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REHABILITATION ENVIRONMENTAL SCAN ATLAS: CAPTURING CAPACITY IN Canadian SCI Rehabilitation

Rick Hansen Institute
Institut Rick Hansen

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REHABILITATION ENVIRONMENTAL E-SCAN ATLAS:

Capturing Capacity in Canadian SCI Rehabilitation

We gratefully acknowledge financial support for this project from the following organizations: Health Canada; Rick Hansen Institute (RHI) grants RHI-2008-14 and 2012-07; the Ontario Neurotrauma Foundation (ONF) grant 2012-RHI-E-Scan-954; and the Rick Hansen Foundation. Dr. Cathy Craven and Professor Molly Verrier were supported by the Toronto Rehabilitation Institute - University Health Network, which receives funding under the Provincial Rehabilitation Research Program from the Ministry of Health and Long-Term Care in Ontario. Dr. Wolfe was supported by Lawson Health Research Institute and the Department of Physical Medicine and Rehabilitation, Western University and by an ONF-RHI Capacity Building Award.

The views expressed do not necessarily reflect those of the Ministry. Rick Hansen Institute does not endorse or recommend any devices, equipment or procedures described in the Atlas unless specified.

The authors remain fully and solely responsible for the atlas and its contents.

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A Matter of Perspective

Foreword – Carl Hiebert

I was honoured when invited by the authors of the **Rehabilitation Environmental Scan Atlas: Capturing Capacity in Canadian SCI Rehabilitation,** to write the foreword for this publication. The Atlas offers individuals with spinal cord injury (SCI), their families and caregivers, clinicians and researchers a unique perspective of current SCI rehabilitation services in Canada. Much can be gained by understanding the current Canadian SCI rehabilitation landscape and, by creating this baseline, I hope that one day, every person with a spinal cord injury living in Canada will receive the best rehabilitation services available in the country.

After my spinal cord injury, rehabilitation was instrumental in my recovery, and was one of the many critical factors that allowed me to move forward and build a career as a motivational speaker, adventurer and photographer.

I remember that day as clearly as if it happened an hour ago. As a senior hang-gliding instructor, I was the one responsible for launching first to test the wind conditions. After checking my harness hookup once more, I ran off the cliff edge, gripping the control bar of my hang glider. It was the shortest flight of my life.

A gust of wind slammed my wing down into the hill. At the moment of impact, it felt like an internal rubber band snapped off its hooks and I realized something serious, something irrevocable, had happened. I turned my head side to side – no problem. Then my arms – full range of motion. Maybe this wasn't so bad after all. But when I went to move my legs, there was nothing. I tried again. Nothing. And then it hit me. I'd broken my back.

My thought process in the next few seconds was crystal clear. "I've broken my back. I'm going to spend the rest of my life in a wheelchair. I don't think I can handle this. I don't think I want to live." There was a slight delay, then the next thought was, "The real problem here is not my broken back, it's my attitude and how I choose to handle this." It was only after I came to this realization, that I yelled for help and began my journey as a paraplegic.

That sequence of events will remain with me forever as the most dramatic and poignant example of how our choice of perspective is fundamental to how we travel through life. We can't control the cards that we are dealt, but we can choose how to play them.

Three weeks into my rehabilitation program, some friends dropped by and told the nurses we were going out to the parking lot to get some fresh air. Before leaving, I hung a "Gone Flying" sign on my hospital room door in anticipation of what was to come. Within two hours, I was back in the sky, strapped in my friend's single-seat ultralight. Looking down on my empty wheelchair was another shift of perspective. Even if I couldn't walk, I could fly. I knew, in that moment, I had been given my gift of wings.

Within two years, I was running my own flight school as the first paraplegic flight instructor in Canada. Three years later, I became the first person to fly coast-to-coast in an ultralight. Through my adventures as a flight instructor and aerial photographer, what I delight in the most is finding a sense of harmony and natural rhythm to the land.

Often, our choice of perspective comes into play in the simple routine of daily living. On a drive home one winter's night, my front tire blew apart, leaving me stranded. Try as I might, the biting cold, snowdrifts and limitations of my wheelchair, made changing the tire impossible. My first reaction was one of complete frustration. And then the inner voice reminded me, "Hey this is about perspective. You had better walk the talk here, if this is really what you believe in." It took a couple of minutes to process that message, to decide that this would be an unexpected adventure, and I would accept whatever the outcome.

I alternated between keeping warm in the car and trying to flag down a vehicle. Eventually, a proverbial Good Samaritan showed and a half hour later, I was back on the road. I smiled all the way home, my change of perspective having made all the difference.

Perspective weighs heavily on how we confront challenges in life. As you read through this Atlas, I hope you appreciate the network of people and resources available to help you with your rehabilitation journey – and to consider that whether you are confronting a life-altering situation or a flat tire, your choice of perspective truly does make all the difference.

Carl Hiebert is a photographer, aviator, motivational speaker, adventurer, philanthropist, and author of six best-selling books. *www.giftofwings.ca*

Dear Reader

Like all good things in rehabilitation, this first Canadian National Atlas of SCI Rehabilitation is the product of interprofessional teamwork from a collaborative community of practice. Throughout the conception, design, implementation and reporting of the E-Scan, this project has been propelled by the genuine compassion and commitment of Canadian rehabilitation professionals to provide the best care to individuals living with the consequences of spinal cord injury.

From the outset, there was consensus that SCI rehabilitation in Canada has a marketing problem – the public does not understand the philosophy, goals or interprofessional nature of the psychological, physical, medical or surgical services necessary for optimal rehabilitation service delivery. In fact, most equate the term *rehabilitation* to reality TV-based drug and alcohol rehab programs. Thus, prior to embarking on this project, we spent a great deal of time developing and refining a framework of SCI rehabilitation, in order to communicate the individualized, goal oriented and multimodal nature of rehabilitation service delivery. Our intent was to ensure that the goals and processes of rehabilitation care are self-evident. Before delving into the content of the E-Scan, please take a few moments to familiarize yourself with this framework.

A brief national overview of the age, gender and injury of individuals with SCI, in Canada, and the duration of time spent in inpatient rehabilitation settings, are presented in the chapter, "*What does the E-Scan tell us about SCI Rehabilitation In Canada?"* These components provide the reader with an overview of where SCI rehabilitation occurs, who is served in SCI rehabilitation programs, and what these programs are all about.

Having developed the rehabilitation framework, we then sought to provide an accurate picture of the current Canadian SCI rehabilitation landscape, by conducting a scoping review. This is scientific speak for, "We used a variety of sources of information to describe current trends and gaps in SCI rehabilitation services in Canada". Data sources included published clinical practice guidelines, recent systematic reviews, care maps, local hospital care protocols; administrative, hospital utilization and billing data; clinical leaders, and nationally or internationally-recognized Canadian SCI content experts. For readers with scientific or epidemiological expertise, the scoping review methods are described, in considerable detail, in *The SCI Rehabilitation Framework, Modified Scoping Review Methods*, and *Report Card Decoding* chapters; as well as a publication in the Journal of Spinal Cord Medicine. The strength of the scoping review is the breadth of perspectives provided.

The scoping review results are reported as they relate to specific rehabilitation goals. Each chapter includes a short explanation of the rehab goal, a description of the current model of SCI service delivery (including the type and number of healthcare professionals and their related resources), and the key outcome measures and references used to inform current practice. Chapters contain a meaningful discussion of what is good, bad or ugly about current practice.

In addition, constructive suggestions regarding how to best implement changes in practice and/or service delivery in clinical care, research and policy are provided. A spotlight best practice organization is profiled within each chapter. Each spotlight site is one with exemplary practices that others should emulate. Each Atlas chapter culminates in a report card summarizing the current state of knowledge generation, clinical application and policy change, and specifies a key priority area to target, in order to facilitate advancement of the field prior to 2020.

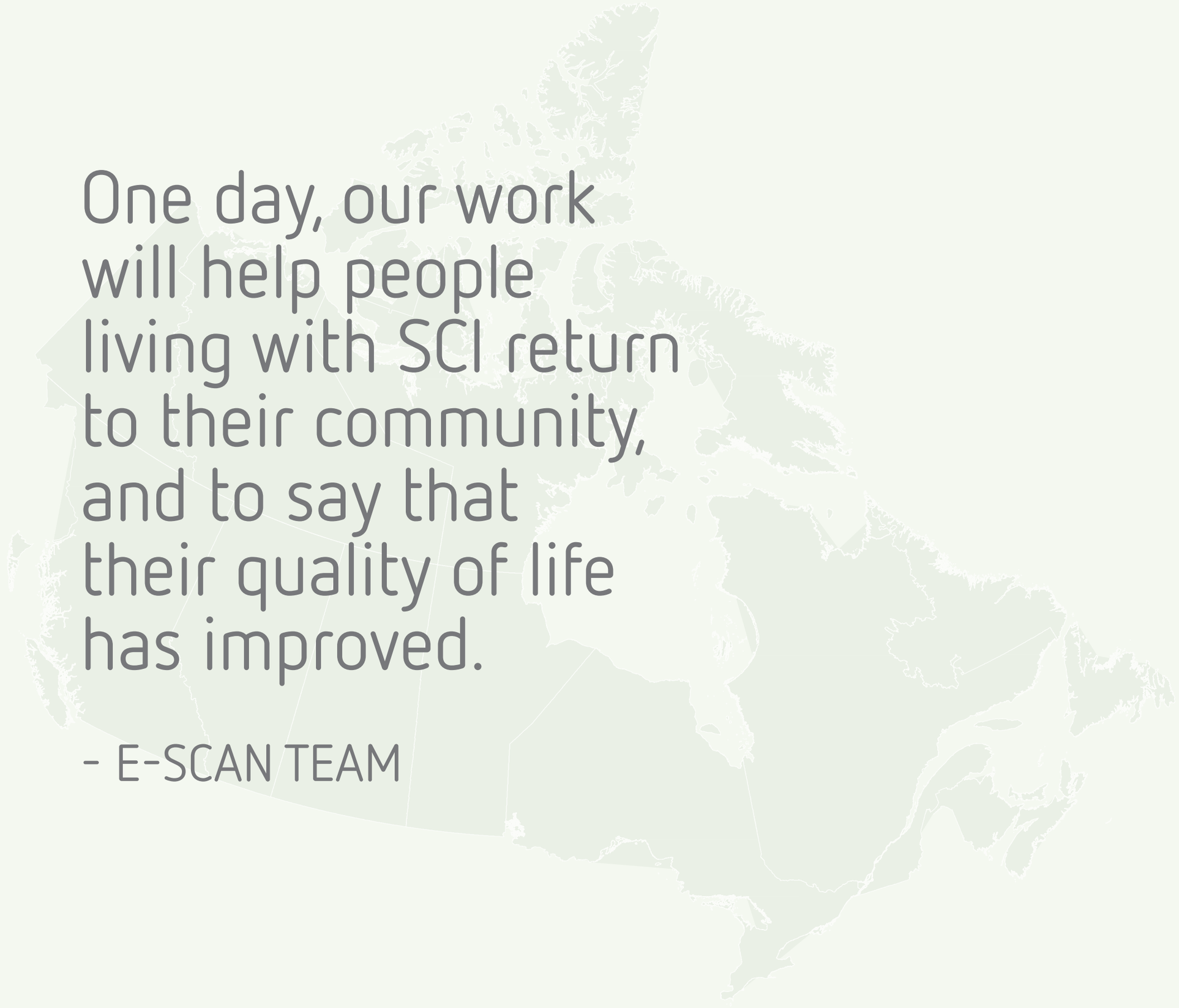
As you review the E-Scan chapters and familiarize yourself with our current capacity in SCI rehabilitation, we ask you to pause, reflect on the content, and commit to a discussion of the key messages at the end of each chapter, and the new perspectives in our final chapter, with friends, stakeholders and colleagues alike. The yield from this endeavor is dependent upon each reader carrying the messages (both positive and negative) contained within, and using them to drive change, within their practice setting or circle of influence. The Atlas may be freely printed and copied, but not altered from its original content, without the express written permission of the Rick Hansen Institute.

The Atlas was intended for use by multiple stakeholders including educators, clinicians, administrators, non-governmental organizations, lobbyists or health policy groups for a variety of purposes, including but not limited to facilitating program self-evaluation and restructuring, forcing future research or policy agendas, and informing current accreditation and best practice implementation activities.

On behalf of the investigative team, I offer our heartfelt thanks to the many unsung heroes who contributed their time, energy and enthusiasm to ensure timely delivery of the Atlas – by volunteering their time during lunch, evenings, weekends and holidays.

Please send us your commentary and feedback regarding the Atlas and its content, at: studies@rickhanseninstitute.org. Please join us in celebrating what rehabilitation has achieved, to date, and in demarcating our future directions! We trust the pioneering and collaborative spirit of Canadian SCI rehabilitation service providers persists to ensure, through realization of the 2020 vision for best practices in SCI rehabilitation, the best care possible for people living with spinal cord injury.

BC Craven, BA, MD, FRCPC, MSc
Physical Medicine & Rehabilitation
On behalf of the E-Scan Team



One day, our work will help people living with SCI return to their community, and to say that their quality of life has improved.

- E-SCAN TEAM

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The SCI Rehabilitation Framework

C Craven, MD; M Verrier, MHSc; C Balioussis, PhD; J Hsieh, MSc; DL Wolfe, PhD

The form and content of the data collection, synthesis and reporting of this scoping review of Canadian SCI rehabilitation stems from the SCI Rehabilitation Framework, (derived from the International Classification of Function, Disability and Health [ICF]) by the study of investigators.

The ICF is a classification system that underlies definition, measurement, and policy formulations in the fields of health and disability. A hybrid of medical and social models of disability, the framework depicts function and disability as interacting factors that relate to the individual, and contextual factors unique to the individual. The dimensions also interact with the environment, which encompasses external factors (such as architectural characteristics, legal and social structures, and climate), and personal factors - or the social context - which relate to the individual and his/her sociocultural surroundings (such as social background, education, profession, experiences, gender and age). The interplay between these factors influences how an individual experiences their SCI-related disability. These concepts are thought to be interactive and dynamic, rather than linear and static.

The Framework of SCI Rehabilitation goals displays the goal-oriented nature of SCI rehabilitation service delivery, within the dimensions of body structure and function, activity and participation. The hexagonal "mosaic" tiles of the rehabilitation goals represent the complex interplay of the individual's unique goals, as well as the interprofessional, multimodal nature of SCI rehabilitation service delivery: the variety of cognitive, physical and medical therapies and diagnostic interventions which target goal attainment. Emphasized is the central role of the individual with SCI, the need to customize and tailor rehabilitation goals and processes, and the consideration of personal factors and the individual's environment. The strength of the Framework is that it enables distinctions in disease, consequences of disease and contributing factors.

The Framework was developed *a priori* to conduct of the scoping review, using the rehabilitation goals to guide selection of relevant data elements, data collection, collation, and the data reporting process. The following case examples are intended to assist the reader in understanding how the rehabilitation framework is applied and customized care provided for each individual with SCI.

IN THIS FRAMEWORK, INFORMATION IS ORGANIZED INTO THE THREE ICF DIMENSIONS:

1

BODY STRUCTURE AND FUNCTION

The physiological and psychological body functions and anatomical body parts, as well as impairments that may occur, as a result of SCI.

2

ACTIVITY

The tasks and actions executed by an individual with SCI.

3

PARTICIPATION

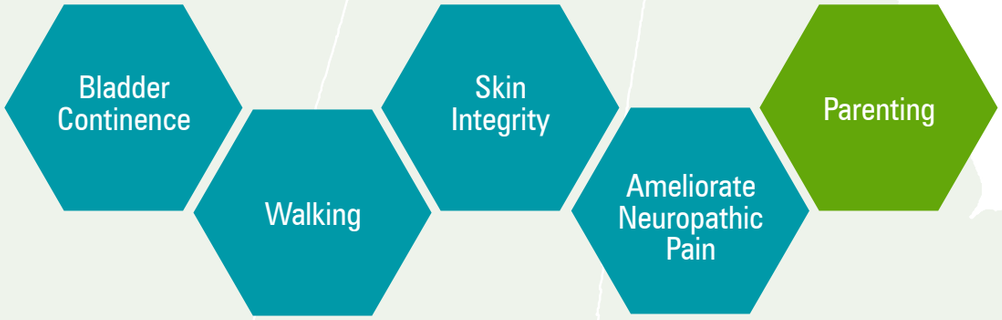
Involvement in life situations.

Framework of Rehabilitation Goals

Application of the Rehabilitation Framework

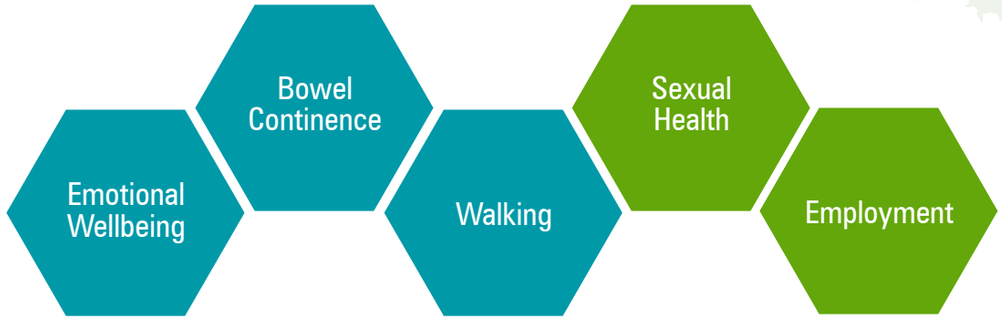
SUNSET

Sunset is a 68-year old woman with T6 incomplete paraplegia (AIS C), secondary to an aneurysm repair. Prior to her injury, she was the primary caregiver for her husband and two granddaughters aged three and four. Since she woke up from her surgery, she has developed burning pain in her legs, difficulties with getting to the toilet in time to void, and a pressure sore on her heel. In addition, she cannot stand for long periods of time or initiate stepping. Her customized rehab goals would include:



CHANCE

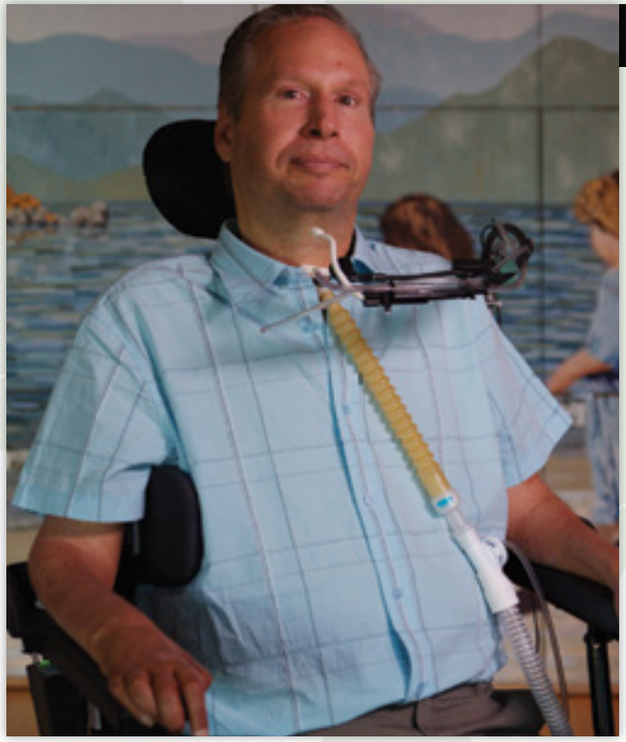
Chance is a 24-year old male who sustained T8 incomplete paraplegia (AIS B), secondary to a gunshot wound in the abdomen. As a result of his injuries, he had abdominal surgery requiring spleen removal and a temporary colostomy. Prior to his injury, he was completing a degree in architecture, and ran a small business on the weekends. He hopes to return to walking, and resume relations with his wife. He is concerned about his financial future and ability to return to work and school. His customized rehab goals would include:



in Clinical Practice

RESTLESS

Restless is a 40-year old woman with T10 complete paraplegia (AIS A) for more than 10 years. She has had ongoing difficulties with lower extremity spasticity for which she takes oral medications, and has Botox injections in her leg muscles, on a quarterly basis. She is afraid that the force of her leg spasms will throw her out of her chair. She recently injured her shoulder and has begun to develop a pressure sore on her ischia, due to deteriorating transfers. She is afraid of losing her community independence. Her customized rehab goals would include:



