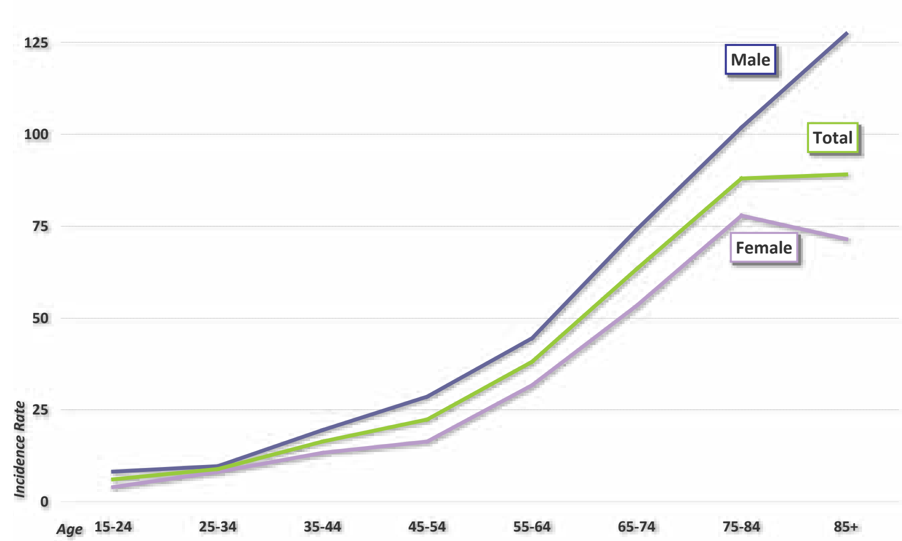


Figure 4

Initial Incidence of ntSCI by Age and Sex ***(based on New, 2008)***



2. SCI is gender-specific

In all age groups, for both ntSCI and tSCI, males are at a higher risk of SCI than females (Couris *et al*, 2010; Dryden *et* al, 2003; Pickett *et al*, 2006; New *et al*, 2010; New & Sundararajan, 2008; Wyndaele & Wyndaele, 2006; Guilcher *et al*, 2010). The greatest difference in tSCI occurs in the 20 -24 and 25-29 age groups, where the initial incidence rates for males is 140 cases per million population compared to 40 per million for females. The greatest difference for ntSCI initial incidence rates occurs in the 85+ age group where the incidence rate for males is 127 cases per million population compared to 70 cases per million population for females. Having noted this, it is important to also note that the differences in age-specific incidence rates are much greater for tSCI than for ntSCI. Overall, the average male rate for tSCI is 65 cases per million population compared to a rate of 24 for females (Dryden *et* al, 2003); the respective rates for ntSCI are only 30 and 22 (New & Sundararajan, 2008).

3. SCI is geography specific

The etiology of SCI differs between regions and countries. For example, although the leading cause of tSCI in many countries is motor vehicle accidents, in others it is not. For example, in Bangladesh the leading cause of tSCI is work-related falls, primarily from trees or while carrying a heavy load on the head, while in South Africa it is violence. As further examples of geographical differences, mean age of injury, male to female ratios, and secondary complications show much different trends in low average income countries than they do in higher income countries (Ackery *et al*, 2004); rural areas have a higher incidence rate of tSCI than urban areas (Dryden *et al,* 2003); and to the extent that workplace injuries lead to SCI, the differences in regions' employment structures will lead to different incidence rates. In this vein, military service (and particularly combat service) carries with it a significant risk of SCI and hence differences in the relative level of military engagement will generate differences in incidence of SCI between countries. While there is scant evidence on ntSCI, differences in underlying disease exposures and pre-conditions for ntSCI will generate differences in SCI prevalence and incidence between countries. Finally, the general level of health care and life expectancy in a region will in turn affect the rate of survival of those with SCI, and hence its prevalence.

IV. Estimates of Incidence and Prevalence Based on Best-Available Evidence

The ideal measure of incidence and prevalence of SCI would provide details on age, sex, cause, severity, mobility limitation, region of occurrence, and place of residence. As the previous section showed, this ideal has not yet been attained in Canada; in fact, there is not a documented evidenced based estimate of either incidence or prevalence for use in research or policy development.

While this ideal will only be found through future completion of comprehensive studies that use standard definitions accepted by the research community, it is possible to use the existing studies to demonstrate how the ideal measures might be applied and to document an evidence-based estimate of incidence and prevalence using what is currently known about them. This is done in this section, which combines the best available current evidence on the incidence of SCI with current estimates of the age and gender composition of Canada's population to generate such estimates of incidence and prevalence of SCI for Canada in 2010.

A. Estimate of Initial and Discharge Incidence

The evidence from Dryden *et al,* 2003 was used as the basis for the estimation of the current incidence of tSCI as it is the Canadian study with the most complete case ascertainment. The study compared multiple sources of data and checked that missed and duplicate cases were minimized. The study also gave gender-specific initial incidence rates for ten year age groups, which is an important factor in both determining incidence and in estimating prevalence. The overall incidence values found in this study were also near the middle of the range of implied incidence rates articulated using published rates in other studies and Canadian demographic variables.

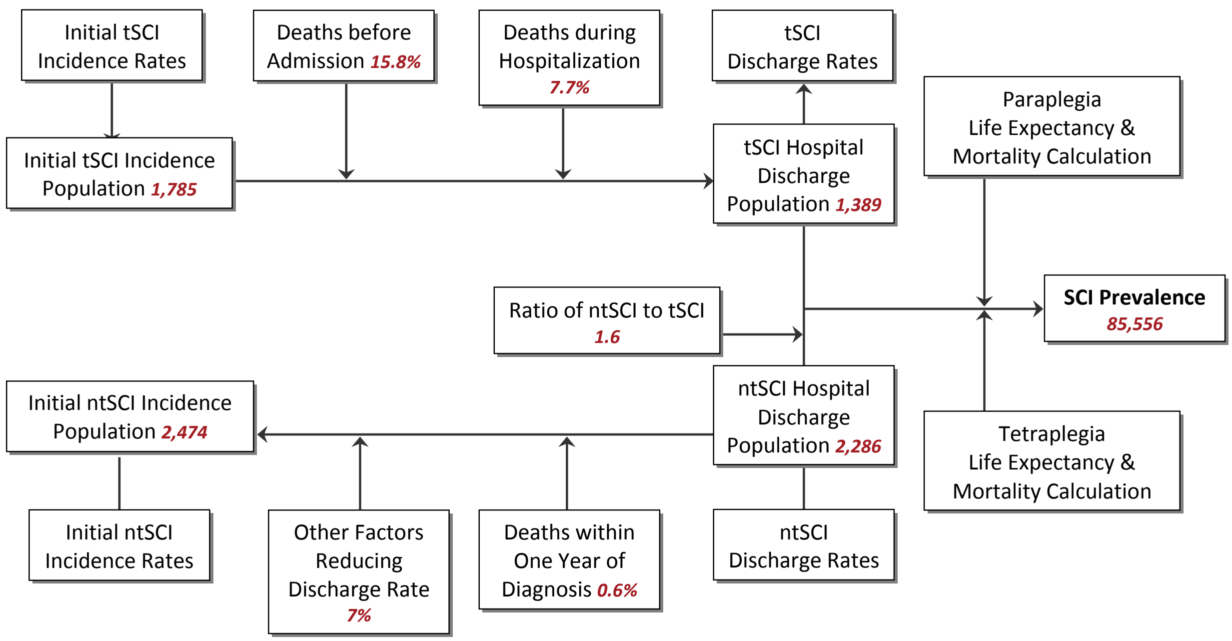
It must be noted that there is no great virtue *per se* in using a mid-range value, for if the highest value reflects the most complete information, it should be used. In this case, however, the high range values came from omnibus studies which included regions with greatly differing demographics and etiologies, and with noted limitations in data collection methodology. For these reasons, these rates were not seen as the most appropriate for use in this context. Furthermore, the use of a mid-range value does reduce the risk of a perception that estimate of incidence and prevalence are intentionally based on outlier values.

The tSCI data from Dryden *et al,* 2003 were vetted with those from Couris *et al,* 2010 (although this is the most recently published study and calculated incidence on the biggest sample size, the study included only patients that were 18 years or older, which is a significant limitation as many tSCIs occur before the age of 18) and from Pickett *et al,* 2006 (which was also considered as it gave age-specific incidence rates, but only in three age groups and which considered only one database without searching a trauma registry to find missed cases).

In using rates generated for Alberta to estimate incidence at the national level, it is important to comment on differences between the province and the national average. Demographically, Alberta is younger (with a median age of 35.6 years compared to the national average of 39.5) and has a greater percentage of males (51.1 percent compared to 49.6 percent), something that, all other things equal, would result in a greater number of new tSCI cases each year. However, the use of age and gender specific incidence rates effectively standardizes for differences in underlying demography, shifting the focus to the behavioural patterns that might result in differences in age-specific rates between Alberta and the rest of Canada. While this may be fruitful ground for further research, the data that are currently available suggest that such differences may not be as great as might be anticipated, as Alberta is both as urban (with 82 percent of the population living in urban areas compared to the national average of 80 percent) and as metropolitan (with 72 percent of its population in census metropolitan areas compared to a national average of 68 percent) compared to Canada as a whole. On this basis, for the purposes of producing a estimate of SCI using best currently available data, the evidence from Dryden *et al,* 2003 is an appropriate starting point.

The process between this starting point and the final estimates of incidence of both tSCI and ntSCI by severity involves a number of steps. These steps are described in the following paragraphs, and are outlined in the following flow chart (Figure 5). While the calculations are performed at the single years of age level, the results are given in aggregate in this section and by 5 year age groups in Appendix IV, 'Age Specific Estimates of Incidence and Prevalence of SCI in Canada'.

Figure 5

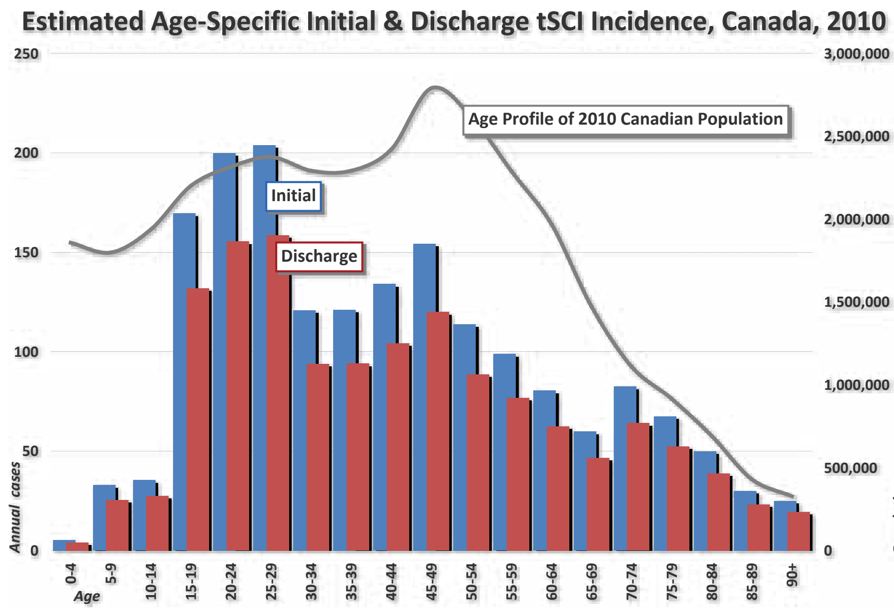


Starting with the ten-year-age-group- and sex-specific initial tSCI incidence rates from Dryden et al, 2003, and using the age group rate as the rate for each age within in it, an estimate of 2010 initial incidence of tSCI in Canada was calculated by multiplying the age- and sex-specific rate by the estimated number of people of each age for both sexes in Canada provided by the Urban Futures Institute. [See http://www.urbanfutures.com/reports/Report%2074.pdf for details of the demographic data base used for this report.] As the tSCI incidence rates published in Dryden *et al*, 2003, include deaths before hospital admission and before hospitalization discharge after injury, the result is an estimate of the 2010 initial incidence of tSCI of 1,785 cases.

