Spinal Cord Injury:
Progress in Care & Outcomes In the Last 25 Years

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Prepared For

The Rick Hansen Institute

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Executive Summary

To reduce the overall burden of neurotrauma demands actions which extend from the political to basic patient care.[1]

This report was commissioned by the Rick Hansen Institute to review the gains made in spinal cord injury (SCI) care and outcomes over the last 25 years, and in this way help to commemorate the historic *Man in Motion* World Tour that was launched by Mr. Hansen in 1985.

Spinal cord injuries have a devastating impact on the health and well-being of individuals. Many would categorize SCI as one of the greatest survivable catastrophes experienced by a human being. The physical effects include loss of sensation and/or paralysis, which often causes long-term disability; further, there are many complications and co-morbidities associated with SCI that can significantly affect quality of life and even be life-threatening. The associated economic burden of SCIs is substantial, due not only to direct health care costs, but also to high rates of physical morbidity and premature mortality that have an impact on productivity at a societal level.

The substantial challenges related to SCI certainly call for concerted leadership. A serious response among health care providers and other leaders has developed in various phases over the previous century, with associated progress that has benefited individuals with SCI. By the 1970s, for instance, the Model Systems network for treatment of SCI was being established in various parts of the U.S. to translate into the civilian sector the many advances that had been gained in the context of caring for disabled veterans. This period also saw the creation of what is still the largest registry of SCI patient information, a valuable source for tracking trends, notwithstanding the unique features of the U.S health care system that may affect the interpretation of any observed patterns.

Understanding the progress related to SCI over the last 25 years may be accomplished in a comprehensive manner by tracking the story across a simplified model of influences and impacts. As indicated in the following diagram, there are four key domains where progress may be identified:

1. *Environment:* the evolving social context within which individuals with SCI live and operate

2. *Research:* the priorities and output related to investigating questions generated by SCI, from basic research (“bench”) to intervention effectiveness (“bedside”)

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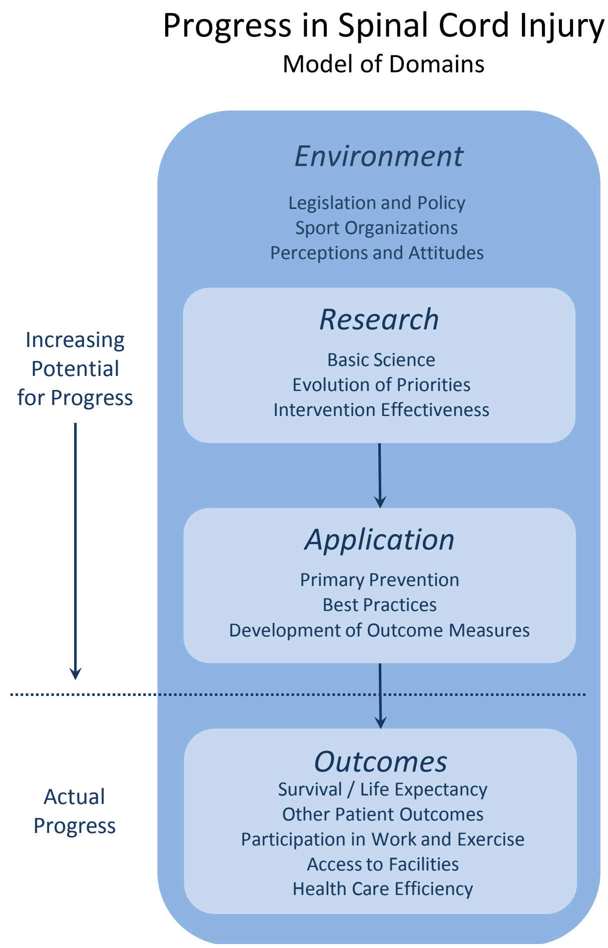
[1] Reilly P. The impact of neurotrauma on society: an international perspective. *Progress in Brain Research.* 2007; 161: 3-9.

3. *Application:* how (and how much) any insights have been translated into clinical practice and public health

4. *Outcomes:* the actual changes experienced by individuals with SCI, from survival to quality of life, as measured at a population level, as well as effects in the health system in terms of efficiency



As indicated, there were a number of themes or sub-domains that emerged under each domain; each was examined by means of a search in the biomedical literature and pertinent grey literature documents. The aim was to provide selected information on each topic that would demonstrate the degree of progress that has been achieved in recent decades.

A high-level summary of the results found for the four overarching domains of progress is provided below, followed by a table that serves as a compressed "snapshot" of advances made in each of the more specific areas.

Environmental Progress

The review herein focused on the larger scale of environmental spheres, that is, society as a whole rather than the context defined by the home, workplace, etc. of a particular individual with SCI. Several of the environmental sub-domains have demonstrated remarkable progress in the last 25 years, especially the dramatic increase in networks, foundations, associations, and institutes dedicated to supporting and expanding SCI-related research and care. The fact that disability legislation has come to fruition in the last two decades is another encouraging development, as is the public profile of individuals from around the world with SCI and other disabilities being involved with sports, including the Paralympic Games. Other environmental sub-domains are at an earlier stage of development, but a platform at least has been built upon which further gains may be made. Thus, the SCI community is being consulted more than ever about its concerns and needs, but this path could be followed further—especially regarding experience of people with such serious disabilities with stereotypes, prejudice, and similar negative attitudes.

Research Production

Quantitatively, there has been a steady increase in scientific publishing related to SCI, partly reflecting the launch of new specialty journals in the last 25 years. Even more encouraging is the large increase in clinical trials being published, as this represents the fountainhead of all translation and implementation work that eventually brings improvements in the medical care and everyday life of individuals with SCI. The sub-domain of basic research into cures remains a mixed affair, evoking both a degree of disappointment and continuing optimism. There is no doubt that great strides in scientific insight have occurred, so that cure/reversal in the near future seems all the more probable. At the same time, current scientific insights about the spinal cord, both damaged and whole, are being translated into therapies that will help preserve function and even see improved function without full organic repair. While the "quest for a cure" has become protracted, one consequence has been a recent expansion of research interest in other areas of care, including pre-hospital, rehabilitation, and preventing/treating secondary complications.

Translation to Application

The work of fostering improvements in SCI care is ongoing. For instance, it is certainly a concern that some 20% of trauma sufferers with SCI still die before being admitted to hospital. Even when basic insights and potential interventions emerge for this and other areas of need, it is just the beginning of the process. The various stages of "translating" the expanding research results into application in the real world starts with sifting the existing body of evidence in systematic ways, developing and testing practice guidelines, and then tracking the ultimate results in terms of patient and other outcomes. Progress has been made on all of these fronts, especially in terms of identifying and developing protocols for applying best practices; the Rick Hansen Foundation has liberally supported this cause by funding systematic reviews of published evidence on clinical and other interventions. One major advance in the realm of practical application has been the development of many more outcome measures specific to SCI; while many of these metrics are still being validated, they do hold out promise for better tracking of SCI outcomes in the future—especially in light of the commitment of the Rick Hansen Institute and other groups to expand and strengthen national and international registries of SCI patients.

Population-Level Outcomes

The intention to develop more robust SCI registries is welcome news, given how important such a tool is to tracking patient outcomes at a population level. Several encouraging results can already be identified, especially through the data set at the National Spinal Cord Injury Statistical Center (NSCISC) in the U.S., the largest and longest-running SCI database, capturing data since 1973. In that context, there has been:

- A 40% reduction in mortality in the first two years post-injury over the last three decades

- A gain in neurologic improvement during inpatient care, combined with lower frequencies of complications

- A long-term improvement in global measures of community integration, although understanding the positive aspect of work participation rates in particular requires a more nuanced assessment

In addition, a number of encouraging trends were identified in the report that extend beyond the individual to society as a whole, including broader compliance with building codes requiring accommodations to permit access to individuals dealing with disabilities such as SCI. The following table offers a brief view of this and other gains over the last quarter century.

A Quarter Century of Progress in Spinal Cord Injury
Care and Outcomes

Domain *Sub-domain*	Then: 25 Years Ago	Now: Circa 2010
Environmental		
Organizational Infrastructure	Limited number of organizations	Major expansion of organizations around the world
Legislative & Policy Frameworks	Major legislation still being developed	Model legislation established in key countries
Sports Organizations & Events	Disabled sports well-established but still limited exposure	Paralympics a major global phenomenon
Public Perceptions & Attitudes	SCI and other disabilities not well understood	Measurable improvement in attitudes in some countries
Preferences in the SCI Community	SCI community consulted about priorities	Individuals with SCI at the centre of decision-making
Research Production		
Publication Volume	Less than 100 scientific articles per year, by title	Almost 450 publications per year related directly to SCI
Investigation of Potential Cures	Focus on the quest for a cure	Focus expanded to other biological aspects of recovery
Evolution of Research Focus	Less focus on rehabilitation and chronic care	Expanded focus on long-term care, including secondary complications
Intervention Effectiveness	Limited analyses of a limted evidence base	Multiple systematic reviews across many interventions
Translation to Application		
Primary Prevention	Limited attention on major causes of SCI	Substantial legislative and educational programs launched
Best Clinical Practices	Few clinical guidelines published	Guidelines published in multiple arenas
Outcome Measures	Small number of measures (mostly not specific to SCI) developed and in use	Majority of SCI-specific measures developed since 1985
Population-level Outcomes		
Survival/Life Expectancy	Enjoying gains in life expectancy across recent decades	Ongoing gains in short-term survival; possible flattening of improvements in long-term survival
Other Patient Outcomes	*One U.S. example:* 8.8% of complete injuries converted to incomplete (1973-81)	15.1% converted to incomplete (2002-6); certain other outcomes also improved
Community Participation	About 40% employment rate among individuals with SCI (1976-91)	Similar employment rate maintained in a much larger pool survivors (1992-2005)
Access to Facilities	Limited legislation and assistive technology	Major breakthroughs in building codes, compliance, and equipment
Health Care Efficiency	*One U.S. example:* mean length of inpatient stay over 130 days (1973-81)	Length of stay about 60 days (2002-6)

The Next 25 Years

Driven by the enormous personal disaster and societal burden that SCI represents, it is clear that even more progress is needed on every front. The last 25 years of positive developments, as summarized in the table above and the preceding commentary, may be attributed to people known and unknown—leaders with high profile such as Rick Hansen and countless other stakeholders, from researchers to health care providers to fund-raisers and volunteers, and most importantly the entire community of individuals dealing with SCI. A similar army will be required to continue to advance the cause over the next 25 years and realize Rick Hansen's original vision from 1985: ***A world without paralysis after spinal cord injury.***

Introduction: Marking a Milestone in SCI Leadership

Today, the opportunity to live fully and completely with the disability is a very reasonable possibility for most, but this has added many dimensions to the problem of SCI for the person, the health care providers, and society at large.[2]

The spinal cord is a long, tube-shaped bundle of nerves that carries impulses between the brain and the rest of the body. It is surrounded by rings of bone called vertebra, which together constitute the spinal column or back bone. **Spinal cord injury (SCI)** is defined as damage to the spinal cord that results in a change, either temporary or permanent, to its normal motor, sensory, or autonomic functions.

Spinal cord injuries have a devastating impact on the health and well-being of individuals. Many would categorize SCI as one of the greatest survivable catastrophes experienced by a human being. The physical effects include loss of sensation and/or paralysis, which often causes long-term disability; further, there are many complications and co-morbidities associated with SCI that can significantly affect quality of life and even be life-threatening. The associated economic burden of SCIs is substantial, due not only to direct health care costs, but also to high rates of physical morbidity and premature mortality that has an impact on productivity at a societal level. And the preceding commentary does not even begin to address the profound psychosocial obstacles that face individuals with SCI.

The substantial challenges related to SCI call for concerted leadership. A serious response among health care providers and other leaders has developed in various phases over the previous century, with associated progress that has benefited individuals with SCI. For example, prior to the early1940s the majority of people experiencing traumatic SCI died within weeks, most often due to infection.[3] The advent of antibiotics and other medicines improved the survival rate dramatically, but those who did survive still "lived fairly restricted lives, and few achieved full reintegration into the normal activities of their family and society."[4] Clearly, further leadership was needed, and several physicians in the United Kingdom and the United States in fact stepped up to advocate (and organize) for a more comprehensive response to the problems and needs related to SCI.

For some whose lives were touched by spinal cord injury, advocacy became a significant focus. In 1974, Kent Waldrep, a star running back for Texas Christian University, received a spinal cord injury in a football game and became a quadriplegic. Post-injury, Waldrep raised the awareness of spinal cord injuries; just five years after he was paralyzed, he formed what became the American Paralysis Foundation. He was appointed to the National Council on Disability by President Reagan and helped to draft the *Americans with Disabilities Act*.

Marc Buoniconti is another football player who experienced a spinal cord injury in a college football game. At the age of 19 years – in 1985 – he was rendered a quadriplegic. His father, Nick, a Hall of Fame former NFL linebacker, leveraged his fame and connections to help Marc establish the Miami Project to Cure Paralysis. The Project is an interdisciplinary research center

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[2]Trieschmann R. *Spinal Cord Injuries: Psychological, Social, and Vocational Rehabilitation*. New York: Demos; 1988.
[3] Ditunno JF, Jr., Formal CS. Chronic spinal cord injury. *New England Journal of Medicine.* 1994; 330(8): 550-6.
[4] Trieschmann R. *Spinal Cord Injuries: Psychological, Social, and Vocational Rehabilitation*. New York: Demos; 1988.

dedicated to research in the field of paralysis and spinal cord injury; it has raised over $350 million to support paralysis research over its first 25 years.

Henry G. Stifel III, Vice Chairman of the Board of Directors of the Christopher and Dana Reeve Foundation, has a personal connection to the SCI community. In 1982, during his junior year of high school, Mr. Stifel was involved in a car accident that shattered his C4 and C5 vertebrae, leaving him paralyzed from the chest down. Later that year, with the goal of changing attitudes in the medical field, Mr. Stifel's family created the Stifel Paralysis Research Foundation. In 1985, the Foundation became the American Paralysis Association, and in 1998, it merged with the Christopher Reeve Foundation (now named the Christopher & Dana Reeve Foundation, CDRF). Mr. Stifel is very active in the Foundation's advocacy efforts. With a goal of increasing awareness and federal dollars for spinal cord injury, he has lobbied members of Congress on behalf of the Christopher Reeve Paralysis Act, which, if passed, will advance collaborative research in paralysis and improve the quality of life today for people living with paralysis and mobility impairments. In addition, Mr. Stifel serves as an ambassador within the spinal cord injured community, helping to keep the CDRF connected with the concerns of those who live with SCI every day.

Another influential figure based in the U.S. is Sam Maddox. He is a journalist with broad experience in news and feature writing who focused his reporting specialty on clinical medicine and neuroscience research related to spinal cord dysfunction. He authored *Spinal Network* in 1988, a critically acclaimed seminal resource for spinal cord dysfunction. Additionally, Mr. Maddox published *Quest for Cure* in 1994, a historical overview of research to restore function after spinal cord injury. He is currently a Member of the Board of Directors of the Foundation for Spinal Cord Injury Prevention, Care & Cure, and is the Knowledge Manager for the CDRF.

It is an unfortunate reality that major aspects of the progress to date have been generated in the context of caring for veterans in the U.S., a situation created by the high number of SCI cases arising from large-scale wars experienced by that country.[5,6] However, by the 1970s the Model Systems network for treatment of SCI was being established in various parts of the U.S. to translate the advances into the civilian sector.[7] A "systems concept" of medical management of high-cost disabilities was established, marking an important shift in focus: "It was demonstrated that the cost of SCI could be reduced…by preventing unnecessary medical complications and providing expert rehabilitation in a timely manner as a result, the length of hospitalization could be reduced to three or four months in uncomplicated cases of paraplegia and quadriplegia."[8]

This advances the story line to the time period of interest in the present report, namely, the last 25 years. Why this period? The mid-1980s was marked both by recognition of new concerns related to SCI care and by a significant international event. First, the shifts in priority and focus throughout the history of SCI research and care continued to the point where two new dimensions dominated the horizon by 1985: the survival of more people with severe disability (including ventilator-dependency) and the survival of many individuals with SCI into older age. Such outcomes were almost "inconceivable" just 25 years earlier. Survival, and then ageing,

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[5] Poer DH. Newer Concepts in the Treatment of the Paralyzed Patients Due to War-Time Injuries of the Spinal Cord : Outline of Plan and Statistical Analysis. *Annals of Surgery.* 1946; 123(4): 510-5.
[6] Lanska DJ. Historical perspective: neurological advances from studies of war injuries and illnesses. *Annals of Neurology.* 2009; 66(4): 444-59.
[7] Hosack K. The model spinal cord injury system. *Case Manager.* 1999; 10(2): 51-3.
[8] Trieschmann R. *Spinal Cord Injuries: Psychological, Social, and Vocational Rehabilitation*. New York: Demos; 1988.

with SCI are thus tremendous markers of health care progress in themselves, plus a clear challenge. The priorities related to emergency and acute care (that is, life saving) and early rehabilitation are certainly maintained at that time, but the urgency about discovering a biological-organic cure becomes intensified; later, the emerging demands of chronic care and dealing with late complications come increasingly to the forefront.

Second, the era of interest in this report began with the *Man in Motion* World Tour. In 1985, at the age of 27, SCI-survivor Rick Hansen was inspired by the dream of creating a world that cares for and is inclusive of all people. Rick wheeled through 34 countries on four continents, travelling the equivalent of more than two marathons a day (40,000 km in total) before returning home to Vancouver, Canada. The accomplishments of the tour were both intangible and tangible: it raised awareness of the potential of people with disabilities, and it also raised $26 million for work related to SCI. Part of the initial fund seeded the beginning of the Rick Hansen Foundation (RHF), which has raised a further $200 million since the original tour ended in 1987. Rick Hansen's international journey marked the start of an era where many new organizations were established (see the pertinent section below) and new fund-raising efforts were launched by high-profile figures such as the late Christopher Reeve to further the cause of SCI research and care. Now, 25 years later, it is important to look back at the accomplishments of the last two-and-a-half decades, partly to celebrate and partly to anticipate and plot further progress to come.

Brief Overview of Spinal Cord Injury

Classification of Injury and its Effects

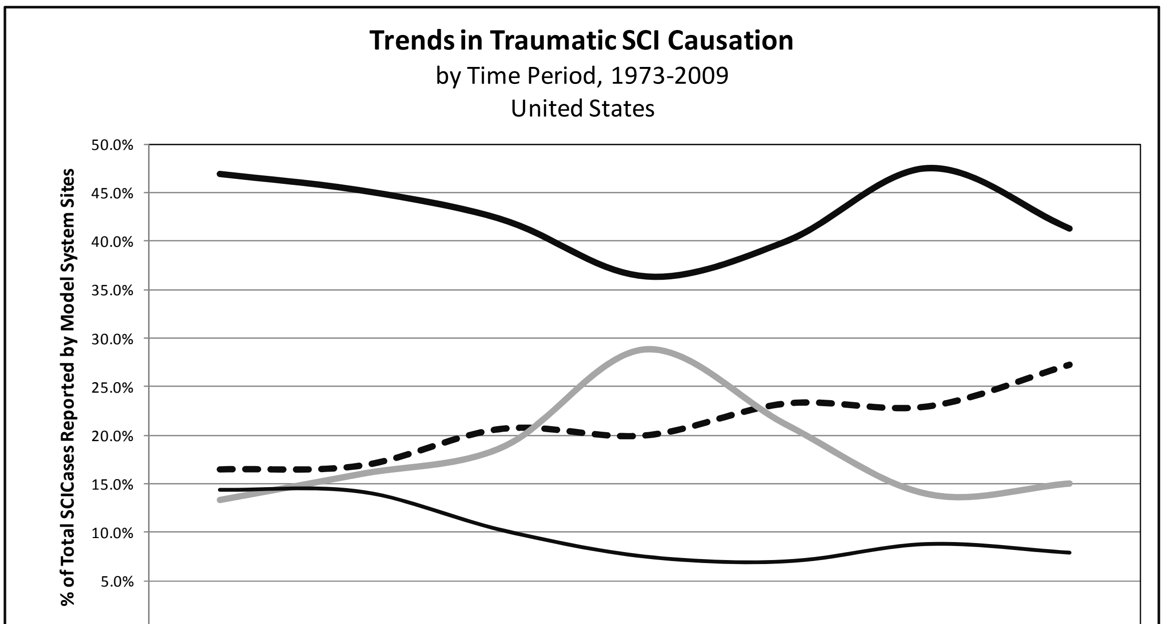
The spinal cord does not have to be severed for loss of function to occur; in fact, for most people with SCI, the cord remains intact but experiences damage through squeezing, bruising, or swelling, or through a decrease in blood flow. This clarifies the common distinction made between **complete** and **incomplete** SCI. A complete SCI means there is no sensory or motor function below the injury site, whereas in an incomplete SCI there is some preservation of sensory or motor function below the level of the injury.

Generally, the higher on the spinal column the injury occurs, the more extensive the dysfunction that a person will experience. SCI is usually classified as tetraplegic (formerly termed quadriplegic) or paraplegic. **Tetraplegia** relates to injury of the spinal cord in the cervical (or neck) region, with associated loss of muscle strength or paralysis in all four extremities. **Paraplegia** relates to an SCI below the cervical region; in such cases, the upper body usually retains motor and sensory functions.

There are various other potential effects of SCI besides loss of sensation or motor functioning. SCI symptoms are dependent on the severity and level of the injury. Complete injury at almost any level will result in bladder and bowel dysfunction, as these are controlled by the sacral nerves that originate near the bottom of the spinal cord. High cervical SCIs result in complete paralysis and loss of breathing control, so that the individual is ventilator-dependent. In individuals with severe or complete SCIs above the mid-thoracic region, **autonomic dysreflexia** may occur. This entails hyperactivity of the autonomic nervous system that may manifest in substantial increases in blood pressure, headaches, elevated heart rate, excessive sweating, nausea, etc. Other effects of SCI can include muscle fatigue, mood disorders, chronic pain, and spasticity, as well as complications that may be considered secondary to care and therefore potentially preventable; the latter include skin ulcers (usually referred to as pressure ulcers) and urinary tract infections.

Etiology

Another common type of classification of SCI involves cause (or etiology). SCIs may be referred to as either **traumatic** or **non-traumatic** in origin. Traditionally, the most frequent cause of traumatic SCI worldwide has been motor vehicle accidents, followed by falls.[9,10] However, more recent reports from some jurisdictions suggests an equalizing of the percentages of SCI due to motor vehicle accidents and falls.[11] The rates for falls seem to have progressively increased over the last 25 years in developed countries, partly mediated by the reality of an ageing population.[12] When stratified by age, falls are in fact the most common cause of traumatic SCI in the over 65-year age group.[13] In young and middle-aged persons, however, motor vehicle accidents remain the most frequent cause of traumatic SCI. In most countries, accidents involving other vehicles, including bicycles and snowmobiles, are the third most common cause, followed by sports-related injuries. Trauma to the spinal cord due to military action and violent crime is a unique causal factor in the U.S. context, as reflected in the following trend chart. Taken together, the shifting etiologic profile of SCI in each jurisdiction should help to set priorities for prevention efforts (see the pertinent section later in the report).



	1973-1979	1980-1984	1985-1989	1990-1994	1995-1999	2000-2004	2005-2009
Vehicular	46.9%	45.2%	42.2%	36.4%	40.0%	47.5%	41.3%
Falls	16.5%	16.9%	20.7%	20.0%	23.3%	23.0%	27.3%
Violence	13.3%	16.0%	18.8%	28.9%	21.1%	13.9%	15.0%
Sports	14.4%	14.2%	10.2%	7.5%	7.0%	8.8%	7.9%

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[9] Pickett GE, Campos-Benitez M, Keller JL et al. Epidemiology of traumatic spinal cord injury in Canada. *Spine*. 2006; 31(7): 799-805.

[10] Pirouzmand F. Epidemiological trends of spine and spinal cord injuries in the largest Canadian adult trauma center from 1986 to 2006. *Journal of Neurosurgery: Spine*. 2010; 12(2): 131-40.

[11] Pickett W, Simpson K, Walker J et al. Traumatic spinal cord injury in Ontario, Canada. *Journal of Trauma.* 2003; 55(6): 1070-6.

[12] Ho CH, Wuermser LA, Priebe MM et al. Spinal cord injury medicine. 1. Epidemiology and classification. *Archives of Physical Medicine and Rehabilitation.* 2007; 88(3 Suppl 1): S49-54.

[13] Pickett GE, Campos-Benitez M, Keller JL et al. Epidemiology of traumatic spinal cord injury in Canada. *Spine*. 2006; 31(7): 799-805.

Non-traumatic SCIs have numerous causes, with the most common being cancerous tumours, degeneration of the spinal disks, and multiple sclerosis. Such diseases can create lesions on the spinal cord that may result in paralysis and other neurologic deficits.[14,15] There is limited information about the epidemiology of non-traumatic SCI. Only one population-based study of the incidence of non-traumatic SCI appears to have been published.[16] According to this Australian report, the age-stratified incidence is very different for traumatic versus non-traumatic SCI. Almost half of traumatic SCI cases occur in individuals aged from 15 to 39 years, producing a peak in the incidence curve for that cohort; by contrast, most of the diseases generating non-traumatic SCI increase steadily with age, so that almost half of the cases ultimately occur in individuals over the age of 65.