BREATHLESS

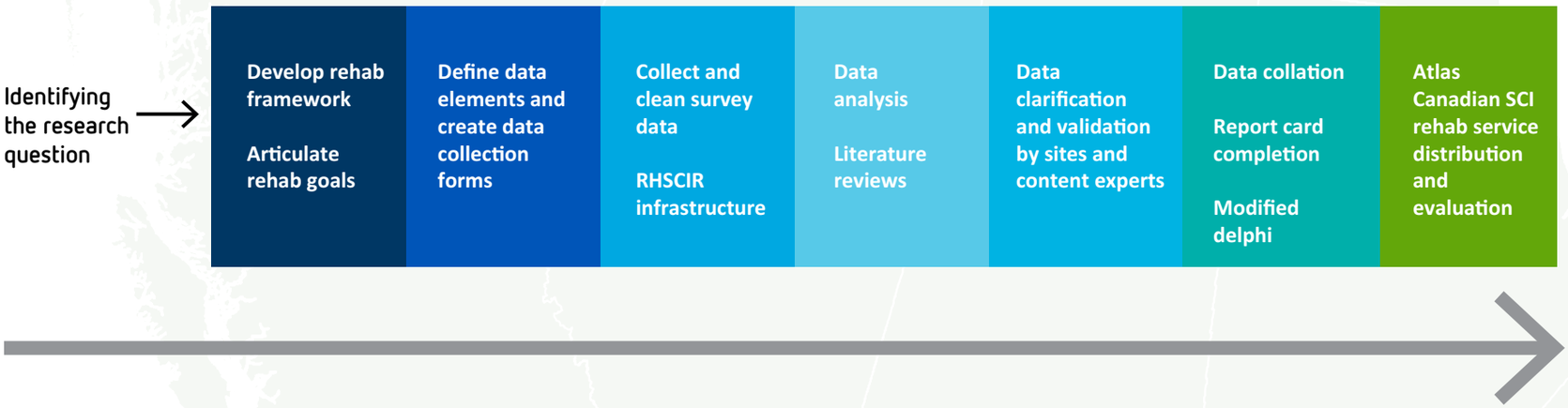
Breathless is a 53-year old male who developed C3 incomplete tetraplegia (AIS C) as a result of a diving accident during a trip to the Caribbean. He is eager to begin breathing on his own, feed himself and brush his teeth. He is anxious to know how he will move about his home and community. He is a strong believer in naturopathic medicine, and is reluctant to take prescription medications. His customized rehab goals include:

E-Scan Scoping Review Methods

The widely used six-step method for scoping reviews, described in the Arksey and O'Malley framework, was modified, by the investigative team, to align with the field and project scope.

Overview of E-Scan Methods

CRAVEN C, BALIOUSSIS C, VERRIER MC, HSIEH JT, CHERBAN E, RASHEED A, NOONAN V, WOLFE D.
USING SCOPING REVIEW METHODS TO DESCRIBE CURRENT CAPACITY AND PRESCRIBE CHANGE IN CANADIAN SCI REHABILITATION SERVICE DELIVERY. *J SPINAL CORD MED.* 2012;35(5):392-9.



Selection of Rehabilitation Goals from the Rehabilitation Framework was Based On:

- Accordance with the ICF framework
- Relevance to the Canadian context
- The state of existing literature/guidelines
- The richness of the dataset available after the multi-centre data collection
- Gaps, regional disparities or inequities
- Stakeholder domains of interest
- Alignment with the Rick Hansen Institute's Best Practice Implementation Program.

The Framework presents 37 goals of rehabilitation practice: 18 in body structure and function, nine in activity, and ten in participation. Each of the 17 selected rehabilitation goals forms a separate chapter of the E-Scan Atlas, and falls within a specific ICF domain:

1. Body structure and function: Walking, Reaching, Grasping and Manipulation, Cardiovascular Integrity, Skeletal Integrity, Skin Integrity, Bowel Continence, Bladder Continence, Ameliorate Neuropathic Pain, Independence in Breathing, Emotional Wellbeing and Optimizing Spasticity.

2. Activity: Wheelchair Mobility.

3. Participation: Community Participation, Employment and Vocation, Informed Self-Management, Physical Activity and Sexual Health.

Throughout this Atlas, we discuss each rehab goal in isolation, in order to clarify the underlying construct, and highlight the interprofessional and multimodal aspects of rehabilitation care. In reality, individuals have more than one rehab goal, and many of the goals and processes described occur concurrently.

Identification of Data Elements Relevant to Primary Objective

The review focused on providing an account of Canadian rehabilitation services and practices. Data elements were selected for their relevance to the rehabilitation goals and current practice. A substantial portion of the data was obtained from the web-based E-Scan survey. Patient utilization, availability and adequacy of staff resources, capital equipment and services were included in 3572 elements; and data regarding current clinical practice guidelines, care maps and publications (used to guide service delivery) were collected. Survey respondents were also asked to identify the clinicians and scientists likely to influence practice in the next five years.

A letter of introduction regarding the survey process, a data element codebook, and survey guide were distributed to participating sites, prior to data collection. Survey administration was web based. Typical respondents were administrators and clinicians from the 13 participating sites. Data were stored in a central online repository. Data cleaning was done prior to analysis.

Selection of Data Elements from Multiple Sources for Inclusion

In order to provide a comprehensive account of current practice, against the backdrop of best available practice, the E-Scan investigative team examined a number and variety of sources. These sources included published systematic reviews (www.scireproject.com), clinical practice guidelines, clinical trial and cohort study registries, recent conference programs, relevant Canadian white papers, and grey literature for data elements relevant to the focus of the scoping review and the 17 rehabilitation goals. Coincidentally, many of the SCIRE systematic review chapter authors (who had recently completed extensive reviews of MEDLINE, CINAHL, etc.) were recruited to assist with data identification, using long-established search terms, and specific data quality assessments tools, including the Downs and Black checklist and PeDRO scoring systems (www.pedro.org.au).

Descriptive Analysis of the Data Elements

The data from the E-Scan survey were analyzed using SPSS (version 19), and initial national summary reports were produced using descriptive statistics.

Collation, Summary and Results

Data for each rehabilitation goal were produced in written form for an initial audit, and review by an E-Scan investigative team member. Conventional scoping review methods for summary and weighting of the data acquired were not used, as the volume, type and nature of the data varied widely across rehabilitation goals, rendering cross-chapter comparisons of data impractical. Rather, experts' perception of the relevance of the data to practice was relied on, as the key filter.

Consultation with Stakeholders

Content experts, appropriate to the selected rehabilitation goals, were invited to participate in a series of WebEx teleconferences, regarding data interpretation and/or validation. Interprofessional working groups comprised at least five Canadian content experts per rehabilitation goal. Content review working groups then collated the summary findings (with information obtained from the aforementioned data sources, and their own expertise), and produced analytical interpretations of the information collected.

Each rehabilitation goal includes a definition of the key construct or goal, descriptors of current service delivery (including staff, resources, practice patterns and outcome assessments, current key practice references and guidelines in use), and a list of Canadian content experts likely to influence practice in the next five years. Reviewers were asked to identify best practice organizations and indicators, and to highlight clinical, research and policy barriers to service delivery, through the data collation process, based on their own expertise and knowledge or new insights obtained from the discussions or data triangulation. Validation of the information obtained was received from practicing clinicians, across the country, via WebEx.

Presentation of the Scoping Review Using a Formal Knowledge Transfer Strategy: Report Cards

The conclusion of each chapter of the Atlas features a report card, to provide an overall rating of SCI rehabilitation service delivery, relative to three domains:

- Knowledge generation
- Clinical application
- Policy change.

Each report card category contains four operationally defined sub-elements, rated on a scale from insufficient to optimal (-5 to +5) and converted to a visual scale. At the bottom of each report card is a priority rating, ranging from one to three (1 to 3), with one indicating the category/domain of highest priority. Priority ratings identify where prospective efforts and funding must be directed, to achieve evolution in rehabilitation service delivery and practice.Specifically, sights are set on the year 2020, to achieve significant enhancement in best practice. **Thus, the report cards serve as summaries for specific goals, as well as a means by which all rehabilitation goals, included in the Atlas, can be compared.** Content and participating experts also provide a "take home message", describing the steps required to revitalize the area of highest priority, between the time of the Atlas publication and 2020.

Report Card Decoding

The conclusion of each chapter of the Atlas features a report card, to provide an overall rating of SCI rehabilitation service delivery, relative to three domains:

1. KNOWLEDGE GENERATION
Current research endeavours (innovation) and their outcomes.

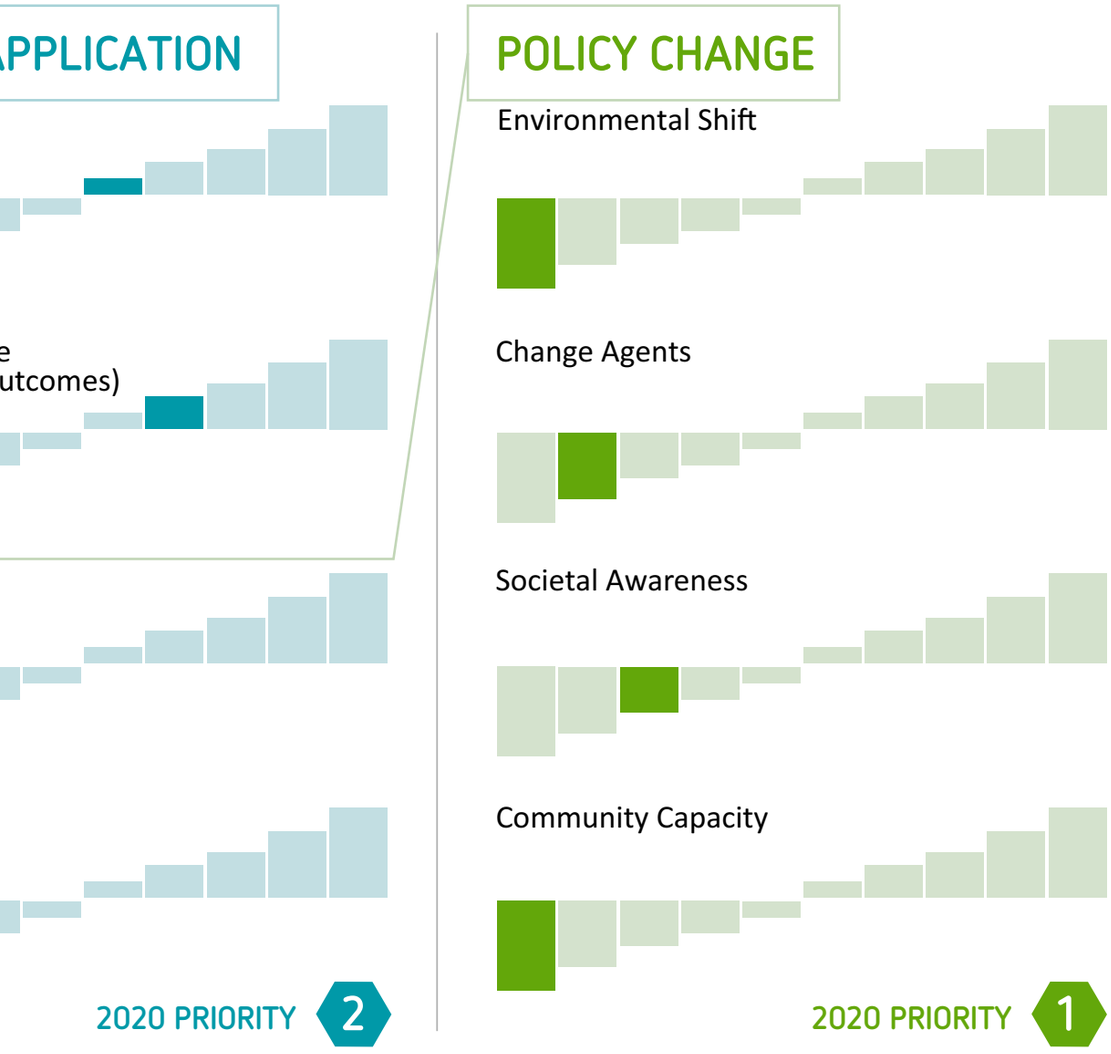
2. CLINICAL APPLICATION
The use of research and best practice findings, and their alignment with current clinical practice.

3. POLICY CHANGE
The extent to which health policy currently enables or impedes changes to service delivery.

TAKE HOME MESSAGE:

Content experts provide this summary, describing the steps required to revitalize the area of highest priority, between the time of the Atlas publication and 2020.

Extreme left below median: ***insufficient***
Extreme right above median: ***optimal***



FOUR OPERATIONALLY-DEFINED SUB ELEMENTS

Rated on a scale from insufficient to optimal (-5 to +5) and converted to a visual scale. Definitions for each sub element are provided on the subsequent pages.

PRIORITY RATING Ranging on a numerical scale from 1 to 3, with 1 indicating the category/domain of highest priority. Priority ratings identify the one category to which prospective efforts and funding must be directed, in order to achieve evolution in rehabilitation service delivery and practice.

Specifically, sights are set on the year 2020, to achieve significant enhancement in best practice. Thus, the report cards serve as summaries for specific goals, as well as a means by which rehabilitation goals in the Atlas, can be compared.

Report Card Decoding

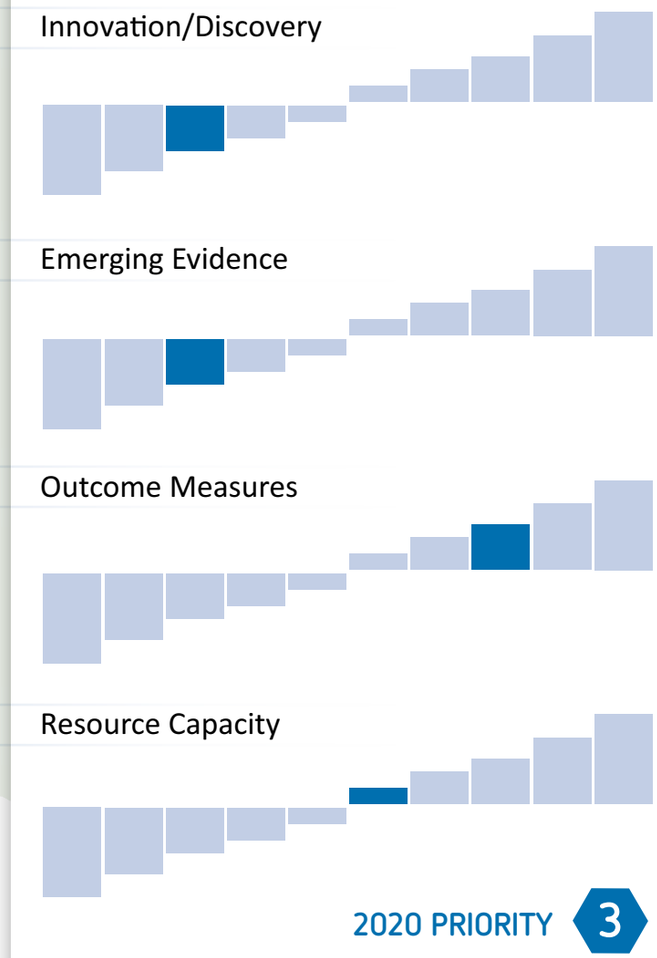
Innovation/Discovery
Novel methods, ideas, and/or practices that lead to advances in the field.

Emerging Evidence
The academic weight and clinical value of findings from ongoing and recently completed research studies.

Outcome Measures
The tools being used to estimate the results of a treatment and evaluate its effectiveness.

Resource Capacity
The extent to which the field has adequate graduate students, and basic and clinical scientists with the appropriate skills to investigate the needs expressed by individuals and service providers.

KNOWLEDGE GENERATION



Integrative Care
The multidisciplinary and synergistic approach to healthcare service delivery.

Effective Practice
The existence of clinical practice guidelines, best practice indicators or other relevant evidence to support practice implementation.

Equity Practice
The equivalence of care provision across the country.

Capacity
The number of specialized staff members and the state of their professional development across the country.

KNOWLEDGE GENERATION

The KNOWLEDGE GENERATION component of the report card provides a visual snapshot of rehabilitation research and research outcomes in Canada. Each indicator speaks to the current VOLUME and QUALITY of discovery and innovation, emerging evidence, outcomes and resources.

The indicators represent human resources, processes and outcomes driving knowledge generation in SCI rehabilitation rather than being direct measures of research dollars or investments.

CLINICAL APPLICATION

The CLINICAL APPLICATION component of the report card reflects the extent to which knowledge generated in rehabilitation research or practice science are IMPLEMENTED, EQUITABLY, throughout the

Environmental Shift
Formation of community groups or coalitions with common SCI rehabilitation/health interests.

Change Agents
Leaders, experts or organizations willing to partner to effect policy change.

Societal Awareness
General community awareness of the need for policy change to alter practice and influence the health of individuals with SCI and/or rehabilitation service delivery.

Community Capacity
Capacity of the SCI community and its' stakeholders to collaborate with policy makers during the planning, implementation, and evaluation of policy change.

country using interprofessional care models predicated upon evidence, using psychometrically valid outcome assessment tools by credentialed clinicians with specific SCI SPECIALTY training.

POLICY CHANGE

The POLICY CHANGE component of the report card provides an account of the state of awareness and readiness to lobby for meaningful change in health policy, based on the important issues to individuals, local and national SCI stakeholders and the broader Canadian society. The issues of importance must have penetrated the public opinion to the extent that there is consensus that policy change is RATIONALE and IMMINENT. These indicators reflect the MAGNITUDE and EFFECTIVENESS of the lobby for SCI health policy change.

Meet the Team

The following pages profile the E-Scan investigative team nembers and E-Scan participating sites.

Dalton L Wolfe PhD

Dr. Dalton Wolfe is an Associate Scientist in the Program of Aging, Rehabilitation and Geriatric Care in the Lawson Health Research Institute, London, ON, Canada; an Assistant Professor in the Bachelor of Health Sciences Program and an Adjunct Professor in the Department of Physical Medicine and Rehabilitation, at Western University. Dr. Wolfe's primary research interests are in the areas of knowledge mobilization and health promotion for individuals with SCI. In addition, Dr. Wolfe has expertise in examining the impact on health of the various secondary health conditions commonly encountered by those with SCI. As a core investigator, he contributed to the rehab framework and report card conception, facilitated site engagement, developed the data collection forms, and monitored data collection and cleaning prior to analysis. In addition, Dr. Wolfe facilitated completion of the Informed Self Management, Physical Activity and Wheeled Mobility chapters of the Atlas.

Beverley Catharine (Cathy) Craven
BA, MD, FRCP(C), MSc, CCD

Dr. Cathy Craven is a Physiatrist with a Clinician Scientist role at Toronto Rehabilitation Institute – University Health Network in Ontario, Canada. Currently an Assistant Professor in the Department of Medicine at the University of Toronto, she was the recipient of the 2011 Division of Physiatry "Innovator of the Year Award". Dr. Craven's clinical and research expertise is in the prevention and treatment of secondary health conditions among individuals with SCI, with a focus on sublesional osteoporosis and health service provision. She has published over 80 articles on related topics. Dr. Craven is the Ontario lead for the SCI-IMPACT team (an Ontario and Québec interprovincial group focused on ameliorating secondary health conditions after SCI, and their related economic, health and quality of life burdens). She has been the Scientific Co-chair of the 1st to 5th National SCI Conference. Dr. Craven conceived and developed the SCI rehabilitation framework, scoping review and report card methodology with colleagues Molly Verrier, Jane Hsieh and Dalton Wolfe; and led the analysis, reporting and production of the Atlas, including summaries of the framework, methods and key perspectives from E-Scan. In addition, she was responsible for facilitating completion of the Sexual Health, Employment, Ameliorating Neuropathic Pain, Bowel Continence and Skeletal Integrity chapters, led the report card scoring process and made substantial editorial contributions to all chapters.