In addition to this estimate of initial incidence, another objective of this research project was to produce an estimate of prevalence, and hence it is necessary next to estimate the discharge incidence rate (the initial incidence net of deaths occurring before reaching hospital and in hospital after initial incidence). According to Dryden *et al*, 2003, 15.8 percent of people who initially suffered tSCI died before hospital admission and a further 7.7 percent died in hospital before discharge. The total case fatality rate before discharge was 22.2 percent, implying a 77.8 percent survival rate. This survival rate was applied to the estimated initial incidence in each age group to calculate a hospital tSCI discharge population of 1,389 new cases of tSCI in 2010 .

From the discharge population, age specific tSCI hospital discharge rates were calculated using the 2010 estimated Canadian population. Figure 6 shows the 2010 age specific incidence for tSCI at both the incidence and discharge levels that resulted from this calculation process. This figure shows the peak in incidence in the 15 to 29 age group, the results of the high incidence rates in the age group; as well it shows another, smaller peak in the 70 to 84 age group, again driven by the relative high incidence rates for tSCI in the older population. Interestingly, there is a third peak between these two, falling in the 40 to 54 age groups: as the graph of the age distribution of the population of Canada that is also shown on this figure indicates, this third local peak is the result of the baby boom bulge in the population profile in this age group in spite of its relatively low incidence rates.

Figure 6



The next step in the calculation process was to estimate the incidence of ntSCI. In this context evidence from New & Sundararajan, 2008, New et al, 2010; and Guilcher et all, 2009, was used. The evidence from New & Sundararajan 2008 provided measures of age- and sex-specific non-traumatic SCI incidence in a rehabilitation setting: these rates were used for the age-specific incidence pattern for Canada. The other two studies were used to estimate the magnitude of ntSCI relative to tSCI in Canada. New et al 2010 provides a ratio of ntSCI to tSCI of 2,241 to 1,361 in the rehabilitation context in Australia, which implies a relative magnitude for discharge incidence of ntSCI that is 1.65 times that of tSCI. As noted in the publication, these data are drawn from all patients with a primary diagnosis of SCI, and hence this ratio is derived from the entire incidence population.

Guilcher *et al* 2010 provides a ratio of ntSCI to tSCI of 1.8 (1,002 cases to 560 cases) for the adult (18-plus) population in Ontario. As SCI is significantly age-related, it is necessary to adjust this ratio to include the younger population. Using the age specific propensities for tSCI from Dryden et al 2003 as applied to the 2010 Canadian population indicates that, in addition to the 560 cases involving the 18-plus population, it would be reasonable to anticipate an additional 89 cases of tSCI in the under-18 population, for a total of 649 tSCI cases. Similarly, using the age-specific propensities for ntSCI derived from New & Sundararajan, 2008 as applied to the Canadian population, suggests that, in addition to the 1,002 cases of ntSCI involving the 18-plus population, it would be reasonable to anticipate an additional 22 cases of ntSCI in the under-18 population, for a total of 1,024 tSCI cases. These expanded figures imply a ratio of ntSCI to tSCI of 1.58 (1,024 cases to 649 cases). [See Appendix IV of this report for the estimated 2010 age specific incidence used to scale the 18-plus population values from Guilcher *et al*, 2010 to the entire population.]

This value is not materially different from the 1.65 scalar derived from New *et al,* 2010; as the 1.65 value was directly obtained from data, rather than requiring additional adjustment, it was selected as the scalar used to estimate the magnitude of ntSCI in Canada. When applied to the estimated 1,389 persons discharged with tSCI based on Dryden *et al*, 2003, the result is an estimate of an incidence of 2,286 new cases of ntSCI in Canada in 2010. Please note that if the 1.58 scalar was used (based on adjustments to Guilcher *et al,* 2010) the magnitude of discharge ntSCI estimated would be 2,192, only four percent lower than the 2,286 used here.

In order to estimate the age specific pattern of ntSCI discharge incidence (an essential component is estimating prevalence), the age specific ntSCI rates from New & Sundararajan, 2008 were re-based so that when they were applied to the 2010 population of Canada by age group the result was the estimate of 2,286 discharge cases with ntSCI derived from Dryden *et al*, 2003 and New *et al,* 2010. The result was a set of estimated age specific ntSCI discharge incidence rates that correspond to the tSCI discharge incidence rates derived from Dryden *et al*, 2003.

The final step in the ntSCI incidence calculations was to calculate initial incidence rates from this discharge level. It is at this juncture that once again the dearth of research on ntSCI presents significant limitations to satisfying the terms of reference for this report, which is to provide measures of the incidence and prevalence of SCI in Canada. The issue at hand is that while the consequences of SCI are essentially the same for tSCI and ntSCI, the paths followed to arrive at these consequences are remarkably different. In the case of tSCI there is clearly an initial incident—a car accident, a fall, a sporting injury—that permits measurement of initial incidence, with subsequent mortality leading to a lower discharge incidence. The identification of initial incidence in the context of tSCI is of significant concern, as prevention measures must be both targeted and evaluated at this point.

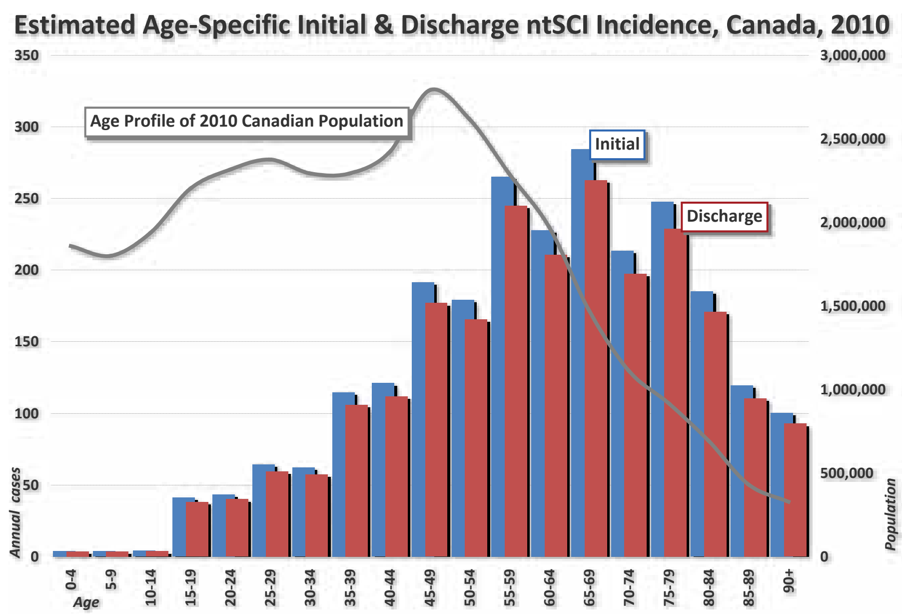
In the context of non-traumatic spinal cord injury, the concept of initial incidence is much different, as ntSCI is largely seen as being a consequence of some other medical condition or disease. As such, prevention and measurement have a much different meaning in the context of ntSCI, falling perhaps more in the realm of the measurement of the degree to which diagnosis of, and treatment for, SCI occurs within the context of these other diseases. Certainly from a policy perspective, the discharge incidence (the annual number of new persons with ntSCI who survive initial hospitalization) and the prevalence of ntSCI (the number of persons with ntSCI living in our communities) are the most important figures. Nonetheless, it remains important to acknowledge that these numbers do not include all of those who suffer ntSCI, and that there is a larger number, one that has implications for the continuum of care for both patients and service providers, than is indicated by the discharge incidence measures. The fact that we may not ever be able to answer the question of how many people annually suffer from ntSCI does not preclude the importance of asking it, as asking it will change how we look at ntSCI, and specifically how we look at ntSCI in the contexts of diagnosis, rehabilitation, and most importantly, care.

There is no direct research that provides any insight into the relationship between the total number of annual occurrences of ntSCI and the number of people recorded in the discharge population. Catz *et al*, 2002 indicates 0.6 percent of those diagnosed with ntSCI die within one year of diagnosis, a value that is used in this report. Additionally, Guilcher *et al*, 2010, indicate that out of the initial admission for inpatient rehabilitation of 1,623 ntSCI cases, 38 percent were excluded and out of 842 cases of tSCI, 33 percent were excluded. As the exclusion criteria included in-hospital mortality, index discharge after the end of study date, and death within one year after discharge, it is possible to hypothesize that the ratio between initial and discharge incidence for both ntSCI and tSCI are of the same order of magnitude. However, discussions of these relative magnitudes conducted during the preparation of this report indicated a general theme that the gap between initial and discharge incidence for ntSCI, while positive, is not as large as the 23.5 percent gap for tSCI. In order to reflect this narrative, a rate one-third of that for tSCI was used for ntSCI.

In doing so, this is not to assert that this 7.6 percent gap is the correct value, but rather to state that if it is, the consequent ntSCI initial incidence rate can be estimated; it *is* to assert that specific research into the incidence of ntSCI would be a valuable contribution to our understanding of this, the most prevalent form of SCI in Canada.

Applying this 7.6 percent margin to the discharge incidence number for ntSCI in each age group results in an estimate of initial ntSCI incidence (2,474 cases in 2010) which, when divided by the 2010 population of Canada by age group, gave an estimate of the 2010 initial incidence rated of ntSCI by age group. Figure 7 shows the resultant estimates of the 2010 age specific initial and discharge levels for ntSCI in Canada, which shows that the incidence of ntSCI peaks in the older age groups, the result of the high incidence rates in these older age groups offsetting the relatively small proportion of the population that is currently of these ages. Please note that using this approach for the calculation of initial incidence for ntSCI has no consequence for the estimates of either its discharge incidence or its prevalence.

Figure 7



To summarize, the process used to estimate incidence and prevalence results in an estimated 2010 initial incidence of new spinal cord injury of 1,785 cases for tSCI and 2,474 cases for ntSCI (4,259 in total), and a discharge incidence of 1,389 cases for tSCI and 2,286 cases for ntSCI (3,675 in total). These estimates are based on the following assumptions:

a) that Dryden *et al,* 2003 rates are representative of tSCI initial incidence by age in Canada; that the survivorship ratios between initial and discharge incidence for tSCI documented in Dryden *et al,* 2003 apply to all age groups;

b) that the ratio of ntSCI to tSCI presented in New *et al,* 2010 prevails in Canada;

c) that the assumed survivorship ratio between initial and discharge incidence for ntSCI is in the order of 7.6 percent and that it applies for all age groups; and

d) the general life cycle pattern of the incidence of ntSCI presented in New & Sundararajan, 2008, also prevails in Canada.

In each case, it can be argued that the assumption may not be valid, and hence the estimates may not be accurate. Unfortunately, there is no evidence available to prove or disprove validity – it is the absence of evidence that necessitates these assumptions. It is here suggested that, with respect to tSCI, Dryden *et al,* 2003 is sufficiently robust as to apply generally in Canada, with the consequences that differences between estimates and what actually occurs would not be in terms of orders of magnitude. With respect to ntSCI, the issues of under reporting of ntSCI will have a greater impact on the estimate of ntSCI than the assumptions made here. Thus the estimated incidence of tSCI is likely proximate to what a detailed measurement study would produce, while the estimated incidence of ntSCI is likely below, and perhaps well below, what direct measurement would reveal.

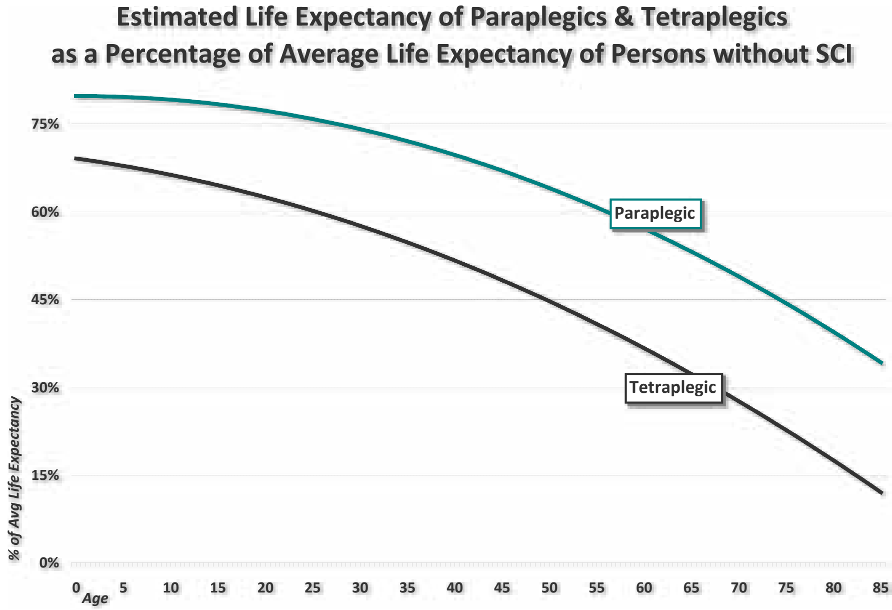
B. Estimate of Prevalence

The estimate of prevalence is based on the estimates of discharge incidence, on the annual number of people by age group who are discharged from hospital with spinal cord injury. As there has never been a census of SCI prevalence in Canada, there is no base on which to develop a current estimate. It is therefore necessary to go as far back as possible in history and model prevalence forward using annual discharge incidence to populate the prevalence group. This demographic acknowledgement was done by using a database maintained by Urban Futures which contains estimates of the Canadian population, and of its death and birth rates, by single years of age and sex, for each year from 1921 to 2010.