Burden

SCI represents one of the relatively unusual medical conditions where there is no inherent primary protection from living in a wealthy country. Indeed, some of the highest incidence rates in the world appear to be in the U.S. and Canada.[17] There is wide variation even among developed countries, however, with North American SCI incidence rates being more than double than those found in Australia and Western Europe.[18]

In Canada, an estimated 1,785 new traumatic SCI cases occurred in 2010, with some 1,500 of these individuals surviving to be hospitalized, and 1,387 surviving their initial hospitalization. Approximately 44,000 individuals are currently living with a traumatic SCI in Canada.[19] The estimated figures for the U.S. are naturally higher in absolute terms, with about 12,000 individuals experiencing a new SCI each year, and 256,000 living with the condition.[20] The prevalence rates, reflecting the pool of individuals surviving SCI beyond the acute phase, generally appears to be higher in Canada and the U.S. compared to most other settings; this would be expected given the higher incidence rate that prevails in those countries and the effective emergency and acute medical care now available. It should be noted that, no matter which country is being considered, adding in SCI cases of non-traumatic origin would obviously increase both the incidence and prevalence figures. A recent report commissioned by the Rick Hansen Institute (RHI) suggested that the prevalence number may almost double in Canada (at 86,000) with the inclusion of non-traumatic SCI.[21]

As already noted, SCI has a devastating impact on an individual, resulting in long-term disability, reduced quality of life, and lower life expectancy. As summed up by researchers in

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[14] McKinley WO, Seel RT, Hardman JT. Nontraumatic spinal cord injury: incidence, epidemiology, and functional outcome. *Archives of Physical Medicine and Rehabilitation.* 1999; 80(6): 619-23.
[15] New PW, Rawicki HB, Bailey MJ. Nontraumatic spinal cord injury: demographic characteristics and complications. *Archives of Physical Medicine and Rehabilitation.* 2002; 83(7): 996-1001.
[16] New PW, Sundararajan V. Incidence of non-traumatic spinal cord injury in Victoria, Australia: A population-based study and literature review. *Spinal Cord*. 2008; 46:406-11.
[17] Chiu WT, Lin HC, Lam C et al. Review paper: epidemiology of traumatic spinal cord injury: comparisons between developed and developing countries. *Asia Pacific Journal of Public Health.* 2010; 22(1): 9-18.
[18] Cripps RA, Lee BB, Wing P et al. A global map for traumatic spinal cord injury epidemiology: towards a living data repository for injury prevention. *Spinal Cord.* 2010: 1-9.
[19] H. Krueger and Associates Inc. *The Economic Burden of Spinal Cord Injury: A Literature Review and Analysis.* 2010. Available at http://krueger.ca/index.asp?Page=Projects. Accessed January 2011.
[20] National Spinal Cord Injury Statistical Center. *Spinal Cord Injury Facts and Figures at a Glance*. 2010. Available at https://www.nscisc.uab.edu/public_content/pdf/Facts%20and%20Figures%20at%20a%20Glance%202010.pdf. Accessed January 2011.
[21] Farry A, Baxter D. *The Incidence and Prevalence of Spinal Cord Injury in Canada: Overview and estimates based on current evidence*. 2010. Available at http://www.urbanfutures.com/reports/Report%2080.pdf. Accessed January 2011.

the U.S. Veterans Affairs system, "SCI is a debilitating and costly condition that compromises the ability to work, engage in social or leisure activities, and pursue many activities usually associated with an independent and productive lifestyle." [22] SCI is also very expensive in economic terms, placing a significant financial burden on the individual, the health care system, and society as a whole. Combining direct costs (i.e., health care, equipment and modifications, and long-term care) with indirect costs (i.e., morbidity, premature mortality, and unpaid caregiving), the total lifetime cost per individual with SCI in Canada is estimated at $1.6 million for paraplegia and $3.0 million for tetraplegia; this translates into an annual economic burden for all traumatic SCI cases of $ 3.6 *billion*.[23] Clearly, fully understanding the cost of SCI can by itself be a driver of improvements in research efforts and actual delivery of care.

Tracking Progress

Understanding the progress related to SCI over the last 25 years may be accomplished in a comprehensive manner by tracking across a simplified model of influences and impacts. As indicated in the following diagram, there are four key domains where progress may be identified:

5. *Environment:* the evolving social context within which individuals with SCI live and operate

6. *Research:* the priorities and output related to investigating questions generated by SCI, from basic research ("bench") to intervention effectiveness ("bedside")

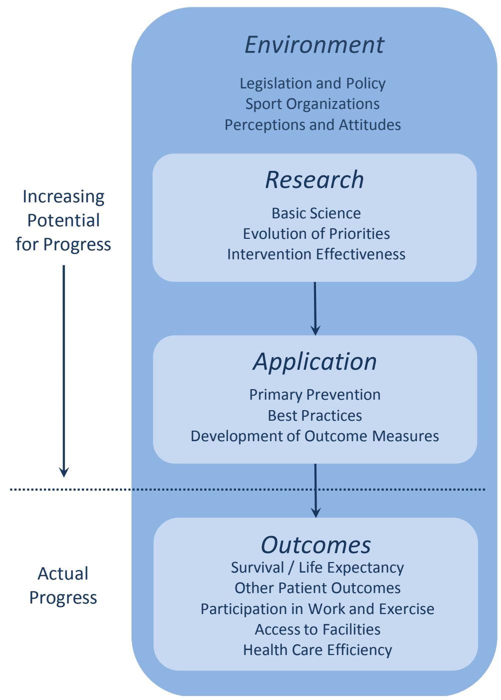
7. *Application:* how (and how much) any insights have been translated into clinical practice and public health

8. *Outcomes:* the actual changes experienced by individuals with SCI, from survival to quality of life, as measured at a population level, as well as effects in the health system in terms of efficiency

[22] Ruff RL, McKerracher L, Selzer ME. Repair and neurorehabilitation strategies for spinal cord injury. *Annals of the New York Academy of Science.* 2008; 1142: 1-20.
[23] H. Krueger and Associates Inc. *The Economic Burden of Spinal Cord Injury: A Literature Review and Analysis.* 2010. Available at http://krueger.ca/index.asp?Page=Projects. Accessed January 2011.

Progress in Spinal Cord Injury

Model of Domains



As indicated in the diagram, these domains may be characterized in terms of "soft" and "hard" progress. The first three, environment, research, and application of insights all represent the potential for actual progress in outcomes at a population level. Outcomes are the ultimate end-point of the process, and the marker of progress that is of greatest interest.

There are a number of themes under each domain that will be examined by means of a search in the biomedical literature and pertinent grey literature[24] documents. The aim is to provide selected information on each topic that will demonstrate the degree of progress that has been achieved in recent decades.

[24] The term 'grey literature' refers to documents available outside of the formal channels of publication and distribution. Examples include scientific and technical reports, government documents, theses, and so on.

Environmental Progress

All the current environmental taxonomies consistently include physical, attitudinal, and policy factors. They also include factors at all 3 of the environmental levels…the micro (personal), meso (community/services), and macro (societal/systems) levels. Together, the taxonomies show that environmental factors are far more than just physical barriers to mobility; they include all external influences on health and how people live their lives.[25]

Before turning to the more traditional topics of biomedical research, application, and outcomes, it is important to acknowledge that there is a broader social context in which individuals with SCI must live and operate. In the present report, this context is referred to as the environment. It is arguable that environmental progress has been as valuable for individuals with SCI as the various improvements in other arenas. For example, a 2004 paper noted that acute treatments aimed at neurologic preservation in SCI have been shown to predict outcomes such as mortality, independence in activities of daily living, and certain medical complications.[26] However, standard acute treatments are *not* strong predictors of perceived stress, long-term employment stability, life satisfaction, marital stability, perceived well-being, or quality of life. Instead, "these outcomes are influenced by such diverse factors as family support, adjustment and coping, productivity, self esteem, financial stability, education, and the physical and social environment." In response to these factors, ones that are not directly related to an injury and its treatment, the perspective on what needs to be addressed in SCI (and disability in general) has steadily broadened in recent years.[27] In this regard, certain countries have led the way; for instance, during the 1980-2002 time period, "several advances were made in the United States that articulated the significant role of the environment in the lives of people with disabilities."[28]

While recognizing that environmental factors may be found at multiple levels, from the personal to the societal, this section will focus mostly on the larger scale. Other sections of the report will address interventions targeting the individual; here the concern is the role of environmental factors that affect whole populations. The following areas of progress will be discussed in subsequent sections:

- Organizational infrastructure, that is, the growth in the organizations dedicated to SCI-related advocacy, investment, research, etc.
- Legislative and policy frameworks aimed at improving the lives of individuals with SCI, especially with respect to employment
- Sports organizations and events, as one key example of an environmental sub-domain that promotes participation and (it is hoped) enhances life satisfaction
- Public and professional attitudes impacting upon individuals with SCI
- Preferences in the SCI community, in other words, the climate where the opinions of those with SCI are consulted and actually count

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[25] Whiteneck GG, Harrison-Felix CL, Mellick DC et al. Quantifying environmental factors: a measure of physical, attitudinal, service, productivity, and policy barriers. *Archives of Physical Medicine and Rehabilitation.* 2004; 85(8): 1324-35.
[26] Whiteneck G, Meade MA, Dijkers M et al. Environmental factors and their role in participation and life satisfaction after spinal cord injury. *Archives of Physical Medicine and Rehabilitation.* 2004; 85(11): 1793-803.
[27] Trieschmann R. *Spinal Cord Injuries: Psychological, Social, and Vocational Rehabilitation*. New York: Demos; 1988.
[28] Whiteneck G, Meade MA, Dijkers M et al. Environmental factors and their role in participation and life satisfaction after spinal cord injury. *Archives of Physical Medicine and Rehabilitation.* 2004; 85(11): 1793-803.

Organizational Infrastructure

Research, advocacy, and service delivery in health care are typically undergirded by formal organizations of patients, professionals, and other stakeholders. This is an important component of the "environment" within which a disease or conditions exists—and this is no less true for the sphere of SCI. Associations, foundations, and institutes devoted to the study of SCI and the support of those with the condition have expanded dramatically since the 1940s, when the first such organizations were established to work with and for injured veterans of World War II. The introduction of penicillin in this period meant that SCI patients who would have previously died from infection were now surviving in larger numbers; to help meet their needs, groups such as the Canadian Paraplegic Association and the Paralyzed Veterans of America were organized in 1945 and 1946, respectively. The creation of these groups inspired the formation of similar support groups for civilians, as well as organizations for health care professionals focused on SCI. From these roots, the complement of SCI-related organizations has continued to grow. As noted in the Introduction, the last 25 years has especially been marked by a flood of new organizations around the world that are dedicated to SCI and affected individuals. The following table provides a selected inventory of recently launched organizations.

Global SCI Organizational Infrastructure
Selected Organizations Established Since 1985

Name	Location	Founded	Key Activities/Features
Networks, Alliances, and Federations			
Consortium for Spinal Cord Medicine	Washington, DC	1995	Develop, produce, and disseminate evidence-based clinical practice guidelines (CPGs)
International Campaign for Cures of Spinal Cord Injury Paralysis	Multiple sites	1998	A network of 13 organizations funding research into cures for paralysis caused by spinal cord injury. Cofounded by the Rick Hansen Foundation.
European Spinal Cord Injury Federation	Office in Nottwil, Switzerland	2005	Collaboration of national organizations from 19 countries
North American Clinical Trials Network for the Treatment of Spinal Cord Injury	Nine hospitals across North America, including one in Toronto	2006	Connected research centres developing therapies for SCI and performing clinical trials. An initiative of the Christopher & Dana Reeve Foundation supported by the American Depatrment of Defense/Veterans Health Administration
The Spinal Cord Injury Network	Australia and New Zealand	2008	An alliance of researchers, clinicians and people with spinal cord injuries; the alliance currently consists of more than 35 organizations and 900 individuals
Foundations and Trusts			
Rick Hansen Foundation	Richmond, BC	1988	Funds research into high impact innovations that will accelerate a cure for SCI and improve quality of life for those with SCI
Spinal Cord Society of New Zealand	Matamata, New Zealand	1988	Established SCI research centre within the Centre for Innovation at the University of Otago, Dunedin, New Zealand
Mike Utley Foundation	Orlando, WA	1992	Offers financial support to pursue an effective function-restoring treatment for SCI
Spinal Cure Australia	East Sydney, NSW, Australia	1994	Aims to end the permanence of SCI through promoting and funding research, fostering cooperation between medical disciplines, and monitoring research progress
Christopher and Dana Reeve Foundation	Short Hills, NJ	1995	Dedicated to curing spinal cord injury by funding research, and improving the quality of life for people living with paralysis through grants, information, and advocacy. Formerly the American Paralysis Foundation (est. 1982), reinvigorated by the involvement of Christopher Reeve and his supporters
International Foundation for Research in Paraplegia	Chêne-Bourg, Switzerland	1995	Promotes and funds clinical research related to SCI
Morton Cure Paralysis Fund	Minneapolis, MN	1995	Funds proof-of-concept data that allows researchers to pursue grants from larger financiers
Neil Sachse Foundation	Adelaide, South Australia, Australia	1995	Raises funds and lobbies for government funding for SCI treatments and technologies. Established a research centre at the University of Adelaide as a centre-of-excellence.
Japan Spinal Cord Foundation	Tokyo, Japan	1996	Promotes research into regeneration, rehabilitation, and development of care systems
Sam Schmidt Paralysis Foundation	Princeton, NJ	2000	Funds research, treatment, rehabilitation and technological advances
South Carolina Spinal Cord Injury Research Fund	Charleston, SC	2000	Funds the Rehabilitation Research and Training Center on Secondary Conditions in Individuals with SCI (University of South Carolina), as well as other research initiatives
Craig H. Neilsen Foundation	Encino, CA	2002	Fund programs supporting SCI research, rehabilitation, and training for SCI professionals
Wings for Life	Salzburg, Austria	2004	Promotes research worldwide in order to expedite scientific and clinical progress towards a cure for SCI paralysis
CatWalk Spinal Cord Injury Trust	Masterton, New Zealand	2005	Raises funds to support research for a cure for SCI

Global SCI Organizational Infrastructure, Continued Selected Organizations Established Since 1985			
Name	**Location**	**Founded**	**Key Activities/Features**
Advocacy, Patient Support, and Professional Organizations			
North American Spine Society	Burr Ridge, IL	1985	Professional organization for physicians and academics; publishes *The Spine Journal*
Back-Up Trust	London, UK	1986	Runs challenging activity programs for people with SCI
Spinal Cord Injury Network International	Santa Rosa, CA	1986	Provides access to information about SCI and health care for SCI survivors, their families, and health care professionals
American Society of NeuroRehabilitation	Minneapolis, MN	1990	Dedicated to advancing clinical care and research in the field of neurorehabilitation
ThinkFirst National Injury Prevention Foundation	Warrenville, IL & Toronto, ON	1992	Promotes public awareness for the prevention of brain and spinal cord injuries
South African Spinal Cord Association	Pretoria, South Africa	1993	Organization for SCI professionals
SCI Quality Enhancement Research Initiative	N/A	1998	Promotes patient health, functioning, and quality of life by implementing evidence-based methods for enhancing self-management and disease prevention. A program of US Veterans Health Administration.
International Spinal Cord Society	Aylesbury, Bucks, UK	2001	Publishes *Spinal Cord* academic journal. Formerly the International Medical Society of Parplegia (est. 1961).
Darrell Gwynn Foundation	Davie, FL	2002	Provides necessary equipment and services for those with SCI and runs programs to raise SCI awareness and prevent injury in children
United Spinal Association	Jackson Heights, NY	2004	Advocacy group speaking to legislators, employers and the public on behalf of those with SCI. Expansion of the Eastern Paralyzed Veterans Association (est. 1946).
Determined2Heal Foundation	Potomac, MD	2005	Provides information and advice for those with SCI and their families
Academy of Spinal Cord Injury Professionals	Washington, DC	2010	Merger of several existing organizations for SCI professionals, including doctors, nurses, psychologists, and social workers
Research Centres and Initiatives			
Miami Project to Cure Paralysis	University of Miami, Miami, FL	1985	Works to organize and get U.S. federal approval for human studies based on successful laboratory studies. Supported by the Buoniconti Fund to Cure Paralysis
Spinal Cord Research Centre	University of Manitoba, Winnipeg, MB	1987	Provides training and research into movement, bowel, and bladder function, and the effects of training on the central nervous system
Reeve-Irvine Research Center	University of California, Irvine, CA	1996	Studies repair, regeneration, and recovery of function after SCI
Spinal Cord and Brain Injury Research Center	University of Kentucky, Lexington, KY	1999	Promotes individual and collaborative studies on SCI resulting in paralysis or other loss of neurologic function
W. M. Keck Center for Collaborative Neuroscience	Rutgers University, NJ	1999	Dedicated to multidisciplinary, collaborative research and accelerating the translation of scientific discoveries into effective human therapies
International Collaboration on Repair Discoveries	University of British Columbia, Vancouver, BC	2001	Studies nervous system development and repair after injury or disease. Funded by the Rick Hansen Foundation.
Center of Excellence for the Medical Consequences of SCI	Bronx, NY	2001	Working toward understanding and treating the secondary medical consequences of SCI. A program of US Veterans Health Administration.
International Center for Spinal Cord Injury	Baltimore, MD	2005	Promotes research into rehabilitation as a means of recovering function after SCI
Rehabilitation Research and Training Center	Washington, DC	2009	A division of the National Rehabilitation Hospital researching secondary conditions of SCI
Rick Hansen Institute*	Vancouver, BC	2010	Integration of existing research initiatives funded by Rick Hansen Foundation and government and private stakeholders

* Amalgamating groups/initiatives established earlier in the decade

As the table indicates, four categories of SCI-related organizations may be helpfully identified:

- International networks and federations of organizations that maintain their individual identity while cooperating on one or more key SCI agendas
- Foundations, mainly focused on fund-raising and grant-making
- Advocacy and support organizations driven by (and serving) patients, professionals, or other stakeholders
- Institutes focusing on management of actual research activity

Sometimes new groups have been formed through amalgamation of two or more existing organizations, or through a major reshaping and re-energizing of a group with a long history. At the same time, organizations are collaborating with more regularity, forming networks such as the International Campaign for Cures of Spinal Cord Injury Paralysis, as well as establishing databases and research initiatives that cross provincial and national borders.

This reality of an extensive organizational infrastructure has generated both direct and indirect benefits for people dealing with SCI either personally or professionally as health care providers. The indirect effects relate to the sheer presence of the SCI theme in the public, academic, and health care spheres, and the encouragement and hope this engenders for those impacted by SCI. Notably, the profile of SCI has been enhanced through efforts such as Rick Hansen's *Man in Motion* World Tour in the early 1980s and his subsequent organizational efforts, as well as the advocacy and fund-raising work of Christopher Reeve after his high-profile injury in 1995.

Legislative and Policy Frameworks

Nations worldwide in the last generation have introduced legislative measures on the human rights and social needs of persons with disabilities.[29]

The general goal of legislation is to create a healthy and balanced society. This is achieved through a variety of means, including allowing, mandating, or restricting certain actions. Legal and policy frameworks constitute an important part of the environment in which SCI exists. Although very little legislation is related to SCI per se, a number of broader legal frameworks have been established in different parts of the world that influence the way in which individuals with SCI interact with their local community and wider society. Progress related to two categories of legislation and policy will be briefly reviewed here; another closely related arena, legislation to prevent injuries such as SCI, will be addressed in a later section of the report.

Disability Legislation

Progress on disability rights in recent decades has been marked by substantial growth, developing from a "nascent movement" in the mid-1970s to an agenda with mixed results and an uncertain future in the 1980s and finally to breakthrough legislation in a number of industrialized countries starting in the 1990s.[30,31] Selected laws, listed in order of their enactment, are indicated below:

- 1990—Americans with Disabilities Act (ADA)
- 1992—Disability Discrimination Act of Australia
- 1995—Disability Discrimination Act of the UK, replaced by Equality Act 2010
- 2001—Ontarians with Disabilities Act
- 2005— Accessibility for Ontarians with Disabilities Act
- 2008—ADA amended
- 2008—UN Convention on the Rights of Persons with Disabilities[32]

At each stage of policy-setting, a complex discourse has prevailed around the meaning of and approaches to disability.[33,34,35, 36] The laws that have been developed seek to provide people

[29] Prince MJ. What about a Disability Rights Act for Canada?: Practices and lessons from America, Australia, and the United Kingdom. *Canadian Public Policy.* 2010; 36(2): 199-214.
[30] Scotch RK. Politics and policy in the history of the disability rights movement. *Milbank Quarterly.* 1989; 67 Suppl 2 Pt 2: 380-400.
[31] Thompson DL, Thomas KR, Fernandez MS. The Americans with Disabilities Act: social policy and worldwide implications for practice. *International Journal of Rehabilitation Research.* 1994; 17(2): 109-21.
[32] Refer to www.un.org/disabilities/convention/conventionfull.shtml. Accessed December 2010.

with disabilities more options and opportunities with respect to employment, access to facilities, access to services (including health care), transportation, and appropriate shelter. Physical access is often important for "opening the door" in more than one way, such as being able to attend classes in order to enhance marketable skills and employability. The issue of particular importance for those with SCI is, of course, wheelchair accessibility. This theme will be revisited in a later section of the report.

It is notable that the legislative milestones have all occurred in the last two decades. The SCI community, as part of the broader disability arena, played its part in setting the pace for this impressive record. It began with the Americans with Disabilities Act (ADA), which "established full participation as the societal goal for all people with disabilities, and ensured their right to reasonable accommodation to achieve that goal."[37]

In most cases, the various national laws have built upon previously laid legal foundations related to civil rights, and are worded accordingly. The ADA, for example, defines failure to make services or employment opportunities accessible for those with disabilities as a form of discrimination. While this sort of framing does facilitate legal recourse for those with disabilities, it also has the unfortunate result of defining the societal agenda of individuals with conditions such as SCI in negative terms—in other words, the mandate to support persons with disabilities is shaped by unacceptable behaviours rather than positive initiatives. The latter approach could include the requirement for affirmative action in education, employment etc., as well as provision of resources to accommodate and promote involvement by disabled persons. In short, a prohibition against discrimination is generally not enough to improve the quality of life for individuals with SCI and other disabilities. This is why concerns have sometimes been expressed about laws such as the ADA, as well as the Disability Discrimination Act of the UK.[38,39,40,41] The critiques levelled have been partly motivated by the static nature of employment levels among the disabled in general[42] and individuals with SCI in particular (see the pertinent section on this sub-domain later in the report).

For these reasons, some national organizations have expressed caution about adopting disability legislation along the lines of the U.S. and UK models. An article published by the Council of Canadians with Disabilities expresses the opinion that existing human rights and employment equity laws should already apply to everyone—including the disabled—thus making additional

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[33] Seelman KD. Assistive technology policy: a road to independence for individuals with disabilities. *Journal of Social Issues.* 1993; 49(2): 115-36.
[34] Peterson W. Public policy affecting universal design. *Assistive Technology.* 1998; 10(1): 13-20.
[35] Cook JA, Burke J. Public policy and employment of people with disabilities: exploring new paradigms. *Behavioral Sciences & the Law.* 2002; 20(6): 541-57.
[36] Palley E. Civil rights for people with disabilities: obstacles related to the least restrictive environment mandate. *Journal of Social Work in Disability & Rehabilitation.* 2009; 8(1): 37-55.
[37] Whiteneck G, Meade MA, Dijkers M et al. Environmental factors and their role in participation and life satisfaction after spinal cord injury. *Archives of Physical Medicine and Rehabilitation.* 2004; 85(11): 1793-803.
[38] Reed KL. History of federal legislation for persons with disabilities. *American Journal of Occupational Therapy.* 1992; 46(5): 397-408.
[39] Vierling LE. The Americans with Disabilities Act, 16 years later. *Case Manager.* 2006; 17(6): 24-8.
[40] Bambra C, Pope D. What are the effects of anti-discriminatory legislation on socioeconomic inequalities in the employment consequences of ill health and disability? *Journal of Epidemiology and Community Health.* 2007; 61(5): 421-6.
[41] Bell D, Heitmueller A. The Disability Discrimination Act in the UK: helping or hindering employment among the disabled? *Journal of Health Econonomics.* 2009; 28(2): 465-80.
[42] Pack TG, Szirony GM. Predictors of competitive employment among persons with physical and sensory disabilities: an evidence-based model. *Work.* 2009; 33(1): 67-79.

legislation unnecessary. At the same time, others consider the ADA a success, and would like to see it reflected in a similar Canadian law.[43] A recent analysis has suggested that this would be a complex endeavour, with success depending on bringing a distinct Canadian perspective to bear; this includes a "positive action" framework that is aimed at an agenda of actual investments rather than stating principles (i.e., related to discrimination) that tend to generate law suits and court rulings more than population-level improvements.[44]

Certainly, the need to add a policy implementation plan, including resources, to basic laws is well-recognized in Canada. Since 1997, the Canadian government has provided $30 million annually to help people with disabilities achieve their employment goals, via the Opportunities Fund for Persons with Disabilities.[45] In 2003, the federal government and the provinces went further, developing Labour Market Agreements for Persons with Disabilities (LMAPDs); these are bilateral, cost-shared agreements designed to generate funding for programs and services that improve the employment situation for Canadians with disabilities, including SCI. The Government of Canada transfers $218 million annually to the provinces for the LMAPDs.[46] This overall effort is consistent with the ongoing commitment in other jurisdictions to offer training, job placement, and workplace support services to persons with disabilities.[47,48]

Legislation Concerning Research

Another area where legislation more directly affects those with SCI is in the field of basic research. For example, between 2001 and 2009, investigation in the promising area of stem cells was limited in the United States by a presidential order because of the controversial nature of a key source of such cells, that is, human embryos. While President Obama signed a more liberal policy related to human embryo stem cells in March 2009, the issue continues to be an apt reminder that politics and policy have the potential to affect those with SCI in important ways.[49,50]

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[43] Refer www.ccdonline.ca/en/socialpolicy/fda/1006. Accessed December 2010.
[44] Prince MJ. What about a Disability Rights Act for Canada?: Practices and lessons from America, Australia, and the United Kingdom. *Canadian Public Policy.* 2010; 36(2): 199-214.
[45] Refer to http://www.hrsdc.gc.ca/eng/disability_issues/funding_programs/opportunities_fund/background.shtml
[46] Refer to http://www.hrsdc.gc.ca/eng/disability_issues/labour_market_agreements/index.shtml. Accessed January 2011.
[47] Sim J. Improving return-to-work strategies in the United States disability programs, with analysis of program practices in Germany and Sweden. *Social Security Bulletin.* 1999; 62(3): 41-50.
[48] Wistow R, Schneider J. Employment support agencies in the UK: current operation and future development needs. *Health & Social Care in the Community*. 2007; 15(2): 128-35.
[49] Refer to edocket.access.gpo.gov/2009/pdf/E9-5441.pdf. Accessed December 2010.
[50] Vogel G, Couzin-Frankel J. Science and the law. With stem cells in court, a history primer. *Science.* 2010; 329(5998): 1450-1.

Sport Organizations and Events

Sports participation with adaptations is expanding and includes a larger variety of organizations and leagues.[51]

Sport has the ability to challenge individuals and change societal perceptions—factors of particular importance for individuals with disabilities such as SCI. While it is true that sporting infrastructure (regulatory bodies, federations, funding, etc.) are closely related to the theme of participation in recreation and organized sports (see pertinent section below), it deserves its own consideration as part of the environment in which individuals with SCI "live and move and have their being." Because of mounting public events with (increasingly) good media coverage, the value of sporting infrastructure extends beyond the impact of physical fitness in the direct participants. As a visible reversal of stereotypes, sports can decrease stigma, accelerate an agenda of inclusion, and emphasize achievement rather than impairment—in addition to the function of role models that encourage individuals with a disability such as SCI to take up physical activity as much as possible.[52] While it is not appropriate to isolate SCI in this context, given that infrastructure and events typically cover a number of disabilities, it does represent an important subset of participants. Indeed, SCI, along with other wheelchair-dependent conditions, has been a driving force throughout the history of disabled sports.