Vanessa K Noonan MSc, PhD, PT

As Director of Research at the Rick Hansen Institute, Dr. Noonan is responsible for scientific leadership of the Translational Research program. Actively involved with the Rick Hansen Spinal Cord Injury Registry since its inception, she is also part of the International SCI Data Set Committee (which has overseen the development of 16 data sets, now used internationally); and is a co-investigator on the Access to Care and Timing project, examining the provision of care for individuals with SCI in 12 Canadian centres. As a physical therapist, she practiced in both the SCI acute and rehabilitation settings, clinically; and her research examines processes and outcomes of care following SCI rehabilitation, to move research into practice and create standards of care. Dr. Noonan obtained her PhD from the UBC School of Population and Public Health in 2009, received a post-doctoral fellowship award from the National Institute on Disability and Rehabilitation Research, and worked with the NIH-sponsored project PROMIS (Patient-Reported Outcomes Measurement Information System), at the University of Washington. Dr. Noonan facilitated completion of the Atlas chapters on Emotional Wellbeing, Community Participation, and Independence in Breathing.

Molly Verrier MHSc, Dip (P&OT)

Molly Verrier trained as a physical and occupational therapist at the University of Toronto (UofT), and practiced physical therapy in neurology/neurosurgery at the Toronto Western Hospital - where she was also a research physical therapist. Following her graduate studies at McMaster University in Clinical Neurophysiology and Health Science she was the lead of the Human Motor Control Laboratory at the Playfair Neuroscience Unit and faculty at UofT. Between 1994 and 2004, she chaired UofT's Department of Physical Therapy and the Graduate Department of Rehabilitation Science, where she implemented a Professional Master's Program in Physical Therapy, and MSc and PhD Programs in Rehabilitation Science. Today, Associate Professor Emeritus Verrier is a Senior Scientist at the Toronto Rehabilitation Institute – University Health Network – Lyndhurst Centre Brain and Spinal Cord Rehabilitation Program where she leads the SCIMobility Laboratory. She has made substantial contributions to the Atlas including, but not limited to, participation in the conceptualization of the E-Scan framework, methodology and report card, and facilitated completion of the chapters on Walking, Grasping, Reaching and Manipulation, and Cardiovascular Integrity; and production of the geocoding maps.

Erin Cherban MSc, CCRP

As Director of Clinical Research Operations at the Rick Hansen Institute, Erin Cherban's primary portfolio is managing clinical research projects, and supporting the Institute's Clinical Research Network – a collaboration of SCI researchers and clinicians, based at acute and rehabilitation centres across Canada. Experienced in academic and pharmaceuti-cal- sponsored clinical research, Ms. Cherban manages a team of project managers, research administrators and finance personnel; provides strategic oversight of multi-centre clinical research projects, the Clinical Research Network and opera-tionalizes integrated knowledge translation within the lifecycle of clinical research projects. Throughout her research career, Ms. Cherban has actively volunteered to promote clinical research, continuing education and professional development. She is a board member of local and national clinical research organizations; she also served as an elected member of the Society of Clinical Research Administrator board of directors, from 2006 to 2009. Ms. Cherban was the research administration liason between the Rick Hansen Institute and the E-Scan Investigators during the later phases of the E-Scan project and atlas production.

Amir Rasheed BSc, OT, MA

Amir Rasheed served as the Rick Hansen Institute's Director of Best Practices until July 2012. Trained as an occupational therapist, Mr. Rasheed worked at the Toronto Rehabilitation Institute where he developed an interest in quality improvement and best practices that led him to Vancouver to pursue a role as a Quality Advisor, in a paediatric rehabilitation centre, within the Provincial Health Services Authority. He advanced to work as a Program Manager, intimately involved in defining and implementing best practices for the assessment of conditions such as Autism and Fetal Alcohol Spectrum Disorder. As a former Project Director with Impact BC, Mr. Rasheed supported various quality improvement projects involving the adoption of best practices. Mr. Rasheed was the administrative liason between the Rick Hansen Institute and E-Scan Investigators, in the early phases of the E-Scan implementation.

Jane TC Hsieh MSc

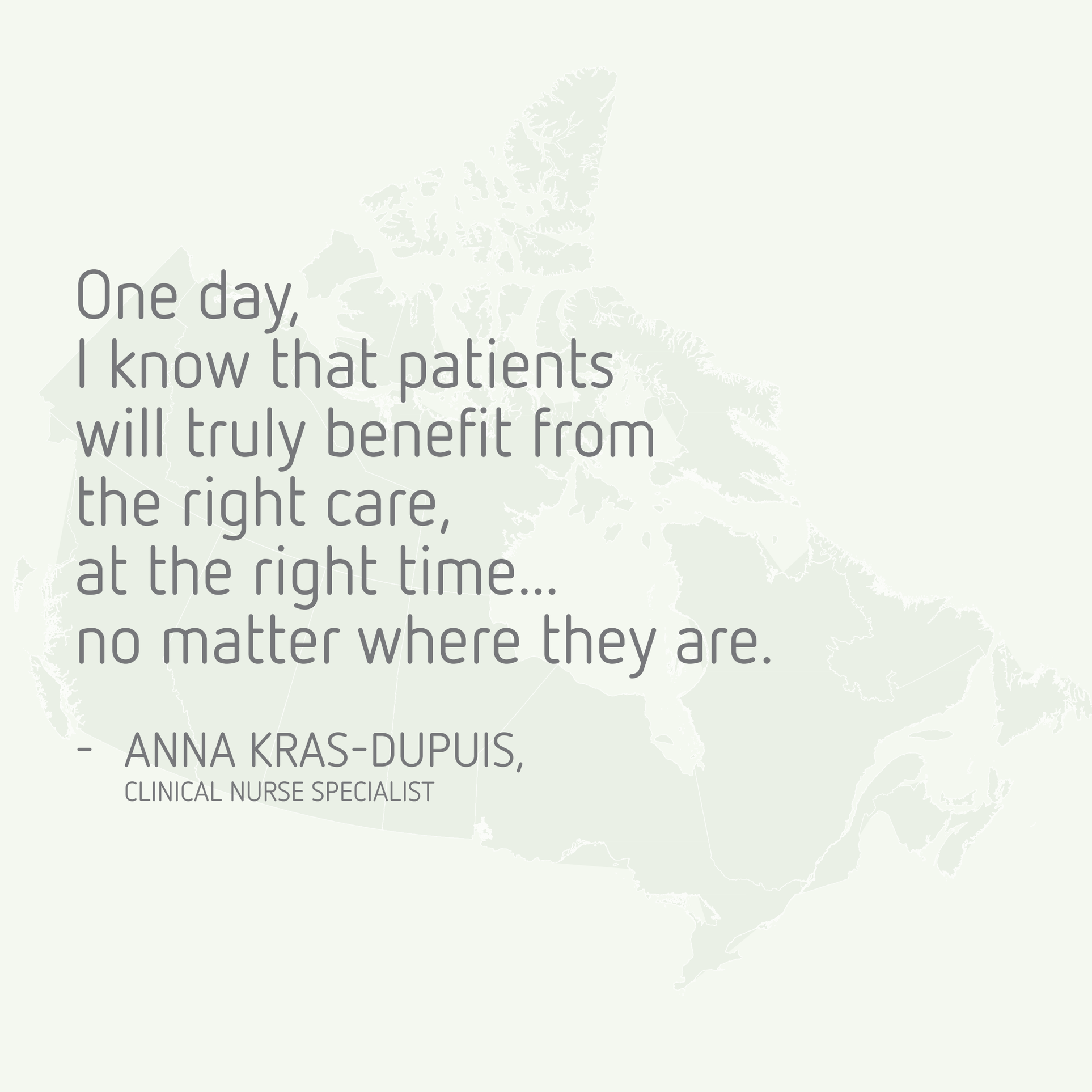
An Associate Scientist at the Lawson Health Research Institute in London, Ontario, Jane Hsieh has over 20 years experience in various senior executive positions in non-governmental and biotechnology organizations, overseeing clinical research in both the academic and industry settings. Although her experience covers several neurological indications, spinal cord injury and translational science are the focus of her ongoing activities. She is a team member in several SCI rehabilitation and research projects, including Spinal Cord Injury Rehabilitation Evidence and Knowledge Mobilization Network. Jane was a core investigator who con-tributed to E-Scan project conception, developed the survey and monitored data collection, and led the completion of the Skin Integrity, Optimizing Spasticity and Bladder Continence chapters.

Christina Balioussis PhD

Dr. Christina Balioussis completed her PhD in Developmental and Cognitive Psychology at York University in Toronto, Canada, and has been working at Toronto Rehabilitation Institute - University Health Network as project coordinator for the Rehabilitation E-Scan, since December 2010. Her research interests include spinal cord injury rehabilitation, alternative/natural therapies in health and medicine, and injury prevention within a developmental context. Dr. Balioussis played a critical role in production of the Atlas, was responsible for communication among team members, conducted data analysis, contributed to data validation, and editing of each atlas component.

Carey Yada Lee BA

Carey Lee is a marketing professional experienced in graphic design, online marketing, web manage-ment, stakeholder engagement and implementa-tion of marketing strategies. After completing a Bachelor's degree in Urban Geography from the University of British Columbia, Ms. Lee worked in a variety of communication roles in the automo-tive, publishing and legal industries before joining the Rick Hansen Institute as Marketing and Communications Specialist. In this capacity, Ms. Lee manages RHI's online and social media platforms, and is responsible for the design, production and publication of all materials, including its national publication on spinal cord injury, Solutions. Ms. Lee helped facilitate publication of the Atlas by managing its design and production.



One day,
I know that patients
will truly benefit from
the right care,
at the right time...
no matter where they are.

- ANNA KRAS-DUPUIS,
  CLINICAL NURSE SPECIALIST

Vancouver

Spinal Cord Injury Program, GF Strong Rehabilitation Centre, Vancouver Coastal Health

Vancouver CoastalHealth GF Strong Rehabilitation Centre

This site comprises a 22-bed dedicated inpatient program located at the GF Strong Rehabilitation Centre, and an outpatient program at both GF Strong and the Blusson Spinal Cord Centre. It offers interdisciplinary assessment clinics, inpatient and outpatient rehabilitation, SCI education classes, a therapy pool and an adapted fitness centre. The SCI program team includes members from physiatry, nursing, occupational therapy, physiotherapy, recreational therapy, peer mentoring and social work. Consultation is also available for assistive technology, driver training, drug and alcohol counselling, nutrition, orthotics, psychiatry, psychology, seating services, sexual health, spasticity and intrathecal baclofen, speech and language therapy, and vocational rehab.

The outpatient SCI clinic, which includes clinics for physiatry, interdisciplinary rehabilitation, spine surgery, urology and sexual health is located within the Blusson Spinal Cord Centre, which also houses the International Collaboration on Repair Discoveries research centre.

In addition, the SCI program has a strong partnership with Spinal Cord Injury BC (formerly the BC Paraplegic Association), which has an office at GF Strong, where all patients are introduced to the resources available, including its peer support program.

The program prides itself on its newly revitalized patient education program.

Calgary

Tertiary Neurological Rehabilitation, Foothills Medical Centre, Alberta Health Services

Alberta Health Services

Foothills Medical Centre provides services to patients and families from southern Alberta to the interior British Columbia, and into western Saskatchewan. Specializing in cardiac, neurology, medical and orthopedic services, Foothills comprises 1,062 beds, approximately 10,000 staff, 600 volunteers and 1,750 physicians. Its Division of Clinical Neurosciences includes Acute Neurology, Neurosurgery, Neurological Rehabilitation, and dedicated acute stroke and acute spinal cord programs.

The Foothills Tertiary Neuro Rehab (Unit 58) provides tertiary rehabilitation to individuals with acute brain injury, stroke and SCI. The unit comprises 45 inpatient beds, located within our special services building, and has established a novel continuum- based approach to care that keeps patient-focused rehabilitation goals at the forefront. This approach sees individuals (and their families) transitioning from acute care to rehab to outpatient settings. Team members include support staff, 24-hour specialized rehab nursing care, specialized allied health including physiotherapy, occupational therapy, speech therapy, social work, psychology and recreational therapy, as well as physician-support team members, who integrate within disciplines, to ensure the best outcomes for individuals with a neurological impairment.

Partnerships in the acute care settings, and within our spinal cord program, allow for linkages to all aspects of the care spectrum, and include those with the Health and Research Innovation Centre, Teach Research and Wellness, Health Sciences Centre, University of Calgary, Tom Baker Cancer Centre and Seaman Family MRI Centre.

These direct links enable seamless integration of practice and easier transitioning of individuals and families. Education and rehabilitation practices are explored and taught on the acute units, prior to transition to the rehabilitation unit, which creates a rehabilitation focus from the start.

To help the SCI population stay focused on health and wellness, individuals in outpatient clinics are followed throughout their lives.

Edmonton

Spinal Cord Injury Program, Glenrose Rehabilitation Hospital, Alberta Health Services

With a focus on education, self-management and secondary prevention, this program comprises a 15-bed inpatient rehabilitation unit and outpatient services, as well as individual and group treatments.

Adults over the age of 18 with traumatic/non-traumatic SCI are served in the Edmonton zone, northern Alberta, northern British Columbia and the Northwest Territories.

Members of the inpatient/outpatient SCI program include physiatrists, nurses, occupational therapists, physiotherapists, therapy assistants, psychologists, recreational therapists and assistants, social workers and dietitians. Consultation is also available for pastoral care, sexual health, urodynamics, feeding and swallowing, seating, orthotics, assistive technology, spasticity, and driver evaluation and training.

Glenrose's SCI program has a strong partnership with the Canadian Paraplegic Association, the Spinal Cord Injury Treatment Centre Society and the Steadward Centre.

Saskatoon

Spinal Cord Injury Program, Saskatoon City Hospital, Saskatoon Health Region and University of Saskatchewan

The Saskatoon Rehabilitation Centre SCI program is located within Saskatoon City Hospital, and includes a 32-bed inpatient unit – up to 16 available for SCI – and outpatient services.

Members of the SCI program include a physiatrist, nurses, PTs, OTs, OT/PT assistants, a recreational therapist, a psychologist, social workers, a dietitian and a pharmacist. Consultation is also available for audiology, pastoral care, geriatrics, chiropody, otolaryngology (Ear, Nose and Throat), orthotics, speech and language pathology, psychiatry, orthopaedics, driver evaluation, and seating.

A full-time nurse practitioner gathers individuals information prior to consultation, provides follow up on investigations ordered in clinic, and screens individuals with chronic SCI.

Recently, a PhD-trained research coordinator, who provides support for a number of SCI-related initiatives, has been added to the department. The SCI program has strong partnerships with the Canadian Paraplegic Association (Saskatchewan) and the Saskatchewan Abilities Council. Through its affiliation with the University of Saskatchewan, education and training in the provision of healthcare for individuals with SCI is provided to physiatrists-in-training, medical students and other healthcare providers.

Winnipeg

Spinal Cord Injury Program, Health Sciences Centre Winnipeg, Winnipeg Regional Health Authority

Health Sciences Centre Winnipeg

The Winnipeg Health Sciences Centre provides specialized rehabilitation care to people with SCI from Manitoba and Northwest Ontario, and comprises a 13-bed inpatient rehabilitation unit, a rehabilitation day hospital, long-term follow up for lifelong, specialized SCI medicine issues, and outpatient physiotherapy, on an as-needed basis.

There are a specialized seating clinic, rehabilitation engineering and assistive technology specialists, as well as the only Ministry of Transportation driver assessment program in the province.

The site also maintains the longest-running baclofen pump program in Canada, and features long-term Canadian Paraplegic Association (CPA) follow up for social, vocational and emotional needs.

The program has been a leader in research and clinical management in many areas, in particular the management of neurogenic bladder, spasticity and neuropathic pain.

It is a member of, and collaborator with, the world-renowned Spinal Cord Research Centre, at the University of Manitoba.

Team members include physiatrists, nurses, OTs and PTs, a therapeutic recreation therapist, a part-time nutritionist, a social worker, a dedicated CPA counsellor, and a part-time pharmacologist who consults on individuals with neuropathic pain and on research projects. The program also offers consultation for audiology, pastoral care, geriatric medicine, chiropody, otolaryngology (Ear, Nose and Throat), orthotics, speech and language pathology, psychiatry, rehabilitation engineering, and seating. There is dedicated research time for one of the physiatrists, and the program collaborates with a number of researchers at the University of Manitoba.

The SCI program maintains a strong partnership with CPA Manitoba, of which the program's medical director is a long-standing board member. All individuals are introduced to the resources available through CPA while they are inpatients.

London

Regional SCI Rehabilitation Program, Parkwood Hospital, St. Joseph's Healthcare London

Focusing on complex care, rehabilitation, specialized geriatric services and veterans care, this site services the acquired brain injury, SCI, amputee, musculoskeletal and stroke/neurological/ neurotrauma populations through inpatient/outpatient and outreach programs that include a driving program, a fitness centre, assistive technologies and other health services.

The Parkwood SCI program has a 15-bed inpatient rehabilitation unit specifically designed for individuals with SCI. In addition to intensive, integrated and specialized inpatient rehabilitation, the program offers post-discharge follow up with specialized clinics, outpatient services, educational/support groups, a research program and an adapted fitness centre. The program's goal is to help the individuals reach an optimal level of functioning and reintegrate into the community.

The site offers services in physiatry, nursing, occupational therapy, physiotherapy, therapeutic recreation, psychology, psychometry, nutrition, pharmacy and social work. Consultation is also available for audiology, pastoral care, geriatric medicine, chiropody, otolaryngology (Ear, Nose and Throat), orthotics, speech and language pathology, psychiatry, optometry and seating. In addition, an SCI resource centre containing SCI-specific consumer health information is located within the Parkwood Hospital patient library. Other services include a driver assessment and rehabilitation program, which is an approved assessment centre with the Ontario Ministry of Transportation. Through the neurotrauma rehab service, individuals can be assessed for assistive-technology applications that facilitate increased independence in areas such as computer access and environmental controls.

The Parkwood research program includes a clinically-embedded researcher who is integrated into the SCI program council, and enhances the learning environment for both individuals and staff through a best practice implementation focus.

The SCI program maintains a strong partnership with Canadian Paraplegic Association (CPA) Ontario. All individuals are introduced to the resources available through CPA Ontario, including its peer support program. The Living Well with SCI education series provides information to SCI survivors and their families.

Hamilton

Spinal Cord Injury Rehabilitation Program, Hamilton Health Sciences, Regional Rehabilitation Centre

This program comprises 13 inpatient rehabilitation beds dedicated to individuals with SCI, as well as outpatient services, specialized clinics and weekly educational sessions. Members of the SCI program include a physiatrist, rehabilitation nurse clinician, dietitian and dietitian assistant, education clinician, pharmacist and pharmacy assistant, OT and OT assistants, recreational therapist, social worker, PTs and PT assistants, nurses and respiratory therapists. Consultation is available for respirology, urology, psychiatry, psychology, chronic pain, chaplaincy, otolaryngology (Ear, Nose and Throat), orthotics, seating clinic, speech language pathology, surgery, audiology, anesthesiology, geriatrics, infectious disease, obstetrics and gynecology, internal medicine, neurology, orthopaedics, plastic surgery and thrombosis.

A hallmark of the program is that it provides – at one site – emergency and trauma care, acute and surgical care, and inpatient and outpatient rehabilitation.

This geographical proximity facilitates individuals' transition between phases in their continuum of care.