The first step in the process of estimation of prevalence was to estimate historical annual discharge incidence by applying the age and sex specific discharge incidence rates for tSCI and ntSCI discussed in the preceding section to the estimated population of Canada by age and sex each year for the 1921 to 2010 period. This annual incidence was then disaggregated into four groups: tSCI with paraplegia and tetraplegia (based on a 43.3% and 56.7% split documented in Dryden *et al*, 2003) and ntSCI with paraplegia and tetraplegia (based on a 69.2% and 30.8% split documented in New *et al*, 2010). Prevalence for each of these four groups was estimated using the general methodology discussed in the following paragraphs, with the only distinction being the different age specific mortality rates applied to paraplegia and tetraplegia. Survival rates after ntSCI and tSCI have been compared in the rehabilitation setting in Israel. These studies report that survival rates between the two sub-types of SCI are similar. When controlling for age at injury, gender, injury severity, and level of injury, no differences were detected between the mortality risks of tSCI and ntSCI (Ronen *et al*, 2004)

The second step was to account for prevalence by adding the current year's discharge incidence to the survivors of the previous year's prevalence. In the absence of a census of prevalence at any time in the past, the 1921 discharge incidence population was equated to that year's prevalence, thereby forming the starting population to which the subsequent year's incidence would be added. To determine the number of people who survived to 1922, the age and sex specific mortality rate for people living with SCI was estimated. This relied on using the average life expectancies of persons with SCI compared to that of persons of the same age not living with SCI. These data are published for the United States population by age group in the NSCISC Annual Statistical Report 2009 (values for these data in 5 year age groups were kindly provided by Dr. H. Krueger by e-mail). Data are for five levels of spinal cord injury (motor functional, any level; paraplegia, tetraplegia C5-C8; tetraplegia C1-C4; ventilator dependent, any level); as incidence estimates prepared for this report are aggregates for paraplegia and tetraplegia, the life expectancy ratios for paraplegia and tetraplegia C5-C8 were used for purposes of prevalence calculations. Values of life expectancies for people living with paraplegia and tetraplegia were calculated as percentages of the average life expectancy for persons of each age, with the result smoothed to single years of age using a best-fit polynomial equation (Figure 8).

Figure 8



As population models use mortality rates rather than life expectancy, it was necessary to estimate the age specific mortality rate for a person with SCI relative to the average mortality rate for a person of the same age without SCI. For example, if the life expectancy of a 40 year old with SCI was 70 percent of that of a person of the same age without SCI, then the mortality rates, both current and over the rest of their life, for persons with SCI who were 40 years of age must be above those of their peers who do not have spinal cord injury. As a wide range of different patterns of age specific mortality rates could generate a 30 percent difference in life expectancy, and in the absence of any information as to the actual path of differences in age-specific mortality over the lifetime of these two peer groups, it was appropriate to take the simplest approach, which was to scale age-specific mortality for persons with SCI up to match the age-specific differences in life expectancy. The same method was applied for each age group for each year in the 1921 to 2010 period: this implicitly assumes that the life expectancy for people with SCI increased at the same rate and followed the same pattern as life expectancy increases for the population as a whole.

After applying the mortality rates to the 1921 discharge incidence population, the survivors were aged one year and the 1922 discharge incident population was added to them to result in the 1922 prevalence. This calculation process was repeated each year up to 2010. Clearly, starting with the equation of the 1921 discharge incidence population with 1921 prevalence underestimates that year's prevalence; however, by continuing to add the incidence each year, and acknowledging aging and mortality in the prevalence group, over time this underestimate will be diminished. By 1961, for example, most of the 1921 prevalence group would have left the population and hence the magnitude of the 1921 starting group would have little impact on the estimated prevalence in 1961. The result of this calculation of prevalence is a consistent estimate of prevalence from 1961 to 2010.

On the basis of this process, the total prevalence for people living with SCI in Canada in 2010 is estimated to be 85,556 persons (0.25 percent of the population). Of this total, 43,974 people (51 percent) would have SCI as a result of traumatic causes and 41,581 (49 percent) as a result of non-traumatic causes. An estimated 37,313 people would be living with tetraplegia (44 percent) and 48,243 people (56 percent) living with paraplegia. As Figure 9 shows, the prevalence of both tSCI and ntSCI is concentrated in the older age groups, the result of both survivorship and the significant incidence of SCI in the older population, both tSCI as a result of falls and ntSCI generally.

Figure 9

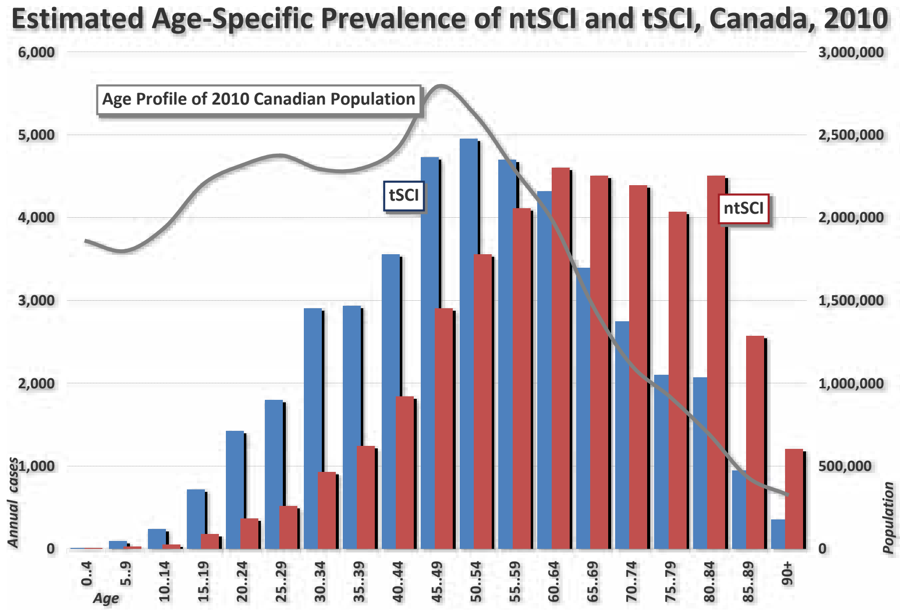
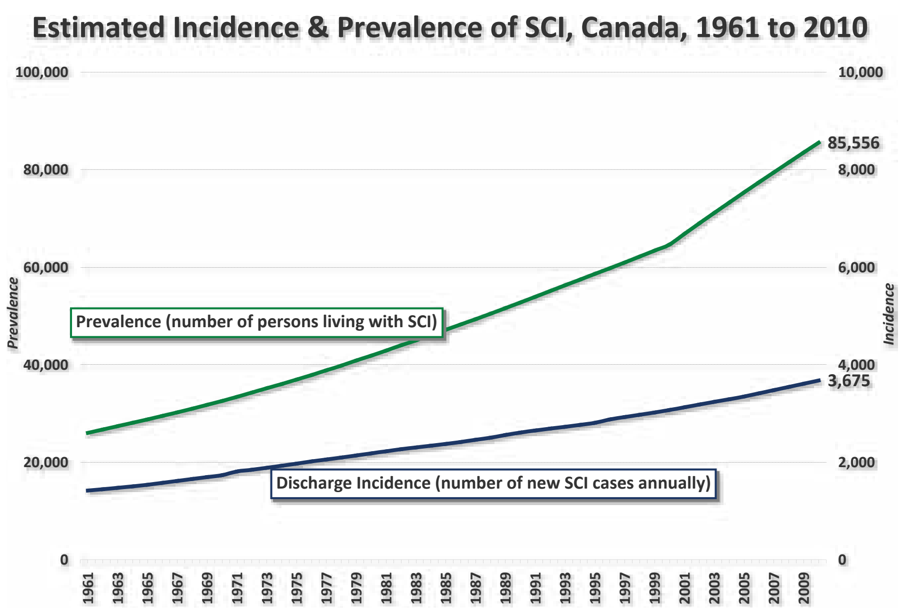


Figure 10 shows the estimated levels of discharge incidence (right hand scale) and prevalence (left hand scale) in Canada over the 1961 to 2010 period, both lines reflecting the growing and aging of the Canadian population and the increases in life expectancies over the past half century. Over the past two decades, for example, annual discharge incidence is estimated to have increased by 41 percent, from 2,607 in 1990 to 3,675 in 2010, and annual prevalence by 62 percent, from 52,759 in 1990 to 85,556 in 2010.

Figure 10



While not within the specific terms of reference for this report, the same methodology that was used to produce the 2010 estimates can be used to project levels in the future given an age- and sex-specific projection of Canada's population. Such a projection may be useful for strategic purposes and hence is presented in brief summary in Appendix V, 'Projection of incidence and prevalence of spinal cord injury in Canada, 2010 to 2030'.

To summarize, using the best available evidence produces an estimated prevalence of 85,556 people living with spinal cord injury in Canada in 2010, with 43,974 people living with SCI that resulted from traumatic causes (19,232 with paraplegia and 24,742 with tetraplegia) and 41,582 with SCI that resulted from non-traumatic causes (29,011 with paraplegia and 12,582 with tetraplegia). In addition to the assumptions that underlie the estimates of annual discharge incidence rates used to calculate these estimates, they are also based on the following assumptions:

a) that age-specific discharge incidence rates have not changed significantly;

b) that the ratio of life expectancy of persons with SCI to average life expectancies observed in the United States prevails in Canada for both tSCI and ntSCI; and

c) that the ratio of life expectancy of persons with SCI to average life expectancies has generally remained constant and hence that the life expectancy of persons with SCI has increased at the rate of the overall average.

The approach used here captures the changes in demography and life expectancy that have occurred in Canada over the past decades; what it does not precisely capture are changes that are specific to SCI. While the methodology does assume constant incidence rates over the entire historical period, given the shorter life expectancy of persons living with SCI, compared to the overall average, effectively this presumed constancy will be for the past twenty to thirty years, something that will reduce its impact on the estimate of prevalence. A similar situation will prevail with respect to the use of the constant ratio of life expectancies. Thus, only if significant change occurred over the past two to three decades would use of the 2010 rates for earlier period have a major impact on the prevalence measure. As with the estimation of incidence, the major concern with the estimation of prevalence will lie with likely under-reporting of ntSCI.

Without any published benchmarks, it is not possible to judge how closely these estimates of prevalence correspond to the actual number of people currently living with spinal cord injury in Canada. Having noted this, they do fall within the range indicated by the simple scaling of incidence rates based on studies conducted in Canada presented in Appendix III, and below the range of values based on studies conducted in the United States.

It is appropriate that prevalence and incidence rates, and specifically rates for tSCI, in Canada are indicated as being below those of United States, as the underlying pattern and level of injury in the United States is significantly different from that of Canada. As examples, Cahill *et al,* 2009 (recall that there is a bias towards tSCI in this research's findings) found that:

a) twenty-four percent of the persons living with spinal cord injury in the United States stated that a motor vehicle accident was the cause of their injury; data from the US NCHS and Statistics Canada indicate that age-specific motor vehicle mortality rates for young adult males in the United States are 75 percent higher than they are for their peers in Canada;

b) victims of violence account for four percent of the people living with spinal cord injury in the United States; US NCHS and Statistics Canada data indicate the age-specific mortality rates as a result of violence for young adult males in the United States are six times what they are for their Canadian peers; and

c) six percent of the people living with SCI in the United States were injured during military service; data published by the federal governments of the two countries indicate that the active military force of the United States represents a rate of 5 per 1000 population while Canada's represents a rate of 2 per 1000.