The history is longer than just the past 25 years. Following the Second World War, Dr. Ludwig Guttman introduced sport in the UK context as a component of rehabilitation for individuals who had suffered SCI in the context of battle. Thus, from the start, sport represented more than a leisure activity; it was seen as a way to improve physical fitness, and endurance, combat fatigue, restore pleasure in life, and aid in social reintegration. In 1948, a sports festival was held on the lawns of the Stoke Mandeville Hospital, the home of the National Spinal Injuries Centre. Competitions continued in following years, ultimately acting as a direct antecedent to the modern Paralympic Games.[53]

The Paralympic Games are the pinnacle of disabled sport—though only representing the tip of a much larger framework that supports many other activities and sports events between the official Olympic years. The Paralympics still offers the best proxy measure of growth, organization, and professionalism in disabled sport, as it brings together many of the sport-specific federations and regulatory bodies; indeed, the organizing committee actually acts as the international federation for 13 of the 25 official Paralympic sports.

Recent growth in the Paralympics has been remarkable. Some of the most notable achievements of the last 25 years include:

- 1988: first Paralympics since 1964 that were held in same city as the Olympics
- 1988: first time the term 'Paralympic' came into official use
- 1989: establishment of the International Paralympic Committee (IPC)
- 1996: first mass-media sponsorship of the Paralympic Games
- 2008: full integration of the Olympic and Paralympic organizing committees

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[51] Stiens SA, Kirshblum SC, Groah SL et al. Spinal cord injury medicine. 4. Optimal participation in life after spinal cord injury: physical, psychosocial, and economic reintegration into the environment. *Archives of Physical Medicine and Rehabilitation.* 2002; 83(3 Suppl 1): S72-81, S90-8.
[52] Kerstin W, Gabriele B, Richard L. What promotes physical activity after spinal cord injury? An interview study from a patient perspective. *Disability and Rehabilitation.* 2006; 28(8): 481-8.
[53] Slater D, Meade MA. Participation in recreation and sports for persons with spinal cord injury: review and recommendations. *NeuroRehabilitation.* 2004; 19(2): 121-9.

Over this same time period, the number of nations participating in the Winter Paralympics doubled from 22 to 44, with the Summer Paralympics seeing even greater growth (involvement rising from 61 to 146 participating nations). [54]

As suggested above, sport has the ability to change attitudes and foster the agenda of inclusion; nowhere is this accomplishment more apparent than in the Paralympic story. When China was invited to the Games in 1960, the official response was that there were no disabled people in China! Since that time, the country has made significant changes. In 1983, the Chinese Sports Association for Disabled Athletes was established and, by 2004, China won the most Paralympic medals. Hosting the Olympics and Paralympics in the summer games of 2008 marked further progress. For instance, the Beijing Municipal People's Congress adopted the country's first local legislation relating to barrier-free access at public facilities.[55] This continues to demonstrate the power of sport in particular and physical activity in general to move a society beyond stigmatization and towards acceptance and inclusion.[56,57]

The profile of SCI in the context of sport advanced dramatically with the involvement of Rick Hansen in the opening ceremonies of the Olympic and Paralympic winter games hosted by Vancouver in 2010—Metro Vancouver of course being the headquarters of the organizations founded by Mr. Hansen.

Progress continues apace as London has affirmed 8 commitments for the Paralympics in 2012, including maximizing media coverage and training all Games staff in the principles of inclusion.[58] However, challenges do remain. Media coverage tends to focus on the courage of Paralympic athletes rather than their physical accomplishments. So, while it is true that sporting infrastructure and events have helped to advance the agenda of inclusion for individuals with SCI and other disabling conditions, other hurdles involving public perception still need to be overcome.

Public Perceptions and Attitudes

The term "attitude" may be defined as a learned evaluative response, either positive or negative, directed at an object or person. Attitudes may be beliefs or feelings held toward ideas, objects, or people that predispose a person to behave a certain way. In studies of societal attitudes, there is little information specific to individuals with SCI; more commonly, it is attitudes toward disabled people as a whole that have been evaluated. The term "disabled" encompasses deficits in physical function (including those experienced by individuals with SCI), sensory impairments, and chronic illness, as well as emotional, mental, and behavioural problems.

A generally positive attitude towards people with disabilities is critical for fostering an inclusive society– that is, a social context in which disabled people have the same opportunities as other citizens to participate in the economic, cultural, political, and spiritual life of the

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[54] Details available at http://www.paralympic.org/Paralympic_Games/. Accessed December 2010.
[55] Gold JR, Gold MM. Access for all: the rise of the Paralympic Games. *Journal of the Royal Society for the Promotion of Health.* 2007; 127(3): 133-41.
[56] Arbour KP, Latimer AE, Martin Ginis KA et al. Moving beyond the stigma: the impression formation benefits of exercise for individuals with a physical disability. *Adapted Physical Activity Quarterly.* 2007; 24(2): 144-59.
[57] Tyrrell AC, Hetz SP, Barg CJ et al. Exercise as stigma management for individuals with onset-controllable and onset-uncontrollable spinal cord injury. *Rehabilitation Psychology.* 2010; 55(4): 383-90.
[58] Gold JR, Gold MM. Access for all: the rise of the Paralympic Games. *Journal of the Royal Society for the Promotion of Health.* 2007; 127(3): 133-41.

community.[59] It is important to note that equity of opportunity involves more than intangibles like perceptions and attitudes. For example, reducing physical barriers is another component of creating an inclusive community; initiatives in this area include modifications to buildings and public transport systems to improve wheelchair accessibility. This topic will be explored further in a later section of the report.

Not surprisingly, measuring and then reducing attitudinal barriers tends to be more challenging than the related tasks with physical barriers. A discussed in the previous section, in the past 25 years, disabled people have campaigned for a “human rights” approach to disability, resulting in pertinent legislation in the U.S., the UK, and various other countries. This has increased the sense that stereotypes, disability-related discrimination, and generally negative attitudes are no longer socially acceptable. Other, more direct “public relations” efforts have also had a positive effect. Rick Hansen’s *Man in Motion World Tour* was instrumental in changing attitudes toward disabled people, as described in Mr. Hansen’s words:[60]

> *Looking back, the greatest impact of the Tour was and always will be the human side of the mission, which was to inspire people as to the potential of people with disabilities—to cause people to think differently about what was possible for anyone when barriers are removed, attitudinal or physical.*

There is some evidence that attitudes to disability in general (and SCI in particular) are improving. In the 2004 Canadian Attitudes Towards Disability Issues survey, there was broad agreement among people with and without disabilities that Canadian society has made progress in becoming more inclusive toward people with disabilities. Respondents did indicate, however, that people with disabilities still face a number of barriers, including negative attitudes. Similarly, in the UK 2002 Attitudes Towards Disability Study, most of the 2064 respondents (of whom 47% themselves had a disability) believed that there had been improvement in the position of disabled people in society, but that structural and attitudinal barriers still remained.[61] Results from Ireland’s National Disability Authority 2006 Survey of Attitudes to Disability suggested that attitudes had become more enlightened in that country since the equivalent 2001 survey.[62]

Some of the key strategies for further countering negative attitudes include expanding education about disability, improving media representation of people with disabilities, and increasing integration of disabled and non-disabled people in public activities and events.[63] While some progress has been made in the area of perceptions in the past 25 years, there is still much work to be done in removing attitudinal (and other) barriers to inclusion.

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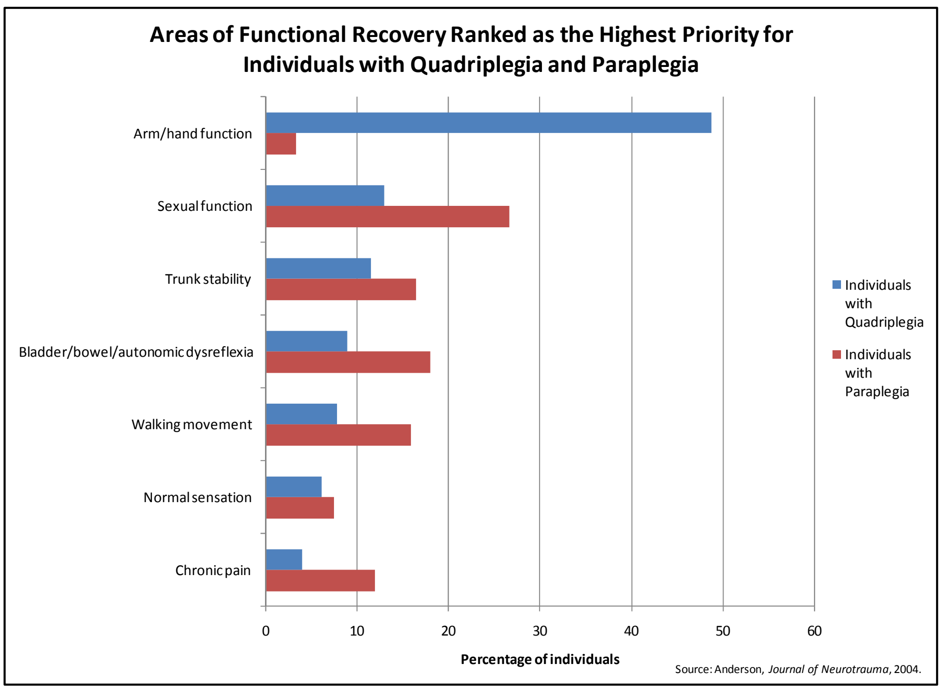
[59] Kleeman J, Wilson E. Seeing is believing: Changing attitudes to disability. A review of disability awareness programs in Victoria and ways to progress outcome measurement for attitude change. 2007. Scope (Vic). Available at http://www.scopevic.org.au/index.php/site/resources/seeingisbelieving. Accessed January 2011.
[60] Refer to http://www.rickhansen.com/code/navigate.aspx?Id=48
[61] National Disability Authority. Literature Review on Attitudes Towards Disability. 2007. Available at http://www.nda.ie/website/nda/cntmgmtnew.nsf/0/B89C8098F9D7A0C8802573B800430A9B?OpenDocument. Accessed January 2011.
[62] National Disability Authority. Public Attitudes to Disability in Ireland. Available at http://www.nda.ie/cntmgmtnew.nsf/0/FD9B9DBF1F1CF617802573B8005DDED5/$File/Survey.pdf. Accessed January 2011.
[63] Grewal I, Joy S, Lewis J et al. ‘Disabled for Life?’ Attitudes towards, and experiences of, disability in Britain. 2002. National Centre for Social Research. Available at http://research.dwp.gov.uk/asd/asd5/rrep173.pdf. Accessed January 2011.

Preferences in the SCI Community

Nowadays, health researchers, funding agencies, governments, and patient organizations are beginning to acknowledge that the passive role of patients in health research is no longer satisfactory.[64]

Attitudes found in the environment occupied by the SCI community have been gradually changing in a very specific way: How actively and respectfully the opinion of those with SCI is being pursued in shaping priorities for further investigation. In fact, there are a variety of means that could be used to establish priorities for research and the development of clinical guidelines. These include consulting with those directly or indirectly affected by a condition like SCI (e.g., through surveys, advisory groups, etc.), building a consensus of professional opinion, and/or some sort of objective evaluation based on incidence of a complication, its health outcome, the related economic burden, etc. For a variety of reasons, professional consensus has often been a dominant voice in this regard.[65] As noted by Abma, "traditionally, patients are rarely seen as partners in health research; their influence on priority setting, research design, the undertaking of research, and interpretation and dissemination of findings has often been marginal at best."[66]

In order to evaluate the relative importance of research into functional recovery for SCI, Kim Anderson conducted a survey of 681 individuals with SCI.[67] Subjects were asked "What gain of function would dramatically improve your life?" and then asked to rank seven functional recoveries in order of importance; for each function, the percentage of individuals with paraplegia and quadriplegia who ranked it highest is shown in the following chart:



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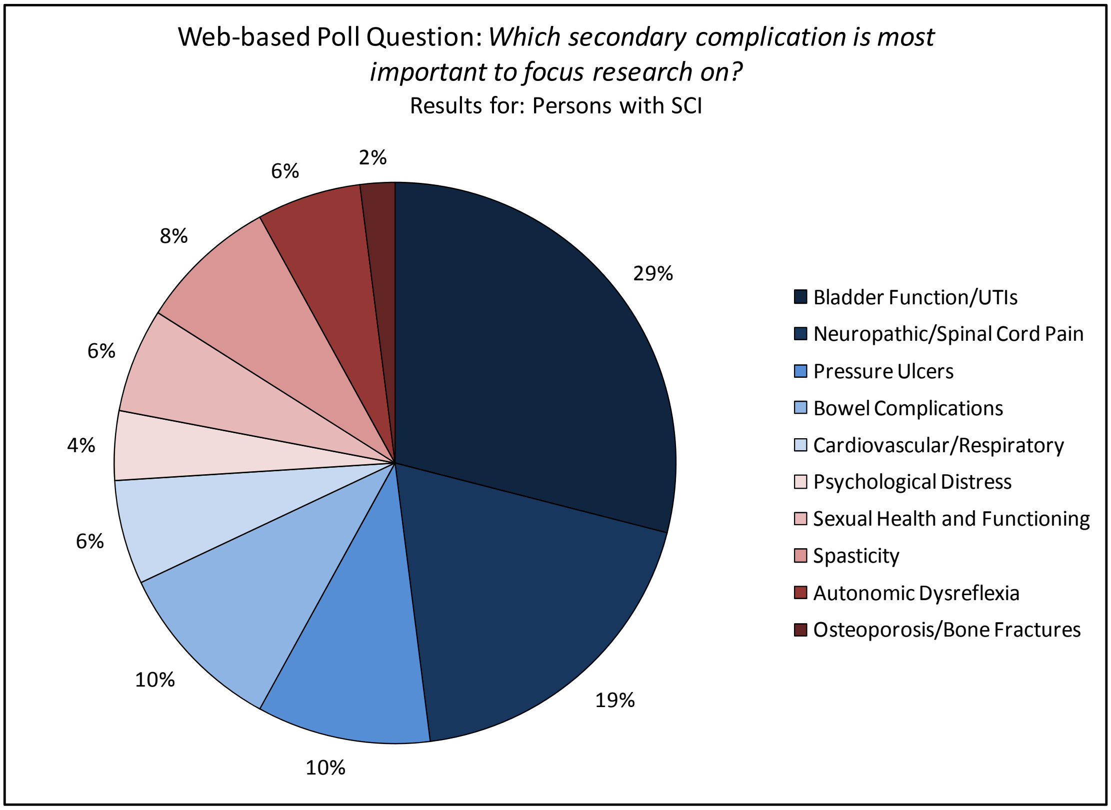
[64] Abma TA. Patient participation in health research: research with and for people with spinal cord injuries. *Qualitative Health Research.* 2005; 15(10): 1310-28.
[65] Ham C. Priority setting in health care: learning from international experience. *Health Policy.* 1997; 42(1): 49-66.
[66] Abma TA. Patient participation in health research: research with and for people with spinal cord injuries. *Qualitative Health Research.* 2005; 15(10): 1310-28.
[67] Anderson KD. Targeting recovery: priorities of the spinal cord-injured population. *Journal of neurotrauma.* 2004; 21(10): 1371-83.

The area of functional recovery ranked highest by individuals with quadriplegia was arm/hand function, whereas among individuals with paraplegia sexual function was given the highest priority. Note that the main purpose of this study was to ascertain what functions are most important to the SCI population in regard to enhancing quality of life.

In 2009, the Rick Hansen Institute initiated a study which involved a literature review, a web-based poll of almost 300 people with SCI or who worked with patients, and an electronic survey of 9 Canadian physiatrists specializing in the management of patients with SCI.[68] There was good agreement among these sources of information on the major concerns facing patients with SCI and the health care system. The results (shown below) for one of the questions from the web-based poll (posed to persons with SCI only) illustrate the overall pattern.



Bladder function/UTIs, pain management, pressure ulcers, and bowel complications were at the top of the priority list, with the next choice(s) then being more equivocal.

The web-based survey conducted by RHI differed from the work by Anderson in that it focused on secondary complications of SCI; thus, categories such as arm/hand function, trunk stability and walking movement were not available responses in the RHI survey, as these are not considered secondary complications.

These types of exercises illustrate the potential role for those with SCI in shaping the research and care agenda for the next 25 years.

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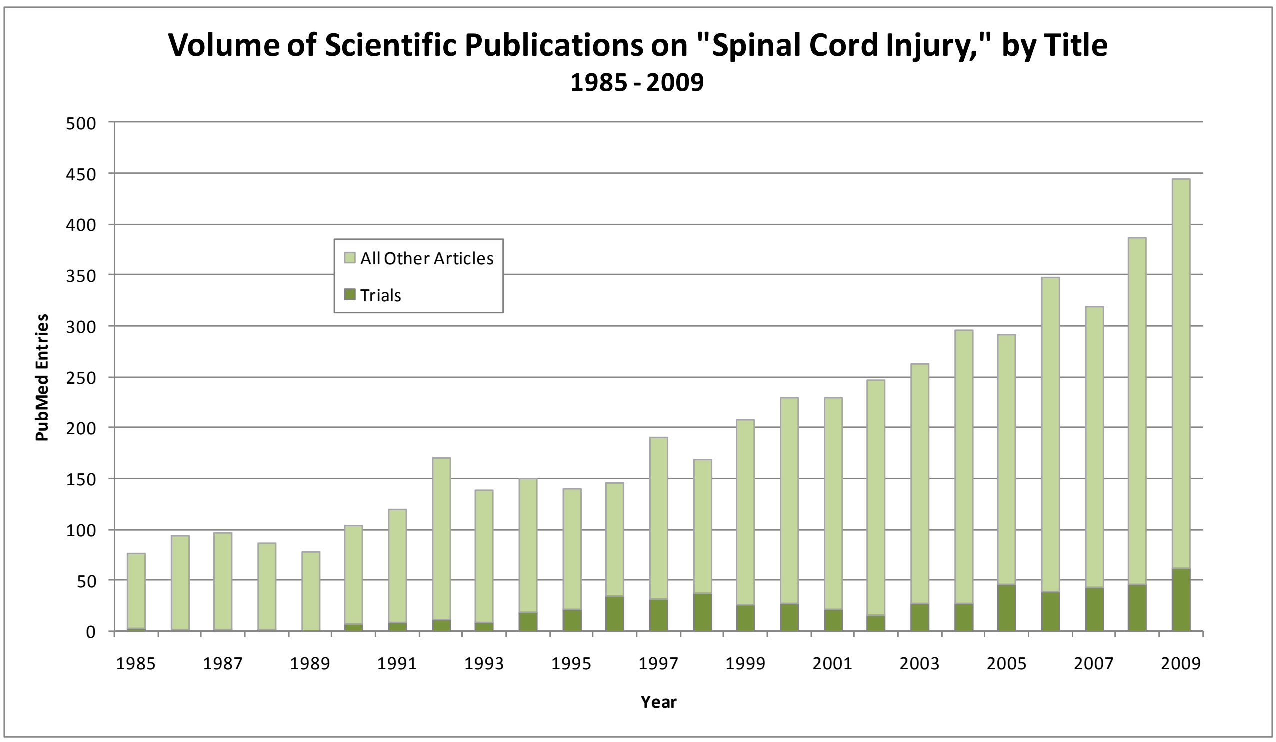
[68] Rick Hansen Institute. *Spinal Cord Injury Secondary Health Complications: Focusing our Translational Research*. 2009.

Research Production

Developing strategies and infrastructure for emergency and early acute care delivery in SCI dominated most of the last century. The basic target was ensuring that people with SCI survived beyond the first few days after the presenting trauma. It was not until the 1980s that a broader research agenda became a primary focus of SCI-related organizations; as seen in the Environmental Progress section of this report, many research centres were in fact launched in the last 25 years. Largely considered a "severe and irreversible" condition before that time, experimental results began to generate hope that the effects of SCI could be mitigated, and the condition even cured.[69] Existing organizations expanded their focus, and many foundations were initiated to provide support for ongoing studies—notably dedicated to the effort to find a cure. In more recent years, additional foundations and research institutes have started all over the world, sometimes reflecting new and unique goals; although the pursuit of a cure is still a key driver of SCI research, more work is now being supported on quality of life issues, aging with SCI, etc.

Publication Volume

The first fact to notice is that the volume of scientific publishing has expanded dramatically. Simple citation analysis in the biomedical literature demonstrates that the number of studies related to SCI appears to have steadily climbed over the last quarter century (see the diagram below), increasing by 500%; the number of clinical trials expanded by an even higher factor.



It is important to not over-interpret this picture; the publication of more articles is partly an artefact of founding of new SCI-related journals. It is true that the last 25 years has seen a number of important journals launched, as shown in the following table.

[69] Refer to christopherreeve.org/site/c.ddJFKRNoFiG/b.4434393/k.290F/History_of_spinal_cord_research.htm. Accessed December 2010.

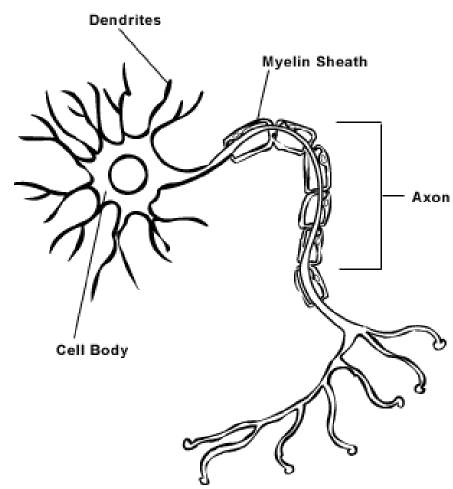
Selected SCI-Related Journals Established Since 1985		
Launch	**Journal Title**	**Editorial Office Location**
1987	Neurorehabilitation and Neural Repair	Los Angeles, CA
1988	Journal of Spinal Disorders & Techniques	Madison, WI
1989	Restorative Neurology and Neuroscience	Magdeburg, Germany
1992	European Spine Journal	Bern, Switzerland
1994	Topics in Spinal Cord Injury Rehabilitation	Atlanta, GA
1997	NeuroRehabilitation	Richmond, VA
2001	The Spine Journal	Stanford, CA

Finally, while it is true that similar expansion in publishing (as a proxy for research activity) would be observed for other medical fields, it is encouraging that leaders, funders, and investigators in the SCI sphere have at least kept pace with the drive to make scientific progress in a number of critical areas affecting individuals with this devastating condition.

Basic Investigation of Potential Cures

The central nervous system has limited capacity of regenerating lost tissue in slowly progressive, degenerative neurological conditions such as Parkinson's disease, Alzheimer's disease or Huntington's disease, or in acute injuries resulting in rapid cell loss for example, in cerebrovascular damage (for example, stroke) or spinal cord injury.[70]

The most extensive feature of a nerve cell or neuron is the long nerve fibre known as the axon that conducts signals away from the cell body, as illustrated in the adjoining diagram.[71] The biological impediment creating the greatest challenge in SCI research is the fact that central nervous system (CNS) axons of mammals essentially do not regenerate after an injury.[72] It seems that the environment within the CNS, especially following trauma, effectively inhibits the repair of myelin and neurons.[73,74] A further challenge involves the degeneration after axons are first damaged by SCI, as described in a 2009 review in *Neuroscientist*:[75]



> *…a direct impact to the spinal cord initiates an injury response that unfolds as a series of cellular and molecular events in the*

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[70] Gogel S, Gubernator M, Minger SL. Progress and prospects: stem cells and neurological diseases. *Gene Therapy.* 2011; 18(1): 1-6.

[71] Source: National Institutes of Health. Available at http://www.nida.nih.gov/jsp/MOD3/page3.html. Accessed December 2010.

[72] Ruff RL, McKerracher L, Selzer ME. Repair and neurorehabilitation strategies for spinal cord injury. *Annals of the New York Academy of Sciences.* 2008; 1142: 1-20.

[73] Blesch A, Tuszynski MH. Spinal cord injury: plasticity, regeneration and the challenge of translational drug development. *Trends in Neurosciences.* 2009; 32(1): 41-7.

[74] Ramer LM, Ramer MS, Steeves JD. Setting the stage for functional repair of spinal cord injuries: a cast of thousands. *Spinal Cord.* 2005; 43(3): 134-61.

[75] Darian-Smith C. Synaptic plasticity, neurogenesis, and functional recovery after spinal cord injury. *Neuroscientist.* 2009; 15(2): 149-65.

subsequent hours, days, and weeks. Primary injury involves direct cell death and bleeding that is caused by the initial mechanical damage sustained. However, within hours, further tissue damage begins to occur around the injury core. This secondary damage involves a cascade of vascular, biochemical, and cellular events.

A final phenomenon of interest is the property known as neuroplasticity, that is, "the capacity of the nervous system to modify its organization…as a consequence of many events, including the normal development and maturation of the organism, the acquisition of new skills ('learning') in immature and mature organisms, after damage to the nervous system and as a result of sensory deprivation."[76] While still not well understood, neuroplasticity is thought to be an important mechanism in potential rehabilitation after SCI, whether accomplished by physical training, drugs, or other intervention.[77,78,79,80,81,82]

The three biological phenomena introduced above provide a map to the main pathways of basic SCI research, as follows:

- Preventing further neurological damage (such as neuronal death) after SCI (sometimes referred to as neuroprotection)
- Restoring neurological (and thus motor/sensory) function without full organic repair (or neurorehabilitation)
- Restoring neurological (and thus motor/sensory) function with actual reversal of organic damage (i.e., a repair or cure)

Tremendous effort has been exerted in all three arenas over the last 25 years, with major breakthroughs, at least in terms of basic science. For instance, "multiple mechanisms limiting central nervous system regeneration have been identified."[83] Nonetheless, there is perhaps no other section of this report that raises more questions about how to define true "progress." When basic science insights have been moved into the realm of clinical investigation in humans, observed results have been negative or, at best, modest.[84,85] On the other hand, the ongoing quest for the "holy grail" of a full cure still continues to generate promising insights, some of which have begun to influence other areas of management.[86] Neurorehabilitation

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[76] Available at http://www.nature.com/nrn/journal/v3/n6/glossary/nrn848_glossary.html. Accessed December 2010.
[77] Darian-Smith C. Synaptic plasticity, neurogenesis, and functional recovery after spinal cord injury. *Neuroscientist.* 2009; 15(2): 149-65.
[78] Kokotilo KJ, Eng JJ, Curt A. Reorganization and preservation of motor control of the brain in spinal cord injury: a systematic review. *Journal of Neurotrauma.* 2009; 26(11): 2113-26.
[79] Sinkaer T, Popovic DB. Neurorehabilitation technologies - present and future possibilities. Introduction. *NeuroRehabilitation.* 2009; 25(1): 1-3.
[80] Sadowsky CL, McDonald JW. Activity-based restorative therapies: concepts and applications in spinal cord injury-related neurorehabilitation. *Developmental Disabilities Research Reviews.* 2009; 15(2): 112-6.
[81] Nishimura Y, Isa T. Compensatory changes at the cerebral cortical level after spinal cord injury. *Neuroscientist.* 2009; 15(5): 436-44.
[82] Edgerton VR, Tillakaratne NJ, Bigbee AJ et al. Plasticity of the spinal neural circuitry after injury. *Annual Review of Neuroscience.* 2004; 27: 145-67.
[83] Blesch A, Tuszynski MH. Spinal cord injury: plasticity, regeneration and the challenge of translational drug development. *Trends in Neurosciences.* 2009; 32(1): 41-7.
[84] Ruff RL, McKerracher L, Selzer ME. Repair and neurorehabilitation strategies for spinal cord injury. *Annals of the New York Academy of Sciences.* 2008; 1142: 1-20.
[85] Hyun J, Kim H-W. Clinical and experimental advances in regeneration of spinal cord injury. *Journal of Tissue Engineering*. 2010: E-pub ahead of print.
[86] Onose G, Anghelescu A, Muresanu DF et al. A review of published reports on neuroprotection in spinal cord injury. *Spinal Cord.* 2009; 47(10): 716-26.

appears to have progressed furthest in this regard. The exploitation of neuroplasticity using a functional training program is now well established; in recent years, this has included the application of robotic devices to allow for longer training sessions, feedback information systems, etc.[87] A current hope is that some form of combination therapy will be effective in SCI, specifically where regeneration stimulation and rehabilitation regimens are brought together.