Strategic, community and research partners include the Rick Hansen Institute, the Canadian Paraplegic Association, the Ontario SCI Solutions Alliance, the YMCA of Hamilton/Burlington/Brantford and McMaster University.

THE PROGRAM'S PRACTICE HIGHLIGHTS INCLUDE:

- A close working relationship between the physiatrist and rehabilitation nurse clinician, who facilitates access to inpatient rehabilitation services through screening, assessment, triage and coordination of individuals with SCI in acute care, rehabilitation and the community.
- A hydrotherapy program.
- **SCI navigators integrated into rehabilitation and acute care teams to work with individuals from ICU to the community, helping them to navigate the system, advocate for change, adjust to life with a physical disability and to achieve goals.**

The SCI Rehabilitation Program is involved in several multi-centre research studies. These include the *Rick Hansen Spinal Cord Injury Registry* (RHSCIR), the *Rick Hansen Institute Access to Care and Timing Project*, the *RHI Rehabilitation Environmental Scan* and the *Graded and Redefined Assessment of Strength, Sensibility, and Prehension Responsiveness.* Previously, the program participated in the *Ontario SCI Registry* and the *Ontario SCI Solutions Alliance's SCI Pilot/ Navigators Program* evaluation. Future research initiatives will include a collaboration with the YMCA of Hamilton/Burlington/Brantford and McMaster University to develop a community-based exercise program for individuals with SCI.

Toronto

Brain and Spinal Cord Rehab Program, Toronto Rehabilitation Institute - University Health Network

Toronto Rehab is Canada's oldest rehabilitation program for individuals with SCI and non-traumatic diseases of the spinal cord. With 60 beds in three inpatient units, the program is the largest of its kind in Canada.

Members of the interprofessional team include seven physiatrists, 55 nurses, 13 OTs, 15 PTs, a dietitian, five social workers, three psychologists, a chaplain, three pharmacists, a speech-language pathologist, three family physicians, a respiratory therapist and three therapeutic recreation therapists. Strategic partners include Canadian Paraplegic Association (Ontario), several long-term care centres (including the hospital's lakeside facility), community organizations and other Toronto Rehab programs, such as the acquired brain injury service.

The site's therapy area includes a large, modern gymnasium that provides an after-hours fitness program with a broad selection of equipment. A second gym area focuses on specialized mobility and gait training, a state-of-the-art customized postural assessment and training system, as well as mobility terrain to help wheelchair skills training. Other program features include a post-discharge follow-up program with specialized clinics (seating, assistive technology, bone density, urology, gynaecology, sexuality and fertility), outpatient services, and educational/support groups.

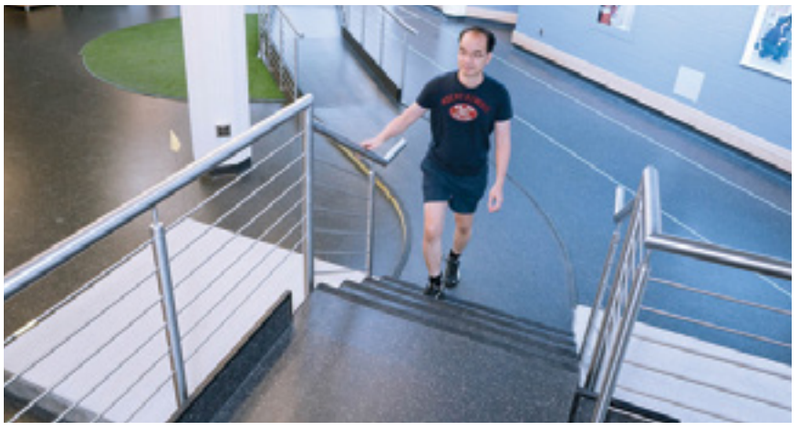
Education to maximize independence is a key component of the rehabilitation program. The Spinal Cord Connections Resource Centre (a CPA Ontario partnership) includes resources, onsite and online at www.spinalcordconnections.ca, including rehabilitation and therapies, nutrition, sexuality and relationships; as well as the multimedia SCI-U, which presents educational information in an engaging and interactive format.

Toronto Rehab is a centre of best practice in walking assessment and rehabilitation following an incomplete SCI.

The team has developed a comprehensive, evidence-based approach to walking assessment and training, which has helped Toronto Rehab understand the characteristics of individuals and create algorithms for walking. Expert clinicians utilize principles of activity-dependent neuro-plasticity through body-weight-support treadmill training, functional electrical stimulation walking, with a focus on maximizing postural control and trunk stability to optimize walking recovery. Linking research and clinical practice on a day-to-day basis, in research laboratories and practice areas, is a major feature of the physical-therapy approach.

Lyndhurst Centre is home to the multidisciplinary, collaborative Neural Engineering and Therapeutics (NET) Team

One of North America's largest and most diverse SCI rehabilitation research groups – that develops and evaluates novel rehabilitation devices and therapies. The NET Team includes seven scientists, eight adjunct scientists, four postdoctoral fellows, 24 graduate students and 24 research staff. Transferring research innovations into clinical best practices ensures that Toronto Rehab patients benefit from the latest therapeutic and technological advancements in SCI rehabilitation.



Kingston

Physical Medicine and Rehabilitation Program, St. Mary's of the Lake Hospital, Providence Care

Providence Care St. Mary's of the Lake Hospital focuses on Complex Care, Physical Medicine and Rehabilitation (PM&R), Specialized Geriatrics and Palliative Care. The PM&R program includes acquired brain injury, SCI, amputee, musculoskeletal and stroke populations through inpatient and outpatient services.

The Spinal Cord Rehabilitation program comprises seven beds with 55 admissions in 2010/11 and an occupancy rate of 118%. There were 194 visits to the Spinal Cord Program Outpatient Clinic, and approximately 290 current and former clients are followed annually, through the outpatient program. While there is limited access to outpatient services, an adapted fitness program (Revved Up) operates twice a week at two separate sites, through a partnership with Queen's University. The SCI team includes a physiatrist, PT, OT and assistants, part-time social worker and TR, and (on a consulting basis) provides access to psychology and psychometry, a dietitian, spiritual care, audiology, speech language pathology and seating clinic services. In addition, a vocational counsellor therapist is part of the inpatient rehab program.

The SCI program maintains a strong affiliation with CPA of Ontario. During their inpatient stay, all individuals are introduced to resources available through the CPA and its Peer Support program, and CPA invites current and former clients to monthly SCI dinners and education or leisure events. The SCI team (including a supportive group of former clients) also hosts an annual SCI BBQ, in partnership with CPA and the Revved Up program. At this event, current and former clients and families enjoy a half day of connecting with others, educational displays, obstacle course competitions and wheelchair basketball games.

PRACTICE HIGHLIGHTS INCLUDE:

- A clinical pathway for initiation of breath stacking
- One of the first institutions to introduce transanal irrigation for managing neurogenic bowel dysfunction
- Highest national scores for rehabilitation patient satisfaction
- A strong emphasis on maintenance of physical exercise for health promotion
- 100% of clients achieving their goals (National Rehabilitation Reporting System data: 2010/11 report)

RESEARCH HIGHLIGHTS INCLUDE:

- Access to primary care for individuals with disabilities
- Knowledge translation – to primary care physicians – of best practice in SCI care
- Exercise promotion and prescription
- Development of a research program in neurogenic bowel function

Providence Care was one of the first institutions to introduce transanal irrigation for managing neurogenic bowel dysfunction.

Ottawa

Neuromuscular Care Stream, The Ottawa Hospital Rehabilitation Centre

This site serves part of Nunavut and the Champlain Local Integrated Health Network in Ontario, and specializes in rehabilitation for persons with acquired brain injury, SCI, amputations and musculoskeletal issues.

The site has the capacity to provide clinical services for 24 inpatients, with traumatic or non-traumatic SCI. In addition to the SCI inpatient service, there are outpatient services, support groups and family services delivered through a community resource centre. Specialized services include physiatry, nursing, occupational therapy, physiotherapy, psychology, psychometry, nutrition, pharmacy and social work. Onsite consultation is available for pastoral care, chiropody, prosthetics/orthotics, therapeutic recreation, speech-language pathology and vocational rehabilitation.

There are inpatient, outpatient, outreach and community-based programs, with direct access to an acute care facility, a therapy pool, driving assessment program, Computer Assisted Rehabilitation Environment (CAREN) extended system, and a nationally-acclaimed CANVent service.

The CANVent respiratory team provides onsite teaching and implementation of non-invasive ventilation techniques. This team is internationally recognized as a leader in initiating and advocating for this type of respiratory therapy.

The site's driving assessment program, accredited by the Ontario Ministry of Transportation, helps ensure optimal reintroduction to driving for individuals with SCI. Individuals also benefit from a peer support program, offered through CPA.

Montréal

Programme lésions médullaires,
Institut de réadaptation Gingras-Lindsay-de-Montréal (IRGLM)

Since 1996, the IRGLM, in partnership with the Hôpital du Sacré Coeur de Montréal and the Centre de réadaptation Lucie Bruneau, has been designated by the Québec Ministry of Health as the expert centre for people with SCI in the western part of the province.

The program comprises a 24-bed inpatient rehabilitation unit, an outpatient clinic and an interdisciplinary outpatient follow-up team. Members of the SCI program include three physiatrists, three general practitioners, 12 registered nurses, a clinical nurse specialist, eight PTs, six OTs, three social workers, two psychologists, as well as a speech therapist, nutritionist, recreational therapist and sexologist. Consultation is also available for psychiatry, neuropsychology, specialized education, urology, orthotics, wheelchair positioning and pastoral care.

In order to facilitate social participation within the community, the IRGLM SCI program has developed strong partnerships with the different regional rehabilitation centres, and with the peer association Moelle épinière et motricité Québec.

Interdisciplinary work is the foundation of the program as it guides and enhances all client-centred interventions. This is an important IRGLM strength and has become a driving force in the development of new expertise.

IRGLM has developed an innovative client-centered education program, leading the province by offering quality care to individuals with ventilator-assisted tetraplegia, and enabling tendon-transfer surgery, in partnership with the Centre Hospitalier de l'Université de Montréal.

The IRGLM is also a member of the Centre for Interdisciplinary Research in Rehabilitation of Greater Montréal, whose mandate is to support various research projects. The program is also privileged to be affiliated with a team of researchers, led by Dany Gagnon, whose wide field of interests allows the advancement of best practices.

Montréal

Programme pour les personnes présentant une pathologie du système locomoteur, Centre de réadaptation Lucie-Bruneau

Centre de réadaptation Lucie-Bruneau

This SCI rehabilitation program consists of 15 beds and includes both outpatient and follow-up services. It is a member of the Centre d'expertise pour les personnes blessées médullaires de l'Ouest du Québec, and is a designated site for inpatient training for the third rehabilitation phase for the western area of the province.

It is also in charge of the professional and social reintegration of ventilo-dependant tetraplegics for the entire province, in cooperation with the National Program of Home Ventilatory Assistance; and has developed a strong partnership with Moelle épinière et motricité Québec to offer programs designed to support the needs of individuals affected by SCI.

Focusing on community integration, the multidisciplinary team offers services for both inpatients and outpatients, most of who come from the Montréal region as outpatients. The program includes services – offered in both individual and group sessions – in medicine, nursing, physiotherapy, occupational therapy, kinesiology, psychology, social services, sexology and specialized education. Psychiatrists, dietitians and speech therapists are also available for consultation. Among the facilities is an adapted fitness center that includes a pool. Specialized programs (driving, return to work, parents with disabilities, pain clinic) can also join, if needed, the SCI rehab team.

A program highlight is an emphasis on activities in the community. Throughout the year, small groups of individuals and therapists leave the facility to participate in activities that can become part of life with SCI. These activities include adapted sports (biking, sailing, kayaking, fishing, tai chi), cultural visits (museums, Old Montréal), outdoor activities (picnics in parks, apple picking), leisure (adapted bowling, shopping).

The community is the best setting for individuals to experiment with their abilities in wheelchairs, their comfort with being the centre of attention and their capacity to prevent and solve problems in the real world.

Québec City

Programme des myélopathies, Institut de réadaptation en déficience physique de Québec (IRDPQ)

IRDPQ and its partner, the Centre Hospitalier Universitaire de Québec—Hôpital de l'Enfant-Jésus (CHU-HEJ), constitute the Centre of Expertise for SCI patients in eastern Québec. It provides services for SCI patients in acute care and intensive rehabilitation phases in seven regions of the province.

IRDPQ's rehabilitation program has an inpatient unit of 26 beds and receives approximately 75 new SCI admissions annually. Individuals benefit from a urology clinic, pool, gym and adapted fitness room, as well as specialized services such as technical aids and assistive devices, environmental controls and assisted communications, driving expertise and rehabilitation, social integration, and work and occupational rehabilitation. The program offers structured education sessions to both individuals and families on more than 12 different themes central to SCI understanding and management, including secondary complications, pressure sores, nutrition, bladder management and sexuality.

The SCI rehabilitation team comprises three general practitioners, two physiatrists, more than 20 nurses and nurses' aides, three clinical coordinators, seven PTs and rehabilitation technicians, seven OTs, four social workers, a psychologist, sex therapists, two specialized education technicians, a leisure technician and a physical educator. Consulting specialists include nutritionists, urologists, psychiatrists, neuropsychologists, vocational counsellors and speech-language therapists. A peer counsellor from the provincial association Moelle épinière et motricité Québec has an onsite office, and works closely with the rehabilitation team on all aspects of service delivery and development.

The program collaborates with researchers at the Université Laval's affiliated research centre, CIRRIS, on a variety of research programs pertaining to social integration, gait/walking, wheeled mobility, and the evaluation of SCI services and outcomes.

IRDPQ's program operates within a well-integrated and fluid continuum of services and partnerships that run from acute care to social integration into the community.

There is a structured, long-term community follow-up program that provides systematized screening and interdisciplinary follow-up visits to more than 1,400 individuals.

Cottonnelle (a nursing approach and methodology) rehabilitates, educates and supports individuals on all aspects of bowel management and complications.

Fredericton

New Brunswick Provincial SCI Program, Stan Cassidy Centre for Rehabilitation

Centre de réadaptation
STAN CASSIDY
Centre for Rehabilitation
Towards Independence / Vers l'autonomie

Located in Fredericton, New Brunswick, the Stan Cassidy Centre is a free-standing neurologic rehabilitation facility, providing bilingual tertiary services for adults and children from New Brunswick and PEI; as well as for complex paediatric patients from Nova Scotia.

With 10 inpatient SCI beds, as well as transitional living suites (accessible apartments) available for individuals and their families, there is a total capacity to accommodate up to 24 inpatients, at any one time. With the addition of a Hostel unit in Spring 2013, we will have three additional onsite accessible accommodations. The centre provides care through inpatient, outpatient and outreach services, as well as expert advice to practitioners throughout the Maritimes.

Combined with inpatients, outpatient services and specialized programs provide 30,000+ patient visits annually, and include an assistive technologies department, adapted driving and seating programs, a rehabilitation engineering clinic, and a restorative and reconstructive clinic.

Uniquely, the Centre also provides outreach services (allowing for home and community visits, and training/ education throughout the province), the only fully-functioning rehabilitation therapeutic park in Canada, and the only pediatric rehabilitation wing in the Maritimes.

An advanced telerehabilitation service with secure web-based video-conferencing allows for evaluation, assessment and education for individuals and caregivers from their homes and/or communities. Community reintegration planning with skilled rehabilitation counsellors is available through a strong partnership with Ability New Brunswick.

SCI program members include dedicated physiatrists, nurses, OT/PTs, neuropsychologists, clinical dietitians, recreation therapists, respiratory therapists, speech language pathologists, social workers and rehabilitation assistants. There is close collaboration with the region's orthopedic surgeons, urologists, endocrinologists, plastic surgeons, internists and otolaryn- gologists, and benefit from a 60m link to the regional acute care hospital, for diagnostic and emergency care.

Affiliated with Dalhousie University Faculty of Medicine, and the University of New Brunswick Institute of Biomedical Engineering, Faculties of Nursing and Graduate Studies, the Centre is an accredited training centre for rehabilitation professionals, and welcomes students and residents from medicine, nursing, psychology, physiotherapy, speech language pathology and occupational therapy.

A long partnership with the Institute of Biomedical Engineering has led to innovative collaborations in research - including treatment of pain and spasticity, quality of life and evaluation biometric data measurement (spasticity, and myoelectric controls systems); as well as clinical programs which combine the ingenuity and expertise of engineers and clinicians to addressing research and patient care questions. In addition, the University of New Brunswick boasts one of the largest technologically-advanced gait and motional analysis labs in Canada.

Viewed as a North American leader in neurological rehabilitation, the Centre enjoys support from generous corporate, private and government investors through the Stan Cassidy Foundation.

Halifax

Spinal Cord Rehabilitation Program, Nova Scotia Rehabilitation Centre
Queen Elizabeth II Health Sciences Centre, Capital Health

Capital Health
Nova Scotia Rehabilitation Centre

The Nova Scotia Rehabilitation Centre (NSRC) is part of the Queen Elizabeth II Health Sciences Centre, and provides inpatient rehabilitation services for individuals with SCI in Nova Scotia, as well as for complex cases in the Atlantic Provinces. Individuals with SCI are treated in the inpatient neuro-rehabilitation unit.

This 17-bed unit has two physiatrists, seven registered nurses, eight licensed practical nurses, two-and-a-half OTs, one OT assistant, three PTs, one PT assistant, a nutritionist, a social worker, a recreation therapist and a vocational counsellor. The unit also provides access to medical, surgical, psychology, addiction and chaplaincy services.

Partnerships include a collaborative relationship with the Canadian Paraplegic Association (Nova Scotia) for access to onsite counsellors and provincial peer counselling; the Rick Hansen Institute, the Abilities Foundation and the TETRA Society (a volunteer organization that develops innovative, adaptive aids for individuals with disabilities). Clinical programs available to the SCI population include a specialty-seating clinic, an interdisciplinary orthotic clinic, a pressure ulcer management clinic and a specialty driving program.

NSRC is internationally renowned for its wheelchair skills program, developed by Dr. R. Lee Kirby and the wheelchairs skills team; and has a strong SCI research program with projects from basic science to clinical trials.

Our basic researchers have ongoing projects aimed at understanding motor programming, in the central nervous system, and the role of stem cells for SCI repair. Active clinical projects are focused on understanding the demographics of SCI in Nova Scotia, and on the prevention of pain after SCI. A hallmark of the research program has been development of the SCI Research Network, through the Atlantic Mobility Action Project (www.amap.ca).

What Does the E-Scan Tell Us About SCI Rehabilitation in Canada?

M Verrier, MHSc; C Craven, MD, MSc; C Balioussis, PhD; and the E-Scan Investigative Team

WHAT IS SPINAL CORD INJURY (SCI)?

A traumatic blow to the spine that fractures or dislocates vertebrae is often the cause of an SCI. The injury is likely to cause fractures of the vertebrae, and displace bone fragments or disc material. Ligaments may bruise or tear into the spinal cord tissue, crushing nerve cells that carry signals up and down the spinal cord, between the brain and the rest of the body. An injury to the spinal cord can damage a few, many, or almost all of these cells. Some injuries allow almost complete recovery while others result in complete paralysis.