To the extent that these differences correspond to differences in the incidence rates for traumatic spinal cord injury, it is reasonable to anticipate that Canada would demonstrate corresponding lower incidence and hence prevalence rates. Thus, based on current evidence, the estimate of 85,556 people living with SCI is an appropriate starting point for both further research and policy.

V. Conclusions and Next Steps

A. Summary

This report has reviewed the current evidence concerned with the incidence and prevalence of spinal cord injury in Canada, commencing with definitional considerations, followed by a review of methodology and of the major publications that have presented such measures. On the basis of this review, the report presented evidence-based estimates of the current levels of incidence and prevalence in Canada, indicating a 2010 annual initial incidence of 4,259 cases of SCI (1,785 of tSCI and 2,474 of ntSCI), a discharge incidence of 3,675 cases (1,388 of tSCI and 2,287 of ntSCI) and annual prevalence of 85,556 persons living with spinal cord injury (43,974 as a result of tSCI and 41,582 from ntSCI). For reference purposes, it is suggested that rounded values of 4,300 for initial incidence, 3,700 for annual discharge incidence, and 86,000 for prevalence be used.

Both the data and the methodology used to produce these estimates have their limitations, as is acknowledged in the report. It is not intended that these estimates be regarded as definitive; their purpose is to say "here are estimates of incidence and prevalence that are documented and supported by the best available evidence" which can and should be revised to remove their acknowledged shortcomings when research is done that improves the evidence that is currently available. Having said this, these estimates provide a valid starting point in the process of determining the precise level of the extent of spinal cord injury in Canada, and as a base for policy until further research has been completed.

Before carrying on with the research process, however, it is important for the spinal cord research and policy community to decide whether there is an urgent need for dedicating significant research resources to refining these estimates. This context raises three questions, the answers to which will be essential to determining the direction of further research. The first question is: "Do the evidence based estimates of annual initial incidence of 4,300 new cases of spinal cord injury and a current prevalence of 86,000 persons living with spinal cord injury provide the RHI, researchers, and the community at large with sufficient information to meet their needs?" If the answer is "yes", then research resources may be directed to other activities.

However, if the answer to this question is "no", then the other two questions must be addressed. The second question is: "Are the limitations perceived in these estimates merely technical and hence can be sufficiently refined without major research resources, or are they fundamental, and hence further significant research is required?" The answer to this question will determine the magnitude of the additional resources that will be required to ultimately get a "yes" as the answer for the first question.

If more than simple refinements will be necessary to obtain an affirmative answer to question one, then the research focus must be clarified. The need for this clarification arises from the reality that the greatest limitations on data and evidence are in the context of ntSCI. This is in part the result of the very limited research that has been conducted on ntSCI, but it is also in part the result of an implicit ambivalence with respect to the inclusion of ntSCI in SCI research. If further research on the measurement of the extent of SCI in Canada is to be pursued, it will also be necessary to answer the third question: "Is the research focus SCI and people living with SCI regardless of cause, or is it a cause specific focus emphasizing tSCI?" If the answer is that the focus is all SCI, then the next step in research would be a priority focus on ntSCI to bring evidence in the Canadian context up to the same level as is available for tSCI. If the answer is a narrower focus, then a much different research path would be followed.

B. Next Steps

Presuming that further research is deemed appropriate, there are a number of approaches and data sources in addition to those outlined in the literature review that might be considered. In the interests of informing the discussion of these paths, this report closes with a very brief overview of some of the data sets/sources that might be consulted.

1. Definition

Fundamental to moving the research on the extent of SCI in Canada forward is agreement on definitions, in the sense of establishment of a single data-based definition of what constitutes both tSCI and ntSCI. Specifically, there must be an accepted standard list of ICD codes that identifies SCI and a medical definition for each code. With this list, information can be extracted from existing databases, such as a hospital discharge database or the National Trauma Registry, and comparable data can be gathered. Furthermore, standards must be articulated to guide hospital and medical coding that identifies SCI (particularly inclusion of cases of SCI with less severe impairment and with cases of ntSCI). A challenge will be measurement of SCI with temporary motor and/or sensory deficit. Note that in the articulation of these standards, consideration should be given to applicability in both the prevalence and incidence contexts.

2. Measurement of Incidence

Incidence is best measured in a hospital context, as it is in this context that initial diagnosis and treatment are routinely performed. Presuming the existence of the standard ICD-based definition of SCI, an accurate way of measuring incidence could be through reporting from hospital databases. For data on deaths before hospital admission, another approach would have to be considered, such as investigation of a medical examiner's database. However, the Pickett *et al* study discussed that this method may still present an under-representation of the number of people with SCI that die before arrival to hospital.

In the specific context of tSCI, the National Trauma Registry (NTR), which provides national statistics on injury in Canada, reported by Canadian Institute for Health Information (CIHI) will prove useful. The data in the NTR comes from the Hospital Morbidity Database, with additional input from provincial trauma registries or trauma centres in Canada. The Hospital Morbidity Database provides hospital discharge statistics as well as administrative, clinical and demographic information on inpatient events. The NTR collects all hospital separations (discharges and deaths), hence when measuring incidence the inclusion criteria must state clearly whether they include deaths or discharges alone.

Currently, the NTR contains the Minimum Data Set (MDS) which includes demographic, diagnostic and procedural information on all admissions to acute care hospitals in Canada due to injury, and the Comprehensive Data Set which contains data on patients hospitalized with major trauma (Injury Severity Score of 12 or greater). The Death Data Set (DDS), which is currently under development, will contain data on all deaths in Canada due to injury (http://secure.cihi.ca/cihiweb). Data from the DDS will be beneficial to the SCI research community as it will allow the measurement of incidence including deaths at the scene and before admission to hospital.

Incidence of ntSCI is harder to measure in the hospital context as the onset of injury may be much earlier than when the patient is admitted into a hospital for diagnosis. Studies in the past have published measures on incidence based on data from rehabilitation centres (Cosar *et al,* 2010; New & Sundararajan, 2008; Scivoletto *et al*, 2010; Guilcher *et al*, 2010), however there are a number of limitations with this method, as it equates incidence of ntSCI with rehabilitation admission. It assumes that all patients with a confirmed ntSCI are referred to rehabilitation, which is untrue as ntSCI is more likely to occur to elderly persons (New *et al*, 2010) and as a result often not transferred to rehabilitation, hence under-estimating the ntSCI population. It would be ideal to capture the ntSCI cases based on admission or discharge from the location of diagnosis.

Alternatively, information from provincial Medical Services Plans (MSPs) may provide a source of data on the incidence of SCI for both ntSCI and tSCI. These plans insure medically required services provided by physicians and supplementary health care practitioners, laboratory services, and diagnostic procedures. To the extent that these points of contact between patients and the health care system are accurately coded in MSP accounting, it may be possible to tabulate data on the incidence of both tSCI and ntSCI. Case reviews would be necessary in order to confirm etiology and level of impairment.

3. Measurement of Prevalence

Once discharged from hospital, people living with spinal cord injury have very diffuse interactions with the health care and medical systems, something that makes routine reporting of the prevalence of SCI much more difficult. Following from the previous section, one approach would be to acknowledge the comprehensive and universal nature of the MSPs, and rely on their coding to identify the prevalence of SCI. The difficulty in this regard would be to discern from a specific treatment or prescription sufficient information to identify SCI. For example, while MSPs cover wheelchairs, it does not identify that SCI is present nor does it capture those people living with SCI who do not use wheelchairs covered by the MSPs.

The wide range of interactions of people living with SCI with the health care system, and the absence of routine reporting suggests that the best direct way to collect data for the measurement of prevalence would be through the use of a survey procedure. One survey approach would be to remain within the medical context, and survey hospitals, clinics and physicians, on either a universal or random sample basis, asking them to provide data on their interactions with persons living with spinal cord injury (if this approach was followed, care would have to be exercised to avoid double counting). Alternatively, the survey could be directed to people living with SCI and distributed by way of either hospitals, clinics and physicians, or by the provincial MSPs.

Another approach is to directly survey the entire population much as the Cahill *et al,* 2008 recently did for the United States population. This is the approach that Statistics Canada has historically used in its Participation and Activity Limitation Survey (PALS) which has been distributed to households in conjunction with the Census: there will be no PALS accompanying the 2011 Census, and it will not be possible to add questions to the voluntary survey of households that will replace the compulsory long form Census questionnaire.

A specific SCI prevalence direct population survey may be conducted (either as a standalone or as part of an omnibus survey), however such an approach may not be cost effective as one would have to contact roughly 400 households to identify one person living with SCI. To facilitate collection of any significant data, the sample size must be large and representative of the overall population: the required sample would need to be even larger if any cross-tabulation of characteristics is to be pursued. The cost involved in this type of survey would need to be carefully considered, given that the larger the sample population, the larger the cost of such a survey would be. The alternative of sampling voluntary participants can introduce strong biases, as those who respond may have different characteristics, whether demographic or other, from those who do not. Another notable limitation of total population surveys is inaccuracy due to self-reporting of medical condition with no supporting clinical or medical information. Finally, such surveys do not reach persons living in institutions and collective dwellings.

If a direct population survey was to be conducted, it would perhaps be most cost effective to recognize the universal nature of Canada's health care system by finding a way to conduct a survey to identify people living with spinal cord injury using the MSPs. To the extent that results of such a survey could be tied to medical records, this could be a particularly attractive way to proceed. Similarly, the public goodwill held by the RHI could be used to attract respondents to a population survey: for example, an on-line survey document could be posted, supported by public service announcements that directed people to the survey site. A RHI-centered survey vehicle could also support development of the Rick Hansen Spinal Cord Injury Registry, either by streaming tSCI respondents to the Registry or by broadening its scope to include ntSCI.

Appendix I: Summaries of Reviewed Articles Concerning SCI

All incidence rates in this Appendix are number of new cases per million population per year and prevalence rates are the number of people living with SCI per million population at a point in time; incidence is the number of new cases per year and prevalence is the number of people living with SCI during the year.

1. Couris *et al.* Characteristics of adults with incident traumatic spinal cord injury in Ontario, Canada, 2010

Objective: To provide recent estimates of the incidence of tSCI in adults living in Ontario, Canada for the fiscal years 2003/04-2006/07. **Method:** A cohort study. Two primary data sources were census data provided by Statistics Canada and the hospital Discharge Abstract Database (DAD) provided by the Canadian Institute for Health Information. **Results:** Majority of SCI cases was male. Falls emerged as leading cause of tSCI in this study. Fall-induced injury increases with age, while other causes of tSCI decrease with age. Incident cases had a mean age of 51.3 years.

Definition of traumatic SCI:

> **Inclusion**: ICD-10-CA Codes (Cervical spinal cord: S14.0, S14.10, S14.11, S14.12, S14.13, S14.18, S14.19; Thoracic spinal cord: S24.0, S24.10, S24.11, S24.12, S24.13, S24.18, S24.19; Lumbar spinal cord: S34.0, S34.10, S4.11, S34.12, S34.13, S34.18, S34.19; Other spinal cord injury: S34.30, S34.38, T06.0, T06.1) (obtained from Rick Hansen Foundation)
> **Exclusion**: Invalid value for gender, less than 18 years of age at time of admission, previous hospital stay for SCI within past year, SCI not most responsible diagnosis.

Definition of non-traumatic SCI: N/A
Incidence rates: Average age-standardized annual rate over 4-year period: 24 per million; In-hospital deaths were included, but pre-hospital deaths were not, hence incidence falls between initial and discharge.
Male-female ratio: 2.9:1
Prevalence rates: N/A **Life expectancy:** N/A
Gender Specific tSCI Incidence Rates (per million population per year): Mean incident rate: Total 24; Male 36.3; Female 12.1

Cause of tSCI in Men & Women

	% Male	% Female
Falls	47.8	54.1
MVC	23	28.5
Struck by/against an object	12.9	5.4
Other	15.1	8.7

The etiological differences found in this study differ from worldwide trends with respect to the causes of SCI, which generally find MVAs as the leading source of tSCI. This difference can be attributed to the inclusion and exclusion criteria that the study was conducted under, one of them being that any tSCI patients under the age of 18 were excluded: as tSCI caused by MVA are highest in adolescents and young adults, this might explain the different causal pattern discovered. Another feasible explanation was changes in seat belt legislation and motor vehicle licensing regulations decreased the number of tSCIs caused by motor vehicle accidents in the locality of study.