Above all, optimism in this area of research is sustained by the remarkable fact that experimental SCI in model animals is no longer incurable,[88] as well as by the advances seen in potential stem cell therapies[89] and the development of imaging tools critical to monitoring any axonal re-growth.[90] A more cautious assessment arises from the relatively slow pace of investigating clinical applications of experimental breakthroughs, and the mixed results from the few human trials that have been pursued.[91,92] Most authorities and advocates agree that a positive attitude should prevail. The latter is important for maintaining hope in those living with SCI and for making sure that research resources continue to be made available. It would be unfortunate to not continue exploring the promising avenues and building upon the many basic scientific gains that have already been achieved.

Evolution of Research Focus: Duration and Quality of Life

Stem cell research is just one of the many avenues being explored by SCI researchers. Addressing the needs of individuals with SCI means looking beyond the cellular level. There are many active areas of multidisciplinary research in engineering, medicine, surgery, psychology, pharmacology, nursing, technology and outcomes.[93]

There have been pendulum swings in SCI-related research priorities. Prior to the 1980s, there was reportedly a shift away from longer-term rehabilitation and chronic care themes to acute interventions, and especially exploration of strategies to reverse SCI at an organic level (see the preceding section).[94] While the most fundamental investigations of reducing or reversing SCI-related paralysis will likely continue apace into the future, the last 25 years has been marked by a rise in research goals related to increasing both survival rates and quality of life of those afflicted with SCI. These two goals are connected in a very important way. Thus, as survival has improved and more individuals with SCI are living longer (see the specific section below on this theme), the need to effectively address secondary complications has intensified. Responding to the various *chronic* aspects of SCI is especially integral to the quality of life enjoyed by individuals now living with SCI into their 60s and beyond.

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[87] Dietz V. Recent advances in spinal cord neurology. *Journal of Neurology.* 2010; 257(10): 1770-3.
[88] Fawcett JW. Recovery from spinal cord injury: regeneration, plasticity and rehabilitation. *Brain.* 2009; 132(Pt 6): 1417-8.
[89] Ronaghi M, Erceg S, Moreno-Manzano V et al. Challenges of stem cell therapy for spinal cord injury: human embryonic stem cells, endogenous neural stem cells, or induced pluripotent stem cells? *Stem Cells.* 2010; 28(1): 93-9.
[90] Harel NY, Strittmatter SM. Functional MRI and other non-invasive imaging technologies: providing visual biomarkers for spinal cord structure and function after injury. *Experimental Neurology.* 2008; 211(2): 324-8.
[91] Tator CH. Review of treatment trials in human spinal cord injury: issues, difficulties, and recommendations. *Neurosurgery.* 2006; 59(5): 957-82; discussion 82-7.
[92] Hawryluk GW, Rowland J, Kwon BK et al. Protection and repair of the injured spinal cord: a review of completed, ongoing, and planned clinical trials for acute spinal cord injury. *Neurosurgical Focus.* 2008; 25(5): E14.
[93] Bodner DR. Expanding the options for spinal cord injury research. *Journal of Spinal Cord Medicine.* 2009; 32(2): 103.
[94] Dilorio C. An analysis of trends in neuroscience nursing research: 1960-1988. *Journal of Neuroscience Nursing.* 1990; 22(3): 139-46.

Basic research is vital to informing clinical trials that ultimately lead to evidence-based protocols along the entire continuum of care for individuals with SCI. The latter includes:

- Pre-hospital care by emergency medical services
- Acute management limiting damage and initial complications in traumatic SCI
- Rehabilitation aimed at restoration of function to enable better social reintegration
- Long-term management of secondary complications of SCI

Progress in the first two spheres has enabled a decrease in early mortality, whereas progress in the latter two areas has allowed for increased productivity and enjoyment over life-spans that are now measured in multiple decades rather months or years. Some of the basic research agendas in these areas will be outlined below.

Pre-Hospital Care

Basic aspects of pre-hospital (and emergency room) care in SCI are well-accepted, including the ABCs of initial assessment and resuscitation: airway, breathing, and circulation. However, other specific therapies preceding transport to the hospital remain unproven or at least controversial.[95]

A potential cause of secondary injury in cases of spinal trauma, especially in the context of pre-hospital care, involves the "inadvertent manipulation of the spinal cord in the setting of an unstable spinal column injury."[96] As a result of this concern, specific practices have emerged. For example, over the course of the 1980s and 1990s manual in-line stabilization became the standard of care for airway management (both pre-hospital and in the emergency room) for patients experiencing a trauma to the upper spinal cord.[97]

As well, spinal immobilization through the best available means is very commonly applied, even though only a small percentage of trauma patients actually sustain SCI. This reality has been reinforced in countless media reports, movies, etc. featuring the iconic image of trauma victim strapped to a rigid board, usually wearing a neck collar. A 2010 review of this area examined the pertinent scientific literature from 1966 to 2008.[98] *Notably, all of the research located on the topic dated from 1987 and later, in other words reflecting the period of interest to this report.* Two overarching issues were the focus of the reviewers:

- Whether pre-hospital care providers could be trained to reliably assess whether a trauma sufferer had experienced an actual SCI
- The optimal type and duration of spinal immobilization in the instance of SCI

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95 Bernhard M, Gries A, Kremer P et al. Spinal cord injury (SCI)--prehospital management. *Resuscitation.* 2005; 66(2): 127-39.

96 Ahn H, Singh J, Nathens A et al. Pre-Hospital Care Management of a Potential Spinal Cord Injured Patient: A Systematic Review of the Literature and Evidence-Based Guidelines. *Journal of Neurotrauma.* 2010: E-pub ahead of print.

97 Manoach S, Paladino L. Manual in-line stabilization for acute airway management of suspected cervical spine injury: historical review and current questions. *Annals of Emergency Medicine.* 2007; 50(3): 236-45.

98 Ahn H, Singh J, Nathens A et al. Pre-Hospital Care Management of a Potential Spinal Cord Injured Patient: A Systematic Review of the Literature and Evidence-Based Guidelines. *Journal of Neurotrauma.* 2010: E-pub ahead of print.

There was modest evidence available on the first question, suggesting that further research is needed, especially to identify a standard triage algorithm.[99] The experimental work informing the second question was more voluminous, with 25 pertinent studies identified. Various configurations of equipment producing vertebral column immobilization can be effective. Information about optimal duration is scarcer, suggesting that there is more room for basic and clinical research in this area. The issue at hand is the tendency for lying on a rigid board to increase pressures at the occipital and sacral points, leading to ulcers; other problems may also develop, including swallowing and breathing. This makes it all the more important to move beyond basic research to clinical investigation. In fact, it may not be ethical to conduct a trial pitting immobilization against non-immobilization; this is similar to the ethical and other obstacles to pursuing controlled trials of whether or not manual in-line stabilization should be applied during airway management.[100] However, it is at least feasible to compare different methods of immobilization following suspected SCI. Since a 2007 Cochrane review suggested that no such trials of different immobilization strategies had yet been conducted,[101] the potential for making more progress in this area of research is clear.

Acute Management

Individuals who sustain an SCI and reach the hospital may experience multiple early complications as a result of the injury, and are therefore at high risk of mortality. While the proximal injury mechanism—usually rapid spinal cord compression caused by a fracture—is irreversible, the secondary injury mechanisms are preventable and may be reversible. These secondary mechanisms lead to tissue destruction within the first few hours after injury. Research around strategies for acute management of SCI, which tend to be neuroprotective in nature, fall into two main categories: surgical and pharmacological.

Surgical Treatment

There are two goals related to surgery for SCI: realignment/stabilization of the spinal column (sometimes known as fixation) and decompression. While extensive research has occurred with respect to spinal fixation,[102] investigations related to decompression have been more limited. The aim of decompression surgery is to increase blood flow (and thus oxygen) to the damaged area, potentially leading to a better neurological outcome. The evidence for benefit to the patient is mixed, however, with compelling outcomes from animal studies but less substantive results from human clinical trials.[103] The timing of surgery is also the subject of some debate, with clinical benefits being weighed against potential risk of aggravating secondary injury when surgery is conducted less than 24 hours post-injury.[104] An RHI-funded review of the pertinent studies ultimately suggested that early surgical decompression (< 24 hr) can reduce the overall length of hospitalization, decrease the length of stay in the intensive care unit,

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[99] Hankins DG, Rivera-Rivera EJ, Ornato JP et al. Spinal immobilization in the field: clinical clearance criteria and implementation. *Prehospital Emergency Care.* 2001; 5(1): 88-93.
[100] Manoach S, Paladino L. Manual in-line stabilization for acute airway management of suspected cervical spine injury: historical review and current questions. *Annals of Emergency Medicine.* 2007; 50(3): 236-45.
[101] Kwan I, Bunn F, Roberts I. Spinal immobilisation for trauma patients. *Cochrane Database of Systematic Reviews.* 2007.
[102] Bagnall AM, Jones L, Richardson G et al. Effectiveness and cost-effectiveness of acute hospital-based spinal cord injuries services: systematic review. *Health Technology Assessment.* 2003; 7(19): iii, 1-92.
[103] Cadotte DW, Fehlings MG. Spinal cord injury: A systematic review of current treatment options. *Clinical Orthopaedics and Related Research*. 2010: E-pub ahead of print.
[104] Fehlings MG, Perrin RG. The timing of surgical intervention in the treatment of spinal cord injury: a systematic review of recent clinical evidence. *Spine.* 2006; 31(11 Suppl): S28-35; discussion S6.

improve neurological outcomes, and reduce the number of secondary complications following injury.[105]

The continuing debate about timing of surgical interventions inspired a new investigation, entitled Surgical Treatment for Acute Spinal Cord Injury Study (STASCIS); the aim was to see whether the consensus developing in the literature could be confirmed. This multicentre trial is ongoing, but early results have been encouraging; 24.2% of patients who underwent surgery within 24 hours of injury improved two steps on the American Spinal Injury Association (ASIA) Impairment Scale, while only 9.6% of those treated more than 24 hours post- injury achieved the same result.[106] Additionally, those treated within the first 24 hours post- injury appear to have 20% fewer complications than those treated afterwards.[107] Final results from STASCIS will be used to inform best practices in the area of spinal decompression surgery. The expectation is that the trial will lead to significant improvements in acute care for individuals experiencing traumatic SCI, while reducing health care costs.

Pharmacological Treatment

Pharmacotherapy in the acute stages of SCI is aimed at limiting secondary injury via various mechanisms, including modulating the immune/inflammatory response, apoptosis, excitotoxicity, or lipid peroxidation. Methylprednisolone was the first pharmacotherapy proven to affect neurologic outcome after SCI in randomized human trials; however, the studies have been highly criticized, with concerns being raised regarding methodology and data quality, as well as increased risks of infections and other complications.[108]

While steroids such as methylprednisolone are now standard in acute SCI care,[109] antibiotics have begun to be introduced as an alternate pharmacotherapy. Minocycline is a tetracycline derivative that shows enhanced uptake into the cerebrospinal fluid and a longer half-life compared with first-generation tetracyclines. In addition to its antimicrobial activities, minocycline has demonstrated neuroprotective effects in a number of animal models of neurologic disorders, including SCI. Various positive impacts have been associated with minocycline, including reduced neuronal cell death and decreased inflammation; related physical benefits include smaller lesion size and sparing of spinal cord tissue.[110,111,112]

Building on this knowledge, RHI funded a single-centre, double-blind, placebo-controlled pilot study evaluating the effectiveness of intravenous minocycline in acute treatment of SCI (< 12 hours after injury). Promising preliminary evidence from this study indicates that treatment

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[105] Furlan JC, Noonan V, Cadotte DW et al. Timing of decompressive surgery of spinal cord after traumatic spinal cord injury: An evidence-based examination of pre-clinical and clinical studies. *Journal of Neurotrauma.* 2010: E-published ahead of print.

[106] Performance Management Network Inc. *Report of the Independent Midpoint Review of Health Canada Funding to the Rick Hansen Institute*. 2010.

[107] Fehlings M, Baptiste D. *Acute Care & Treatment Network Operations: 2008-12 Business Plan*. Rick Hansen Institute Internal Document. 2008.

[108] Wuermser LA, Ho CH, Chiodo AE et al. Spinal cord injury medicine. 2. Acute care management of traumatic and nontraumatic injury. *Archives of Physical Medicine and Rehabilitation.* 2007; 88(3 Suppl 1): S55-61.

[109]

[110] Kim HS, Suh YH. Minocycline and neurodegenerative diseases. *Behavioural Brain Research.* 2009; 196(2): 168-79.

[111] Domercq M, Matute C. Neuroprotection by tetracyclines. *Trends in Pharmacological Sciences.* 2004; 25(12): 609-12.

[112] Kwon BK, Okon E, Hillyer J et al. A systematic review of non-invasive pharmacologic neuroprotective treatments for acute spinal cord injury. *Journal of Neurotrauma.* 2010: E-published ahead of print.

with minocycline results in enhanced motor recovery and improvements in other functional outcomes; results have been received very positively by the research community, with a number of experts acknowledging the clinical potential of the project. The trial is currently being expanded to include multiple participating centers.[113]

There are various other pharmacotherapies currently being researched for possible use in the acute management of SCI; some that have entered human clinical trials include riluzole, a sodium channel-blocking agent that is reported to have neuroprotective properties, and Rho antagonists, which show promise in promoting axonal sprouting and regeneration.[114]

Rehabilitation

In the past quarter-century, there have been significant advances in rehabilitation therapies for individuals with SCI. Research in this area is mainly focused on improving functional outcomes; key areas of SCI rehabilitation research include functional electric stimulation (FES), brain-based command signals, and locomotor training.[115]

The use of electrical stimulation devices to overcome functional limitations in people with SCI has become commonplace over the last 25 years.[116] FES works by generating muscle contractions through stimulation of peripheral nerves by electrodes. Electrodes can either be placed on the surface of the skin or implanted subcutaneously; although implantation is more invasive, it has the advantage of precise stimulation of target muscles. Functional improvements in upper- and lower-extremity use, bladder control, respiration, and cardiovascular and tissue health have been demonstrated through the use of FES systems.[117] To date, various types of neuroprostheses based on this technology have been commercialized, while others are at the clinical testing stage.[118] However, commercial success for such systems has been limited due to the high cost of the equipment and various technological shortcomings. Currently, researchers are making use of advances in design (such as decreasing the physical size and costs of devices) and methodology (such as implantation techniques that lower the risk of infection) in order to develop a "totally implantable, easily manufactured, modular FES system that can be used for all purposes." [119]

The cutting edge of rehabilitation engineering research includes the use of brain-based command signals for controlling assistive technology. Similar to FES, the approach involves electrodes that are either placed on the surface or implanted at various levels between the surface of the brain and the scalp; this enables the collecting and processing of brain signals. Such an "awareness" system has the ability to integrate and reflect "functional activities, context, previous experience, human and social behaviours, physiology, physical capacity, and

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[113] Casha S, Hurlbert RJ. *RRA Application - MASC – Minocycline in Acute SCI Proposal*. Rick Hansen Institute Internal Document. 2009.
[114] Cadotte DW, Fehlings MG. Spinal cord injury: A systematic review of current treatment options. *Clinical Orthopaedics and Related Research*. 2010: E-pub ahead of print.
[115] Kirshblum SC, Priebe MM, Ho CH et al. Spinal cord injury medicine. 3. Rehabilitation phase after acute spinal cord injury. *Archives of Physical Medicine and Rehabilitation.* 2007; 88(3 Suppl 1): S62-70.
[116] Ragnarsson KT. Functional electrical stimulation after spinal cord injury: current use, therapeutic effects and future directions. *Spinal Cord.* 2008; 46(4): 255-74.
[117] Kirshblum SC, Priebe MM, Ho CH et al. Spinal cord injury medicine. 3. Rehabilitation phase after acute spinal cord injury. *Archives of Physical Medicine and Rehabilitation.* 2007; 88(3 Suppl 1): S62-70.
[118] Peckham PH, Knutson JS. Functional electrical stimulation for neuromuscular applications. *Annual Review of Biomedical Engineering.* 2005; 7: 327-60.
[119] Ragnarsson KT. Functional electrical stimulation after spinal cord injury: current use, therapeutic effects and future directions. *Spinal Cord.* 2008; 46(4): 255-74.

cognition."[120] While no clinical product is yet available, trends indicate that this type of adaptive technology presents the future of SCI rehabilitation.[121,122]

Understandably, the restoration of walking function is a high priority for individuals with SCI. There have been a number of interventions introduced in the past decade that have improved the ambulatory function of those with incomplete SCI. These include task-specific functional training performed by physiotherapists, in combination with manual or robotic assisted bodyweight-supported treadmill training.[123]

As evidenced in this section, technology has and will continue to play a vital role in ongoing research related to the SCI continuum of care. This appears to be especially true of the rehabilitation phase, as researchers have successfully translated technological advances into functional gains for individuals with SCI—with a number of additional gains within reach. Techniques such as FES, which today is used to address individual functional limitations, is on the cusp of being able to provide multiple benefits simultaneously. The fact that even more advanced approaches using brain signals are now considered feasible is a testament to the vigour with which researchers approach this area of SCI care.

Secondary Complications

As summarized by an international study team in 2006, "injury to the cervical and upper dorsal spinal cord produces a variety of changes in the physiological function of different body systems."[124] Thus, while loss of function is one of the most immediate and serious consequences of SCI, many other conditions related to the injury also require medical management. In recent years, for example, chronic or recurring secondary complications have occupied a higher position on the research priority list. While only occasionally life-threatening in a direct way, these conditions certainly represent erosion in quality of life. The psychological consequences thus may be as serious as the physical effects of any complications; in the most extreme cases, this may actually contribute to an increase in SCI-related mortality, specifically through suicide.

A number of secondary complications of SCI have been identified as priorities in recent years, including:

- Urinary tract infection
- Chronic pain
- Pressure ulcers

This list could be expanded (e.g., impaired sexual function, bowel incontinence, etc.), but as indicated in an earlier section of the report, these conditions do represent critical areas often

[120] Cooper RA, Cooper R. Quality-of-life technology for people with spinal cord injuries. *Physical Medicine and Rehabilitation Clinics of North America.* 2010; 21(1): 1-13.
[121] Kirshblum SC, Priebe MM, Ho CH et al. Spinal cord injury medicine. 3. Rehabilitation phase after acute spinal cord injury. *Archives of Physical Medicine and Rehabilitation.* 2007; 88(3 Suppl 1): S62-70.
[122] Cooper RA, Cooper R. Quality-of-life technology for people with spinal cord injuries. *Physical Medicine and Rehabilitation Clinics of North America.* 2010; 21(1): 1-13.
[123] van Hedel HJ, Dietz V. Rehabilitation of locomotion after spinal cord injury. *Restorative Neurology and Neuroscience.* 2010; 28(1): 123-34.
[124] Vaidyanathan S, Peloquin C, Wyndaele JJ et al. Amikacin dosing and monitoring in spinal cord injury patients: variation in clinical practice between spinal injury units and differences in experts' recommendations. *ScientificWorldJournal.* 2006; 6: 187-99.

identified by the SCI community itself. Each of these three conditions will be briefly introduced here in terms of research and clinical progress over the last two decades. It should be noted that none of these complications are restricted to SCI; they occur as serious concerns in various other disorders, especially those involving the nervous system and/or some form of limitation to mobility. However, just as individuals with SCI have generated insights and interventions of use to other areas of medicine, disorders and disabilities unrelated to SCI per se have offered benefits within that specific community.

Urinary Tract Infections

The urinary system, and especially the bladder, is one part of the body that is particularly affected as a result of SCI. The bladder has two main functions, the storage of urine under low pressure, and the "periodic release of urine in a controlled coordinated manner during an acceptable time to void."[125] Logically, this suggests two major dysfunctions: uncontrolled voiding (leakage or incontinence) and failure to void.[126] A so-called neurogenic bladder refers to dysfunction of lower urinary tract control mechanisms due to disease or injury to neural pathways; the most common cause of such dysfunction is in fact SCI. Both incontinence and failure to void are common occurrences in SCI, with the latter problem arguably being the more critical medical issue.

As will be seen below, the list of concerns related to bladder management in SCI is often dominated by infection. Historically, infection was (literally) a grave matter in SCI. Before the advent of antibiotics, many individuals experiencing SCI died early from some sort of infection. While urinary tract and other infections continue to cause a certain proportion of deaths in the SCI population, many more such cases are now routinely treated. This may be considered a form of progress in SCI care, albeit one that was developed through a broader avenue of medical research (i.e., the introduction of penicillin).

Notwithstanding the discomfort of UTIs, the change in the deadliness of classic infections in SCI is why the dominant cause of mortality has now shifted to respiratory diseases. Another consequence is that the goals of bladder management research and practice have been able to multiply in new directions, which again can be considered a form of progress. According to authorities Samson and Cardenas, the aims of urinary system/bladder management that move beyond basic UTI prevention and treatment are as follows:[127]

- Ensuring social continence to facilitate reintegration into the community
- Allowing low-pressure storage of urine and efficient bladder emptying
- Preventing urinary tract complications from high pressures in the bladder
- Avoiding stretch injury from repeated over-distension of the bladder wall

Despite progress in prevention and control, infection in the urinary system of individuals with SCI continues to be a morbidity concern, especially recurring episodes that erode quality of life and generate expense for the health care system. Some investigators have theorized that the risk of UTIs is elevated as a direct, chronic complication of the neurogenic bladder, but most

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[125] Samson G, Cardenas DD. Neurogenic bladder in spinal cord injury. *Physical Medicine and Rehabilitation Clinics of North America.* 2007; 18(2): 255-74, Samson G, Cardenas DD. Neurogenic bladder in spinal cord injury. *Physical Medicine and Rehabilitation Clinics of North America.* 2007; 18(2): 255-74.
[126] Benevento BT, Sipski ML. Neurogenic bladder, neurogenic bowel, and sexual dysfunction in people with spinal cord injury. *Physical Therapy.* 2002; 82(6): 601-12.
[127] Samson G, Cardenas DD. Neurogenic bladder in spinal cord injury. *Physical Medicine and Rehabilitation Clinics of North America.* 2007; 18(2): 255-74.

clinicians implicate the phenomenon of infection as a by-product (i.e., a so-called iatrogenic effect) of the routine management of bladder dysfunction. Specifically, the main culprit appears to be the catheterization that is routinely used to drain urine from the bladder of most SCI patients.

Given its invasive nature, it is understandable that catheterization would be suspected as a culprit in infection. In fact, the two major approaches to catheterization (i.e., permanent or indwelling catheters and intermittent catheters) *both* increase the risk of symptomatic lower tract infection.[128] Nonetheless, there still has been a shift towards using some type of intermittent catheterization, engendering a shift away from the once dominant method of indwelling catheterization.[129]

The choice between the two major categories of catheterization has ultimately been driven less by UTIs per se and more by other types of primary and secondary complications that are elevated with the use indwelling catheters. For example, multiple retrospective studies have shown that squamous cell cancer of the bladder, although still rare, is elevated in patients using indwelling as opposed to intermittent catheters over a longer period of time.[130] This sort of variation in the conditions following different types of catheterization may account for the decreased mortality rate for SCI patients in an earlier era that coincides with the increased use of intermittent catheterization (i.e., since the early 1970s).[131]

Finally, there has been one infection-related difference demonstrated between the two catheterization methods: patients using indwelling catheters appear to be at elevated risk for recurrent symptomatic UTIs. Despite this result, it must be admitted that the present evidence base *related specifically to UTIs* for distinguishing the two types of catheterization is quite modest.

In fact, the pertinent Cochrane Library review group has focused on three types of catheterization used in medicine: "permanent urethral catheters (in the tube draining the bladder), suprapubic catheters (via the abdomen) or intermittent catheters (when a catheter is inserted via the urethra several times a day)."[132] They noted that, as of August 2008, there were *no eligible trials comparing these different methods*. They further concluded that there was "weak evidence that using antibiotics all the time reduced the chance of having a urinary tract infection while using intermittent catheters, but there was not enough information about side effects." A different review group focusing on catheterization strategies with neurogenic bladder found a similar lack of conclusive data in the scientific literature.[133] The same characterization may be made about choosing *within* the various catheter categories. This is

[128] Consortium for Spinal Cord Medicine. Bladder management for adults with spinal cord injury: a clinical practice guideline for health-care providers. *Journal of Spinal Cord Medicine.* 2006; 29(5): 527-73.
[129] Cameron AP, Wallner LP, Tate DG et al. Bladder management after spinal cord injury in the United States 1972 to 2005. *Journal of Urology*. 2010; 184(1): 213-7.
[130] Consortium for Spinal Cord Medicine. Bladder management for adults with spinal cord injury: a clinical practice guideline for health-care providers. *Journal of Spinal Cord Medicine.* 2006; 29(5): 527-73.
[131] Jamil F. Towards a catheter free status in neurogenic bladder dysfunction: a review of bladder management options in spinal cord injury (SCI). *Spinal Cord.* 2001; 39(7): 355-61.
[132] Niel-Weise B, van den Broek P. Urinary catheter policies for long-term bladder drainage. *Cochrane Database of Systematic Reviews*. 2008.
[133] Jamison J, Maguire S, McCann J. Catheter policies for management of long term voiding problems in adults with neurogenic bladder disorders. *Cochrane Database of Systematic Reviews*. 2007.

why the Cochrane Library, for instance, indicated in 2007 that there is not enough evidence yet to choose between different types of indwelling catheter technologies.[134]

In summary, while progress has been made in the treatment of infections and therefore their worse sequelae, it is clear that further research is warranted in order to reduce UTI-related morbidity in the context of essential bladder management approaches in individuals with SCI.