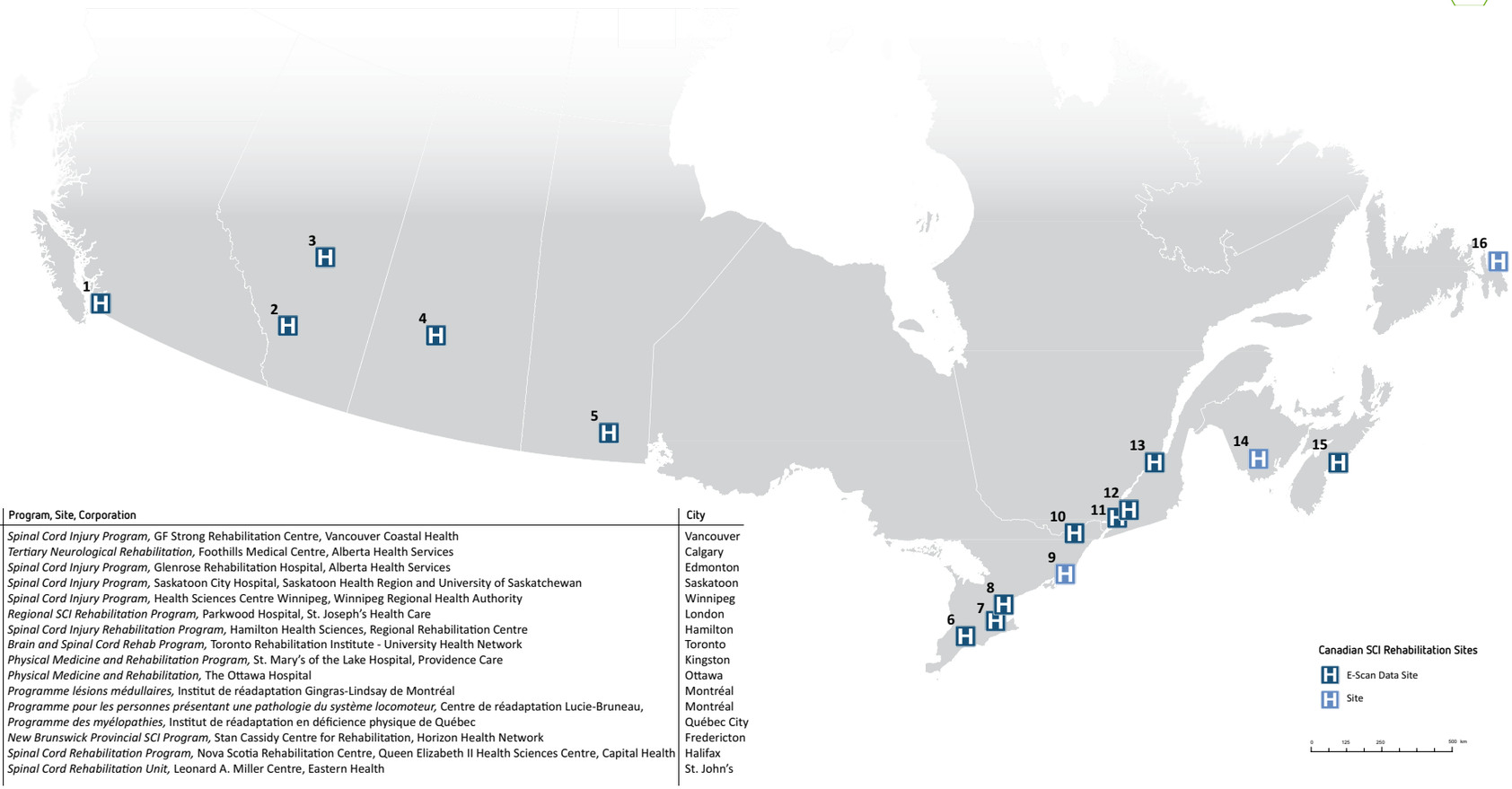
The consequence is that SCI can result in diverse sensory, motor and autonomic impairments. The types of impairments individuals with SCI develop can include pain, mobility impairment, bowel and bladder incontinence, difficulty breathing, controlling body temperature and blood pressure, muscle weakness, increased muscle tone (spasticity), loss of sensation and sexual dysfunction, as well as associated secondary health conditions. The frequency and severity of spinal cord impairment varies with the cause of injury and location in the spinal cord. The majority of these impairments persist over time, and represent challenges to the individual, his or her extended family, and the healthcare system.

What are the Most Common Causes of SCI?

Common traumatic causes of injury include falls, motor vehicle collisions, being struck by an object, and unintentional transport incidents.[1] Conversely, non-traumatic causes include transverse myelitis, vasculitis, degenerative central nervous system (CNS) diseases, neoplasms, vascular or inflammatory disease and spinal stenosis.[2] Currently, there is no internationally accepted standard for defining the cause of disease or disability for the non-traumatic SCI population, although there is an international group working to refine the definitions.

Who Gets SCI?

In Canada, Ontario data suggests that the traumatic SCI incidence rate ranges from 20 to 26 cases per million, per annum.[1] Using these numbers, 897 new cases of traumatic SCI, per annum, are estimated. The typical age of SCI onset is 51.3 years, with the majority of cases (over 70%) occurring in males.[1] Unfortunately, there are no good systems for tracking the incidence of non-traumatic SCI nationally, due to difficulties with case identification, but Ontario data demonstrate twice as many non-traumatic cases per annum, as traumatic SCI. These individuals are older at injury onset (61.6 years), with more co-morbidities, and twice as likely to be female.[3] The average age for both groups has increased, over the last decade, and rehabilitation centres are now serving individuals with a complex array of health and life issues, in addition to the neurological injury.



	Program, Site, Corporation	City
1	*Spinal Cord Injury Program,* GF Strong Rehabilitation Centre, Vancouver Coastal Health	Vancouver
2	*Tertiary Neurological Rehabilitation,* Foothills Medical Centre, Alberta Health Services	Calgary
3	*Spinal Cord Injury Program,* Glenrose Rehabilitation Hospital, Alberta Health Services	Edmonton
4	*Spinal Cord Injury Program,* Saskatoon City Hospital, Saskatoon Health Region and University of Saskatchewan	Saskatoon
5	*Spinal Cord Injury Program,* Health Sciences Centre Winnipeg, Winnipeg Regional Health Authority	Winnipeg
6	*Regional SCI Rehabilitation Program,* Parkwood Hospital, St. Joseph's Health Care	London
7	*Spinal Cord Injury Rehabilitation Program,* Hamilton Health Sciences, Regional Rehabilitation Centre	Hamilton
8	*Brain and Spinal Cord Rehab Program,* Toronto Rehabilitation Institute - University Health Network	Toronto
9	*Physical Medicine and Rehabilitation Program,* St. Mary's of the Lake Hospital, Providence Care	Kingston
10	*Physical Medicine and Rehabilitation,* The Ottawa Hospital	Ottawa
11	*Programme lésions médullaires,* Institut de réadaptation Gingras-Lindsay de Montréal	Montréal
12	*Programme pour les personnes présentant une pathologie du système locomoteur,* Centre de réadaptation Lucie-Bruneau,	Montréal
13	*Programme des myélopathies,* Institut de réadaptation en déficience physique de Québec	Québec City
14	*New Brunswick Provincial SCI Program,* Stan Cassidy Centre for Rehabilitation, Horizon Health Network	Fredericton
15	*Spinal Cord Rehabilitation Program,* Nova Scotia Rehabilitation Centre, Queen Elizabeth II Health Sciences Centre, Capital Health	Halifax
16	*Spinal Cord Rehabilitation Unit,* Leonard A. Miller Centre, Eastern Health	St. John's

What Happens from the Time of Injury to Rehabilitation Admission?

Improved emergency care - often to address respiratory complications which may be an indication of SCI severity - aggressive treatment, and robust rehabilitation can minimize damage to the nervous system, and assist with the restoration of functional abilities. In the acute setting, surgery is often necessary to relieve compression of the spinal tissue, caused by bones broken or dislocated, during the injury. The Surgical Timing in Acute Spinal Cord Injury Study (STASCIS), a recent prospective multicenter study, suggests that performing decompression surgery early (less than 24 hours following injury) can improve outcomes for patients with bone fragments or other tissues pressing on the spinal cord.[4] Patients are usually treated in acute, designated trauma centres, staffed with spine surgeons and health professionals, who are trained to address the many consequences of the injury, until they are medically stable. They are then admitted to specialized rehabilitation centres where customized services are provided. These specialized rehabilitation centres are where individuals learn how to optimize their neurological recovery, become functionally independent in daily activities; and utilize strategies to improve their health status and wellbeing.

Who is Admitted to Inpatient Rehabilitation and Why?

Sixteen tertiary rehabilitation sites in Canada provide extensive rehabilitation for individuals with SCI. Of these, thirteen participated in the E-Scan Demographic and Impairment data collection. Changing trends in the etiology of SCI, and associated volumes of patients requiring rehabilitation services, are altering the landscape of admissions to specialized rehabilitation facilities, the services offered, lengths of stay and discharge disposition. The location of SCI rehabilitation sites mirrors other health services in Canada, which are concentrated around urban, academic health science centres. This leaves rural and northern areas of the country underserviced.

Table 1.0 shows that there are 288 SCI-specific beds, across the 16 SCI rehabilitation sites, with a range of 8-60 beds per site. A cadre of dedicated, rehabilitation professionals service both traumatic SCI and non-traumatic SCI patients.

TABLE 1.0 SPINAL CORD INJURY REHABILITATION SITES IN CANADA.

	SITE	PROVINCE	SCI BEDS
1	Spinal Cord Injury Program, GF Strong Rehabilitation Centre, Vancouver Coastal Health, Vancouver	British Columbia	24
2	Tertiary Neurological Rehabilitation, Foothills Medical Centre, Alberta Health Services, Calgary	Alberta	18
3	Spinal Cord Injury Program, Glenrose Rehabilitation Hospital, Alberta Health Services, Edmonton		15
4	Spinal Cord Injury Program, Saskatoon City Hospital, Saskatoon Health Region and University of Saskatchewan, Saskatoon	Saskatchewan	16
5	Spinal Cord Injury Program, Health Sciences Centre Winnipeg, Winnipeg Regional Health Authority, Winnipeg	Manitoba	13
6	Regional SCI Rehabilitation Program, Parkwood Hospital, St. Joseph's Healthcare, London	Ontario	15
7	Spinal Cord Injury Rehabilitation Program, Hamilton Health Sciences, Regional Rehabilitation Centre, Hamilton		10
8	Brain and Spinal Cord Rehab Program, Toronto Rehabilitation Institute, University Health Network, Toronto		60
9	Physical Medicine and Rehabilitation Program, St. Mary's of the Lake Hospital, Providence Care, Kingston*		8
10	Physical Medicine and Rehabilitation, The Ottawa Hospital, Ottawa		9**
11	Programme lésions médullaires, Institut de réadaptation Gingras-Lindsay de Montréal	Québec	24
12	Programme pour les personnes présentant une pathologie du système locomoteur, Centre de réadaptation Luc-ie-Bruneau		15
13	Programme des myélopathies, Institut de réadaptation en déficience physique de Québec, Québec City		26
14	New Brunswick Provincial SCI Program, Stan Cassidy Centre for Rehabilitation, Horizon Health Network, Fredericton	New Brunswick	10+
15	Spinal Cord Rehabilitation Program, Nova Scotia Rehabilitation Centre, Queen Elizabeth II Health Sciences Centre, Capital Health, Halifax*	Nova Scotia	17
16	Spinal Cord Rehabilitation Unit, Leonard A. Miller Centre, Eastern Health, St. John's*	Newfoundland	8++

* Contribution to the E-Scan data collection was contingent on having RHSCIR registry infrastructure in place, for data collection.

** Capacity is up to 24

+ Capacity is up to 22

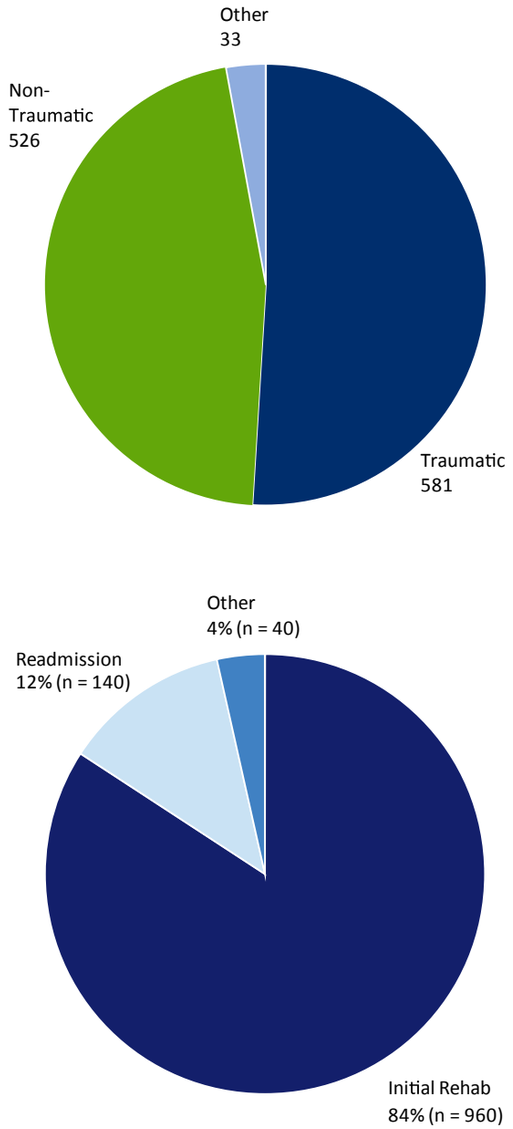
++ Capacity is up to 18.

With a bed base of 300, and growing numbers of individuals with SCI, non-traumatic capacity, is becoming a major issue. In Canada, sites are forced to predict length of stay (LOS) at admission, shorten rehabilitation LOS, and develop strategies to optimize patient flow, without decreasing quality of care.

Who Receives Rehabilitation?

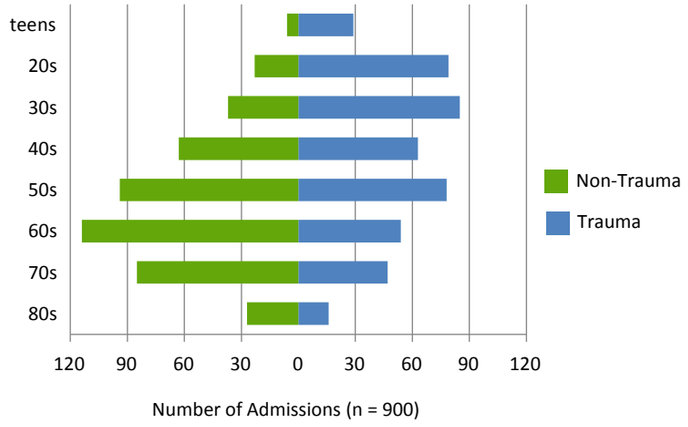
In the fiscal year 2009, the total number of inpatient admissions, across Canada, was 1140. The majority of these were in initial rehabilitation (n = 960, 84%, 658 males), followed by readmissions (n = 140, 12%, 111 males) and then other admissions (n = 40, 4%, 29 males), comprised typically of patients with similar impairments and different disease entities. The total number of other cases admitted (any etiology) was 33, with 28 (13 males) in initial rehabilitation, four (two males) in readmission, and one (male) in any other admission class. Figure 1.0 shows the distribution of admission, by etiology of impairment. The 12% readmission rate is high, and it is important to know the reason(s) for readmission, when planning services.

FIGURE 1.0 ADMISSIONS AND TYPE, FOR INDIVIDUALS WITH SPINAL CORD PATHOLOGY, TO TERTIARY SCI REHABILITATION SITES (N = 13).



As seen in Figure 2.0, the majority of patients receiving rehabilitation, in the 13 participating E-Scan sites, are between the ages of 50 and 70. Patient assessment and rehabilitation is a more complex process, in the non-traumatic group. With the high proportion of patients in their 70s and 80s, comes the potential for an increased rate of multi-morbidity and secondary health complications.

FIGURE 2.0 AGE AT ADMISSION, FOR INDIVIDUALS WITH NON-TRAUMATIC AND TRAUMATIC SCI, ADMITTED FOR SCI REHABILITATION.



What is the Patient's Neurological Status at Admission?

The neurologic level of injury and American Spinal Injury Association (ASIA) impairment scale scores are used to describe sensory and motor impairments, following traumatic SCI, based on neurological responses, and the degree of preservation of motor and sensory function around the anus, and preservation of motor and sensory function in the arms and legs. The neurologic level is defined as the most caudal segment with normal motor and sensory function. There are five categories on the ASIA Impairment Scale (AIS):

A - indicates complete SCI, with no preservation of motor or sensory function in the sacral segments.

B - indicates an incomplete SCI, with preservation of sensory function in the sacral segments.

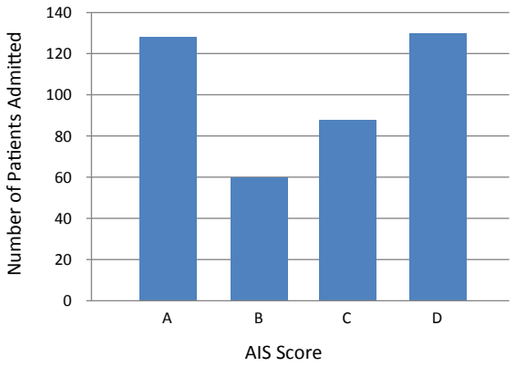
C - indicates incomplete SCI, with preservation of sensory motor function below the neurological level including the sacral segments. More than half of the key muscles below the neurologic level of injury are unable to perform full active range on motion against gravity.

D - indicates incomplete SCI, with preserved sensory and motor function below the neurological level including the sacral segments. At least half of the key muscles below the neurologic level of injury are able to perform full active range of motion against gravity.

E - indicates normal motor and sensory function.

Across the 13 sites, 409 traumatic admissions, consisting of 128 at AIS A, 60 at AIS B, 88 at AIS C, and 130 at AIS D (Figure 3.0), were reported. Discharge data was incomplete, making discharge reporting impossible, in all cases. It is, however, important to examine a change in AIS scale (e.g., A to C), at a patient level. Understanding conversion scores is important, at the population level, which can be used to determine LOS, and inform program planning and resource allocation.

FIGURE 3.0 NUMBER OF PATIENTS ADMITTED BY ASIA IMPAIRMENT SCORE (AIS) ACROSS 13 SITES.



As seen in Table 2.0, incomplete paraplegia and incomplete tetraplegia account for the highest proportion of individuals with SCI. Non-traumatic SCI accounts for the highest number of individuals admitted with incomplete paraplegia. In contrast, traumatic SCI accounts for most of the individuals admitted with complete paraplegia and both incomplete and complete tetraplegia. Included in the table are other admissions, with different etiologies, but these individuals present with similar impairments and symptoms to individuals with SCI, and require similar rehabilitation. Regardless of paraplegia or tetraplegia, incomplete injuries make provision of therapies more challenging, as therapeutic approaches need to be customized to the individual.

TABLE 2.0 NUMBER OF TRAUMATIC, NON-TRAUMATIC AND TOTAL ADMISSIONS WITH PARAPLEGIA AND TETRAPLEGIA (N=12)

NEUROLOGICAL LEVEL	TRAUMATIC	NON-TRAUMATIC	TOTAL
Complete Paraplegia	63	30	93
Incomplete Paraplegia	60	137	197
Unspecified Paraplegia	7	20	27
Complete Tetraplegia	51	7	58
Incomplete Tetraplegia	148	95	243
Unspecified Tetraplegia	8	10	18
Total	337	299	636

Table 3.0 shows the completeness of injury, including "unknown", as reported by the sites. As an ASIA Impairment Score (AIS) is not consistently reported for non-traumatic SCI, and not used for other conditions, individuals with SCI are classified as AIS A (complete) or AIS B-D (incomplete). There are more individuals with incomplete injuries (B-D); this group is largely comprised of individuals with non-traumatic paraplegia. However, 70% of individuals are reported to have incomplete SCI. With differing neurological status at injury onset, these individuals require customized assessments because of major differences in the trajectory of neurological recovery and secondary health complications.