2. Dryden *et al*, 2003. The Epidemiology of Traumatic Spinal Cord Injury in Alberta, Canada, 2003

Objective: To describe incidence and pattern of tSCI in Alberta, Canada from 1 April 1997 to 31 March 2000. **Method:** A population-based study. Data was gathered from: admin data from the Alberta Ministry of Health and Wellness, records from the Alberta Trauma Registry, and death certificates from the Office of the Medical Examiner. **Results:** Incidence rates for males were higher than for females for all age groups. MVC accounted for majority of injuries (highest rates in 15-29 years), falls next (highest rates in people older than 60 years). Rural resident incidence 2.5 times that of urban residents.

Definition of traumatic SCI:

> **Inclusion**: ICD, 9th revision, Clinical Modification diagnostic codes: 806.x (fracture of the vertebral column with SCI) or 952.x (SCI without evidence of spinal bone injury). Injuries of cauda equina were included. Cases were included if they had an external cause of injury code (E code) consistent with tSCI, and were admitted for at least one day to a trauma centre in Alberta.
> **Exclusion**: Diagnosis of a "conversion" disorder (ICD-9-CM code 300.11), patients who sustained a SCI as a result of medical/surgical complications ICD-9-CM codes 998.2 (accidental puncture or laceration during a procedure and E870.x-E879.x (misadventures to patients during surgical and medical care).

Definition of non-traumatic SCI: N/A
Incidence rates: Mean incidence rate 52.5; rates are initial incidence rates.

tSCI Incidence Rates

	Total	Male	Female
Mean Incidence rate	**52.5**	75.4	29.8
Mean Incidence rate only including those who survived to hospitalization	**44.3**	64.9	23.8

Male-female ratio: 2.5:1
Prevalence rates: N/A **Life expectancy:** N/A
Urban and Rural tSCI Incidence Rates:

Urban and Rural tSCI Incidence Rate

	Urban	Rural
Mean Incidence Rate	32.0	72.6

Gender Specific Peak Incidence Rates:

Gender Specific Peak Incidence Rates

	Male		Female	
Peak Age Groups	20-29 yrs	70+ yrs	15-19 yrs	70+ yrs
Incidence Rates	138.0	98.9	65.3	58.7

Etiology of tSCI in Alberta:

Etiology of tSCI in Alberta	
Etiology	**% of Total**
MVC	56.4
Falls	19.1
Sports & Recreation	11.3
Struck by object/person	5.3
Intentional (Assault/self-inflicted)	4.4
Other/Unspecified	3.3

tSCI Incidence:

tSCI Incidence Rate		
Age Group	**Male**	**Female**
0..4	3.8	1.9
5..14	22.0	14.4
15..19	91.0	62.5
20..29	132.1	38.3
30..39	71.8	33.5
40..49	91.0	19.1
50..59	71.8	15.3
60..69	57.4	24.9
70+	94.7	56.2

3. Pickett GE *et al.* Epidemiology of Traumatic Spinal Cord Injury in Canada, 2006

Objective: To determine the incidence, clinical features and treatment of tSCI with a particular interest in defining population at risk for injury in south-western Ontario, Canada between Jan 1998 and Jun 2001. **Method**: A retrospective, descriptive study identified 151 cases defined by ICD-9 diagnostic codes after a search of London Health Sciences Centre medical records database. **Results**: tSCI due to falls are increasing (Table 1.1), but leading cause of tSCIs are motor vehicle accidents (Table 1.2). Mean age of patients with tSCI is increasing (Table 1.3), as well as number of elderly with tSCI (Table 1.4), so focus of prevention programs should also expand to home safety and avoidance of falls.

Definition of traumatic SCI:

Inclusion: ICD-9, Clinical Modification diagnostic codes 952.x (SCI without evidence of spinal bone injury) and 806.x (fracture of vertebral column with SCI)

Exclusion: spine fracture without SCI, SCI unrelated to trauma (tumour, vascular lesion, iatrogenic injury), neurologic deficit cause by peripheral nerve lesion.

Definition of non-traumatic SCI: N/A
Incidence rates: 3.370 for ages 0-14 years; 41.79 for ages 15-64 years; 50.87 for ages 65 and older
Male-female ratio: 3:1; includes all hospital admissions as rates fall between initial and discharge.
Prevalence rates: N/A **Life expectancy**: N/A
Mortality in SCI Patients: Percent of patients – total 8%; 0-59 years of age 5%; 60 + years of age 18%
Percentage of tSCI due to MVA and Falls in Various Years:

Percentage of tSCI due to MVA & Falls		
Study	**% of tSCI - MVA**	**% of tSCI - Falls**
Sekhon & Fehlings, 2001	40-50	20
Pickett et al, 2003	43.2	42.8
Pickett et al, 2006	35	31

Causes of tSCI According to Gender: (Note that only 39 females were included in the study compared to 112 males.)

Causes of tSCI by Gender			
Leading causes of tSCI	% of Total tSCI	% of Males	% of Females
Motor Vehicle Accidents	35	28.6	53.8
Falls	31	30.4	33.2
Other Vehicles	12	15.2	2.6
Sports/Recreation	9	11.6	2.6
Work-related Accident	7	8	2.6
Violence	5	5.4	2.6
Suicide	1	0.8	2.6

Mean Patient Age in Various Years:

Mean Patient Age in Various Years	
Source	Mean Patient Age
US National SCI Database, 1973-79	28.6
Major Trauma Outcome Study for US & Canada, 1982-89	33.5
Sekhon et al, 2001	35.3
Pickett et al, 2006	42

Percentage of tSCI in Patients 60 Years or Older in Various Years: (Note that the 2003 study attributed its results to an increase in elderly incidence that was a recent phenomenon not captured in earlier reports.)

Percentage of tSCI in Patients Aged 60+		
Source	Observation Period	% of tSCI in Elderly (60+)
Sekhon & Fehlings, 2001	1970s	4.7%
Sekhon & Fehlings, 2001	2001	10.0%
US National SCI Database	2000-2006	10.9%
Pickett et al, 2003	2003	30.0%

Annual Incidence of Acute Hospitalization for tSCI in Ontario:

Annual Incidence of Acute Hospitalization for tSCI in Ontario		
Source	Observation Period	Estimates of Incidence
Botterell et al, 1975; Tator et al, 1993	1947-1981	13 - 16
CIHI, 1996-1999	1996-1999	44 - 50
Pickett et al, 2006	1997	21
Pickett et al, 2006	2000	49

4. Guilcher *et al*. Health care utilization in non-traumatic and traumatic spinal cord injury: a population-based study, 2010

Objective: To compare the prevalence and impairment characteristics of ntSCI and tSCI patients admitted to inpatient rehabilitation; to determine and compare the outpatient health care utilization patterns of patients with ntSCI and tSCI during the first year after their index inpatient rehabilitation admission; and to determine factors that are associated with outpatient health care utilizations in both ntSCI and tSCI populations. **Method:** Used a retrospective cohort design with administrative data from the Institute for Clinical Evaluative Sciences for the province of Ontario for the fiscal years April 2003 to June 2005 for patients 18 years of age and older. **Results:** Initial admissions for inpatient rehabilitation were 1,623 ntSCI and 842 tSCI: the exclusion criteria (in-hospital mortality, index discharge after March 31 2006, and died within one year after discharge) reduced the numbers to 1,002 ntSCI cases and 560 tSCI cases, a 38 percent and 33 percent reduction respectively. In the context of the adult population in rehabilitation clinics the prevalence of ntSCI was 1.8 times that of tSCI. Individuals admitted to inpatient rehabilitation for ntSCI were older, more likely to be paraplegic, and have more co-morbidities than individuals with tSCI.

Definition of traumatic SCI: From National Rehabilitation Reporting Systems Rehabilitation Client Group Codes 04.2.

Definition of non-traumatic SCI: From National Rehabilitation Reporting Systems Rehabilitation Client Group Codes 04.1.

Incidence rates: N/A
Male-female ratio: ntSCI 52.2% to 47.8%; tSCI: 75.4% to 24.6%
Prevalence rates: N/A **Life Expectancy:** N/A
Demographic Characteristics of tSCI and ntSCI:

ntSCI & ntSCI by Characteristics

	ntSCI	tSCI
Demographic		
Male	523 (52.2%)	422 (75.4%)
Female	479 (47.8%)	138 (24.6%)
Total	1,002	560
Median age	64	46
Level of injury		
Paraplegia	396 (39.5%)	216 (38.6%)
Tetraplegia	186 (18.6%)	264 (47.1%)
Other	420 (41.9%)	80 (14.3%)
Location		
Urban	483 (86.3)	882 (88.0%)

5. New & Sundararajan. Incidence of non-traumatic spinal cord injury in Victoria, Australia, 2008

Objective: To determine the incidence of ntSCI in Victoria, Australia between 1 July 2000 and 30 June 2006. **Method:** Population-based study and literature review. Data extraction from a state-wide, population-based, health-administration database of hospital admissions. Medline and Embase databases were searched with Ovid search engine. **Results:** Incidence of ntSCI was significantly greater than the reported incidence for tSCI. Men had a higher incidence of ntSCI compared to women.

Definition of traumatic SCI: N/A
Definition of non-traumatic SCI:

Inclusion: A new onset of ntSCI or who developed ntSCI after hospitalization. ICD-10-AM codes: acute paraplegia (G8201, G8203, G8205, G8211, G8213, G8215, G8221, G8223, G8225); acute tetraplegia (G8231, G8233, G8235, G8241, G8243, G8245, G8251, G8253, G8255) or cauda equina syndrome (G834). Patients with cauda equina syndrome and C prefix (occurred during course of hospitalization) were included. If the P prefix (conditions were present on admission to hospital and underwent evaluation and treatment) was used, only those patients with the cauda equina SCI listed as the first of the presenting diagnoses were included.

Exclusion: For identified cases, if a previous admission that included an SCI was found, the following cases were excluded: ICD-10-AM exclude codes 2000-2006: T91; 1998-2000: G82, G83, S140, S141, S240, S241, S340, S341, S343; ICD-9-AM exclude codes 1996-1998: 336, 340, 341, 344, 440, 441, 806, 952, 953, 013.4, 013.5, 192.2, 192.3 198.3, 198.4, 225.3, 225.4, 324.1, 721.1, 721.4, 722.7, 907.2, 907.3, 721.91). Patients with congenital conditions causing ntSCI, or patients with motor neurone disease or multiple sclerosis were excluded. Non-Victorian residents and immigrants and residents moving from other states of Australia or overseas after ntSCI were excluded.

Prevalence rates: N/A **Life expectancy:** N/A
Incidence rates: In Victoria 11.9; in all of Australia 11.9; Average age-adjusted incidence rate of ntSCI in Victoria: adults was 26.3; male 30.5; female 22.9; under age 15 0.7; as study included hospital admissions, rates fall between initial and discharge.

ntSCI Incidence Rates

Age group	Male	Female	Total	Indexed to 15-24 Total
15-24	8.2	4	6.1	**1.0**
25-34	9.7	8.1	8.9	**1.5**
35-44	19.5	13.3	16.4	**2.7**
45-54	28.6	16.4	22.4	**3.7**
55-64	44.5	31.7	38.1	**6.2**
65-74	74.1	53.4	63.4	**10.4**
75-84	101.9	77.9	88	**14.4**
85+	127.4	71.5	89.1	**14.6**

ntSCI Studies

Author, year published	Country	Observation Period	Incidence of ntSCI
Kurtzke, 1975	USA	1969-1972	80
Minaire, 1978	France	1970-1975	6.6
Murray, 1984	USA	Not specified, 3 yrs	51.9
Biering-Sorensen, 1990	Denmark	1975-1984	8.3
Garcia-Reneses, 1991	Spain	1984-1985	5.1
Schonherr, 1996	Netherlands	1982-1993	8.3
Maharaj, 1996	Fiji	1985-1994	8.7
Caldana, 1998	Italy	1994-1995	42.7
New, 2006	Australia	2005	26
New, Unpublished	Australia (Victoria)	1995-1997	17
New, Unpublished	Australia	2005	19

6. New *et al.* A population-based study comparing traumatic spinal cord injury and non-traumatic spinal cord injury using national rehabilitation database, 2010

Objective: To compare the demographic characteristics and outcomes between ntSCI and tSCI patients in Australia between 1 January 2002 and 31 December 2006. **Method:** An open cohort population-based study using a national database of in-patient rehabilitation admissions. **Results:** Total of 3610 patients indentified. There were more patients admitted with ntSCI than with tSCI. Compared to tSCI patients, ntSCI patients tended to be older, more likely to be female, have a shorter rehabilitation LOS, and be less disabled on admission.