Chronic Pain

The management of pain is in fact common in all phases of SCI care—initial hospitalization, early rehabilitation, and long-term support. SCI-related chronic pain, which is the focus of most research, is typically categorized as nociceptive pain (i.e., due to non-neurogenic tissue damage) or the neuropathic pain related to damage in central and/or peripheral nervous tissue. The second category, neuropathic pain (also known as neurologic or central pain), usually includes frank pain and other unpleasant sensations (known as dysaesthesia) directly arising from sensory abnormality; it tends to be the predominant focus for SCI patients and researchers.

In the simplest terms, then, there is pain resulting from damage to the spinal cord itself, and pain that arises due to collateral damage, medical complications, and the lifestyle restrictions imposed by the neurological lesion. Beyond these basic distinctions, the experience of pain in SCI patients is heterogeneous and complex; as a consequence, classification schemes for pain following SCI have become more elaborate and numerous over the years.[135,136] Fortunately, a consensus has begun to emerge.[137] It appears that two schemes introduced a decade ago now dominate the field.[138,139]

A common feature of the two classification approaches is the general localization of pain in the body in terms of being above, at, or below the level of the injury to the spinal cord. This basic pattern was identified in reference to neuropathic pain as early as World War I.[140] Neuropathic pain at the level of the injury tends to have an early onset (days or weeks), while pain below the level of the injury can take months or years to emerge. There is an ongoing effort to rationalize the location of neuropathic pain in terms of chronic pain syndromes afflicting SCI patients; this includes increasing the understanding of underlying both the pathophysiological mechanisms and the psychosocial influences related to chronic pain.[141]

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[134] Jahn P, Preuss M, Kernig A et al. Type of indwelling urinary catheters for long-term bladder drainage in adults. *Cochrane Database of Systematic Reviews.* 2007.
[135] Calmels P, Mick G, Perrouin-Verbe B et al. Neuropathic pain in spinal cord injury: identification, classification, evaluation. *Annals of Physical and Rehabilitation Medicine.* 2009; 52(2): 83-102.
[136] Ullrich PM. Pain following spinal cord injury. *Physical Medicine & Rehabilitation Clinics of North America.* 2007; 18(2): 217-33, vi.
[137] Bryce TN, Budh CN, Cardenas DD et al. Pain after spinal cord injury: an evidence-based review for clinical practice and research. Report of the National Institute on Disability and Rehabilitation Research Spinal Cord Injury Measures meeting. *Journal of Spinal Cord Medicine.* 2007; 30(5): 421-40.
[138] Bryce TN, Ragnarsson KT. Pain after spinal cord injury. *Physical Medicine & Rehabilitation Clinics of North America.* 2000; 11(1): 157-68.
[139] Siddall PJ, Yezierski RP, Loeser JD. Following spinal cord injury: clinical features, prevalence, and taxonomy. *International Association for the Study of Pain Newsletter.* 2000; (3): 3-7.
[140] Bryce TN, Dijkers MP, Ragnarsson KT et al. Reliability of the Bryce/Ragnarsson spinal cord injury pain taxonomy. *Journal of Spinal Cord Medicine.* 2006; 29(2): 118-32.
[141] Hulsebosch CE, Hains BC, Crown ED et al. Mechanisms of chronic central neuropathic pain after spinal cord injury. *Brain Research Reviews.* 2009; 60(1): 202-13.

It is fair to say that the optimum approach to screening, diagnosis, and evaluation of pain after SCI is still a "work in progress." According to a research team sponsored by RHI, "no adequate measure for the symptomatic assessment of SCI-related neuropathic pain has been developed to date."[142] It continues to be a very important quest. There is value in devising well-accepted assessment tools (and possibly even classification schemes), both to guide clinical interventions and to create consistency in outcomes research.[143]

Identifying effective interventions for pain management can be a complex and even elusive process no matter what underlying disease mechanism or injury, and this is no less true for the specific phenomenon of SCI-related pain. Despite the challenges involved with classification, knowing the source and cause of pain is the typical starting point with any treatment approach. The various types of nociceptive pain require heterogeneous approaches. For example, overuse pain may be addressed by physical therapy, non-steroidal anti-inflammatories, and opioids. Muscle spasms are usually treated with antispasticity medications. Pain related to spine instability may be alleviated by immobilization and surgery—including spinal fusion procedures. Visceral pain management usually tries to target the source, from UTIs and urinary obstructions to bowel impaction.[144]

Neuropathic pain is generally more challenging to control. First-line treatments involve anti-convulsants; some authorities suggest that these may be more effective if administered with tricyclic antidepressants. Opioids are also commonly used for both acute and chronic neuropathic pain. There are problems with most approaches, as summarized in a brief review by Charles Booker of the Pain Management Research Institute in Australia:[145]

> *Pharmacological management is difficult and is fraught with ineffective drugs and difficulties coping with side effects. For example constipation and weight gain from trycyclics are a particular issue for SCI patients. Opioids have concerns due to the lifelong issues with pain and tolerance problems.*

Electrical nerve stimulation or spinal cord stimulation have offered relief of pain at the level of injury; applying this modality to the brain itself remains controversial, albeit controlled trials have produced some positive results for SCI pain. It has long been recognized that psychological factors play a substantial role in the experience and consequence of SCI-related pain.[146] Thus, cognitive-behavioural approaches continue to be recommended as part of an interdisciplinary response to pain following SCI—despite the fact that controlled trials have not been conducted and the acceptance of this approach by SCI patients remains limited.[147] Finally, interpersonal support, even in the face of severe pain, has been shown to increase life control and decrease life interference.[148,149]

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[142] Sawatzky B, Bishop CM, Miller WC. Classification and measurement of pain in the spinal cord-injured population. *Spinal Cord.* 2008; 46(1): 2-10.
[143] Finnerup NB, Jensen TS. Mechanisms of disease: mechanism-based classification of neuropathic pain-a critical analysis. *Nature Clinical Practice Neurology.* 2006; 2(2): 107-15.
[144] Ullrich PM. Pain following spinal cord injury. *Physical Medicine & Rehabilitation Clinics of North America.* 2007; 18(2): 217-33, vi.
[145] Brooker C. Spinal cord injury pain. *Acute Pain.* 2008; 10: 187-8.
[146] Summers JD, Rapoff MA, Varghese G et al. Psychosocial factors in chronic spinal cord injury pain. *Pain.* 1991; 47(2): 183-9.
[147] Ullrich PM. Pain following spinal cord injury. *Physical Medicine & Rehabilitation Clinics of North America.* 2007; 18(2): 217-33, vi.
[148] Widerstrom-Noga EG, Felix ER, Cruz-Almeida Y et al. Psychosocial subgroups in persons with spinal cord injuries and chronic pain. *Archives of Physical Medicine & Rehabilitation.* 2007; 88(12): 1628-35.

As has already been suggested, the "holy grail" in managing SCI pain is to match interventions to identified mechanisms.[150,151] This leads back to the theoretical issue of SCI pain classification, and onward to the practical issue of relevant and consistent assessment methods. Both of these areas continue to be active fields of investigation and debate. Additional clinical examinations appear to be warranted for certain types of pain, to confirm an initial diagnosis.[152] However, there continue to be substantial knowledge gaps in all aspects of pain identification and characterization in SCI, creating many opportunities for further research and analysis.

Beyond the important objectives of assessment and classification, leaders in this area have begun to agree that SCI pain treatments (especially for pain of the neuropathic type) will have to be multimodal and interdisciplinary in order to maximize effectiveness.[153] In particular, a comprehensive approach must pay attention to educational, cognitive, and behavioural components, as well as taking into account the contribution of social and other environmental factors. [154,155,156] These are relatively easy directions to affirm concerning conservative interventions; the more challenging questions continue to be centred on the effective medical therapies for SCI-related pain.[157]

Pressure Ulcers

Despite the investment of tremendous research and care resources over many years, pressure ulcers remain a dominant health problem for persons with SCI. In fact, it may be the most common secondary complication, although probably exceeded by UTIs in terms of hospital readmissions.[158,159,160]

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[149] Raichle KA, Hanley M, Jensen MP et al. Cognitions, coping, and social environment predict adjustment to pain in spinal cord injury. *Journal of Pain.* 2007; 8(9): 718-29.
[150] Finnerup NB, Jensen TS. Spinal cord injury pain--mechanisms and treatment. *European Journal of Neurology.* 2004; 11(2): 73-82.
[151] Jensen TS, Finnerup NB. Management of neuropathic pain. *Current Opinion in Supportive and Pallitative Care.* 2007; 1(2): 126-31.
[152] Le Chapelain L, Perrouin-Verbe B, Fattal C. Chronic neuropathic pain in spinal cord injury patients: what relevant additional clinical exams should be performed? *Annals of Physical and Rehabilitation Medicine.* 2009; 52(2): 103-10.
[153] Ullrich PM. Pain following spinal cord injury. *Physical Medicine & Rehabilitation Clinics of North America.* 2007; 18(2): 217-33, vi.
[154] Norrbrink Budh C, Kowalski J, Lundeberg T. A comprehensive pain management programme comprising educational, cognitive and behavioural interventions for neuropathic pain following spinal cord injury. *Journal of Rehabilitation Medicine.* 2006; 38(3): 172-80.
[155] Goossens D, Dousse M, Ventura M et al. Chronic neuropathic pain in spinal cord injury patients: what is the impact of social and environmental factors on care management? *Annals of Physical and Rehabilitation Medicine.* 2009; 52(2): 173-9.
[156] Perry KN, Nicholas MK, Middleton JW. Comparison of a pain management program with usual care in a pain management center for people with spinal cord injury-related chronic pain. *Clinical Journal of Pain.* 2010; 26(3): 206-16.
[157] Dworkin RH, O'Connor AB, Backonja M et al. Pharmacologic management of neuropathic pain: evidence-based recommendations. *Pain.* 2007; 132(3): 237-51.
[158] Mortenson WB, Miller WC. A review of scales for assessing the risk of developing a pressure ulcer in individuals with SCI. *Spinal Cord.* 2008; 46(3): 168-75.
[159] Jaglal SB, Munce SE, Guilcher SJ et al. Health system factors associated with rehospitalizations after traumatic spinal cord injury: a population-based study. *Spinal Cord.* 2009; 47(8): 604-9.
[160] Cardenas DD, Hoffman JM, Kirshblum S et al. Etiology and incidence of rehospitalization after traumatic spinal cord injury: a multicenter analysis. *Archives of Physical Medicine & Rehabilitation.* 2004; 85(11): 1757-63.

A pressure ulcer (also known as a pressure sore) is a lesion of the skin and underlying tissues; although multifactorial in nature, it appears to be primarily caused (as the name indicates) by prolonged, uninterrupted pressure localized on those tissues by the weight of the body.

The literature on this topic is vast, especially if one considers information that may be gleaned from the full range of conditions and situations where pressure ulcers are prevalent. These include diseases marked by impairment of mobility, sensation, skin integrity, and/or psychological responsiveness; included in the list are relatively common conditions such as diabetes mellitus and Alzheimer's disease.[161,162]

It is important to note that, contrary to the popular notion that equates pressure ulcers with being "bedridden" in a hospital, the lesions also occur in people at home and/or in ambulatory care. On the other hand, it is true that a large proportion of pressure ulcers arise during hospital stays or long term care. A 2004 study examined the prevalence of pressure ulcers in a variety of health care settings across Canada; it found that 25% of patients in acute care settings and 30% in non-acute settings experienced one or more pressure ulcers.[163] Alarmingly, there is evidence that the prevalence of pressure ulcers is actually increasing in some countries.[164,165] Since the usual assumption is that a certain proportion of hospital-acquired cases may be traced to inadequate care, the phenomenon remains a great concern of health care planners.[166] In particular, there is intensive focus on any medical context involving bed care or prolonged sitting, including critical illness or injury requiring intensive care and chronic conditions requiring long-term care.

The classic example of such care is of course the acute and early rehabilitation phases following SCI, as well as any re-hospitalization occasioned by later complications. It is important to reiterate that community-dwelling individuals with SCI are also very susceptible to pressure ulcers, underlining the importance of risk reduction by self-management, the support of well-coached caregivers at home, and the provision of professional assistance and specialized equipment.[167] To this end, while biomechanical explanations of pressure ulcers understandably dominate the discussion in SCI care, the role of behavioural components in pressure ulcer development is a growing area of interest.[168]

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[161] Margolis DJ, Knauss J, Bilker W et al. Medical conditions as risk factors for pressure ulcers in an outpatient setting. *Age & Ageing.* 2003; 32(3): 259-64.
[162] Singh N, Armstrong DG, Lipsky BA. Preventing foot ulcers in patients with diabetes. *Journal of The American Medical Association.* 2005; 293(2): 217-28.
[163] Woodbury MG, Houghton PE. Prevalence of pressure ulcers in Canadian healthcare settings. *Ostomy Wound Management.* 2004; 50(10): 22-4, 6, 8, 30, 2, 4, 6-8.
[164] Chen Y, Devivo MJ, Jackson AB. Pressure ulcer prevalence in people with spinal cord injury: age-period-duration effects. *Archives of Physical Medicine & Rehabilitation.* 2005; 86(6): 1208-13.
[165] Chicano SG, Drolshagen C. Reducing hospital-acquired pressure ulcers. *Journal of Wound, Ostomy, and Continence Nursing.* 2009; 36(1): 45-50.
[166] Baranoski S. Raising awareness of pressure ulcer prevention and treatment. *Advances in Skin & Wound Care.* 2006; 19(7): 398-405; quiz -7.
[167] Raghavan P, Raza WA, Ahmed YS et al. Prevalence of pressure sores in a community sample of spinal injury patients. *Clinical Rehabilitation.* 2003; 17(8): 879-84.
[168] Guihan M, Garber SL, Bombardier CH et al. Lessons learned while conducting research on prevention of pressure ulcers in veterans with spinal cord injury. *Archives of Physical Medicine & Rehabilitation.* 2007; 88(7): 858-61.

Intervention Effectiveness

Evidence-based medicine (EBM) as a discipline has been developed since the 1970s, before gaining widespread acceptance in the early 1990s.[169] EBM is defined as "a systemic approach to analyze published research as the basis of clinical decision making."[170] A commitment to scientific evidence was developed in part due to Archibald Cochrane's suggestion that "many of the treatments, interventions, tests and procedures used in medicine had no evidence to demonstrate their effectiveness, and may in fact be doing more harm than good." [171] Of course, the famous and influential Cochrane evidence review program was launched due to these concerns.

According to Bigby, EBM is comprised of four fundamental steps:[172]

1. Formulating well-built clinical questions
2. Finding the best evidence to answer the questions
3. Critically appraising the evidence
4. Applying the evidence to specific patients

Assessing intervention effectiveness is a subset of the entire EBM program, specifically answering questions about the effectiveness of an intervention of interest by analyzing available scientific literature; in this process, it plays an important role in bridging the gap between research and clinical practice.

Not surprisingly, evidence review publications related to SCI have grown exponentially over the years.[173] This sort of volume expansion is also observed in related areas such as outcome measures (covered later in the report). A scan of systematic reviews specific to SCI acute care, rehabilitation, and chronic care revealed a substantial number of publications (see following table).

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[169] Biering-Sorensen F. Evidence-based medicine in treatment and rehabilitation of spinal cord injured. *Spinal Cord.* 2005; 43(10): 587-92.
[170] Claridge JA, Fabian TC. History and development of evidence-based medicine. *World Journal of Surgery.* 2005; 29(5): 547-53.
[171] Cohen AM, Stavri PZ, Hersh WR. A categorization and analysis of the criticisms of Evidence-Based Medicine. *International Journal of Medical Informatics.* 2004; 73(1): 35-43.
[172] Bigby M. Evidence-based medicine in a nutshell. A guide to finding and using the best evidence in caring for patients. *Archives of Dermatology.* 1998; 134(12): 1609-18.
[173] Biering-Sorensen F. Evidence-based medicine in treatment and rehabilitation of spinal cord injured. *Spinal Cord.* 2005; 43(10): 587-92.

Systematic Reviews in Medline Supporting Evidenced-Based SCI Care				
Issue/Intervention	**Year**	**Lead Author**	**Review Group**	**Lead Country**
Acute Care				
Acute respiratory management	2011	Berney	Austin Hospital	Australia
Vasopressor support in acute SCI	2010	Ploumis	University of Ioannina	Greece
Electromagnetic therapy for the treatment of pressure sores	2010	Aziz	Cochrane	Malaysia
Methylprednisolone in acute SCI	2009	Botelho	IAMSPE	Brazil
Therapeutic interventions for pressure ulcers	2009	Regan	SCIRE	Canada
Gangliosides for acute SCI	2009	Chinnock	Cochrane	U.K.
Steroids for acute SCI	2008	Bracken	Cochrane	U.S.
Spinal injuries centers for acute traumatic SCI	2008	Jones	Cochrane	U.K.
Spinal fixation surgery for acute traumatic SCI	2008	Bagnall	Cochrane	U.K.
Review of treatment trials in SCI	2006	Tator	Toronto Western Hospital	Canada
Effectiveness and cost-effectiveness of acute hospital-based services	2003	Bagnall	NHS Centre for Reviews & Dissemination	U.K.
Spinal immobilization for trauma patients	2001	Kwan	Cochrane	U.K.
Rehabilitation				
Robot-assisted gait training	2010	Swinnen	Vrije Universiteit	Belgium
Gait-training for walking with incomplete SCI	2010	Wessels	Vrije Universiteit	The Netherlands
Acupuncture for SCI in the Chinese literature	2009	Shin	Pusan National University	South Korea
Effectiveness of physical interventions	2009	Harvey	University of Sydney	Australia
Clinical relevance of gait research	2009	Ditunno	Thomas Jefferson University	U.S.
Locomotor training for walking after SCI	2008	Mehrholz	Cochrane	Germany
Repiratory muscle training	2006	Van Houtte	Katholieke Universiteit Leuven	Belgium
Walking after spinal cord injury: evaluation	1999	Barbeau	McGill University	Canada
Chronic Care				
Secretion remove techniques to increase airway clearance	2010	Reid	University of British Columbia	Canada
Heterotopic ossification: therapeutic interventions	2010	Teasell	SCIRE	Canada
Cranberry for the prevention of UTIs	2010	Opperman	University of Guelph	Canada
Pharmacological treatment of pain	2010	Teasell	SCIRE	Canada
The management of orthostatic hypotension	2009	Krassioukov	SCIRE	Canada
Phosphodiesterase type 5 inhibitors	2009	Lombardi	Careggi University Hospital	Italy
Effect of exercise on disorders of carbohydrate and lipid metabolism	2009	Carlson	VA Medical Center	U.S.
Pharmacological interventions for spasticity	2009	Taricco	Cochrane	Italy
Pregabalin and gabapentin for neuropathic pain	2008	Tzellos	Aristotle University of Thessaloniki	Greece
Neurotoxin treament for urinary incontinence	2008	MacDonald	Veterans Affairs Medical Center	U.S.A.
Oxygen consumption during FES-assisted exercise	2008	Hettinga	Brunel University	U.K.
Botulinum toxin for treatment of urinary incontinence	2007	MacDonald	Veterans Affairs Medical Center	U.S.
Male erectile dysfunction	2006	Deforge	Ottawa Hospital	Canada
Algorithm for the management of pain	2006	Siddall	University of Sydney	Australia
Follow-up care in the community	2005	Bloemen-Vrencken	Rehabilitation Centre Hoensbroeck	The Netherlands
Dorsal root entry zone lesioning to treat central neuropathic pain	2002	Denkers	McMaster University	Canada
Effectiveness of vibratory stimulation in anejaculatory men	1993	Beckerman	Free University Hospital	The Netherlands

SCI = Spinal cord injury
IAMSPE = Institute for Medical Assistance to Civil Servants (translated from Portuguese)
SCIRE = Spinal Cord Injury Rehabilitation Evidence
UTI = Urinary tract infection
FES = Functional electrical stimulation

Several key observations can be made related to this table.

- **The field is rapidly expanding**, as the great majority of publications have occurred in the last decade
- **Research and related reviews comprehensively cover the SCI continuum of care**, though it appears that rehabilitation may be lagging as a focus and/or in terms of volume of scientific papers to analyze
- **SCI research is truly a global effort**, with review groups from a variety of institutions representing all continents except Africa (and Antarctica)

As well, **Canadian investment in the EBM program is well represented**, especially through the work of the Spinal Cord Injury Rehabilitation Evidence (SCIRE) project. It represents a synthesis of the research evidence underlying different rehabilitation interventions to improve the health of people living with SCI.[174] SCIRE is secondary research collaboration between scientists, clinicians, and consumers drawn from Vancouver, BC and London, ON health centres, research institutions, and universities. The full report covers more topics than have been published in Medline to date, including upper and lower limb rehabilitation, respiratory management, bone health, sexual health, neurogenic bowel, pressure ulcers, and bladder health and function.[175]

The basic fact that all of these reviews have been funded, completed, and reported is already a testament to the level of progress made in applying EBM principles to SCI. Given the short time frame during which most of these systematic reviews have been published (over 70% since 2008), it is generally not possible to perform a content analysis of how one topic has evolved over a long period. However, focusing on one specific area over the past decade offers a snapshot of the progress than may be anticipated for the entire SCI field in years to come.

Barbeau et al. (1999)[176] and Wessels et al. (2010)[177] published reviews on walking after spinal cord injury just over a decade apart. Despite this relatively short time frame, dramatic changes were observed that have important clinical implications. The most obvious difference is between the scope of each review; the more recent publication has a more refined focus, evaluating body-weight supported training rather than the general topic of post-injury walking. The more recent publication included a full17 studies, with all but one published since the earlier review. The pertinent section of the earlier review focused on the technological advances made to that point, such as the pulley, spring, pneumatic, and robotic systems necessary to perform body weight-assisted training. Building on this introductory research, researchers are now at a stage where they can conduct trials informing clinical direction on specific types of body weight-assisted training, such as over-ground and treadmill methods.

This example helps to illustrate how quickly primary research that is prioritized and funded can answer clinically relevant questions and then be systematically incorporated into a developing evidence picture. As highlighted in the table above, the potential progress in building and analyzing a body of evidence is not isolated to one intervention; however, all areas are not yet showing the same promise. For instance, Bloemen-Vrencken et al. have examined studies of follow-up care in the community; although they located 24 relevant publications, they also found that “in general the quality of studies was low.” As a result, the reviewers concluded that “there is a need for the development, the publication and the well-designed evaluation of follow-up care programmes for persons with SCI.” [178]

In areas where clinical questions have been well answered, ensuring that effective interventions are incorporated into best practice guidelines and that these guidelines see widespread

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[174] Available at http://version2.scireproject.com/chapters.php. Accessed January 2010.
[175] Wolfe D, Ethans K, Hill D et al. Bladder Health and Function Following Spinal Cord Injury. In: Eng JJ, Teasell RW, Miller WC et al., eds. *Spinal Cord Injury Rehabilitation Evidence. Version 3.0.* Vancouver: 2010.
[176] Barbeau H, Ladouceur M, Norman KE et al. Walking after spinal cord injury: evaluation, treatment, and functional recovery. *ARchives of Physical Medicine and Rehabilitation.* 1999; 80(2): 225-35.
[177] Wessels M, Lucas C, Eriks I et al. Body weight-supported gait training for restoration of walking in people with an incomplete spinal cord injury: a systematic review. *Journal of Rehabilitation Medicine.* 2010; 42(6): 513-9.
[178] Bloemen-Vrencken JH, de Witte LP, Post MW. Follow-up care for persons with spinal cord injury living in the community: a systematic review of interventions and their evaluation. *Spinal Cord.* 2005; 43(8): 462-75.

distribution, implementation, and validation becomes the next step; this topic will be covered in greater detail later in the report.

Translation to Application

Basic epidemiological and biological research needs to be taken from the realm of theory or laboratory insight to clinical trials then to actual practice in the real world. This movement from "bench to bedside" is customarily referred to as "translation." [179]

The preceding section already suggested that there is substantial opportunity for scientific research extending the evidence base that compares SCI interventions and their respective indications; there is also a great deal of room for further translational research to maximize the adoption of the best practice for various areas of care, calibrated to the relevant subgroups of SCI patients. For example, it is clear that there continues to be great challenges in managing the secondary complications of SCI, and therefore good reason to invest in basic, clinical, and translational research.

The fact that more progress is required should not take away from the positive developments that have occurred over the last quarter century. This section of the report will examine three important areas of translation and application work related to SCI where substantial investment and encouraging movement has occurred, as follows:

1. Primary prevention
2. Guidelines for best clinical practices
3. Development of outcome measures

Public Health Practice and Primary Prevention

Clearly, the most effective means of reducing the rate, severity, and mortality from craniospinal trauma is through prevention.[180]

The most common cause of traumatic SCI is motor vehicle crashes (including motorcycles), followed by falls and sport activities. As noted in the Introduction to the report, falls may be overtaking traffic accidents as the dominant cause of SCI. This finding, and the fact that the number of fall-induced injuries increases steadily with age, may suggest a new prevention target. As noted by Couris et al., "further work is needed to understand this trend in age and gender and the causes of falls to develop effective fall prevention strategies."[181]

Because the consequences of SCI are so devastating, it is of paramount importance to prevent the injury from occurring in the first place. Primary prevention of SCI seeks to reduce susceptibility, eliminating or minimizing behaviours and environmental factors that increase the risk of injury. The two main approaches to injury prevention are *legislation* and *education*. Progress has been made on both fronts in recent decades, as detailed below. Unfortunately, given the difficulty in tracking accurate statistics for traumatic SCI incidence in most jurisdictions, it is not clear how the various initiatives may have reduced actual cases at the

[179] Kwon BK, Sekhon LH, Fehlings MG. Emerging repair, regeneration, and translational research advances for spinal cord injury. *Spine (Phila Pa 1976).* 2010; 35(21 Suppl): S263-70.
[180] Kelly DF, Becker DP. Advances in management of neurosurgical trauma: USA and Canada. *World Journal of Surgery.* 2001; 25(9): 1179-85.
[181] Couris CM, Guilcher SJ, Munce SE et al. Characteristics of adults with incident traumatic spinal cord injury in Ontario, Canada. *Spinal Cord.* 2010; 48(1): 39-44.

population level. However, based on substantial reductions in the rate of head injuries in the U.S., the SCI incidence rate is now also probably lower.[182]

Legislation

Legislation has been developed to modify human behaviour (e.g., reduction in legal blood alcohol concentrations when driving), change environmental factors (e.g., better highways, anti-locking brake systems), and decrease access to hazards (e.g., increasing the cost of alcohol, prohibiting use of handheld devices). There are also laws that are aimed at limiting injury during a traffic accident, such as mandatory usage of motorcycle helmets, bicycle helmets, and seat-belts.[183] In fact, since 1990, all new cars manufactured in the U.S. have been equipped with automatic seat belts and/or a driver's side airbag.[184] While there is research showing increased usage of helmets or seat-belts and reductions in acute mortality rates,[185,186,187] there are no studies available confirming the long-term incidence effect specific to SCI. Overall, the greatest promise of reduction in injury rates is associated with legislation that is perceived by the public to be strictly enforced.