TABLE 3.0 NUMBER OF TRAUMATIC, NON-TRAUMATIC AND TOTAL ADMISSIONS, BY ASIA IMPAIRMENT SCORE (AIS), FOR TETRAPLEGIA AND PARAPLEGIA

	TETRAPLEGIA			PARAPLEGIA		
AIS	A	B-D	Unknown	A	B-D	Unknown
Trauma	51	148	8	63	60	7
Non-Trauma	7	95	10	30	137	20
Total	58	243	18	93	197	27

TABLE 4.0 PRACTICE PATTERN DIFFERENCES ACROSS PROVINCES (N = 12)

	TETRAPLEGIA			PARAPLEGIA		
Province	Non-Traumatic	Traumatic	Total/%	Non-Traumatic	Traumatic	Total/%
BC	4	20	24/7.5	10	17	27/6.5
Alberta*	11	16	27/8.5	18	11	29/7
Saskatchewan*	2	8	10/3.1	26	6	32/7.7
Manitoba	–	–	–/–	–	–	–/–
Ontario*	41	67	108/33.9	160	65	225/54.4
Québec*	37	77	114/35.7	28	46	74/17.9
Nova Scotia	17	19	36/11.3	19	8	27/6.5
Total	112	207	319	261	153	414
Percentage of Total SCI Admissions	43.5			56.5		

"–" INDICATES DATA NOT PROVIDED.

Interesting to note are the practice pattern differences, across the provinces (Table 4.0). Alberta*, Saskatchewan*, Ontario* and Québec* have a higher proportion of non-traumatic admissions, for those with paraplegia versus tetraplegia. For tetraplegia, it is quite striking that none of the facilities have comparable admission rates for the non-traumatic population. This raises questions as to the nature, or etiology, of injury for this population, with perhaps more oncology cases in the group with non-traumatic paraplegia. These differences need to be further investigated. For the 12 reporting sites, 62% of individuals with tetraplegia had injuries between C1-C4, with 27 (9%) of individuals sustaining a complete injury (*including two SCI patients admitted with ventilator dependency (Table 5.0)). Developing the necessary respiratory resources for the group, with complete high tetraplegia, is expensive and requires specific expertise. This suggests that some focused attention should be paid to the incidence, nationally, and on how programming is addressed, for this unique group.

TABLE 5.0 NUMBER OF TRAUMATIC, NON-TRAUMATIC AND TOTAL ADMISSIONS FOR TETRAPLEGIA, BY LEVEL OF INJURY (N = 12).

LEVEL OF INJURY	TRAUMATIC	NON-TRAUMATIC	TOTAL	% OF TOTAL
Incomplete C1-4	91	69	160	53.2
Incomplete C5-8	57	26	83	27.6
Complete C1-4	23	4	27*	9.0
Complete C5-8	28	3	31	10.3

How Long do Individuals Stay in Rehabilitation?

Across the 13 sites, length of stay (LOS) LOS ranges from 41 to 336 days, with an average of 103 days. The average service interruption is four days, ranging from 0 to 13 days, depending largely on the complexity of the injury and acquired secondary complications.

Where do People Go after Rehabilitation?

Forty-two percent of total SCI individuals (45% traumatic, 38% non-traumatic), from all 13 sites, went home, after discharge from rehabilitation. Although many of these individuals would also have received some type of outpatient rehabilitation, only 15% were reported to have some type of outpatient therapy. Surprising, is the number who transferred to some type of rehabilitation (n = 61) or long-term institutional care (n = 39). Clearly, as a rehabilitation community, we need to better understand the long-term rehabilitation needs, of these individuals. Table 6.0 shows the locations and number of transfers for traumatic and non-traumatic discharges, from SCI rehabilitation sites.

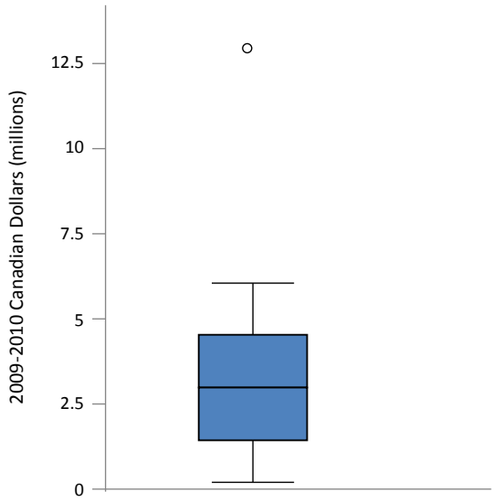
What is the Cost of Rehabilitation?

The total estimated budget, across 12 sites (one site did not provide this information), for the fiscal year 2009, was $43,161,435, with individual site budgets ranging from $107,398 to $12,555,416 (Figure 4.0). These data are too complex to interpret, as many of the sites are embedded in a larger hospital corporation, and have resources (funded by global budgets) that were not reported in the E-Scan data. Clearly, detailed economic studies must be conducted, to understand (at least on the inpatient level) the cost of rehabilitation, for individuals with SCI.
A recent Ontario study of direct costs of health services, reports that the average, first-year, per-person cost of inpatient rehabilitation was $119,945, for traumatic SCI (2005/06).[5] With the extensive resources required for SCI rehabilitation, it is essential that health utility analyses be conducted on the individual components of care across the continuum from acute care to community living, to ensure that resources are optimized for the best outcomes.

TABLE 6.0 LOCATIONS AND NUMBER OF TRANSFERS, FROM SCI REHABILITATION SITES, FOR TRAUMATIC AND NON-TRAUMATIC DISCHARGES (N = 13).

	TRAUMA		NON-TRAUMA	
DISPOSITION SECTOR	LOCATION	NUMBER OF TRANSFERS	LOCATION	NUMBER OF TRANSFERS
HOME	Home	160	Home	101
TOTAL (% OF TOTAL)		160 (45.5%)		101 (38.5%)
ACUTE	Acute Care Hospitals	63	Acute Care Hospitals	74
	Subacute Care	6		
		69 (19.6%)		74 (28.2%)
REHAB	Other Rehab Centre	34	Rehab Facility	24
			Assisted Living Facility	3
			Transitional Living	-
TOTAL (% OF TOTAL)		34 (9.7%)		27 (10.3%)
INSTITUTION	Long-term Care Facility	12	Long-term Care	15
	Acute and Continuing Care	5		
	Residential Care	3		
	Nursing Home	1		
	Extended Care	2		
	Continuing Care	1		
TOTAL (% OF TOTAL)		24 (6.8%)		15 (5.7%)
COMMUNITY	Community Centre	26	Community Centre	18
	Outpatient Care	5	Outpatient Care	4
	Privacy Home Care	1		
	Private Practice	19	Private Practice	22
	Agency	1	Outreach	1
TOTAL (% OF TOTAL)		52 (14.8%)		45 (17.2%)
OTHER	Out-of-Province/ Regional Hospitals	11		
	Other (unspecified)	2		
TOTAL (% OF TOTAL)		13 (3.7%)		0 (0%)
TOTAL		352		262

FIGURE 4.0 BOXPLOT OF THE MEAN AND RANGE OF BUDGETS REPORTED FOR SCI REHABILITATION SITES (N = 13).



Who Provides Rehabilitation Services?

In 13 sites, the number of providers, for inpatient and outpatient rehabilitation, and the number of sites providing services, on a consulting basis (within or outside the rehabilitation site or hospital corporation), are reported in full-time equivalents (FTEs) in Table 7.0. Given the diversity of bed capacity, and different admission rates, in each site, it is inappropriate to look at staffing ratios without carefully considering each site's capacity, in more detail. The E-Scan data provides a picture that shows healthcare human resources, working with the SCI population (457.4 for inpatients and 74.2 for outpatients), form a relatively small "community of practice", compared with other types of health conditions. It should be possible to capture this well-defined, specialized group of health professionals, for continuing professional development and best practice implementation, to enhance future rehabilitation for individuals with SCI.

Rehabilitation services, are predominantly provided by nurses (Figure 5.0), by occupational therapists (for activities of daily living (ADLs, etc.), and by physical therapists (for mobility, etc.). Chapters on Informed Self-Management, Walking, Wheeled Mobility and Reaching, Grasping and Manipulation, as well as others, describe the services provided by these professionals. Relatively few psychologists and psychiatrists provide psychosocial counselling services to this population. They are, for the most part, provided by social workers (Figure 6.0). In a modern healthcare system, the small number of FTEs, dedicated to help individuals to adjust to such catastrophic injuries, is somewhat surprising.

TABLE 7.0 TOTAL HEALTH PROFESSIONALS (FTEs) FOR E-SCAN SCI REHABILITATION SITES (N = 13).

HEALTH PROVIDER	HAVE SERVICE	INPATIENT (TOTAL FTE)	OUTPATIENT (TOTAL FTE)	CONSULTS (WITHIN OR EXTERNAL)
Family Practitioner Physician	11/13	9/13 (8.46)	2/13 (0.45)	Within 2/13 External 1/13
Occupational Therapist	13/13	13/13 (44.28)	11/13 (18.14)	Within 2/13
Physiatrist	13/13	12/13 (10.06)	10/13 (7.49)	Within 1/13 External 1/13
Physical Therapist	13/13	13/13 (46.16)	12/13 (22.34)	Within 2/13 External 1/13
Rehabilitation Therapist	4/13	2/13 (1.7)	2/13 (0.8)	Within 2/13
Speech-Language Pathologist	13/13	7/13 (2.27)	3/13 (0.76)	Within 8/13
Social Worker	13/13	13/13 (21.62)	9/13 (4.88)	Within 1/13
Therapeutic Recreation Specialist	12/13	11/13 (9.11)	6/13 (1.91)	Within 2/13
Internist	9/13	-	-	Within 6/13 External 3/13
Neurologist	11/13	-	-	Within 7/13 External 5/13
Nurse (RN)	13/13	13/13 (195.13)	9/13 (13.36)	Within 2/13
Nurse (RNA/RPN)	11/13	11/13 (107.28)	-	Within 1/13
Psychologist	13/13	11/13 (11.13)	6/13 (4.3)	Within 4/13
Psychiatrist	13/13	-	-	Within 9/13 External 3/13
Urologist	13/13	1/13 (0.2)	2/13 (0.3)	Within 8/13 External 4/13
Total FTE		457.4	74.7	

FIGURE 5.0 TOTAL FTE OF NURSES FOR INPATIENTS AND OUTPATIENTS ACROSS SITES (N = 13).

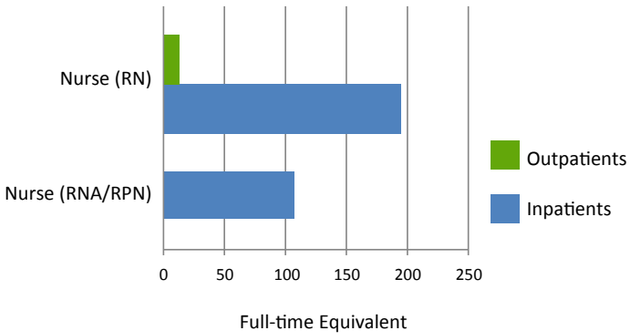
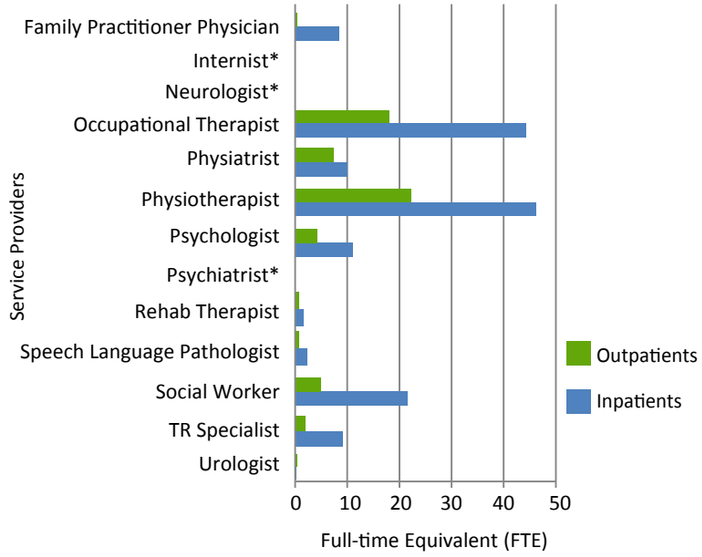


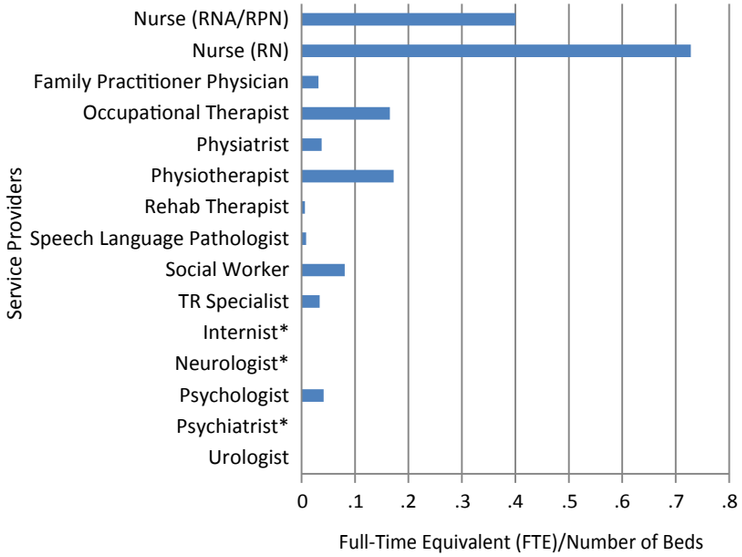
FIGURE 6.0 TOTAL FTE OF SERVICE PROVIDERS, FOR INPATIENTS AND OUTPATIENTS ACROSS SITES (N = 13).



**Internists, Neurologists and Psychiatrists are consultants.*

Understanding staffing ratios, for rehabilitation services, is complex. However, the FTE/bed ratio is one method to compare across environments (Figure 7.0). The high nursing staff ratio clearly points out the extensive services required by this patient population, for personal care, bowel and bladder, and (often) pressure ulcer management, during inpatient rehabilitation; in addition to dispensing of medication and other nursing services received in rehabilitation.

FIGURE 7.0 TOTAL FTE OF KEY HEALTH PROFESSIONALS/ TOTAL NUMBER OF SCI-SPECIFIC BEDS.



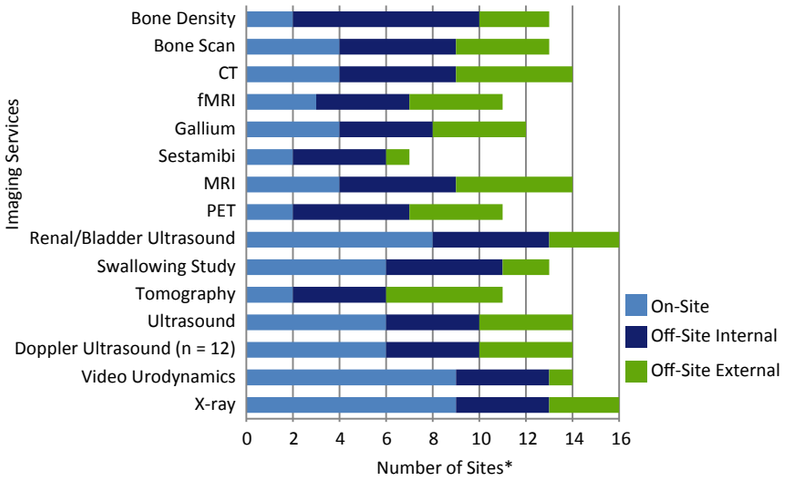
**Internists, Neurologists and Psychiatrists are consultants.*

In addition to the health professionals providing rehabilitation services, across the 13 sites, there are 41 (18.9 FTE) members of administration (e.g., Directors, Medical Directors, Program Leaders, etc.), 38 (24.6 FTE) managers (e.g., unit managers, coordinators, etc.), and 32 (26.2 FTE) service agents (e.g., directors' assistants, secretaries, intake coordinators, etc.). Eighty-nine administrators are dedicated to inpatients, 66 to outpatients, and six to outreach. There are six (1.2 FTE) administrators consultative to service, with four consultative to inpatients, and four to outpatients. At present, there are no administrators consultative to outreach. With the changing patient demographic, and focus on patient flow and integrated care across the care continuum, a refocus on how administrative services are allocated is needed, to produce optimal results within modern models of healthcare.

What Types of Resources do Canadian Rehabilitation Sites Use for Assessment and Service Delivery?

In order to gain a clear understanding of the underlying neurological pathology of SCI, it is essential to have a full spectrum of electrodiagnostic testing, to help inform patients of their health status and potential for neurological recovery. Most sites are well resourced for imaging, electrodiagnostic and laboratory services, with the exception of sestamibi scanning for thyroid or heart disease (Figures 8.0, 9.0, and 10.0). This is not surprising, as most rehabilitation sites are embedded inside a larger, general hospital or healthcare corporation.

FIGURE 8.0 IMAGING SERVICES FOR SCI REHABILITATION SITES (N = 13).



**Some sites reported services both on- and off-site.*

FIGURE 9.0 ELECTRODIAGNOSTIC SERVICES IN SCI REHABILITATION SITES (N = 13)

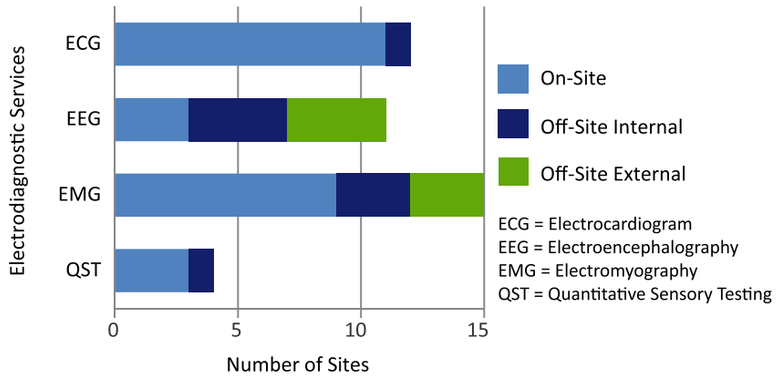


FIGURE 10.0 LABORATORY SERVICES FOR SCI REHABILITATION SITES (N = 12)

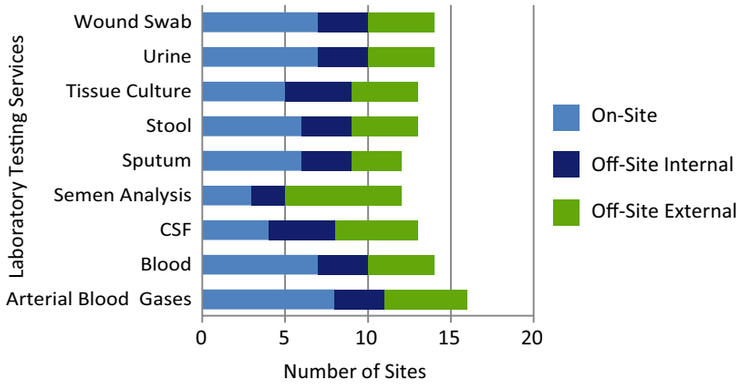


FIGURE 11.0 RESOURCES FOR COMMUNITY INTEGRATION

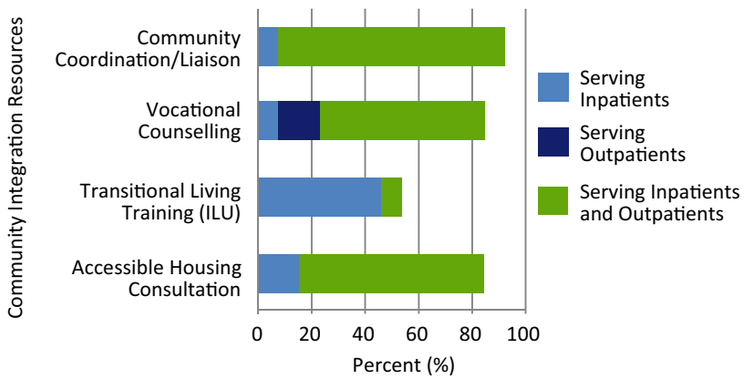


FIGURE 12.0 RESOURCES FOR COMMUNITY INTEGRATION THAT ASSIST INDIVIDUALS WITH HOUSING AND EMPLOYMENT

For individuals with SCI, whether the cause is traumatic or non-traumatic, or the incident is of sudden onset or insidious, the consequences are the same. Therefore, rehabilitation site resources that assist individuals to enhance health, quality of life and wellbeing, are essential and should be universally accessible. The E-scan was conceptualized within a framework of data fields to address health, quality of life and wellbeing. The resources, for this full suite of rehabilitation services, were incorporated in the data collection, and abstracted to demonstrate what is required, to ensure that inpatient rehabilitation transitions smoothly, from discharge to outpatient care. Figures 11.0 and 12.0 show how well prepared are the SCI rehabilitation sites, for ensuring this transition and facilitation to community integration. Chapters on Community Participation, Emotional Wellbeing and Employment and Vocation discuss, in detail, the approaches taken, important aspects of community participation that influence health and wellbeing, how a full spectrum of service delivery integrates with community life, and highlights best practices that make a difference, in the lives of individuals with SCI.