Definition of traumatic SCI:

> **Inclusion**: Australasian Rehabilitation Outcome Centre (AROC) impairment classification codes for tSCI and ntSCI. **Exclusion**: If admitted for less than 7 days, only for assessment or were a re-admission.

Definition of non-traumatic SCI:

> **Inclusion**: AROC impairment classification codes for tSCI and ntSCI. **Exclusion**: as above

Incidence rates: N/A
Male-female ratio: N/A
Prevalence rates: N/A **Life expectancy:** N/A
Demographic Characteristics of tSCI and ntSCI:

tSCI & ntSCI by Gender

	ntSCI	tSCI
Male	1,179 (52.5%)	976 (71.6%)
Female	1,067 (47.5%)	388 (28.4%)
Total	2,246 (62.1%)	1,364 (37.7%)
Median age	67	46

7. Wyndaele and Wyndaele. Incidence, prevalence and epidemiology of spinal cord injury: what learns a worldwide literature survey?, 2006

Objective: The objective was to present an overview of data on incidence, prevalence, and epidemiology of SCI and a study of their evolution since 1977. **Method**: Literature survey from 1995 onwards, searched on Pubmed, an online digital archive of biomedical and life sciences journals. Three older studies were included for evolutionary data. **Results**: Incidence and prevalence had not changed considerably over the past 30 years. A higher percentage of patients with SCI are tetraplegic and a higher percentage of SCI patients have a complete lesion.

Definition of traumatic SCI:

> **Inclusion**: No specifics on classification, however, in order to make comparison with prevalence estimates, only incidence studies based on a post-injury acute care and on a rehabilitation population were included.
> **Exclusion**: SCI cases that died before hospitalization

Definition of non-traumatic SCI: N/A

Incidence rates: 21 to 254 per million
Male-female ratio: 3.8:1
Prevalence rates: Range 223-755 per million inhabitants (data insufficient, not representative globally)

Life expectancy: Median survival time of patients with tSCI between ages 24 and 35: 38 years post-injury; 43 percent surviving at least 40 years
Estimated years of life left post-injury at 40 years of age: Paraplegia 28.3; low tetraplegia 24.4; high tetraplegia (as reported by NSCISC) 21.5.

Incidence Rates of SCI in Studies in Various Countries Since 1995:

Incidence rates of SCI in Studies in Various Countries, 1995-present

Study	Observation Period	Country	Incidence (per million p/a)
Karamehmetoglu et al, 1995	1992	Istanbul, Turkey	21
Warren et al, 1995	1991-1993	Alaska, USA	83
Shingu et al, 1995	1990-1992	Japan	40.2
Silberstein et al, 1995	1989-1993	Novosibirsk, Russia	29.7
Maharaj, 1996	1985-1994	Fiji Islands	18.7
Chen et al, 1997	1992-1996	Taiwan	18.8
Otom et al, 1997	1988-1993	Jordan	18
Karamehmetoglu et al, 1997	1994	Rural areas, Turkey	16.9
Martins et al, 1998	1989-1992	Coimbra, Portugal	254
van Asbeck et al, 2000	1994	The Netherlands	10.4
Karacan et al, 2000	1992	Turkey	12.7
Surkin et al, 2000	1992-1994	Mississippi, USA	59
Burke et al, 2001		Kentucky, Indiana, USA	27.1
O'Connor, 2002	1998-1999	Australia	14.5
Pickett et al, 2003	1994-1999	Ontario, Canada	37.2-46.2
Dryden et al, 2003	1997-2000	Alberta, Canada	44.3
Albert et al, 2005	2000	France	19.4

Evolution of Incidence and Prevalence of SCI in North America:

Evolution of Incidence & Prevalence of SCI in North America

Review	Incidence	Prevalence
Tricot, 1981	43.3	-
Blumer & Quine, 1995	46	681
Wyndaele & Wyndaele, 2006	51	755

8. Cahill *et al.* Christopher & Dana Reeve Foundation Paralysis Study, 2009

Objective: To find the prevalence of paralysis, including spinal cord injury and other causes of paralysis, in the United States. **Method**: Random-digit dial population survey of over 33,000 households with telephones in U.S. **Results**: Approximately 1.84% of the U.S. population reported some form of paralysis, 0.4% of the U.S. population reported being paralyzed due to a SCI.

Definition of Paralysis: Paralysis is a central nervous system disorder resulting in difficulty or inability to move the upper or lower extremities. For someone to be counted as “paralysed” in this national survey, they had to answer yes to the initial screening question “Do you or does anyone in this household have any difficulty moving their arms or legs?” and give one of the following causes of the difficulty:

Spinal Cord Injury, Traumatic Brain Injury, Stroke, Poisoning, Complications from surgery, ALS/Lou Gehrig’s, Guillain Barre Syndrome, Multiple Sclerosis, Neurofibromatosis, Epidural infection, Chiari malformation, Syringomyelia, Post-Polio Syndrome, Spinal Muscular Atrophy, Fredrich’s Ataxia, Transverse Myelitis, Cerebral palsy, or Spina Bifida.

Incidence rates: N/A **Life expectancy:** N/A
Male-female ratio: N/A
Prevalence rates: 1.84% of U.S. with paralysis**,** 0.4% of U.S. with paralysis as a result of SCI
Gender distribution of Respondents reporting paralysis due to SCI: 61 percent male; 39 percent female

Reported causes of SCI by respondents reporting paralysis due to SCI:

Reported Causes of SCI by those Reporting Paralysis due to SCI

Causes of SCI	% of Respondents
MVA	24
Accident Working	28
Fall	9
Sporting/Recreation Accident	16
Victim of Violence	4
Birth Defect	3
Natural Disaster	1
Other	6
Unknown/No response	9

This distribution clearly indicates a strong bias towards traumatic spinal cord injury, with 82 percent of causes being clearly traumatic and only 3 percent being clearly non-traumatic (birth defects). The structuring of the question, where spinal cord injury was presented as an alternative to other sources of injury (such as transverse myelitis, multiple sclerosis, chiari malformation, cerebral palsy, ALS/Lou Gehrig's, neurofibromatosis, syringomyelia, Fredrich's Ataxia, or spina bifida) which can be a cause of spinal cord injury, is the likely cause of this skewed response.

Age Distribution of respondents reporting paralysis due to SCI:

Age Distribution of those Reporting Paralysis due to SCI

Age (years)	% of Respondents
0-19	1
20-29	12
30-39	11.5
40-49	30.1
50-59	24.9
60-69	11.1
70-79	5.7
80+	3.7

Appendix II: Comparison of ICD Codes Used In SCI Research

A table of the ICD-Codes used in published studies reviewed in Appendix II, and other selected sources, is presented in Table A.II-1. As a general commentary on this tabulation, it was noted that every study had different inclusion and exclusion criteria using ICD-9 or ICD-10 codes. The ICD-10 codes are more specific in describing the level and severity of injury, therefore providing more information than the ICD-9 codes.

There is general agreement on the codes used in the inclusion criteria for tSCI, although differences across the studies remain. ICD-9 codes most commonly used were 806.x and 952.x for all studies that used ICD-9 codes. The common ICD-10 codes were: injury to the cervical spinal cord: S14.0, S14.1; thoracic: S24.0, S24.1; lumbar: S34.0, S34.1; other: T06.0, T06.1). Laceration of cauda equina (S34.30) was included in three of the four studies that addressed ICD-10 codes.

In this review, only one study (New & Sundararajan) presented ICD codes for non-traumatic SCI, hence no conclusions could be drawn. The lack of agreement in the ICD codes for tSCI, and the absence of studies of ntSCI, calls strongly for discussion in the SCI research community to address the limitation these have on preparation of comparable research and to develop a code standard.

Table A.II-1: Inclusion and Exclusion Criteria for tSCI and ntSCI from Multiple Sources

Study	traumatic SCI	non-traumatic SCI
Cahill *et al*, 2009	N/A	N/A
Couris *et al*, 2010	Inclusion: ICD-10-CA Codes (Cervical spinal cord: S14.0, S14.10, S14.11, S14.12, S14.13, S14.18, S14.19; Thoracic spinal cord: S24.0, S24.10, S24.11, S24.12, S24.13, S24.18, S24.19; Lumbar spinal cord: S34.0, S34.10, S4.11, S34.12, S34.13, S34.18, S34.19; Other spinal cord injury: S34.30, S34.38, T06.0, T06.1) (obtained from Rick Hansen Foundation) Exclusion: Invalid value for gender, less than 18 years of age at time of admission, previous hospital stay for SCI within past year, SCI not most responsible diagnosis	N/A
Dryden *et al*, 2003	Inclusion: ICD, 9th revision, Clinical Modification diagnostic codes: 806.x (fracture of the vertebral column with SCI) or 952.x (SCI without evidence of spinal bone injury). Injuries of cauda equina were included. Cases were included if they had an external cause of injury code (E code) consistent with tSCI, and were admitted for at least one day to a trauma centre in Alberta. Exclusion: Diagnosis of a “conversion” disorder (ICD-9-CM code 300.11)	N/A

Jaglal *et al,* 2009	Inclusion: ICD-10 diagnostic codes: injury to cervical spinal cord (S14.0, S14.10, S14.11, S14.12, S14.13, S14.18, S14.19), injury to the thoracic spinal cord (S24.0, S24.10, S24.11, S24.12, S24.13, S24.18, S24.19), injury to lumbar spinal cord (S34.0, S34.10, S34.11, S34.12, S34.13, S34.18, S34.19), other SCI S34.30 (laceration of cauda equina), T06.0 (injuries of brain and cranial nerves with injuries of nerves and spinal cord at neck level) and T06.1 (injuries of nerves and spinal cord involving other multiple body regions).	N/A
New *et al,* 2010	Inclusion: Australasian Rehabilitation Outcome Centre (AROC) uses separate impairment classification codes for tSCI and ntSCI. Exclusion: If admitted for less than 7 days, only for assessment or were a readmission.	Inclusion: Australasian Rehabilitation Outcome Centre (AROC) uses separate impairment classification codes for tSCI and ntSCI. Exclusion: If admitted for less than 7 days, only for assessment or were a readmission.