Education

Educational approaches to reducing traumatic SCI are usually integrated into injury prevention programs. For example, there are two major organizations devoted to injury prevention in Canada: ThinkFirst and SMARTRISK.

ThinkFirst Canada

ThinkFirst Canada is a national non-profit organization founded in 1992 that is dedicated to the prevention of brain and spinal cord injuries; it has 19 local chapters across the country. The goal of ThinkFirst Canada is to achieve a measurable reduction in traumatic brain and spinal cord injuries through the creation, dissemination, and evaluation of educational activities; by public advocacy activities; and by providing kids with the tools and information they need to "use their minds to protect their bodies."[188] Some of the various ThinkFirst programs are outlined below:

- *TD ThinkFirst for Kids:* School-based curriculum program for children in grades K-8. Designed as a teacher's resource, the program teaches children how to think first and play safely to prevent brain and spinal cord injuries. It is available free of charge to all Canadian schools and public health agencies; more than 12,000 curriculum sets are in use across Canada.

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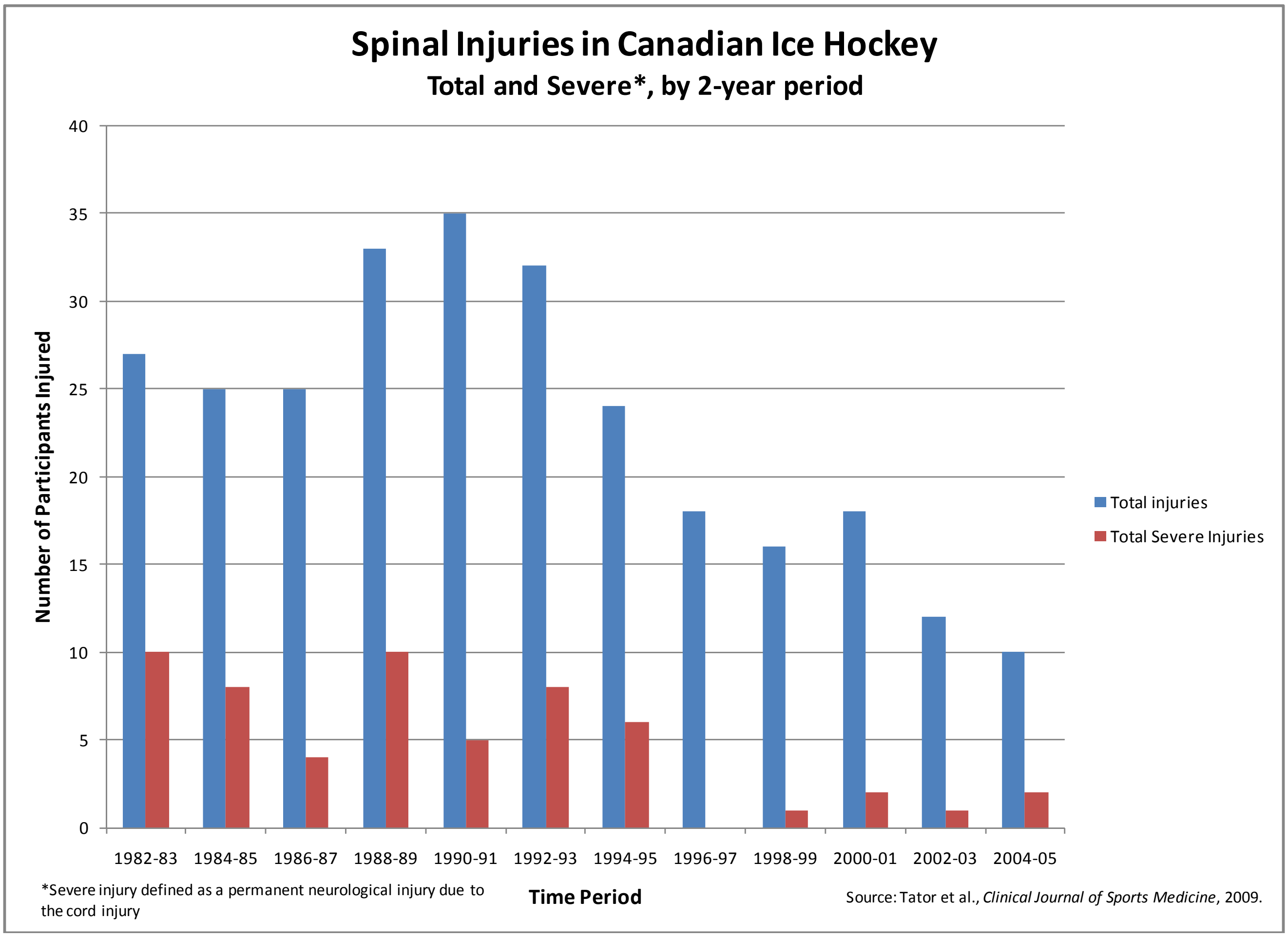
[182] Kelly DF, Becker DP. Advances in management of neurosurgical trauma: USA and Canada. *World Journal of Surgery.* 2001; 25(9): 1179-85.
[183] Reid-Arndt SA, Frank RG, Hagglund KJ. Brain injury and health policy: twenty-five years of progress. *Journal of Head Trauma and Rehabilitation.* 2010; 25(2): 137-44.
[184] Kelly DF, Becker DP. Advances in management of neurosurgical trauma: USA and Canada. *World Journal of Surgery.* 2001; 25(9): 1179-85.
[185] Sen A, Mizzen B. Estimating the impact of seat belt use on traffic fatalities: Empirical evidence from Canada. *Canadian Public Policy.* 2007; 33(3): 315-35.
[186] Cummings P, Rivara FP, Olson CM et al. Changes in traffic crash mortality rates attributed to use of alcohol, or lack of a seat belt, air bag, motorcycle helmet, or bicycle helmet, United States, 1982-2001. *Injury Prevention.* 2006; 12(3): 148-54.
[187] MacLeod J, DiGiacomo JC, Tinkhoff GH. *An Evidence Based Review: Helmet efficacy to reduce head injury & mortality in motorcycle crashes.* 2010. Eastern Association for the Surgery of Trauma. Available at http://www.east.org/tpg/MotorcycleHelmet.pdf. Accessed January 2011.
[188] Refer to http://www.thinkfirst.ca/aboutus/mission.aspx. Accessed January 2011.

- *Give-A-Kid-A-Helmet:* A program created in 2003 that provides children with a helmet when costs are prohibitive for their family; over 35,000 children have been supplied with vital protective gear in this manner.
- *Concussion Road Show:* A traveling information clinic that presents information about the science of concussion, including risk factors, prevention techniques, and concussion management guidelines.
- *Smart Hockey:* An entertaining and educational DVD in which hockey stars share tips and demonstrate how to avoid causing and sustaining hockey injuries. This is part of the Sport Smart series, which also includes programs on diving, equestrian, soccer, and skiing safety.

Almost all scientific evaluations of ThinkFirst programs have concluded that these programs improve knowledge and reduce risk-related behaviour. Tator et al. have recently published a study specific to spinal injuries in ice hockey; examining incidence trends over the long term, the authors concluded that there has been a reduction in such injuries in Canada, and attributed this reduction to the development and dissemination of targeted injury prevention programs.[189] The following chart illustrates the findings, including the improvements since the early 1990s.



[189] Tator CH, Provvidenza C, Cassidy JD. Spinal injuries in Canadian ice hockey: an update to 2005. *Clinical Journal of Sports Medicine.* 2009; 19(6): 451-6.

SMARTRISK

A second pertinent charitable organization in Canada is SMARTRISK, dedicated to preventing injuries and saving lives.[190] Similar to ThinkFirst, the main focus is youth safety; the five messages of the organization are Buckle up, Look First, Wear the Gear, Get Trained, and Drive Sober. Some of their programs and services are as follows:

- *SMARTRISK No Regrets:* A high school program that trains students and teachers to help young people learn to take smart risks. Once trained, they choose and plan activities, events, and campaigns throughout the school year that promote the five key messages (as noted above). No Regrets was created in 2003; by the end of 2009 over 100 schools in 9 provinces and one territory in Canada were equipped to run the program.
- *SMARTRISK Heroes:* A one-hour presentation hosted by an injury survivor who describes how he or she got hurt, and explains how youth can choose smart risks to avoid injury.
- *Ontario Injury Prevention Resource Centre:* Aids in developing injury prevention initiatives across Ontario, including: Canadian Falls Prevention Curriculum, Canadian Injury Prevention Curriculum, and Ontario Injury Compass.

SMARTRISK has evaluated the No Regrets program each year since the program was created. A recent study found students reported 17% fewer injuries requiring medical care following a single year of exposure to the organization's key messages.[191]

SMARTRISK also offers a program designed for seniors and their caregivers that focuses on falls prevention. Falls are the most common cause of SCI in the over 65 age group. The Smart Moves toolkit focuses on four categories key to fall prevention in the elderly—bone health, exercise, medication management, and home modifications.

It is clear that there has been encouraging progress in the prevention initiatives in Canada and other jurisdictions. To better assess the impact of these efforts at the population level, it is important to improve the tracking of SCI statistics through population-based registries—an initiative that is still at an early stage of development in most jurisdictions.[192]

Guidelines for Best Clinical Practices

The development of best practices and their incorporation into practice guidelines for SCI care appears to be a steadily expanding enterprise. For example, an extensive set of guidelines has been published by the Consortium for Spinal Cord Medicine, funded and administered by the Paralyzed Veterans of America. The Consortium—a group of 22 health care professional, payer, and consumer organizations—was initiated in 1995 to develop, produce, and disseminate evidence-based clinical practice guidelines (CPGs) for the SCI clinical and consumer communities. The CPGs are recommendations to health care providers based on current research findings that experts have graded for their scientific strength and validity. There is a clear connection between the present topic of best practices/CPGs and the primary investigations of intervention effectiveness that are then summarized and analyzed in a systematic review of the current body of evidence (see the pertinent section earlier in the

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[190] Refer to http://www.smartrisk.ca/index.php/aboutSR/C10. Accessed January 2011.
[191] Refer to http://www.smartrisknoregrets.ca/index.php/aboutNR/. Accessed January 2011.
[192] Harrison CL, Dijkers M. Spinal cord injury surveillance in the United States: an overview. *Paraplegia.* 1991; 29(4): 233-46.

report); the main difference between the two efforts is that practice guidelines build on the evidence summary to make clear recommendations about a set of standard practices that should be adopted.

The 11 CPGs currently available through the Consortium are as follows:[193]

- Bladder Management for Adults with SCI
- Respiratory Management following SCI
- Neurogenic Bowel Management in Adults with SCI
- Acute Management of Autonomic Dysreflexia
- Prevention of Thromboembolism in SCI
- Early Acute Management in Adults with SCI
- Preservation of Upper Limb Function following SCI
- Depression following SCI
- Outcomes following Traumatic SCI
- Pressure Ulcer Prevention and Treatment Following SCI
- Sexuality and Reproductive Health in Adults with SCI

In addition, the American Dietetic Association has published evidence-based practice guidelines for registered dietitians on nutrition care for patients with SCI.[194] The American Association of Neurological Surgeons has also developed a set of guidelines for the management of acute cervical spine and cervical spinal cord injuries; these guidelines are for the most part related to specific surgical techniques.[195]

Several other researchers and organizations worldwide are working towards the goal of establishing guidelines for best practice in SCI care.[196] The European Spinal Cord Injury Federation, founded in 2005, is engaged in a guideline development project as part of its vision to improve the quality of life of individuals living with SCI. In Canada, the Rick Hansen Institute is funding a translational research project with the ultimate goal of creating a national standard of care for acute SCI; the project will build on systematic reviews of many areas of SCI care in order to create a consensus on best practice recommendations.[197]

These commitments are laudable; however, guidelines are only as good as the evidence reviews upon which they are built. Clearly, more work is required at the level of basic and clinical research in order to provide the evidence base for guideline development. One example of the gaps in evidence was provided by McMaster University's Evidence-based Practice Centre report from 10 years ago on the management of chronic neuropathic pain following SCI.[198] The reviewers concluded that weak methods (e.g., small samples) had been used in the few studies

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[193] Available at http://www.pva.org/site/PageServer?pagename=pubs_main#CPG. Accessed January 2010.
[194] Available at http://www.adaevidencelibrary.com/topic.cfm?cat=3485&library=EBG. Accessed January 2010.
[195] Available at http://www.spineuniverse.com/professional/acute-cervical-spine-injury-guide. Accessed January 2010.
[196] For examp0le, Perrouin-Verbe B, Ventura M, Albert T et al. Clinical practice guidelines for chronic neuropathic pain in the spinal cord injury patient: introduction and methodology. *Annals of Physical and Rehabilitation Medicine*. 2009; 52(2): 77-82.
[197] Refer to http://www.rickhansen-institute.org/index.php?option=com_content&view=article&id=62%3Aacute-care-and-treatment-systematic-review-of-the-literature&catid=41%3Acurrent-research-projects&Itemid=70&lang=en. Accessed January 2010.
[198] Jadad A, O'Brien MA, Wingerchuk D, and the McMaster University Evidence-based Practice Centre. *Management of Chronic Central Neuropathic Pain Following Traumatic Spinal Cord Injury*. 2001. Available at http://www.ncbi.nlm.nih.gov/bookshelf/br.fcgi?book=erta45. Accessed July 2010.

of pain after SCI that had been published, making it difficult to develop recommendations based on intervention evidence. In fact, a traditional clinical practice guideline for pain management in SCI has not been published; this may be a reflection of the currently weak evidence base. According to a more recent review, progress has continued to be slow in this area, with the controlled trials being "surprisingly rare given the high prevalence and impact of pain in this population."[199] The conclusion as late as 2007 was that there were still no routinely effective treatments for SCI pain. Nonetheless, efforts at improving this situation continue to be pursued. For instance, two different study groups, from Denmark and Australia, did devise an algorithm for pain treatment following SCI that synthesized the available evidence 4-5 years ago; a French organization followed up with an algorithm in 2009.[200] This sort of algorithm development represents the state-of-the-art that is a likely direction for future CPG work in chronic pain management and other areas of care. Reflecting the incomplete knowledge base, a leading authority recently acknowledged that all pain treatment modalities need further exploration to refine the management algorithm.[201]

Another example of gaps in SCI protocol development is offered by pressure ulcers. Despite the amount being invested in dealing with SCI-related pressure ulcers, the research on effective therapy is still limited, as is the evidence to guide improvements in care. As a consequence, pressure ulcers remain a complex and often chronic problem for which "no gold standard for prevention or treatment has yet been established."[202] Again, the opportunities to expand research into the management of pressure ulcers appear to be substantial, including ways to encourage consistent implementation of best practices, which represents the next step in any translation program. Poor adherence to clinical guidelines is a problem facing people with SCI and others who suffer from pressure ulcers. A well-known study in the Netherlands highlighted this issue through a survey of over 16,000 patients in 89 health care centres on one day; no more than a third of the patients at risk for pressure ulcers were found to be receiving recommended interventions.[203]

Development and Tracking of Outcome Measures

Although some measures approach a century in origin, it is important for the next generation of researchers to appreciate how the past has shaped our current concepts so that they may project their future role in SCI care and cure.[204]

There are in excess of a hundred and fifty measures which have been developed for use with individuals with SCI.[205] The oldest measures of neurological impairment trace their origins back to 1912; indeed, certain ones were incorporated into the American Spinal Injury

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[199] Ullrich PM. Pain following spinal cord injury. *Physical Medicine & Rehabilitation Clinics of North America.* 2007; 18(2): 217-33, vi.
[200] Attal N, Mazaltarine G, Perrouin-Verbe B et al. Chronic neuropathic pain management in spinal cord injury patients. What is the efficacy of pharmacological treatments with a general mode of administration? (oral, transdermal, intravenous). *Annals of Physical Medicine and Rehabilitation.* 2009; 52(2): 124-41.
[201] Siddall PJ. Management of neuropathic pain following spinal cord injury: now and in the future. *Spinal Cord.* 2009; 47(5): 352-9.
[202] Thomas DR. Prevention and treatment of pressure ulcers. *Journal of the American Medical Directors Association.* 2006; 7(1): 46-59.
[203] Bours GJ, Halfens RJ, Abu-Saad HH et al. Prevalence, prevention, and treatment of pressure ulcers: descriptive study in 89 institutions in the Netherlands. *Research in Nursing & Health.* 2002; 25(2): 99-110.
[204] Ditunno JF. Outcome measures: evolution in clinical trials of neurological/functional recovery in spinal cord injury. *Spinal Cord.* 2010; 48(9): 674-84.
[205] Miller WC, Sakakibara BM, Noonan VK et al. Outcome Measures. In: Eng JJ, Teasell RW, Miller WC et al., eds. *Spinal Cord Injury Rehabilitation Evidence. Version 3.0.* Vancouver: 2010.

Association (ASIA) measurement instrument, the current clinical gold standard for assessing and reporting the severity of SCI.[206] Given the fast-paced evolution of outcome measures in SCI, tracking the development and clinical usage of specific measures is challenging. Furthermore, quantity is not the same thing as quality; most SCI metrics still need to be tested in real world application. Johnston and Graves explained that "the scarcity of fully validated outcome measures can be particularly problematic in many low-frequency conditions, including the different levels and types of spinal cord injury." [207] While the research community is unanimous in calling for further validation studies, it is still important to acknowledge the progress has been made over the last 100 years.[208]

Initially, objective outcome measures served a critical purpose in classifying the severity of neurological impairment following spinal cord injury.[209] Over time these measures were modified in order to evaluate therapeutic treatments in the acute and rehabilitation phase. In recent years, topics such as overall quality of life, sexual health, psychological functioning, and community participation have gained increased attention from researchers, resulting in the development of a variety of new measures.[210,211,212,213]

The table below provides a comprehensive but not exhaustive list of outcome measures related to SCI.

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[206] Ditunno JF. Outcome measures: evolution in clinical trials of neurological/functional recovery in spinal cord injury. *Spinal Cord.* 2010; 48(9): 674-84.
[207] Johnston MV, Graves DE. Towards guidelines for evaluation of measures: an introduction with application to spinal cord injury. *Journal of Spinal Cord Medicine.* 2008; 31(1): 13-26.
[208] Alexander MS, Anderson KD, Biering-Sorensen F et al. Outcome measures in spinal cord injury: recent assessments and recommendations for future directions. *Spinal Cord.* 2009; 47(8): 582-91.
[209] Ditunno JF. Outcome measures: evolution in clinical trials of neurological/functional recovery in spinal cord injury. *Spinal Cord.* 2010; 48(9): 674-84.
[210] Hill MR, Noonan VK, Sakakibara BM et al. Quality of life instruments and definitions in individuals with spinal cord injury: a systematic review. *Spinal Cord.* 2010; 48(6): 438-50.
[211] Abramson CE, McBride KE, Konnyu KJ et al. Sexual health outcome measures for individuals with a spinal cord injury: a systematic review. *Spinal Cord.* 2008; 46(5): 320-4.
[212] Sakakibara BM, Miller WC, Orenczuk SG et al. A systematic review of depression and anxiety measures used with individuals with spinal cord injury. *Spinal Cord.* 2009; 47(12): 841-51.
[213] Noonan VK, Miller WC, Noreau L. A review of instruments assessing participation in persons with spinal cord injury. *Spinal Cord.* 2009; 47(6): 435-46.

Selected Outcome Measures Applied to SCI

Outcome Measure	Date 1st Published
Body Function/Structure	
Beck Depression Inventory	1961
Norton Measure	1962
Ashworth and Modified Ashworth	1964
Gosnell Measure	1973
Center for Epidemiological Studies Depression Scale	1977
Sexual Attitude and Information Questionnaire	1978
Donovan SCI Pain Classification System	1982
American Spinal Injury Association (ASIA): Neurological Classification*	1982
Brief Symptom Inventory	1983
Tunk's Classification Scheme	1986
Braden Scale	1987
Sexual Interest and Satisfaction Scale	1990
Stirling's Pressure Ulcer Severity Scale	1994
Emotional Quality of the Relationship Scale	1994
Depression Anxiety Stress Scale	1995
Wheelchair Users Shoulder Pain Index	1995
Spinal Cord Injury Pressure Ulcer Scale Measure	1996
Sexual Interest, Activity, and Satisfaction Scale	1996
Sexual Activity and Satisfaction Scale	1996
Sexual Behaviour Scale	1996
Knowledge, Comfort, Approach and Attitude Toward Sexuality Scale	2003
Spinal Cord Injury Pressure Ulcer Scale – Acute	1999
Surface Electromyography	2000
Classification System for Chronic Pain in SCI	2002
Moorong Self-Efficacy Scale	2003
Patient Health Questionnaire (PHQ-9)*	2004
Penn Spasm Frequency Scale	2005
The Multidimensional Pain Inventory – SCI version	2006
Spinal Cord Injury Secondary Conditions Scale	2007
Spinal Cord Assessment Tool for Spastic Reflexes	2007
The Spinal Cord Injury Spasticity Evaluation Tool	2007
SCI Exercise Self-Efficacy Scale	2007
Six-Minute Arm Test	2007
Spinal Cord Lesion Coping Strategies Questionnaire	2008
Multidimensional Pain Readiness to Change Questionnaire	2008
Spinal Cord Lesion Emotional Wellbeing Questionnaire	2008
Quantitative Sensory Testing	2009
The Appraisals of DisAbility: Primary and Secondary Scale	2009

Outcome Measure	Date 1st Published
Mobility	
Jebsen Hand Function Test	1969
Berg Balance Scale	1989
Hand-Held Myometer	1992
Functional Standing Test	1994
Sollerman Hand Function Test	1995
Tool for assessing mobility in wheelchair-dependent paraplegics	1998
Capabilities of Upper Extremity Instrument	1998
Wheelchair Circuit	1998
Walking Index for Spinal Cord Injury	2000
The Grasp and Release Test	2001
The Spinal Cord Injury Functional Ambulation Inventory	2001
Wheelchair Skills Test	2002
Functional Tests for Persons who Self-Propel a Manual Wheelchair	2003
Clinical Outcome Variables Scale	2003
Tetraplegia Hand Activity Questionnaire	2004
Timed Motor Test	2004
10 Meter Walking Test	2005
The Van Lieshout Test Short Version	2006
Self-Care	
The Barthel Index	1965
Quadriplegia Index of Function	1980
Frenchay Activities Index	1983
Functional Independence Measure (FIM)*	1990
Self Care Assessment Tool	1992
The Spinal Cord Independence Measure	1997
Spinal Cord Injury Lifestyle Scale	1998
Quadriplegia Index of Function	1999
Skin Management Needs Assessment Checklist	1999
Physical Activity Scale for Individuals with Physical Disabilities	2002
Participation	
The Craig Handicap Assessment & Reporting Technique (CHART)*	1980
The Community Integration Questionnaire	1994
Impact on Participation and Autonomy Questionnaire	1999
Reintegration to Normal Living Index	2002
Physical Activity Recall Assessment for People with SCI	2005
Quality of Life	
The Sickness Impact Profile 68	1981
Satisfaction with Life Scale	1985
Life Satisfaction Questionnaire	1991
The Short Form 36	1992
Quality of Life Profile for Adults with Physical Disabilities	1996
Qualiveen	2001
Quebec User Evaluation of Satisfaction with Assistive Technology	2002

= Measure specific to SCI

* = Tracked in U.S. National Spinal Cord Injury Database

Source: Miller et al., *Spinal Cord Injury Rehabilitation Evidence*, 2010.

Three markers of progress observable in the table that are specific to the last 25 years include:

1. **Increasing rate of emergence** of new outcome measures
2. **Growing range of categories—**as noted above, the focus on research has expanded in recent years to include areas such as quality of life and sexual health
3. The growing number of **SCI-specific measures** (indicated by the shading)

Generally speaking, development and validation efforts have focused on the following aims:

- Refining current outcome measures or developing and validating new measures
- Combining metrics to create more inclusive "global measures"

- Standardizing measures for use in databases to allow easier comparison between jurisdictions

An example of these aims in operation is offered by the International Spinal Cord Injury Data Set.[214] The core data set that has been proposed consists of 24 variables, including basic demographic characteristics, cause of injury, hospitalization data, place of discharge, measures of neurological condition (such as ASIA score), and ventilator status. The plan is for this standardized data set, if accepted and adopted, to be used to accurately describe and compare patient populations around the world.

While the SCI Data Set project is ongoing, there are already a number of registries that have been developed at a national level. The most long-standing example is the Spinal Cord Injury Database in the U.S. This registry has been collecting data since 1973; its annual reports now cover four outcome measures:[215]

- ASIA motor and sensory scores
- Functional Independence Measure (FIM)
- Patient Health Questionnaire (PHQ-9)
- Craig Handicap Assessment & Reporting Technique (CHART)

Two of these four measures (FIM and PHQ-9) have been developed in the time period of interest to this report, and the PHQ-9 as recently as 2004. It is encouraging that new, validated measures are being integrated into clinical and public health practice. However, neither of these measures are SCI- specific, which poses some limitations. For instance, researchers have noted that the FIM might not accurately reflect functional recovery after SCI. In response, there have been SCI-specific measures developed, such as the Spinal Cord Independence Measure (SCIM), to provide an update to the FIM.[216] These newer measures have not yet seen widespread adoption by registries or centralized databases. Moving forward, this will be one of the greatest challenges facing the SCI research community: ensuring standardization and adoption of measures that will allow better tracking progress in population-level outcomes—the topic to which this report will now turn.

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[214] Biering-Sorensen F, Charlifue S, DeVivo M et al. International Spinal Cord Injury Data Sets. *Spinal Cord.* 2006; 44(9): 530-4.
[215] DeVivo MJ, Go BK, Jackson AB. Overview of the national spinal cord injury statistical center database. *Journal of Spinal Cord Medicine.* 2002; 25(4): 335-8.
[216] Alexander MS, Anderson KD, Biering-Sorensen F et al. Outcome measures in spinal cord injury: recent assessments and recommendations for future directions. *Spinal Cord.* 2009; 47(8): 582-91.