Despite the large number of sites, with access to a number of SCI Discharge Planning/Discharge Services, many do not have facilities onsite, which limit their usefulness and availability. Clearly, the rehabilitation field needs to ensure a model of SCI rehabilitation care that provides a full spectrum of services, to demonstrate that Canadian rehabilitation is an international forerunner in community integration.

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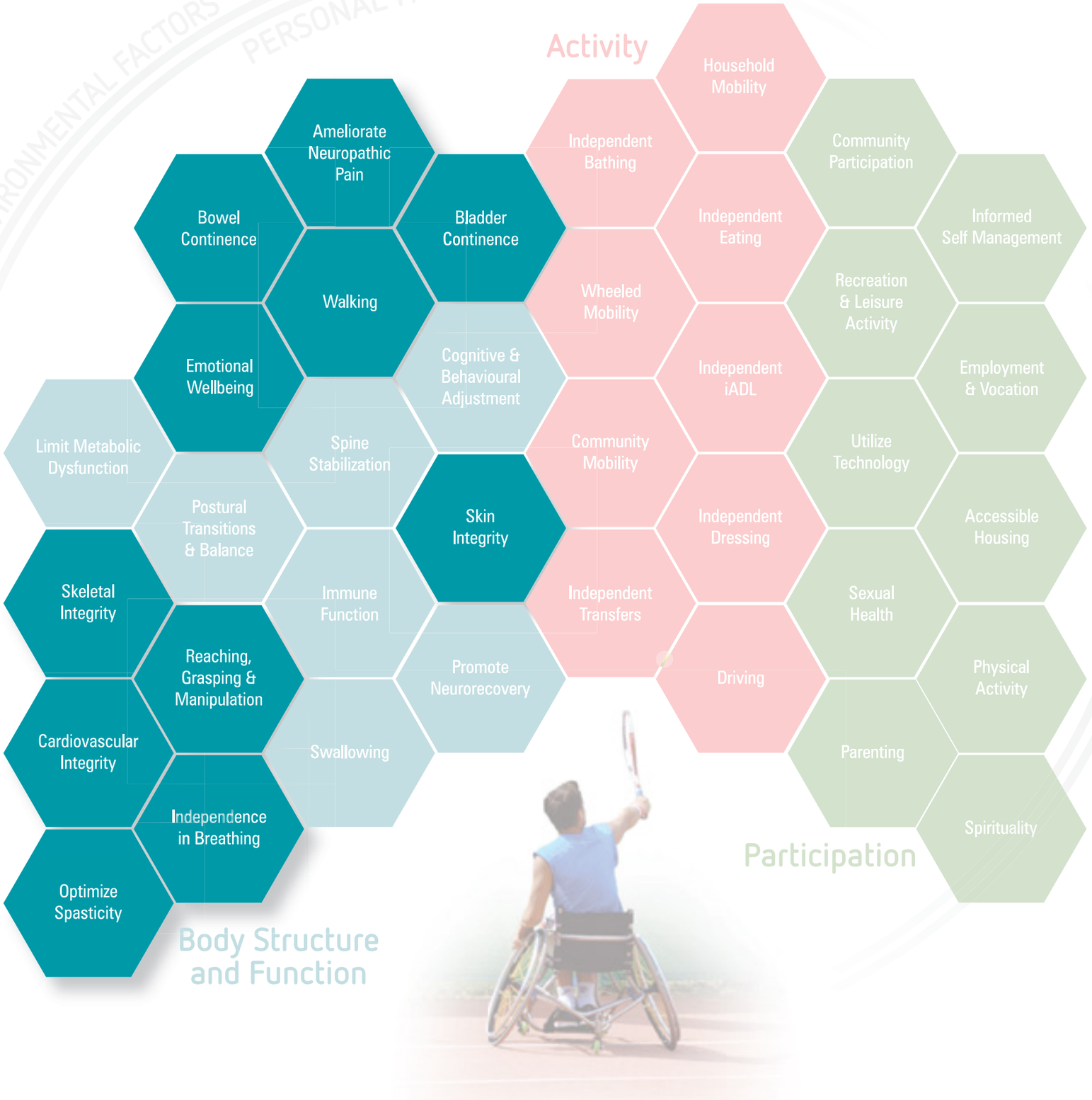
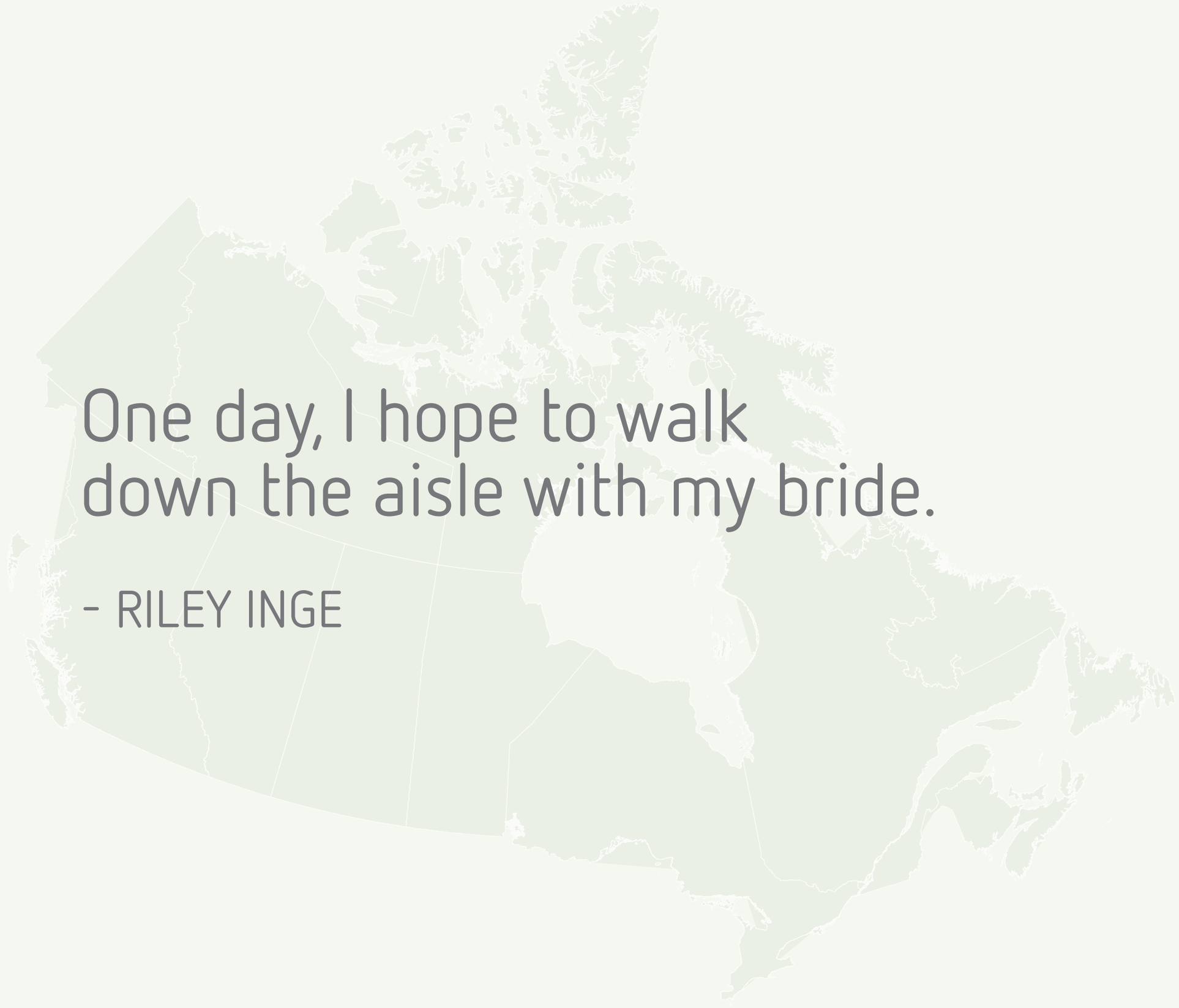
Body Structure and Function





One day, I hope to walk
down the aisle with my bride.

- RILEY INGE

Walking

MC Verrier, MHSc; C Craven, MD; HM Flett, MSc; K Guy, MSc; S Nadeau, PhD; and the E-Scan Investigative Team

Walking is the ability to move forward over ground while assuming an upright posture and controlling one's balance, trunk and lower-limb sensorimotor function. Safe and efficient walking allows individuals to purposefully move from place to place to explore and participate in their external environments, with or without the assistance of others and/or assistive technologies – in other words, to be independent moving about their home and community, and in their life activities.

For individuals with spinal cord injury (SCI), walking has many long-term health benefits including pressure relief for weight-bearing surfaces of the body and maintenance of fitness levels. The ability to walk is one of the top six articulated goals of individuals with SCI.[1] Hence, gait training is a major focus of many rehabilitation programs in Canada and consumes substantial resources at most rehabilitation centres.

Walking is a complex sensorimotor functional task. Internal individual factors must be aligned with external environmental factors for successful community mobility. When developing best practices in assessment and therapeutic interventions for rehabilitation walking programs, physical therapists use a model for walking that considers the individual in concert with his/her environment.

Walking Model: Individual and Environmental Influencing Factors

THE SCI FUNCTIONAL AMBULATION PROFILE (SCI-FAP), CAPTURES FUNCTIONAL WALKING; CARRYING OBJECTS, MANEUVERING AROUND OBSTACLES.

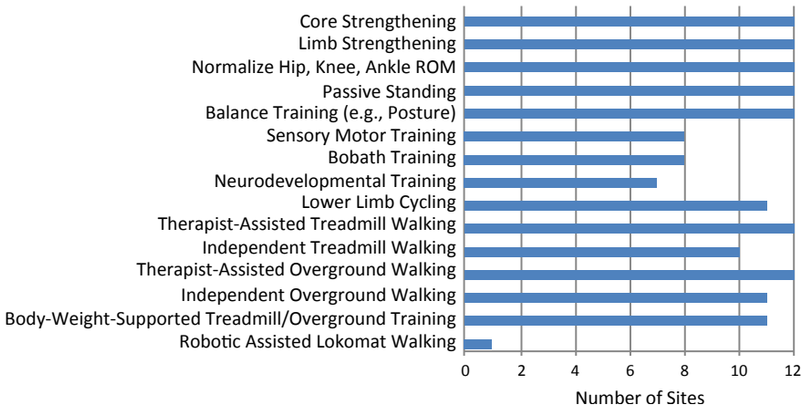
Current Practice: Assessing Walking Ability

The recovery of walking ability has been measured using many different approaches and constructs: kinetics and kinematics in research laboratories, metrics such as speed, cadence and distance in the clinical setting, and categorical measures such as the use of assistive devices, level of independence, walking ability scales and patient preference/satisfaction. Lam et al.[2] have conducted a seminal review regarding the psychometric properties of the measures. However, depending on the clinical site, only some have been incorporated into clinical practice. Despite a plethora of literature on walking, there are no current guidelines regarding best practices in walking assessment. What is less well documented is the meaningfulness of functional walking, at the patient level. The most recent assessment approach, the SCI Functional Ambulation Profile (SCI-FAP), which captures functional walking (carrying objects, maneuvering around obstacles, etc.), has been developed by Musselman et al.[3] However the psychometric properties of the test - the sensitivity of the measure to detect change and the minimal clinically important difference - still need to be determined.

In general, only about 50% of patients being admitted to active rehabilitative centres have the ability to walk at the time of discharge, though they continue to gain improved walking performance over the course of the first year to 18 months post-injury, particularly if they are enrolled in outpatient rehabilitation programs. How much the healthcare system in Canada is willing to fund outpatient walking rehabilitation programs requires immediate attention from a policy perspective.

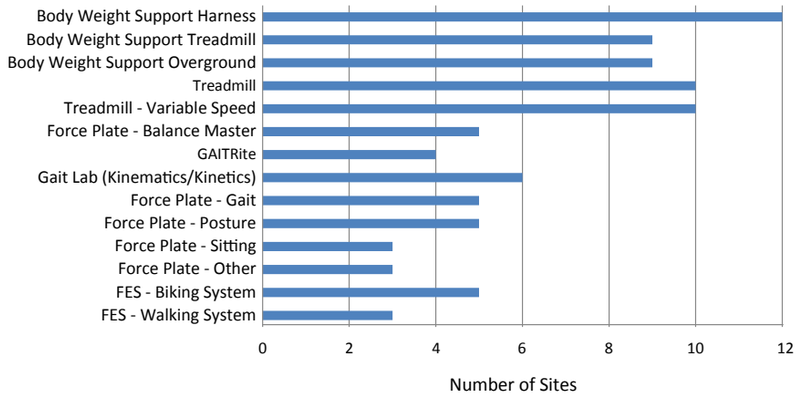
Therapeutic interventions for facilitating functional walking using standard equipment (parallel bars, walkers, forearm crutches, canes, walkers and lower limb bracing) are in place in all 12 clinical spinal cord programs, as is therapist-assisted treadmill walking. Standard therapeutic approaches such as strengthening and balance training are being practiced in clinical sites (Figure 1.0). Other traditional therapies, like neurodevelopment approaches, appear to be less popular (approximately 60% of the centres are using these approaches). The clinical use of a robotic system is present in only one inpatient site (Glenrose), and in one private outpatient facility in Ontario. There were no reported standard guidelines or protocols for walking or related physical therapy in any Canadian site.

FIGURE 1.0 THERAPEUTIC APPROACHES FOR POSTURE AND GAIT TRAINING



Specialized equipment for body-weight-supported treadmill training (BWSTT) has been adopted in only nine of the 12 sites, but treadmill training itself is now commonplace in 10 of the 12 centres (Figure 2.0). More sophisticated postural approaches like the use of the Balance Master are only available in less than 50% of the sites, and Functional Electrical Stimulation (FES) systems for biking and walking are available in only 25% of the facilities.

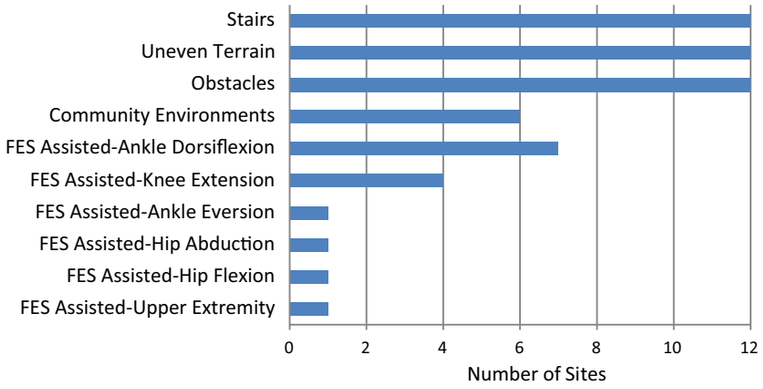
FIGURE 2.0 SPECIALIZED EQUIPMENT FOR POSTURE AND GAIT ASSESSMENT AND TRAINING



Advanced gait-training approaches are in place in all sites (Figure 3.0). However, only 50% of the programs train for walking in community environments. This practice needs to be addressed, as community ambulation is a priority for individuals with SCI and a benchmark for some programs. There is almost no customization of FES for specific muscle groups to facilitate walking. It is important to know whether this is an equipment, practice or practitioner issue.

There are no reports of the use of whole-body vibration as an approach for improving walking function (inter-limb coordination, speed and cadence) as has been demonstrated by Ness and Field-Fote.[4] Nor was there mention of having the equipment in the clinical setting, with the exception of Lyndhurst Centre where it is being used in phase two research studies.

FIGURE 3.0 ADVANCED GAIT SKILLS TRAINING AND CUSTOMIZED FES APPROACHES

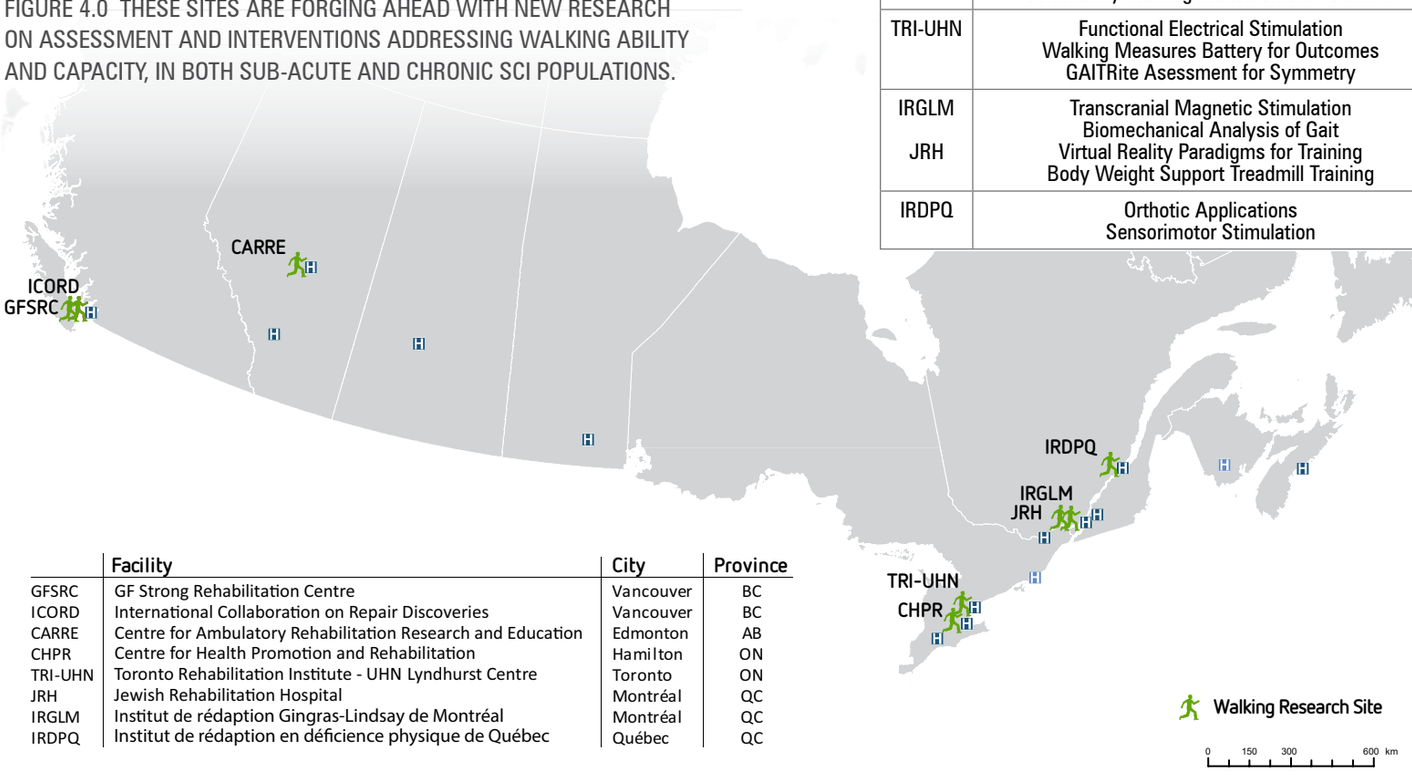


Current Canadian Practice: Understanding the Assessment and Recovery of Walking Ability

Much of what we know globally about walking ability, post-SCI, has come from the researchers in the academic health science centres in Canada (University of British Columbia, Simon Fraser University, University of Alberta, University of Toronto, McMaster University, Unversity of Montréal, McGill Univerity, and Laval University), spear-headed by MSc/PhD-trained neuroscientists, physical therapists and kinesiologists (Figure 4.0). These research programs, initiated in the early 1980s by Barbeau, have continued to flourish and have now gained international recognition. Most of the research programs are now aligned with clinical rehabilitation programs (GF Strong, Toronto Rehab, Jewish Rehabilitation Hospital, the Institut de Réadaptation Gingras-Lindsay-de-Montréal and the Institut de réadaptation en déficience physique de Québec) where therapists and scientists often interact regarding best practices in gait training.