New & Sundararajan, 2008	N/A	Inclusion: A new onset of ntSCI or who developed ntSCI after hospitalization. ICD-10-AM codes: acute paraplegia (G8201, G8203, G8205, G8211, G8213, G8215, G8221, G8223, G8225); acute tetraplegia (G8231, G8233, G8235, G8241, G8243, G8245, G8251, G8253, G8255) or cauda equina syndrome (G834). Patients with cauda equina syndrome and C prefix (occurred during course of hospitalization) were included. If the P prefix (conditions were present on admission to hospital and underwent evaluation and treatment) was used, only those patients with the cauda equina SCI listed as the first of the presenting diagnoses were included. Exclusion: For identified cases, if a previous admission that included an SCI was found, the following cases were excluded: ICD-10-AM exclude codes 2000-2006: T91; 1998-2000: G82, G83, S140, S141, S240, S241, S340, S341, S343; ICD-9-AM exclude codes 1996-1998: 336, 340, 341, 344, 440, 441, 806, 952, 953, 013.4, 013.5, 192.2, 192.3 198.3, 198.4, 225.3, 225.4, 324.1, 721.1, 721.4, 722.7, 907.2, 907.3, 721.91). Patients with congenital conditions causing ntSCI, or patients with motor neurone disease or multiple sclerosis were excluded. Non-Victorian residents and immigrants and residents moving from other states of Australia or overseas after ntSCI were excluded.
Pickett *et al*, 2006	Inclusion: ICD-9, Clinical Modification diagnostic codes 952.x (SCI without evidence of spinal bone injury) and 806.x (fracture of vertebral column with SCI). Exclusion: spine fracture without SCI, SCI unrelated to trauma (tumour, vascular lesion, iatrogenic injury), neurologic deficit cause by peripheral nerve lesion.	N/A

Wyndaele & Wyndaele, 2006	Inclusion: No specifics on classification, however, in order to make comparison with prevalence estimates, only incidence studies based on a post-injury acute care and on a rehabilitation population were included. Exclusion: SCI cases that died before hospitalization	N/A
Codes used for ACT (Access to Care/ Timing) request to National Trauma Registry	Inclusion: ICD-9: cervical spinal cord injury (806.0, 806.1, 952.0); thoracic spinal cord injury (806.2, 806.3, 952.1); lumbar spinal cord injury (806.4, 806.5, 952.2, 952.3); cauda equina spinal cord injury (952.4) ICD-10: cervical spinal cord injury (S14.0, S14.1); thoracic spinal cord injury (S24.0, S24.1); lumbar spinal cord injury (S34.0, S34.1); cauda equina spinal cord injury (S34.30, S34.38) Other/unspecified: T06.0, T06.1	N/A
Public Health Agency of Canada codes provided to Statistics Canada	Inclusion: ICD-9: 805-809, 952 ICD-10: S12-S12.7, S12.9, S14.0, S14.1, S22.0, S22.1, S24, S24.1, S32.0-32.2, S34, S34.1, T06.0, T06.1, T08, T09.3	N/A

Appendix III: Preliminary Estimates of Prevalence of Spinal Cord Injury in Canada Using Published Incidence Rates

A. Preliminary Estimates of Prevalence of tSCI in Canada

A simple preliminary estimate of prevalence of a condition in one population can be calculated by using the incidence rate and the duration of the condition for another population. In this section this approach is employed to estimate the prevalence of tSCI using published incidence rates for tSCI and life expectancies for people living with SCI. These examples are presented starting with the simplest application, considering published crude rates, followed by more complex examples using age and gender specific rates. The purpose of including these calculations in this report is to demonstrate what the extent of SCI in Canada would be if the rates that prevail elsewhere prevailed here: what they also demonstrate is that, in aggregate, use of the published rates provides such a wide range of possibilities as to be of little value in the Canadian context. The same analysis is repeated for ntSCI in Section B of this Appendix.

1. Wyndaele & Wyndaele, 2006

Wyndaele and Wyndaele published a summary of crude incidence rates (rates per million population) from a number of studies done in different countries from 1985 on that have been published since 1995: these are listed in order of increasing incidence rates on Table III-3. These incidence rates were multiplied by Statistics Canada's current estimate of the population of Canada of 33,739,000 to estimate what the annual number of new cases of tSCI would be if the published rates applied in Canada: the result was a range from a low of 351 cases per year to a high of 2,800. The study also presented an estimate of years of life left after injury of 38 years which was in turn applied to the calculated incidence to estimate the corresponding level of prevalence, which resulted in a range from 13,334 to 106,416 persons living with spinal cord injury in Canada today.

Prevalence of tSCI Using Incidence Rates from Selected Studies

Country	Incidence (per million p/a)	Implied Annual New Cases	Implied Canadian Prevalence
The Netherlands	10.4	351	13,334
Turkey	12.7	428	16,283
Australia	14.5	489	18,591
Rural areas, Turkey	16.9	570	21,668
Jordan	18	607	23,078
Fiji Islands	18.7	631	23,976
Taiwan	18.8	634	24,104
France	19.4	655	24,873
Istanbul, Turkey	21	709	26,924
Coimbra, Portugal	25.4	857	32,566
Kentucky, Indiana, USA	27.1	914	34,745
Novosibirsk, Russia	29.7	1,002	38,079
Ontario, Canada (Range lower limit)	37.2	1,255	47,695
Japan	40.2	1,356	51,541
Alberta, Canada	44.3	1,495	56,798
Ontario, Canada (Range upper limit)	46.2	1,559	59,234
Mississippi, USA	59	1,991	75,645
Alaska, USA	83	2,800	106,416

Wyndaele and Wyndaele also present two post 1985 studies that provide direct estimates of prevalence (in contrast to those derived from incidence rates). The two prevalence estimates were for North America for the years 1995 (681 cases of tSCI per million inhabitants) and 2006 (755 per million). Applying these prevalence estimates to Canada's estimated population in 2010 results in estimated prevalence of 22,976 and 25,473 persons, respectively.

Estimated Prevalence of tSCI, 2010

Review	Prevalence Rate (per million p/a)	Implied Canadian Prevalence	Incidence	Implied Canadian Prevalence
Blumer & Quine, 1995	681	22,976	46	62,080
Wyndaele & Wyndaele, 2006	755	25,473	51	68,828

Accompanying these prevalence estimates were corresponding incidence rates from the same studies, which when multiplied by Canada's population and scaled by remaining years of life provided incidence based estimates of prevalence of 62,080 and 68,828 new cases per year that were significantly higher than those based on the corresponding directly measured prevalence rates (22,976 and 25,473, respectively).

The variability of incidence and prevalence shown in these studies highlights both the limitations of the data and the methodology. On the data side, the study does not specify the inclusion and exclusion criteria used to calculate each incidence rate, omitting, in some cases, to even note whether the rate was for tSCI, ntSCI, or both; furthermore, there is no indication whether these are initial or discharge incidence rates. On the methodology side, the underlying demography, economy, and social structure of these countries are all different from that of Canada, clearly limiting the applicability of crude rates from one region in studies of incidence and prevalence in another.

2. Couris *et al*, 2010

Couris *et al* published gender specific tSCI incidence rates for 2003-2006 for Ontario for the population aged 18 years of age and older (age specific rates were charted but no numerical values were given), and these rates were then applied to Statistics Canada's estimated male and female 2010 Canadian population aged 18 plus. When scaled by an average of 40 years of life remaining after injury (longer than the 38 years of Wyndaele & Wyndaele to reflect Canada's longer life expectancies), the result is an estimated prevalence of 24,816 cases of tSCI.

This estimate is not without its own limitations, as it excludes incidence under the age of 18, is limited to tSCI, and is not specified as to whether it is initial or discharge incidence.

Selected Statistics, tSCI

	Male	Female
Population aged 18+	12,698,100	13,178,000
Incidence rate	36.3	12.1
Annual new cases of tSCI	461	159
Hypothetical average years of life left for person with tSCI	40	40
Gender-specific prevalence	18,438	6,378
Implied Canadian Prevalence	24,816	

3. Pickett *et al,* 2006

Pickett *et al* published tSCI rates for southern Ontario at a finer level of demography, giving rates for three age groups; 0-14 years (an incidence rate of 3.37 per million in the age group), 15-65 years (41.79), and 65 years and older (50.87). The 2010 population of Canada in these three age groups was multiplied by the corresponding incidence rates to produce the estimated number of annual new cases of tSCI in each age group, resulting in a total incidence of 1,237 new cases.

The midpoint of the 0 to 14 age group is 7.5 years of age, and of the 15 to 64 age group is 40 years of age. With an average life expectancy of 80 years, the result is an average of 72.5 and 40 years of life remaining, respectively. For the 65 and older age group, assuming that most tSCI occurs between ages 65 and 75, a midpoint of 70 years of age was used, resulting in 10 years of life left after injury. For each of these age groups, the product of annual cases and years of life left were summed to produce an estimated 2010 tSCI prevalence of 43,000:

Selected Statistics, tSCI

Age	Incidence rate	Annual new cases	Hypothetical Avg Years of Life Post-injury	Implied Canadian Prevalence
0-14	3.4	19	72.5	1,371
15-64	41.8	980	40	39,183
65+	50.9	238	10	2,385
Total				**42,939**

This estimate of prevalance applies only to tSCI and it is not clear whether the incidence rate is an intial or a discharge rate.

4. Dryden *et al,* 2003

Dryden *et al* published gender specific tSCI incidence rates for 1997-2000 for Alberta for standard age groups. These rates were applied to Statistics Canada's estimated 2010 male and female Canadian populations, aggregated into the appropriate age groups, which resulted in an incidence estimate of 1,762 annual new cases of tSCI. When scaled by an average of life remaining after injury estimated according to age group, the result was a prevalence of 68,916 persons.

Selected Statistics, tSCI

	Incidence rate		Annual New cases		Estimated Average Yrs of Life Post-Injury	Implied Canadian Prevalence		
Age Group	**Male**	**Female**	**Male**	**Female**		**Male**	**Female**	**Total**
0..4	3.8	1.9	4	2	78	282	134	**415**
5..14	22.0	14.4	43	26	70	2,986	1,846	**4,833**
15..19	91.0	62.5	105	69	63	6,608	4,328	**10,936**
20..29	132.1	38.3	314	88	55	17,282	4,826	**22,107**
30..39	71.8	33.5	165	76	45	7,407	3,427	**10,834**
40..49	91.0	19.1	241	50	35	8,451	1,756	**10,207**
50..59	71.8	15.3	171	37	25	4,265	925	**5,191**
60..69	57.4	24.9	92	42	15	1,385	630	**2,015**
70+	94.7	56.2	132	106	10	1,315	1,063	**2,378**
Total			**1,266**	**496**		**49,982**	**18,934**	**68,916**

This estimate is limited to tSCI, including deaths before hospital admission and during hospitalization, hence the incidence rates need to be adjusted so that only hospital discharge cases of tSCI are included in the prevalence calculation.

B. Preliminary Estimates of Prevalence of ntSCI in Canada

1. New & Sundararajan, 2008

New and Sundararajan provided crude incidence rates for both tSCI and ntSCI for Australia for 2000 to 2006. These values permit use of the same methodology used above for values published by Wyndaele and Wyndaele in the estimation of prevalence of SCI for Canada. With respect to tSCI, the incidence rates ranged from 11.9 to 17 per million population, resulting in a prevalence range in Canada from 16,060 to 22,943 persons living with SCI as a result of tSCI:

Selected Statistics, tSCI

	Australia *(lower range)*	Australia *(upper range)*	Victoria, Australia
Population	33,739,800	33,739,800	33,739,800
Incidence rate	15	17	12
Annual new cases of tSCI	506	574	402
Hypothetical average years of life left for person with tSCI	40	40	40
Prevalence	20,244	22,943	16,060

With respect to ntSCI, the incidence rates were provided for two age groups, 0 to 14 and 15 and older and for both males and females. When multiplied by the number of people in the Canadian population in these age and sex groups, total prevalence of 30,261 persons living with ntSCI in Canada was calculated:

Selected Statistics, ntSCI

Population	Male	Female
0-14 years	2,880,900	2,730,700
15+	13,851,400	14,276,800
Incidence rate		
0-14 years	0.7	0.7
15+	30.5	22.9
Annual New		
0-14 years	2	2
15+	422	327
Hypothetical average years of life left for persons with SCI		
0-14 years	72.5	72.5
15+	40	40
Implied Cdn Prevalence	17,045	13,216
Total Prevalence	30,261	

This study does not indicate whether these are initial or discharge incidence rates and is limited to cases of ntSCI.

This publication also tabulates the results of a literature review, similar to that found in the Wyndaele & Wyndaele, 2006, for published rates of incidence for ntSCI. These rates were applied to the Canadian population and scaled by a presumed 40 years of remaining life expectancy to estimate the prevalence of ntSCI in Canada should the published rates apply here, resulting in a range from 6,883 to 107,967.

Selected Statistics, ntSCI			
Country	Incidence of ntSCI	Annual New Cases	Implied Canadian Prevalence
Spain	5.1	172	6,883
France	6.6	223	8,907
Denmark	8.3	280	11,202
Netherlands	8.3	280	11,202
Fiji	8.7	294	11,741
Australia (Victoria)	17	574	22,943
Australia	19	641	25,642
Australia	26	877	35,089
Italy	42.7	1,441	57,628
USA	51.9	1,751	70,044
USA	80	2,699	107,967

As with Wyndaele and Wyndaele, this 2006 publication does not indicate whether the incidence rates are initial or discharge, nor what is included in ntSCI in each of the underlying studies. The range of prevalence estimates that result from these calculations is largely the product of data differences and underlying differences in demography, economy, social structure, and health care in the countries studied.