Progress in Population-level Outcomes

Historically, clinical outcomes following spinal cord injury have been dismal. Over the past 20 years, the… long-term outcome of patients with spinal cord injury [has] improved with advances in both medical and surgical treatment.[217]

Outcomes are critical to evaluating progress in all areas of health care, including the high-burden condition of SCI. As covered in the previous section, there are many outcome measurements of interest in SCI research and care. The critical aspect to note is that the focus of this section is *population-level* outcomes rather than those generated in patient series and other types of studies. The main aim is to see where actual improvements have occurred in the personal and social experience of individuals with SCI. As well, there are outcomes relevant to society as a whole, including the area of health care efficiency. In a time of financial constraint and in the face of growing costs for ageing SCI survivors, issues of cost-effectiveness become all the more important. In a previous section of the report, what little is known about reduced incidence of SCI following prevention efforts was introduced. As will be made clear below, this outcome tracking suffers from the same limitation that affects other aspects of SCI care, namely, the dearth of national registries and clear trend information.

Five outcome areas will be addressed in this final part of the report:

- Survival/Life Expectancy
- Other Patient Outcomes
- Participation in Work and Physical Activity
- Access to Public Facilities and Transportation
- Health Care Efficiency

Survival/Life Expectancy in Traumatic SCI

Changes in life expectancy following SCI are a direct and strong reflection of the quality of care received across the continuum, including acute care, rehabilitation, and the ongoing management of chronic conditions. Tracking changes in life expectancy is challenging, as it requires a large data set that is tracked over a long period of time. The data set at the National Spinal Cord Injury Statistical Center (NSCISC) in the U.S. is substantially larger than those in other countries, and thus is the best source of data on this subject. For the present analysis, a number of published studies from other jurisdictions were also evaluated for comparison purposes. While changes in life expectancy are often reported in terms of the entire life course, changes in mortality (or, conversely, survival) are often reported for the first year, or the first two years, post-injury.

Trends indicating an overall decrease in mortality following a traumatic SCI have been consistently reported in the literature from various countries.[218] For example, a study from Canada estimated that there had been a 5-year increase in life expectancy post-SCI between 1980 and 1990; [219] in Denmark the 10-year probability of survival following SCI improved from 78.7% to 86.8% for men, and 72.1% to 86.9% for women between the periods 1953-1971

[217] Gupta R, Bathen ME, Smith JS et al. Advances in the management of spinal cord injury. *Journal of the American Academy of Orthopedic Surgery.* 2010; 18(4): 210-22.
[218] van den Berg ME, Castellote JM, de Pedro-Cuesta J et al. Survival after spinal cord injury: a systematic review. *Journal of Neurotrauma.* 2010; 27(8): 1517-28.
[219] McColl MA, Walker J, Stirling P et al. Expectations of life and health among spinal cord injured adults. *Spinal Cord.* 1997; 35(12): 818-28.

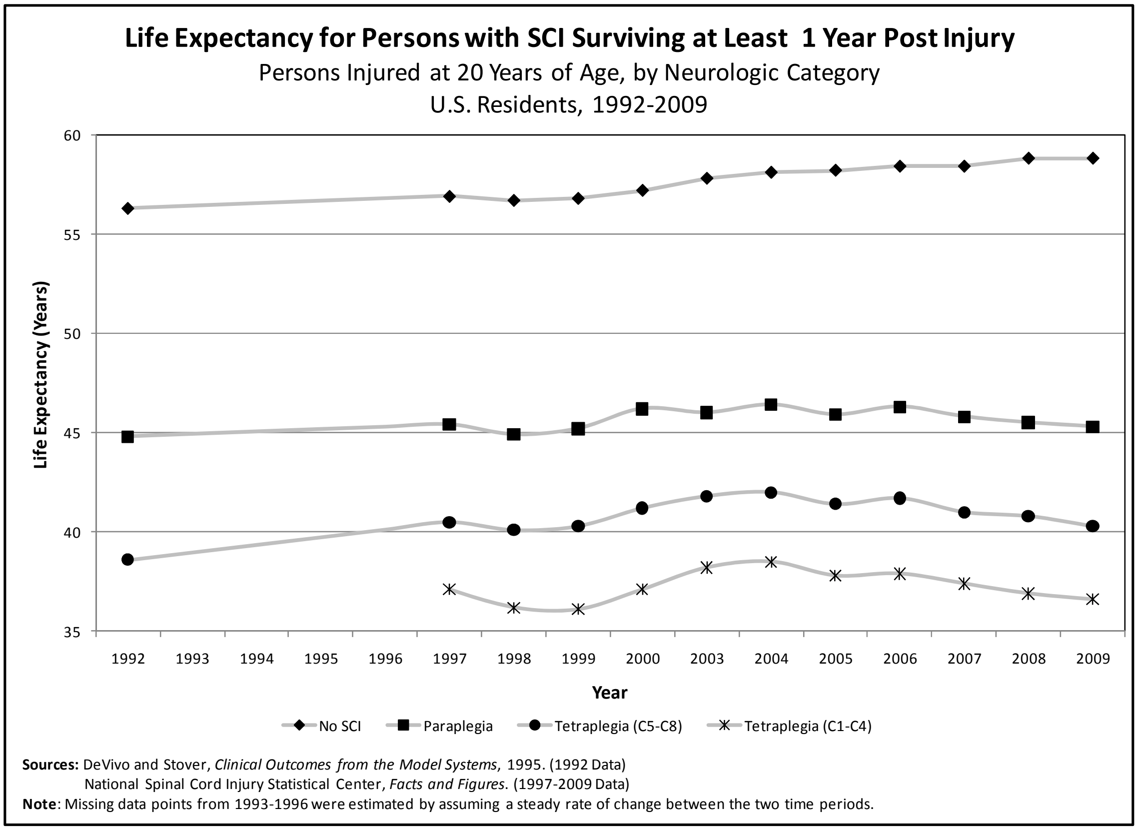
and 1972-1990.[220] In the UK, Frankel et al. observed a reduction in mortality of 70-80% between 1943 and 1990.[221] More recent research in Australia found a 36% reduction in death at two months post- injury, and a 27% reduction in death at one year post-injury between 1986-1991 and 1992-1997. However, all of these studies are restricted in that they are based on small sample sizes. For example, the Canadian and Danish studies included only 142 and 139 deaths, respectively.

Using the NSCISC database, DeVivo et al. assessed survival trends between 1973 and 1998 in a sample of 28,239 individuals with SCI.[222] They found that the odds of dying during the first year post-injury were reduced by 67% for persons injured between 1993 and 1998 compared to persons injured between 1973 and 1977. For those who survived at least one year, however, "mortality rates...which had been declining from 1973 to 1992, increased by 33% between 1993 and 1998 relative to persons injured between 1988 and 1992."

In a 2006 follow-up study by the same research group, trends in mortality during and after the first two years post-SCI were assessed. [223] In the first two years post-injury they observed a 40% reduction in mortality over the last three decades. For individuals with an SCI who survived at least two years, they observed a non-significant 17% reduction in mortality between 1970 and 1980, but no decline at all over the 25-year period from 1980 to 2004.

Data from the NSCISC between 1992 and 2009 confirm this lack of improvement in life expectancy, especially over the last decade. While the life expectancy of the average 20-year-old U.S. resident has increased consistently during this time period, there has not been a similar increase over time for individuals with an SCI (see following chart). This lack of an increase in life expectancy for an individual with an SCI is consistent for injuries occurring at 20, 40, or 60 years of age.

[220] Hartkopp A, Bronnum-Hansen H, Seidenschnur AM et al. Survival and cause of death after traumatic spinal cord injury. A long-term epidemiological survey from Denmark. *Spinal Cord.* 1997; 35(2): 76-85.
[221] Frankel HL, Coll JR, Charlifue SW et al. Long-term survival in spinal cord injury: a fifty year investigation. *Spinal Cord.* 1998; 36(4): 266-74.
[222] DeVivo MJ, Krause JS, Lammertse DP. Recent trends in mortality and causes of death among persons with spinal cord injury. *Archives of Physical Medicine & Rehabilitation.* 1999; 80(11): 1411-9.
[223] Strauss DJ, Devivo MJ, Paculdo DR et al. Trends in life expectancy after spinal cord injury. *Archives of Physical Medicine & Rehabilitation.* 2006; 87(8): 1079-85.



As outlined above, some substantial gains in life expectancy for persons with SCI have been realized over the past half-century. Short-term survival gains are particularly compelling; data from the NSCISC indicates a 40% improvement in 2-year survival post-injury over the past three decades, but no significant increase in long-term survival between 1980 and 2004. The most recent review drew the following conclusions:[224]

> *The absence of a substantial decline in mortality after the first 2 years post-injury is contrary to widely held impressions. Nevertheless, the finding is based on a large database and sensitive analytic methods and is consistent with previous research. Improvements in critical care medicine after spinal cord injury may explain the marked decline in short-term mortality. In contrast, although there have no doubt been improvements in rehabilitative care, their effect in enhancing the life span of persons with SCI appears to have been overstated.*

One possible explanation for the discrepancy in mortality improvements is that health care is privately funded in the U.S. for a large proportion of the population, and individuals with SCI may experience difficulties in paying for treatment, rehabilitation, and other management of their condition. These challenges may result in decreased life expectancies, and may explain why other jurisdictions with universal public funding of health care are still reporting increases in long-term survival for persons with SCI.

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[224] Strauss DJ, Devivo MJ, Paculdo DR et al. Trends in life expectancy after spinal cord injury. *Archives of Physical Medicine & Rehabilitation.* 2006; 87(8): 1079-85.

Other Patient Outcomes

Improving patient outcomes naturally represents the pinnacle of the "progress pyramid." It is the ultimate goal sought by SCI advocacy groups, researchers, and clinicians. However, tracking outcomes at a population level is currently very challenging. It requires a large, standardized dataset that has been sustained over a considerable period of time; at least ten years of comparable data are required in order to draw meaningful conclusions about any positive trends (i.e., progress). The largest dataset in the world that meets these requirements is derived from the SCI model systems program in the U.S., introduced earlier in this report. The program involves institutions providing comprehensive, multi-disciplinary care; it currently comprising SCI centres from 13 states.[225] National, standardized data collection, including medical and psychosocial outcomes, has been conducted by the model systems program since 1973. The database is currently housed at the National Spinal Cord Injury Statistical Center (NSCISC), located at the University of Alabama.

In order to evaluate the effectiveness of the model systems program, DeVivo conducted a comprehensive review of the NSCISC database, comparing the experiences of persons registered in its early stages (from 1973) with those derived from a similar cohort treated in more recent years (up to 2006). Some of the population-level improvements in outcomes noted in the past 30 years were as follows:[226]

- *Gains in neurologic improvement during acute care*. For the 2002-2006 period, among injuries that were initially neurologically complete, 15.1% became incomplete by discharge; by comparison, from 1973 to 1981 only 8.8% of neurologically complete injuries became incomplete.
- *Lower frequencies of in-patient (i.e., early) complications.* The risk of pneumonia and deep vein thrombosis were reduced by 64% and 51%, respectively, during initial hospitalization in 2002-2006 relative to 1992-1996.
- *Long-term improvements in measures of community integration.* The Craig Handicap Assessment and Reporting Technique (CHART) scores measured at 5 years post-injury increased for physical independence, occupational independence, social integration, and economic self-sufficiency from the 1992-1996 period to the 2002-2006 period.

It has been suggested that some of these improvements in outcomes may be traced to patient transfer from the emergency department or regular wards to specialized SCI units at the earliest opportunity; delay in such a transfer appears to cause further medical complications and prolonged rehabilitation.[227] Others have attributed the progress to the utilization of evidence-based treatment guidelines (discussed earlier in the report) and improved intensive care monitoring capabilities.[228]

Although gains have been made in some SCI outcomes, progress in other areas has proved more challenging. According to DeVivo, at 5 years post-injury there recently have been increased odds of medical complications such as renal stones, pulmonary emboli, and pneumonia compared with past decades; depression and pain levels also showed small

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[225] It is worth noting that some states in the U.S. (e.g., South Carolina) have developed state-of-the-art SCI care programs and data collection systems but are *not* part of the model system of care.
[226] DeVivo MJ. Sir Ludwig Guttmann Lecture: trends in spinal cord injury rehabilitation outcomes from model systems in the United States: 1973-2006. *Spinal Cord.* 2007; 45(11): 713-21.
[227] Inman C. Effectiveness of spinal cord injury rehabilitation. *Clinical Rehabilitation.* 1999; 13 Suppl 1: 25-31.
[228] Kelly DF, Becker DP. Advances in management of neurosurgical trauma: USA and Canada. *World Journal of Surgery.* 2001; 25(9): 1179-85.

increases.[229] Also, at 5 years post-injury there have been no significant improvements in self-reported health or life satisfaction—which likely relates to the aforementioned increased odds of medical complications and secondary conditions. The reasons for these discouraging results in the SCI population of the U.S. are still being elucidated, but one explanation may coincide with how the recent lack of improvement in life expectancy can be understood (see the preceding section of the report); in short, the negative effects on any ageing SCI patients dealing with the combination of constrained financial resources and private health care delivery in the U.S. may be coming into play, simultaneously increasing exposure to late complications and mortality. Whatever the causes, it appears that, after gains achieved earlier in history with respect to critical care, survival, and early rehabilitation, it is the long-term, post-acute rehabilitative phase of SCI care where some of the greater health challenges now lie and where important inroads have yet to be made.[230]

Participation in Work and Physical Activity

The increasing life expectancy after spinal cord injury has given social participation a new recognition as one of the ultimate goals of a comprehensive rehabilitation process.[231]

Community participation/integration was brought into special focus for health service providers with the 1980 publication *Health for All by the Year 2000* by the World Health Organization. Despite concerted efforts by the research community, defining and measuring the concept of participation and the closely related theme of community integration has proven to be complex and challenging.[232,233] One SCI-specific definition of community integration is as follows: "resuming age, gender, and culturally appropriate roles/statuses/activities, including independence/ interdependence in decision making, and productive behaviours performed as part of multivaried relationships with family, friends, and others in natural community settings."[234]

Based on this definition, the connection between a broad view of health and well-being among individuals with SCI and their level of community integration becomes very evident. Two of the most studied aspects of community integration, employment and sports and recreation participation, have been shown to decrease significantly following SCI.[235,236] Combating such trends is important. Being employed is positively correlated with measures of health, both

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[229] DeVivo MJ. Sir Ludwig Guttmann Lecture: trends in spinal cord injury rehabilitation outcomes from model systems in the United States: 1973-2006. *Spinal Cord.* 2007; 45(11): 713-21.

[230] Special Interest Group on SCI Model System Innovation. *Toward a model system of post-rehabilitative health care for individuals with SCI*. 2010. National Capital Spinal Cord Injury Model System. Available at http://www.ncscims.org/SCIModelSystemInnovationReport.pdf. Accessed January 2011.

[231] Noreau L, Fougeyrollas P, Post M et al. Participation after spinal cord injury: the evolution of conceptualization and measurement. *Journal of Neurologic Physical Therapy.* 2005; 29(3): 147-56.

[232] McColl MA, Davies D, Carlson P et al. The community integration measure: development and preliminary validation. *Archives of Physical Medicine & Rehabilitation.* 2001; 82(4): 429-34.

[233] Carpenter C, Forwell SJ, Jongbloed LE et al. Community participation after spinal cord injury. *Archives of Physical Medicine and Rehabilitation.* 2007; 88(4): 427-33.

[234] De Wolf A, Lane-Brown A, Tate RL et al. Measuring community integration after spinal cord injury: validation of the Sydney psychosocial reintegration scale and community integration measure. *Quality of Life Research.* 2010; 19(8): 1185-93.

[235] Tasiemski T, Bergstrom E, Savic G et al. Sports, recreation and employment following spinal cord injury--a pilot study. *Spinal Cord.* 2000; 38(3): 173-84.

[236] Schonherr MC, Groothoff JW, Mulder GA et al. Participation and satisfaction after spinal cord injury: results of a vocational and leisure outcome study. *Spinal Cord.* 2005; 43(4): 241-8.

subjective (e.g., life satisfaction) and objective (e.g., fewer medical treatments).[237,238] Similarly, recreation and sport participation has been correlated with higher indices of community integration and integration with "normal living," better psychological status (e.g., reduced depression, life satisfaction), physiological measures (e.g., reduced pain and fatigue), and even increased life expectancy among individuals with SCIs.[239,240,241,242,243,244] It is well known that individuals with SCI have among the lowest levels of physical activity participation, higher rates of cardiovascular disease risk factors (such as hypertension), and early onset of chronic diseases in general; while there is some evidence that exercise is an important avenue of prevention in this regard,[245] more study is needed concerning the specific impact of physical activity in reversing chronic disease risk patterns in the SCI population.[246]

The benefits of *resuming* appropriate roles enters into the equation with athletes who had been active pre-SCI; according to one study of such athletes, the social aspects of sports participation, such as fun and competition, were at least as important as fitness and health effects.[247] Exercise cannot be limited to athletes, however. The regular involvement of all persons with SCI in some form of leisure-time physical activity is a good way to maintain and extend the benefits of the targeted training programs that are the centrepiece of rehabilitation following the initial injury.[248] The importance of this area was summed up well in a 2004 review: "As the daily lifestyle of the average person with SCI is without adequate stress for conditioning purposes, structured exercise activities must be added to the regular schedule if the individual is to reduce the likelihood of secondary complications and/or to enhance their physical capacity."[249]

Attempts to track trends over the decades have been more apparent with employment than with sports or exercise. A recent review covering research from 1992-2005 showed that the

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[237] Krause JS. Adjustment to life after spinal cord injury: A comparison among three participant groups based on employment status. *Rehabilitation Counseling Bulletin.* 1992; 35(4): 218-29.
[238] Krause JS. The relationship between productivity and adjustment following spinal cord injury. *Rehabilitation Counseling Bulletin.* 1990; 33(3): 188-99.
[239] McVeigh SA, Hitzig SL, Craven BC. Influence of sport participation on community integration and quality of life: a comparison between sport participants and non-sport participants with spinal cord injury. *Journal of Spinal Cord Medicine.* 2009; 32(2): 115-24.
[240] Gioia MC, Cerasa A, Di Lucente L et al. Psychological impact of sports activity in spinal cord injury patients. *Scandanavia Journal of Medicine & Science in Sports.* 2006; 16(6): 412-6.
[241] Tasiemski T, Kennedy P, Gardner BP et al. The association of sports and physical recreation with life satisfaction in a community sample of people with spinal cord injuries. *NeuroRehabilitation.* 2005; 20(4): 253-65.
[242] Tawashy AE, Eng JJ, Lin KH et al. Physical activity is related to lower levels of pain, fatigue and depression in individuals with spinal-cord injury: a correlational study. *Spinal Cord.* 2009; 47(4): 301-6.
[243] Ditor DS, Latimer AE, Ginis KA et al. Maintenance of exercise participation in individuals with spinal cord injury: effects on quality of life, stress and pain. *Spinal Cord.* 2003; 41(8): 446-50.
[244] Slater D, Meade MA. Participation in recreation and sports for persons with spinal cord injury: review and recommendations. *NeuroRehabilitation.* 2004; 19(2): 121-9.
[245] Kehn M, Kroll T. Staying physically active after spinal cord injury: a qualitative exploration of barriers and facilitators to exercise participation. *BMC Public Health.* 2009; 9: 168.
[246] Fernhall B, Heffernan K, Jae SY et al. Health implications of physical activity in individuals with spinal cord injury: a literature review. *Journal of Health and Human Services Administration.* 2008; 30(4): 468-502.
[247] Wu SK, Williams T. Factors influencing sport participation among athletes with spinal cord injury. *Medicine and Science in Sports and Exercise.* 2001; 33(2): 177-82.
[248] Devillard X, Rimaud D, Roche F et al. Effects of training programs for spinal cord injury. *Annals de Readaption et de Medecine Physique.* 2007; 50(6): 490-8, 80-9.
[249] Jacobs PL, Nash MS. Exercise recommendations for individuals with spinal cord injury. *Sports Medicine.* 2004; 34(11): 727-51.

employment rate of individuals with SCI has remained at approximately 40%,[250] about the same level determined in an earlier study of the 15 prior years (1976-1991).[251] Despite what appears to be a static situation, maintaining employment levels can be seen as highly positive given the steadily increasing pool of SCI survivors;[252] furthermore, a "steady state" in terms of work involvement needs to be evaluated against the backdrop of *declining* employment rates among all disabled individuals in the U.S. in the last 25 years.[253] Finally, there is reason for encouragement with respect to the apparent growing interest in the vocational arena of community integration; the more recent review identified 48 pertinent studies over the 13 year period, compared to only 17 studies over a similar period located by the earlier research group.

Currently there is no population-based tracking of sports or recreation participation within the SCI community. However, as seen in the earlier section of this report that focused on sports infrastructure and events, it is clear that there is a growing interest and support for such activities at the elite level; there have been dramatic increases over the last 25 years in the number of nations, athletes, and sporting events in the Paralympic Games (see the table below).

Paralympic Games, 1960 - 2010

Summer

	1960	1964	1968	1972	1976	1980	1984	1988†	1992	1996‡	2000	2004	2008
Nations	23	21	29	41	32	42	45	61	82	104	127	136	148
Athletes	400	375	750	1,004	1,657	1,973	2,900	3,057	3,020	3,259	3,846	3,806	4,200
Sports	8	9	10	10	13	12	15	16	15	20	20	19	20

Winter

	1976	1980	1984	1988	1992	1994	1998	2002	2006	2010
Nations	16	18	21	22	24	31	32	36	39	44
Athletes	198	299	419	377	365	471	571	416	486	506
Sports	2	2	3	4	3	5	5	4	5	5

† First time games took place in same city as Olympic Games (since 64). First time Paralympic was used.
‡ First Paralympics to get mass media sponsorship.

Individuals participating at the elite level represent only a small portion of the overall SCI population; however, growth in the Paralympic movement is likely a good reflection for participation in organized sports, recreational activities, and exercise at all levels. While researchers have been active in constructing and validating instruments to allow more global measurements of community integration and participation for use with the SCI population,

250 Young AE, Murphy GC. Employment status after spinal cord injury (1992-2005): a review with implications for interpretation, evaluation, further research, and clinical practice. *International Journal of Rehabilitation Research.* 2009; 32(1): 1-11.
251 Murphy GC, Athanasou J. Vocational potential and spinal cord injuries: a review and evaluation. *Journal of Occupational and Organizational Psychology.* 1994; 85: 1782-92.
252 Strauss DJ, Devivo MJ, Paculdo DR et al. Trends in life expectancy after spinal cord injury. *Archives of Physical Medicine & Rehabilitation.* 2006; 87(8): 1079-85.
253 Bjelland MJ, Burkhauser RV, von Schrader S et al. *2009 Progress report on the economic well-being of working-age people with disabilities.*2009. Available at http://digitalcommons.ilr.cornell.edu/cgi/viewcontent.cgi?article=1283&context=edicollect. Accessed December 2010.

further comparison of the utility of the several candidate instruments is required.[254,255,256] Ultimately, the cause of SCI care and rehabilitation would be served internationally by "a standardized approach to reporting measures of activities and participation…for purposes of comparing rehabilitation outcomes in settings of differing socio-economic environments."[257] In the meantime, the benefits of sport participation, recreation, and leisure-time physical activity, as well as employment, for individuals with SCI are already clear; in fact, a recent study has shown that the employment rate among those with SCI increases with involvement in physical activity.[258] Thus, these two arenas of participation will continue to offer an important picture of community integration among those affected by SCI. At this juncture, there is solid reason for optimism concerning further progress on both fronts, that is, for the arenas of work and physical play. Maintaining and extending gains will require more research and policy focus on the individual and environmental barriers to participation.[259,260,261,262]

Access to Public Facilities and Transportation

A defining feature of SCI is the resulting impairment of function and (usually) mobility. Although there are a variety of functional outcomes that are possible post-SCI, the vast majority of individuals with SCI experiences mobility limitations; very commonly, this results in either permanent or intermittent use of a wheelchair. Individuals so affected are part of a broad and visible population that often faces challenges when attempting to access public spaces, facilities, and transportation services. With the establishment in many parts of the world of legislation to protect the rights of those with disabilities, there is now a strong mandate for improved access to public spaces. Such improvements, in tandem with technological advances in mobility devices, have led to considerable progress in access over the past 25 years.

Removal of Architectural Barriers

The primary way that wheelchair accessibility is improved is by providing features such as ramps and automatic doors in place of stairs and manual doors. This approach is commonly summed up as the removal of architectural barriers, and is mandated by law for public buildings in many parts of the world.

Measuring actual progress in this area, however, can be difficult. As described in an earlier section of this report, accessibility legislation in various jurisdictions has become more

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[254] De Wolf A, Lane-Brown A, Tate RL et al. Measuring community integration after spinal cord injury: validation of the Sydney psychosocial reintegration scale and community integration measure. *Quality of Life Research.* 2010; 19(8): 1185-93.

[255] Magasi SR, Heinemann AW, Whiteneck GG. Participation following traumatic spinal cord injury: an evidence-based review for research. *Journal of Spinal Cord Medicine.* 2008; 31(2): 145-56.

[256] Noonan VK, Kopec JA, Noreau L et al. Comparing the reliability of five participation instruments in persons with spinal conditions. *Journal of Rehabilitation Medicine.* 2010; 42(8): 735-43.

[257] Wee JY. Adjusting expectations after spinal cord injury across global settings: a commentary. *Disability and Rehabilitation.* 2006; 28(10): 659-61.

[258] Anneken V, Hanssen-Doose A, Hirschfeld S et al. Influence of physical exercise on quality of life in individuals with spinal cord injury. *Spinal Cord.* 2009; 48(5): 393-9.

[259] Kehn M, Kroll T. Staying physically active after spinal cord injury: a qualitative exploration of barriers and facilitators to exercise participation. *BMC Public Health.* 2009; 9: 168.

[260] Kennedy P, Sherlock O, McClelland M et al. A multi-centre study of the community needs of people with spinal cord injuries: the first 18 months. *Spinal Cord.* 2009; 48(1): 15-20.

[261] Boschen KA, Tonack M, Gargaro J. Long-term adjustment and community reintegration following spinal cord injury. *International Journal of Rehabilitation Research.* 2003; 26(3): 157-64.