C. Preliminary Estimates of Prevalence of SCI in Canada - Cahill *et al,* 2009

Cahill *et al* provide an estimate of prevalence of spinal cord injury in the United States of 0.4 percent of the population; given Canada's estimated 2010 population, such a prevalence rate would result in a prevalence estimate of 134,959 persons with spinal cord injury living in Canada. In this study, what is included as spinal cord injury is primarily the result of traumatic injury, with 82 percent of the causes of spinal cord injury specifically identified as traumatic, three percent from birth injury (and hence non-traumatic), and 15 percent from other and unknown causes.

Appendix IV: Age specific estimates of incidence and prevalence of spinal cord injury in Canada, 2010

This appendix presents the detailed results of the calculations of the estimates of incidence and prevalence following the methodology described in Section IV of this report.

Total Population, Canada, 2010

Age	Male	Female	Total
0..4	952,454	905,954	1,858,408
5..9	926,149	873,002	1,799,151
10..14	993,572	944,098	1,937,671
15..19	1,125,036	1,076,326	2,201,362
20..24	1,184,776	1,131,400	2,316,176
25..29	1,204,094	1,170,958	2,375,052
30..34	1,148,825	1,144,085	2,292,910
35..39	1,154,231	1,138,513	2,292,744
40..44	1,222,287	1,198,868	2,421,155
45..49	1,404,910	1,384,959	2,789,869
50..54	1,305,819	1,311,470	2,617,289
55..59	1,129,037	1,160,225	2,289,262
60..64	965,953	1,004,079	1,970,032
65..69	714,031	758,170	1,472,200
70..74	522,597	587,678	1,110,274
75..79	413,813	502,637	916,450
80..84	285,194	406,630	691,823
85..89	150,999	279,886	430,885
90+	169,478	159,125	328,603
Total	16,973,254	17,138,063	34,111,316

Estimated Age- and Gender-specific Incidence Rates of tSCI & ntSCI, Canada, 2010

Age	tSCI Initial		ntSCI Initial		tSCI Discharge		ntSCI Discharge	
	Male	Female	Male	Female	Female	Female	Male	Female
0..4	3.8	1.9	2.1	2.1	3.0	1.5	2.0	2.0
5..9	22	14.4	2.1	2.1	17.1	11.2	2.0	2.0
10..14	22	14.4	2.1	2.1	17.1	11.2	2.0	2.0
15..19	91	62.5	25.0	12.2	70.8	48.6	23.1	11.3
20..24	132.1	38.3	25.0	12.2	102.8	29.8	23.1	11.3
25..29	132.1	38.3	29.6	24.7	102.8	29.8	27.3	22.8
30..34	71.8	33.5	29.6	24.7	55.9	26.1	27.3	22.8
35..39	71.8	33.5	59.4	40.5	55.9	26.1	54.9	37.4
40..44	91	19.2	59.4	40.5	70.8	14.9	54.9	37.4
45..49	91	19.2	87.1	50.0	70.8	14.9	80.5	46.2
50..54	71.8	15.3	87.1	50.0	55.9	11.9	80.5	46.2
55..59	71.8	15.3	135.6	96.6	55.9	11.9	125.3	89.2
60..64	57.4	24.9	135.6	96.6	44.7	19.4	125.3	89.2
65..69	57.4	24.9	225.8	162.7	44.7	19.4	208.6	150.3
70..74	94.7	56.2	225.8	162.7	73.7	43.7	208.6	150.3
75..79	94.7	56.2	310.5	237.3	73.7	43.7	286.9	219.3
80..84	94.7	56.2	310.5	237.3	73.7	43.7	286.9	219.3
85..89	94.7	56.2	388.1	217.8	73.7	43.7	358.6	201.3
90+	94.7	56.2	388.1	217.8	73.7	43.7	358.6	201.3

*based on Dryden *based on New's ratio

Estimated Age-, Gender-, Severity-specific Incidence of tSCI and ntSCI, Canada, 2010*

Age	tSCI Initial		ntSCI Initial		tSCI Discharge		ntSCI Discharge	
	Male	Female	Male	Female	Paraplegia	Tetraplegia	Parapelegia	Tetraplegia
0..4	4	2	2	2	2	2	3	1
5..9	20	13	2	2	11	15	2	1
10..14	22	14	2	2	12	16	3	1
15..19	102	67	28	13	57	75	26	12
20..24	157	43	30	14	67	88	28	12
25..29	159	45	36	29	69	90	41	18
30..34	82	38	34	28	41	53	40	18
35..39	83	38	69	46	41	53	73	33
40..44	111	23	73	49	45	59	77	34
45..49	128	27	122	69	52	68	123	55
50..54	94	20	114	66	38	50	115	51
55..59	81	18	153	112	33	44	170	75
60..64	55	25	131	97	27	35	146	65
65..69	41	19	161	123	20	26	182	81
70..74	49	33	118	96	28	36	137	61
75..79	39	28	128	119	23	30	158	71
80..84	27	23	89	97	17	22	118	53
85..89	14	16	59	61	10	13	76	34
90+	16	9	66	35	8	11	64	29
Total	**1,284**	**501**	**1,415**	**1,059**	**601**	**787**	**1,582**	**704**

**Data may not sum to totals due to rounding.*

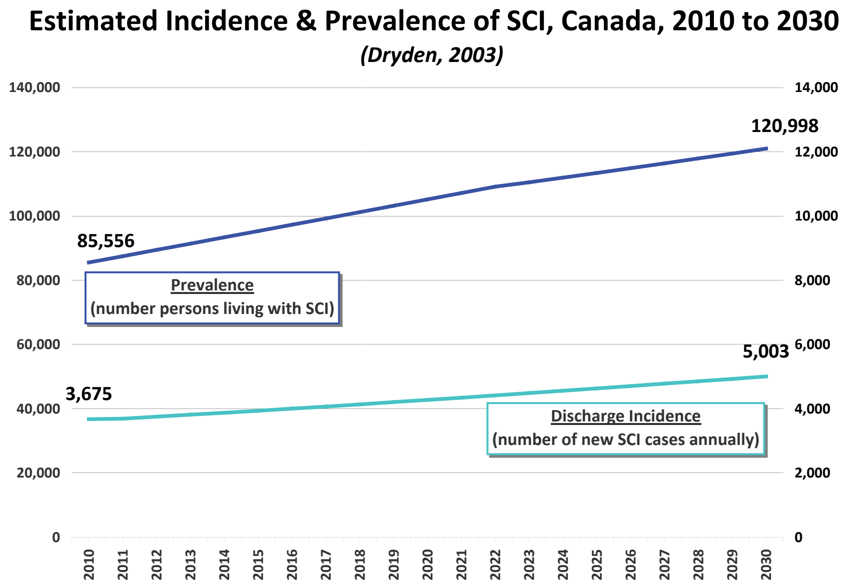
Estimated Age- and Severity-Specific Prevalence of SCI in Canada, 2010

Age	tSCI			ntSCI			Total		
	Para	Tetra	Total	Para	Tetra	Total	Para	Tetra	Total
0..4	5	7	12	7	3	11	13	10	23
5..9	41	54	95	19	8	27	60	62	123
10..14	102	134	236	33	15	48	135	149	284
15..19	310	406	716	121	54	175	431	460	891
20..24	616	806	1,422	253	113	366	869	919	1,788
25..29	778	1,019	1,797	359	160	519	1,138	1,179	2,317
30..34	1,257	1,646	2,903	643	286	929	1,900	1,932	3,832
35..39	1,271	1,663	2,935	858	382	1,240	2,130	2,045	4,175
40..44	1,542	2,016	3,559	1,273	566	1,839	2,815	2,583	5,398
45..49	2,051	2,679	4,731	2,011	894	2,905	4,062	3,573	7,635
50..54	2,148	2,802	4,950	2,463	1,094	3,557	4,611	3,896	8,507
55..59	2,040	2,656	4,696	2,851	1,265	4,116	4,891	3,920	8,812
60..64	1,879	2,437	4,316	3,191	1,412	4,603	5,070	3,849	8,920
65..69	1,482	1,909	3,390	3,128	1,379	4,506	4,609	3,287	7,897
70..74	1,208	1,537	2,745	3,053	1,335	4,388	4,261	2,873	7,134
75..79	933	1,165	2,097	2,842	1,227	4,070	3,775	2,392	6,167
80..84	941	1,127	2,068	3,175	1,329	4,504	4,116	2,456	6,572
85..89	447	500	947	1,842	730	2,572	2,289	1,230	3,519
90+	179	179	357	887	319	1,206	1,066	497	1,563
Total	19,232	24,742	43,974	29,011	12,571	41,582	48,243	37,313	85,556

Appendix V: Projection of incidence and prevalence of spinal cord injury in Canada, 2010 to 2030

Urban Futures maintains a projection series for the Canadian population by single years of age and sex, as well as for their accompanying projected birth and death rates for the period 2010 to 2060. The data on the incidence and characteristics of SCI and the methodology used to estimate the 2010 prevalence of spinal cord injury in Canada was used with this projection series to estimate the future level of incidence and prevalence of spinal cord injury in Canada. These estimates of future levels are subject to the same assumptions that are described for the 2010 estimates. Given the constancy of the spinal cord rates used, the changing extent of spinal cord injury shown in these projections is the result of the changes in the underlying demography of Canada.

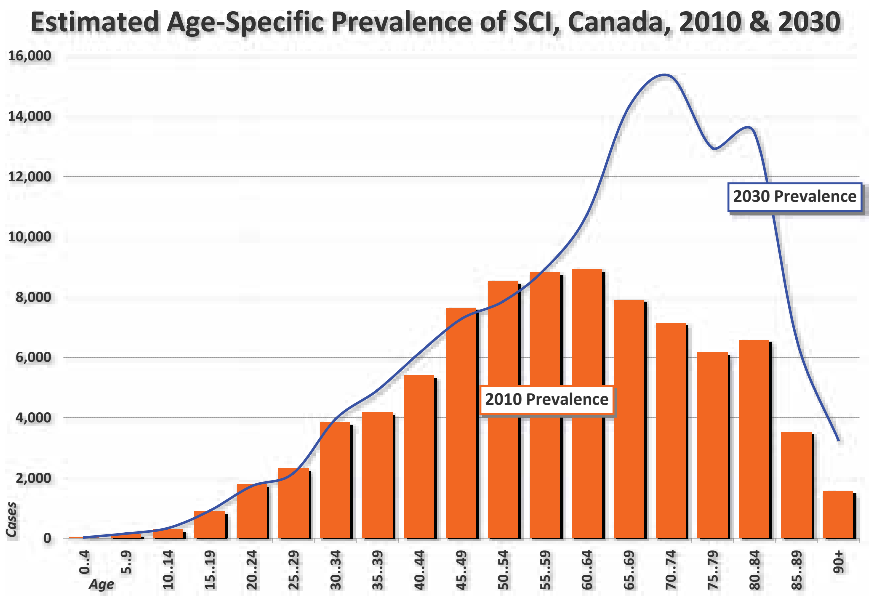
Figure V-1



Both incidence and prevalence of SCI is projected to increase over the next two decades, with initial incidence increasing from the 4,300 cases estimated for 2010 to 5,800 cases in 2030; discharge incidence increasing from the 3,700 cases estimated for 2010 to 5,000 in 2010; and prevalence increasing from the estimated 86,000 persons living with SCI in 2010 to 121,000 persons in 2030. The greatest increase would be in the number of people with SCI as a result of ntSCI (posting an increase of 52 percent), and in the number with tetraplegia (an increase of 43 percent). The number of people living with SCI as a result of traumatic causes would increase to the 58,000 range (a 32 percent increase) while those with SCI as a result of non-traumatic causes would increase to the 63,000 range (a 52 percent increase).

This pattern is largely the result of the aging of the Canadian population that will result over the coming two decades, something that will be reflected in the age profile of the population living with SCI (Figure V-2). Today 49 percent of people living with spinal cord injury are 60 years of age or older; by 2030, given aging of the population as a whole, the secondary peak in tSCI due to falls in the older population, and the general increasing rate of ntSCI with increasing age, over 63 percent of the people living with spinal cord injury will be 60 years of age and older.

Figure V-2


Estimated Age-Specific Prevalence of SCI, Canada, 2010 & 2030
16,000
14,000
12,000
10,000
8,000
6,000
4,000
2,000
0
Cases
2030 Prevalence
2010 Prevalence
0..4
5..9
10..14
15..19
20..24
25..29
30..34
35..39
40..44
45..49
50..54
55..59
60..64
65..69
70..74
75..79
80..84
85..89
90+
Age

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