[262] Lysack C, Komanecky M, Kabel A et al. Environmental factors and their role in community integration after spinal cord injury. *Canadian Journal of Occupational Therapy.* 2007; 74 Spec No.: 243-54.

complete and targeted since 1990. This development has generated obvious benefits, but it has also led to a challenge when evaluating progress. Accessibility is generally assessed in terms of how closely a building or transportation system adheres to legal requirements, rather than the actual reported or measured ability of wheelchair users to navigate to and through public spaces and services.

A review of the academic literature by Welage and Liu highlights the regular method of tracking accessibility. The review examines the findings of 12 separate studies (from 1987-2009) on wheelchair accessibility in the U.S., Mexico, Nigeria, Turkey, the United Arab Emirates, and Zambia; wheelchair accessibility is defined almost exclusively in terms of compliance to regulations rather than actual experience of access. The positive news is that adherence in fact has steadily improved over this time period, from rates below 50% in the 1990s to 90% or higher in more recent years. A primary driver for this change has been new construction; new buildings were shown to comply more fully with accessibility guidelines in every decade since the very earliest disability legislation was enacted.[263]

There are, of course, barriers to accessibility that are not architectural in nature. A 2002 study by Meyers et al. suggested that the most common environmental barriers are curbs and other structures that fall outside of the usual building codes. The authors also describe other categories, including interpersonal barriers such as prejudice and other forms of incivility expressed by people in society.[264] These more intangible impediments can hinder accessibility at least as much as architectural barriers. The present report covered the related topic of public perceptions and attitudes more fully in an earlier section.

Mobility Technology

Given the functional impairment that is typical following SCI, technologies aimed at restoring mobility can have a profound effect on the daily lives of individuals. Examples of such equipment include modified automobiles and, perhaps most notably, wheelchairs.

Surprisingly, depending upon design, wheelchairs themselves are sometimes seen as a barrier; a 2004 study by Chaves et al. found that inadequate wheelchair design that rivalled functional impairments per se or the physical environment in terms of participation.[265] Researchers and engineers have taken note, with technological advances in wheelchair design leading to improved, lighter-weight wheelchairs that are easier to manoeuvre, and thus increase functional independence. As well, powered wheelchairs have evolved rapidly over the past two decades, thereby providing previously impossible levels of unassisted mobility.[266,267,268] One popular example is the pushrim-activated power-assist wheelchair, which requires less force for propulsion than the standard manual wheelchair; this is particularly important for those with weakness in the upper extremities, for reducing physical strain on all users. Cutting-edge

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[263] Welage N, Liu KP. Wheelchair accessibility of public buildings: a review of the literature. *Disability and Rehabilitation: Assistive Technology*. 2010: Epub ahead of print.
[264] Meyers AR, Anderson JJ, Miller DR et al. Barriers, facilitators, and access for wheelchair users: substantive and methodologic lessons from a pilot study of environmental effects. *Social Science & Medicine.* 2002; 55(8): 1435-46.
[265] Chaves ES, Boninger ML, Cooper R et al. Assessing the influence of wheelchair technology on perception of participation in spinal cord injury. *Archives of Physical Medicine and Rehabilitation.* 2004; 85(11): 1854-8.
[266] Edlich RF, Nelson KP, Foley ML et al. Technological advances in powered wheelchairs. *Journal of Long-Term Effects of Medical Implants.* 2004; 14(2): 107-30.
[267] Cooper RA, Koontz AM, Ding D et al. Manual wheeled mobility--current and future developments from the human engineering research laboratories. *Disability and Rehabilitation.* 2010; 32(26): 2210-21.
[268] Attali X, Pelisse F. Looking back on the evolution of electric wheelchairs. *Medical Engineering and Physics.* 2001; 23(10): 735-43.

wheelchairs, termed robotic mobility devices, are being developed that can climb stairs and negotiate curbs. [269]

What has been very clear in recent decades is that everything must work together to enable full access to the community for individuals with SCI. As Chaves et al. note, “providing a wheelchair that fits well and is simple to operate without addressing environmental access may limit the potential benefits of the equipment. Similarly, an accessible environment is of no benefit if the equipment is difficult for the user to operate.” [270]

In addition, the personal dimension of access cannot be overlooked. As Meyers et al. report, wheelchair users are often only able to access public buildings and services with the assistance of friends, family members, or paid helpers, and must plan their lives accordingly.[271] Overall, the improvements that have been made to date in the area of accessibility have depended on taking many factors into account: physical barriers, assistive technology, public awareness, the availability of personal aides, and skill development. In order to continue the rate of progress, it is important to continue to integrate all of these aspects of the access sphere.

Health Care Efficiency

Given the global rise of health care costs, it is not surprising that scientific publications evaluating health care efficiencies have risen dramatically in recent decades. The U.S. Institute of Medicine defines health care efficiency as “avoiding waste, including waste of equipment, supplies, ideas, and energy.”[272] Creating efficiency in the health care system is always a tug-of-war between resources and care, with the ultimate goal of maximizing output from a given amount of input. Efficiencies can be generated by refining current practices and adopting new practices. Generally, any discussion of health care efficiency falls into one of two categories: improvements observed in real-world settings (actual) and improvements that have been measured in controlled settings (potential). In the SCI context, progress has been seen on both these fronts. In the real-world setting, the metric that is most often tracked is length of stay in in-patient care, whether acute or rehabilitation. In terms of potential gains, one of the best indicators is the pursuit of, and positive results from, cost-effectiveness (CE) studies. Each of these areas will be examined below from the perspective of SCI care.

Length of Stay

A common measure of actual efficiency improvement is a reduction in the average length of stay in a hospital or in-patient rehabilitation setting. As the chart below shows, the average acute hospital stay in the U.S. in 2002-2006 was less than half it was in 1973-1981.[273]

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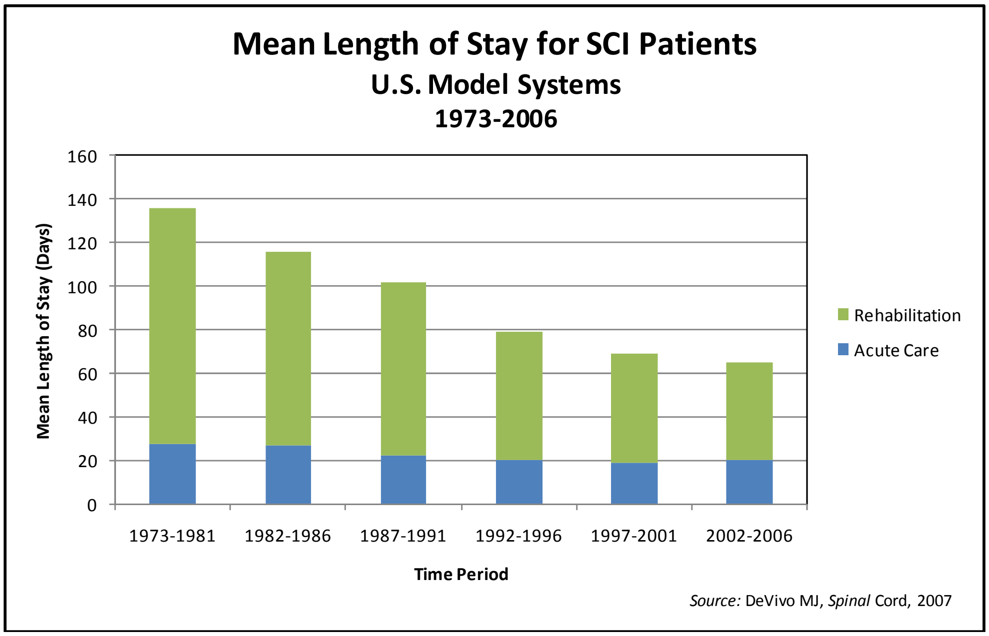
[269] Cooper RA, Cooper R. Quality-of-life technology for people with spinal cord injuries. *Physical Medicine and Rehabilitation Clinics of North America.* 2010; 21(1): 1-13.
[270] Chaves ES, Boninger ML, Cooper R et al. Assessing the influence of wheelchair technology on perception of participation in spinal cord injury. *Archives of Physical Medicine and Rehabilitation.* 2004; 85(11): 1854-8.
[271] Meyers AR, Anderson JJ, Miller DR et al. Barriers, facilitators, and access for wheelchair users: substantive and methodologic lessons from a pilot study of environmental effects. *Social Science & Medicine.* 2002; 55(8): 1435-46.
[272] Hussey PS, de Vries H, Romley J et al. A systematic review of health care efficiency measures. *Health Services Research.* 2009; 44(3): 784-805.
[273] DeVivo MJ. Sir Ludwig Guttmann Lecture: trends in spinal cord injury rehabilitation outcomes from model systems in the United States: 1973-2006. *Spinal Cord.* 2007; 45(11): 713-21.



This development has positive ramifications for the patient, as they are able to return home or to a community setting more quickly following injury, while at the same time reducing hospital crowding and health care costs. An important factor that must accompany decreasing lengths of stay is the maintenance of outcomes. In fact, this very issue is tracked in the Canadian setting by a combined metric introduced by the National Rehabilitation Reporting System (NRS),[274] namely, Length of Stay Efficiency.[275] The decreases in inpatient rehabilitation length of stay over the last decade have not resulted in any reduction in the average improvement in motor function score (which is based on the FIM instrument introduced earlier in this report).

The dramatic decrease in recovery/rehabilitation time in the U.S., Canada, and other jurisdictions has been credited to various changes in hospital management and specific advances in technology. There is a caveat, however, that must be added to this positive picture; according to DeVivo, daily health care costs *and* total costs in SCI care have continued to rise.[276] The increase is beyond inflation, perhaps driven (as in other parts of medicine) by the price of emerging drugs and technology. The challenge will be to create even more efficiency gains as the SCI population ages and patients incur greater costs related to managing late complications, both primary and secondary; to this end, various efforts to contain costs being examined in the U.S. managed care context may offer valuable insight.[277]

[274] The NRS data includes demographic, administrative and clinical information on clients from 101 participating facilities in nine provinces; managed by the Canadian Institute for Health Information (CIHI), the NRS has been collecting information on rehabilitation services and outcomes in the country since 2001, and reporting on specific client groups, including spinal cord dysfunction.
[275] CIHI. *Inpatient Rehabilitation in Canada, 2006-2007.* Available at http://secure.cihi.ca/cihiweb/products/NRS_2006_IRC_EN.pdf. Accessed January 2011.
[276] DeVivo MJ. Sir Ludwig Guttmann Lecture: trends in spinal cord injury rehabilitation outcomes from model systems in the United States: 1973-2006. *Spinal Cord.* 2007; 45(11): 713-21.
[277] Sundance P, Cope DN, Kirshblum KC. Systematic care management: Clinical and economic analysis of a national sample of patients with spinal cord injury. *Topics in Spinal Cord Injury Rehabilitation.* 2004; 10(2): 17-34.

Intervention Cost-Effectiveness

A previous section of this report examined the growing attention that has been paid to researching and synthesizing results concerning intervention effectiveness in SCI care. To this body of information must be added the insights derived from cost-effectiveness (CE) studies, an essential tool for evaluating new interventions prior to widespread implementation; as the information derived is related to the controlled environment of scientific studies, it may be fairly characterized as a marker of *potential* efficiency gains in the real-world setting.

Measuring the potential for progress in efficiency generally involves a comparison of relative efficiency, that is, evaluating two practices against one another in terms of costs and benefits, or one practice against a predetermined threshold.[278]

To date, CE studies in the SCI field have covered topics such as:

- Treatments for erectile dysfunction[279]
- Bowel management[280]
- Detection and treatment of thromboembolic disease[281,282,283]
- Respiratory pacemakers and mechanical ventilators[284]
- Drugs and other techniques for the control of muscle spasticity[285,286]
- Strategies to prevent urinary tract infections[287,288]

Results of such research can be helpful in selecting interventions to implement and in designing practice guidelines. For instance, Christensen et al. conducted a study comparing bowel management techniques for SCI patients; the authors found that transanal irrigation using a self-administered system, despite higher costs of operation, resulted in reduced symptoms of bowel dysfunction and a lower total cost to society compared with other available methods.[289]

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278 Hollingsworth B. The measurement of efficiency and productivity of health care delivery. *Health Economics.* 2008; 17(10): 1107-28.
279 Mittmann N, Craven BC, Gordon M et al. Erectile dysfunction in spinal cord injury: a cost-utility analysis. *Journal of Rehabilitation Medicine.* 2005; 37(6): 358-64.
280 Christensen P, Andreasen J, Ehlers L. Cost-effectiveness of transanal irrigation versus conservative bowel management for spinal cord injury patients. *Spinal Cord.* 2009; 47(2): 138-43.
281 Kadyan V, Clinchot DM, Colachis SC. Cost-effectiveness of duplex ultrasound surveillance in spinal cord injury. *American Journal of Physical Medicine & Rehabilitation.* 2004; 83(3): 191-7.
282 Wade WE, Spruill WJ. Cost comparison of tinzaparin versus enoxaparin as deep venous thrombosis prophylaxis in spinal cord injury: preliminary data. *Blood Coagulation & Fibrinolysis.* 2001; 12(8): 619-25.
283 Wade WE, Chisholm MA. Venous thrombosis after acute spinal cord injury: cost analysis of prophylaxis guidelines. *American Journal of Physical Medicine & Rehabilitation.* 2000; 79(6): 504-8.
284 Okuma I, Hayashi J, Kaito T et al. Functional electrical stimulation (FES) for spinal cord injury. *Acta Neurochirurgica.* 2003; 87: 53-5.
285 Rushton DN, Lloyd AC, Anderson PM. Cost-effectiveness comparison of tizanidine and baclofen in the management of spasticity. *Pharmacoeconomics.* 2002; 20(12): 827-37.
286 Midha M, Schmitt JK. Epidural spinal cord stimulation for the control of spasticity in spinal cord injury patients lacks long-term efficacy and is not cost-effective. *Spinal Cord.* 1998; 36(3): 190-2.
287 Barber DB, Woodard FL, Rogers SJ et al. The efficacy of nursing education as an intervention in the treatment of recurrent urinary tract infections in individuals with spinal cord injury. *SCI Nursing.* 1999; 16(2): 54-6.
288 Wielink G, Essink-Bot ML, van Kerrebroeck PE et al. Sacral rhizotomies and electrical bladder stimulation in spinal cord injury. 2. Cost-effectiveness and quality of life analysis. Dutch Study Group on Sacral Anterior Root Stimulation. *European Urology.* 1997; 31(4): 441-6.
289 Christensen P, Andreasen J, Ehlers L. Cost-effectiveness of transanal irrigation versus conservative bowel management for spinal cord injury patients. *Spinal Cord.* 2009; 47(2): 138-43.

Despite progress on a number of fronts related to cost-effectiveness, there are still gaps in the research literature. In a 2003 review of spinal injury units (SIUs), Bagnall et al. found no studies that looked at costs and patient outcomes side by side, meaning that cost-effectiveness has yet to be properly examined.[290] SIUs have the potential to improve efficiency, as prompt admission appears to lead to shorter average length of stay; furthermore, studies have shown that such units actually provide better care for patients.[291] In theory, these units should be able to act as centres for professional training, public awareness and primary prevention efforts; it remains to be proven if they will also work towards further improving the cost-effectiveness of SCI care.

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[290] Bagnall AM, Jones L, Richardson G et al. Effectiveness and cost-effectiveness of acute hospital-based spinal cord injuries services: systematic review. *Health Technology Assessment.* 2003; 7(19): iii, 1-92.
[291] Cardenas DD, Haselkorn JK, McElligott JM et al. A bibliography of cost-effectiveness practices in physical medicine and rehabilitation: AAPM&R white paper. *Archives of Physical Medicine and Rehabilitation.* 2001; 82(5): 711-9.

Conclusion: Making Progress in the Past, Present, and Future

In the past several decades there has been significant progress in improving patient survival and emergency care and in expanding the range of rehabilitative options.[292]

The statement above was already true before 1985; the aim of this report was to show how much more progress has occurred in the years since. There are many reasons to land on this particular timeline of interest, but one very important one stands out: Twenty-five years ago, SCI-survivor Rick Hansen began his famous *Man in Motion* World Tour, travelling in a wheelchair by manual power through 34 countries over two years. His message was an important one: given its devastating impacts, finding a full cure for spinal cord injury requires serious international attention; in the meantime, the best care needs to be delivered to individuals with SCI, so that they might enjoy the highest function and the fullest life possible.

The immediate benefits of the tour were clear: increased awareness of the needs and potential of individuals who have experienced SCI, many millions of dollars raised, and the first of many influential organizations and programs launched, the Rick Hansen Foundation. However, the effects have also been more long-term; when combined with the efforts of other leaders, such as Christopher and Dana Reeve, and building on societal momentum across many spheres of activity and concern, the accomplishments by and for those with SCI have been remarkable. As Rick Hansen is in the midst of his 25th anniversary tour, it is apt to take a moment to look back and examine the progress and anticipate the ongoing needs for attention. This report has begun this process, categorizing the topics under four domains that move from the “softer” areas of the environment experienced by the SCI community, through the record of research progress and developments in public health and clinical practice related to SCI, and finally to the “harder” results of actual patient and other outcomes—including improvements in the health care system itself.

Notwithstanding the need for focus in the report, the ultimate picture of progress that emerges is both varied and comprehensive. As noted below, other commentators have summed up the momentum and positive results related to specific aspects of SCI—but the compilation of topics assembled for this report tells a uniquely wide-ranging story.

The following table summarizes some highlights from this report covering the last 25 years of progress on SCI care and outcomes. Following the table are subsections offering a summation of the four main domains examined in this project, and some key directions that still need to be pursued.

[292] Committee on Spinal Cord Injury. *Spinal Cord Injury: Progress, Promise, and Priorities*. Washington, DC: National Academies Press; 2005.

A Quarter Century of Progress in Spinal Cord Injury *Care and Outcomes*		
Domain ***Sub-domain***	**Then: 25 Years Ago**	**Now: Circa 2010**
Environmental		
Organizational Infrastructure	Limited number of organizations	Major expansion of organizations around the world
Legislative & Policy Frameworks	Major legislation still being developed	Model legislation established in key countries
Sports Organizations & Events	Disabled sports well-established but still limited exposure	Paralympics a major global phenomenon
Public Perceptions & Attitudes	SCI and other disabilities not well understood	Measurable improvement in attitudes in some countries
Preferences in the SCI Community	SCI community consulted about priorities	Individuals with SCI at the centre of decision-making
Research Production		
Publication Volume	Less than 100 scientific articles per year, by title	Almost 450 publications per year related directly to SCI
Investigation of Potential Cures	Focus on the quest for a cure	Focus expanded to other biological aspects of recovery
Evolution of Research Focus	Less focus on rehabilitation and chronic care	Expanded focus on long-term care, including secondary complications
Intervention Effectiveness	Limited analyses of a limited evidence base	Multiple systematic reviews across many interventions
Translation to Application		
Primary Prevention	Limited attention on major causes of SCI	Substantial legislative and educational programs launched
Best Clinical Practices	Few clinical guidelines published	Guidelines published in multiple arenas
Outcome Measures	Small number of measures (mostly not specific to SCI) developed and in use	Majority of SCI-specific measures developed since 1985
Population-level Outcomes		
Survival/Life Expectancy	Enjoying gains in life expectancy across recent decades	Ongoing gains in short-term survival; possible flattening of improvements in long-term survival
Other Patient Outcomes	*One U.S. example:* 8.8% of complete injuries converted to incomplete (1973-81)	15.1% converted to incomplete (2002-6); certain other outcomes also improved
Community Participation	About 40% employment rate among individuals with SCI (1976-91)	Similar employment rate maintained in a much larger pool of survivors (1992-2005)
Access to Facilities	Limited legislation and assistive technology	Major breakthroughs in building codes, compliance, and equipment
Health Care Efficiency	*One U.S. example:* mean length of inpatient stay over 130 days (1973-81)	Length of stay about 60 days (2002-6)

Environmental Progress

The present report focused on the larger scale of environmental spheres, that is, society as a whole rather than the context defined by the home, workplace, etc. of a particular individual with SCI. Several of the environmental sub-domains have demonstrated remarkable progress in the last 25 years, especially the dramatic increase in networks, foundations, associations, and institutes dedicated to supporting and expanding SCI-related research and care. The fact that disability legislation has come to fruition in the last two decades is another encouraging development, as is the public profile of individuals from around the world with SCI and other disabilities being involved with sports, including the Paralympic Games.

Other environmental sub-domains are at an earlier stage of development, but a platform at least has been built upon which further gains may be made. Thus, the SCI community is being consulted more than ever about its concerns and needs, but this path could be followed further—especially regarding experience of people with such serious disabilities with stereotypes, prejudice, and similar negative attitudes.

Research Production

Quantitatively, there has been a steady increase in scientific publishing related to SCI, partly reflecting the launch of new specialty journals in the last 25 years. Even more encouraging is the large increase in clinical trials being published, as this represents the fountainhead of all translation and implementation work that eventually brings improvements in the medical care and everyday life of individuals with SCI. A 2010 review summed up this essential marker of progress as follows:[293]

> *There has been a tremendous increase in the number of basic science and clinical studies on spinal cord injury. Current areas of investigation include early acute management, including early surgical intervention, as well as new pharmacotherapy and cellular transplantation strategies. It is unlikely that a single approach can uniformly address all of the issues associated with spinal cord injury. Thus, a multidisciplinary approach will be needed.*

The sub-domain of basic research into cures—or at least partial organic reversal of SCI (as opposed to "work-arounds" that depend on classic rehabilitation, assistive devices, etc.)—remains a mixed affair, representing both a degree of disappointment and continuing optimism. There is no doubt that great strides in scientific insight have occurred, so that cure/reversal in the near future seems all the more probable. The recent state-of-the-art is aptly summed up in a U.S. Institute of Medicine (IOM) review monograph from 2005:[294]

> *The breadth and depth of neuroscience discoveries relevant to spinal cord injury have widely expanded the horizons of potential therapies. What once was dogma – that the central nervous system cannot regenerate—has been dismissed. This newly discovered potential for central nervous system (CNS) regeneration and repair has opened up numerous therapeutic targets and opportunities.*

On the other hand, the most important current story in this area may be the expansion of focus to see biological insights about the spinal cord, both damaged and whole, translated into therapies that will preserve function and even see improved function without full organic repair. Again, the IOM review of basic research in recent decades sums up this reality very well:

> *The new challenge facing researchers is to harness the expanding knowledge to develop effective treatments to protect and repair the spinal cord and improve or restore altered and lost function. To address this challenge, researchers must focus on a set of strategies to prevent further tissue loss, maintain the health of living cells and replace cells that have died through apoptosis or necrosis, grow axons and ensure*

[293] Gupta R, Bathen ME, Smith JS et al. Advances in the management of spinal cord injury. *Journal of the American Academy of Orthopedic Surgery*. 2010; 18(4): 210-22.
[294] Committee on Spinal Cord Injury. *Spinal Cord Injury: Progress, Promise, and Priorities*. Washington, DC: National Academies Press; 2005.

functional connections and re-establish synapses that restore the neural circuits required for functional recovery.

However, despite the need to maintain hope for a full cure or partial reversal of SCI, it is important to be realistic about the timeline. Multiple clinical trials are under way, seeking to advance pertinent insights from the "bench to the bedside." However, as Kwon et al. noted in 2010, "the task of clinical evaluation…is substantial, and many years will be required before the actual efficacy of the treatments currently in evaluation will be determined."[295]

While the "quest for a cure" (utilizing the title of a book from 1993 by Sam Maddox[296]) has become protracted, one consequence has been a recent expansion of research interest in other areas of care, including pre-hospital, rehabilitation, and preventing/treating secondary complications. The IOM monograph quoted earlier captures the importance of an expanded research focus as follows:

Spinal cord injury research should focus on preventing the loss of function and on restoring lost functions—including sensory, motor, bowel, bladder, autonomic, and sexual functions—with the elimination of complications, particularly pain, spasticity, pressure sores (decubitus ulcers), and depression, with the ultimate goal of fully restoring to the individual the levels of activity and function that he or she had before injury.

Translation to Application

The work of fostering improvements in SCI care is certainly not completed. For instance, it is certainly a concern that some 20% of trauma sufferers with SCI still die before being admitted to hospital.[297] Even when basic insights and potential interventions emerge for this and other areas of need, it is just the beginning. The various stages of "translating" the expanding research results into application in the real world starts with sifting the existing body of evidence in systematic ways, developing and testing practice guidelines, and then tracking the ultimate results in terms of patient and other outcomes. Progress has been made on all of these fronts, especially in terms of identifying and developing protocols for applying best practices; the Rick Hansen Foundation has liberally supported this cause by funding systematic reviews of published intervention evidence. One major advance in the realm of practical application has been the development of many more outcome measures specific to SCI; while many of these metrics are still being validated, they do hold out promise for better tracking of SCI outcomes in the future—especially in light of the commitment of the Rick Hansen Institute and other groups to expand and strengthen national and international registries of SCI patients.

Population-Level Outcomes

The intention to develop more robust SCI registries is welcome news, given how important such a tool is to tracking patient outcomes at a population level. Several encouraging results can already be identified, especially through the largest and longest-running SCI database that captures information from 13 states in U.S. In that context, there has been:

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[295] Kwon BK, Sekhon LH, Fehlings MG. Emerging repair, regeneration, and translational research advances for spinal cord injury. *Spine (Phila Pa 1976).* 2010; 35(21 Suppl): S263-70.

[296] Maddox S. *The Quest for a Cure: Restoring Function after Spinal Cord Injury.* Paralyzed Veterans of America, Washington, D.C.: 1993.

[297] Bernhard M, Gries A, Kremer P et al. Spinal cord injury (SCI)--prehospital management. *Resuscitation.* 2005; 66(2): 127-39.

- A 40% reduction in mortality in the first two years post-injury over the last three decades
- A gain in neurologic improvement during inpatient care, combined with lower frequencies of complications
- A long-term improvement in global measures of community integration, although understanding the positive aspect of work participation rates in particular requires a more nuanced assessment

In addition, a number of encouraging trends were identified in the report that extend beyond the individual to society as a whole, including broader compliance with building codes requiring accommodations to permit access to individuals dealing with disabilities such as SCI, and signs of improvements related to health care efficiency (notably, reduced length of stay in costly inpatient care settings).

The Next 25 Years

Driven by the enormous personal disaster and societal burden that SCI represents, it is clear that even more progress is needed. The last 25 years of positive developments, as summarized in the earlier table and the preceding commentary, may be attributed to people known and unknown—leaders with high profile such as Rick Hansen and countless other stakeholders, from researchers to health care providers to fund-raisers and volunteers, and most importantly the entire community of individuals dealing with SCI. A similar army will be required to continue to advance the cause over the next 25 years and realize Rick Hansen’s original vision from 1985: ***A world without paralysis after spinal cord injury.***