SITE	RESEARCH AND DEVELOPMENT	LEADS
GFSRC ICORD	Cardiovascular Capacity for Walking Lokomat Assisted Training	Janice Eng Tania Lam
CARRE	Motor Cortical Enhancement Overground Training Paradigms Community Walking Measurement - SCI-FAP	Monica Grossini Jaynie Yang Kristen Musselman
TRI-UHN	Functional Electrical Stimulation Walking Measures Battery for Outcomes GAITRite Asessment for Symmetry	Milos Popovic Molly Verrier Kristina Guy
IRGLM JRH	Transcranial Magnetic Stimulation Biomechanical Analysis of Gait Virtual Reality Paradigms for Training Body Weight Support Treadmill Training	Dorothy Barthelemy Sylvie Nadeau Joyce Fung Hugues Barbeau
IRDPQ	Orthotic Applications Sensorimotor Stimulation	Laurent Bouyer Carol Richards

FIGURE 4.0 THESE SITES ARE FORGING AHEAD WITH NEW RESEARCH ON ASSESSMENT AND INTERVENTIONS ADDRESSING WALKING ABILITY AND CAPACITY, IN BOTH SUB-ACUTE AND CHRONIC SCI POPULATIONS.



	Facility	City	Province
GFSRC	GF Strong Rehabilitation Centre	Vancouver	BC
ICORD	International Collaboration on Repair Discoveries	Vancouver	BC
CARRE	Centre for Ambulatory Rehabilitation Research and Education	Edmonton	AB
CHPR	Centre for Health Promotion and Rehabilitation	Hamilton	ON
TRI-UHN	Toronto Rehabilitation Institute - UHN Lyndhurst Centre	Toronto	ON
JRH	Jewish Rehabilitation Hospital	Montréal	QC
IRGLM	Institut de rédaption Gingras-Lindsay de Montréal	Montréal	QC
IRDPQ	Institut de rédaption en déficience physique de Québec	Québec	QC

SPOTLIGHT BEST PRACTICE ORGANIZATION

BRAIN AND SPINAL CORD REHAB PROGRAM

– Toronto Rehabilitation Institute (TRI), University Health Network, Toronto

The breadth, depth and integration of the clinical and research expertise of the clinicians and scientists at this site are noteworthy. Walking assessments using a standardized, valid and reliable battery of measures are routinely collected during admission and at discharge from rehabilitation. GAITRite technology is being used to identify patients, with particular impairments in symmetry as well as variability, especially since gait symmetry doesn't appear to be a major problem for many individuals with SCI. GAITRite data is then used to tailor therapeutic approaches to specifically target the asymmetry and variability of gait.

Algorithms using Lower Extremity Motor Scores (LEMS) are employed to determine the timing for initiation of an enhanced walking-training program. Therapeutic interventions are patient specific, and incorporate all interventional approaches (with the exception of robotics).
The therapy interventions are individually customized to capture the capacity of the individual's ability to sit, to stand, to step and to walk, with a major emphasis on strengthening and enhancing posture and trunk control during transitions, propulsion and progressions. Refinement of each of these components is captured during therapy paradigms requiring weight shifting, unilateral and bilateral stepping activities, and walking at various speeds incorporating rotation. All components are initiated and practiced with body weight support, when required, during treadmill and/or over-ground walking. There is limited use of gait aids, and careful attention is paid to customizing their application to progress walking performance, over time. Once the basics are captured, contextual and circumstantial challenges are incorporated such as inclines, obstacle avoidance and altered terrains. Careful attention is paid to repetition, with timely progression to more challenging components and longer durations of activities. Quality and safety are emphasized and performance and endurance are routinely assessed during rehabilitation.

Ongoing research studies are investigating the effectiveness of FES-assisted posture and gait training, BWSTT, whole-body vibration and postural feedback training. Outpatient walking rehabilitation programs are being strengthened to address the gaps in rehabilitation service. Lyndhurst investigators belonging to the SCIMobility Team, funded by a grant from Réseau provincial de recherche en adaptation-réadaptation (REPAR) and the Ontario Neurotrauma Foundation (ONF), are interacting on a routine basis to enhance the development of patient-specific training protocols. The interactive approach of researchers and clinicians is also present in other centers, at different levels. The integration of research, evaluation and intervention at this site is transforming physical therapy clinical practice.

Best Clinical Practices

Best practices in walking rehabilitation are now underway in individual centres and could be implemented in multiple clinical sites. These practices are at the patient, program and rehabilitation practice levels, and need to be initiated in a formalized manner across Canada.

PATIENT LEVEL

- Develop and employ methods to predict which patients have the most potential for walking recovery
- Ensure each patient has access to a walking rehabilitation program on an outpatient basis
- Align and strategically implement physical therapy interventions customized to specific patient goals, physiological, actual and potential capabilities.

PROGRAM LEVEL

- Validate and implement standardized assessment tools for functional walking into clinical practice
- Utilize walking programs for health benefits as part of clinical practice
- Develop and participate in clinical trials designed to evaluate interventions to optimize walking capacity.

PRACTICE LEVEL

- Understand the meaningfulness of walking ability in the home, workplace and community for individuals with SCI
- Analyze and track patient population walking outcomes at rehabilitation admission/discharge and longitudinally
- Resource walking rehabilitation programs over the life course for fitness purposes.

Key Clinical Issues: What is Needed for Best Practice?

1. Demonstrate and advocate for the value of clinical assessment paired with clinical decision making regarding therapeutic protocols. The accuracy of physical therapists' ability to predict future mobility, at the time of rehabilitation admission, has been demonstrated to be extremely robust.[5] This is important for patient goal setting, designing therapy protocols, discharge planning and equipment prescription; and for policy development for funding regarding outpatient locomotor training, given how important mobility is to long term outcomes.

2. Identify and determine the appropriate intensity, timing, duration, customization and type of walking interventions and programs. To date, studies have demonstrated that there is no superior method for gait training for individuals with SCI, thus making therapeutic intervention largely a clinical decision-making process, based on best evidence, for the varying combinations of therapies. Of import, intensity of therapy seems to optimize walking recovery. Understanding that biomechanical gait analysis can reveal information pertinent to the selection of a task-oriented approach to enhance gait training, as well as the therapeutic response that clinical evaluations alone cannot provide, is vital to

customize interventions.[6] Similarly, understanding the neurophysiologic findings from assessments, such as transmagnetic stimulation and imaging the spinal cord and the brain, may prove valuable for designing the metrics of therapy in the future. Unfortunately, walking rehabilitation programs are under threat as a result of cost-containment measures that have decreased the length of funded inpatient rehabilitation. This makes the development of outpatient rehabilitation walking programs paramount.

3. Optimize the integration of posture and walking capacity during recovery. Little is known about the integration of upright posture and walking, although individuals who demonstrate improved scores on the Berg Balance Scale are reported to have better walking function,[7] making attention to postural training an important aspect of a walking rehabilitation program.

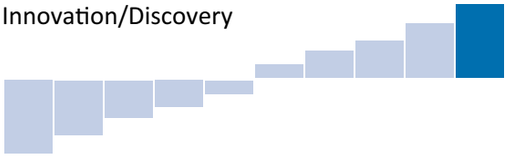
4. Monitor the longitudinal effects of walking capacity and how walking ability relates to body-structure and functions, secondary complications, participation in activities and quality of life. Monitoring longitudinal effects of walking capacity and the relationship to health status and wellbeing is another clinical issue. Although physical activity guidelines for SCI have been implemented across Canada, rehabilitation centres are not funded to provide walking programs as a means for maintaining fitness; and publicly-funded recreational venues do not have the adaptive equipment to support the SCI population. The clinical physical therapy community needs funding to develop walking programs for individuals with SCI, in outpatient clinics.

REPORT CARD: Walking

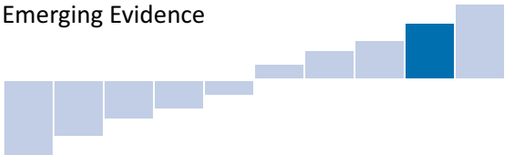
Extreme left below median: ***insufficient***
Extreme right above median: ***optimal***

KNOWLEDGE GENERATION

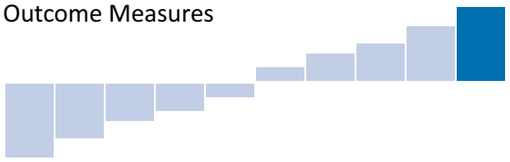
Innovation/Discovery



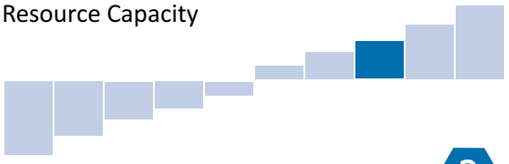
Emerging Evidence



Outcome Measures



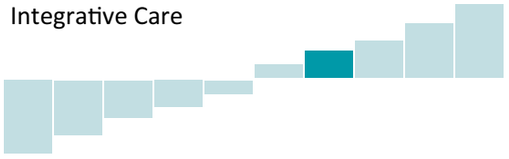
Resource Capacity



2020 PRIORITY 3

CLINICAL APPLICATION

Integrative Care



Effective Practice
(Evidence and Outcomes)

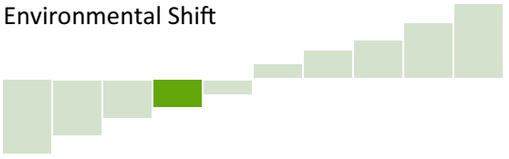
Equity Practice

Capacity

2020 PRIORITY 1

POLICY CHANGE

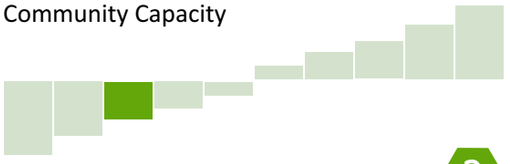
Environmental Shift



Change Agents

Societal Awareness

Community Capacity



2020 PRIORITY 2

TAKE HOME MESSAGE:

Walking is a critical function for all individuals – essential for health status, quality of life and wellbeing. Individuals with SCI in Canada have challenges obtaining access to rehabilitation services – for assistance, with enhancing and maintaining their walking ability, particularly over the first year, post injury. As a collective rehabilitation community, it is imperative this is addressed in health policy and service, at both provincial and federal levels. The Rick Hansen Spinal Cord Injury Registry (RHSCIR) could compile a team of PT practitioners from across the country, tasked to align routine assessment and data elements with clinical decision- making rules, in order to customize therapy delivery and advocate for appropriate resources.

RESOURCES

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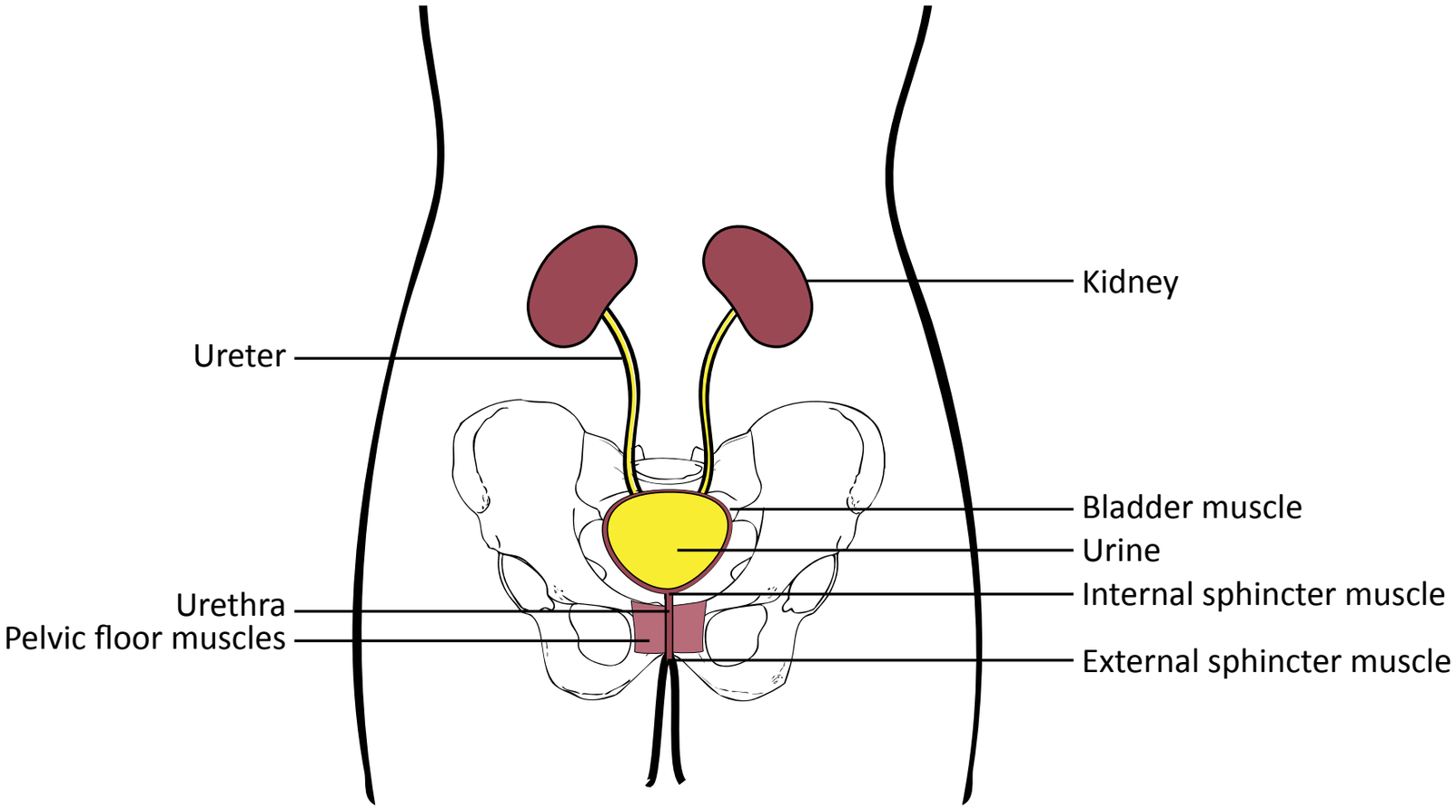
Bladder Continence

J Hsieh, MSc; K Ethans, MD; M Hassouna, MD; B Welk, MD; C Craven, MD; and the E-Scan Investigative Team

The goals of neurogenic bladder management after spinal cord injury (SCI) are to achieve continence, with regular and timely bladder emptying to avoid urinary stasis, high filling and voiding pressures; to reduce urinary frequency and urgency, and to prevent and treat complications such as urinary tract infections (UTIs), stones, strictures and autonomic dysreflexia. The focus of this chapter is the management of neurogenic overactive bladder.

After SCI, individuals experience loss of control over bladder function. This results in a bladder that may be overactive, have a reduced ability to hold urine, and a urinary sphincter that does not relax properly while voiding. In addition, an individual with SCI often cannot feel when the bladder is full, so may have incontinence as it fills. An inability to empty the bladder effectively leads to urinary stasis, and can cause urinary tract infections. High bladder pressures can cause the urine to transmit pressure back up to the kidneys and cause kidney damage (see Figure 1.0). Infections may worsen incontinence, and/or cause increased pain, body spasms or fever. Most people with this type of bladder dysfunction have to catheterize (insert a tube in the bladder) every few hours, to empty the bladder, and to reduce bladder pressure and incontinence. Individuals with SCI are often prescribed medications to relieve a spastic overactive bladder, increase bladder capacity, and decrease loss of bladder control, between catheterizations.

FIGURE 1.0 THE URINARY SYSTEM

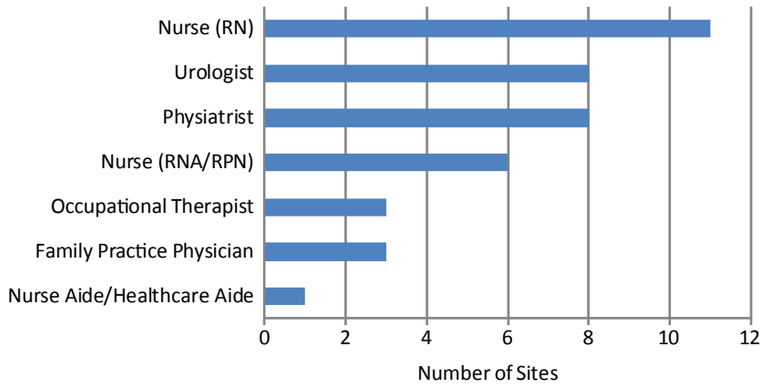


Regaining bladder and bowel function is the top priority for just under 40% of individuals with spinal cord injury who were asked to rank the importance of these specific health issues.[1]

Neurogenic Bladder Services in Canada: Where Are We Now?

The majority of the 12 participating E-Scan sites report that bladder management is achieved through the coordinated efforts of individuals, nurses, physicians (physiatrists, urologists and family practitioners) and occupational therapists (OTs), in descending order of contribution across sites (see Figure 2.0). Coordination of services among individuals, nurses, physiatrists and urologists is essential for effective bladder care.

FIGURE 2.0 NUMBER OF SITES REPORTING STAFF MEMBERS PARTICIPATING IN BLADDER MANAGEMENT SERVICES



Typically, if an individual with SCI has a neurogenic bladder, and cannot voluntarily void, staff start him or her on an intermittent catheterization (IC) every four to six hours routinely, to keep volumes less than 600 cc (ideally ≤ 500 cc). This process is usually initiated in the first few weeks after SCI, often in acute care, prior to rehabilitation admission, and once the initial trauma phase and fluid management is under control. Generally, once urine output is less than 2600 cc daily, the IC routine will start.

If an individual has good hand function, cognition and is enthusiastic, instruction to perform independent IC is started in acute care. Once in rehabilitation, the instruction continues until the individual has mastered the IC technique in different positions (e.g., in bed, in a wheelchair). For those who have little hand function, a tenodesis orthosis or catheter advancer may be introduced, by the OT.

For those unable to learn self-catheterization, due to poor hand function, long-term plans are discussed with the physiatrist, individual, caregiver(s), spouse, etc., and the urologist about who will be responsible for the ongoing IC routine. If this is infeasible, an indwelling catheter is usually placed until a decision on other potential long-term management strategies (such as a sphincterotomy with condom drainage in men, or continent or incontinent stoma in women), is made.

For those unable to perform self-catheterizations, the primary goal is teaching them to direct their own care, including prevention and recognition of Urinary Tract Infections (UTIs). When an individual is in hospital and being catheterized by staff, a sterile technique with a new catheter is used each time. Once self-catheterization is learned, individuals often switch to a “clean” technique once discharged from rehabilitaton - to wash (with soap and water). Unfortunately, individuals who have financial constraints often choose to reuse catheters for several days.

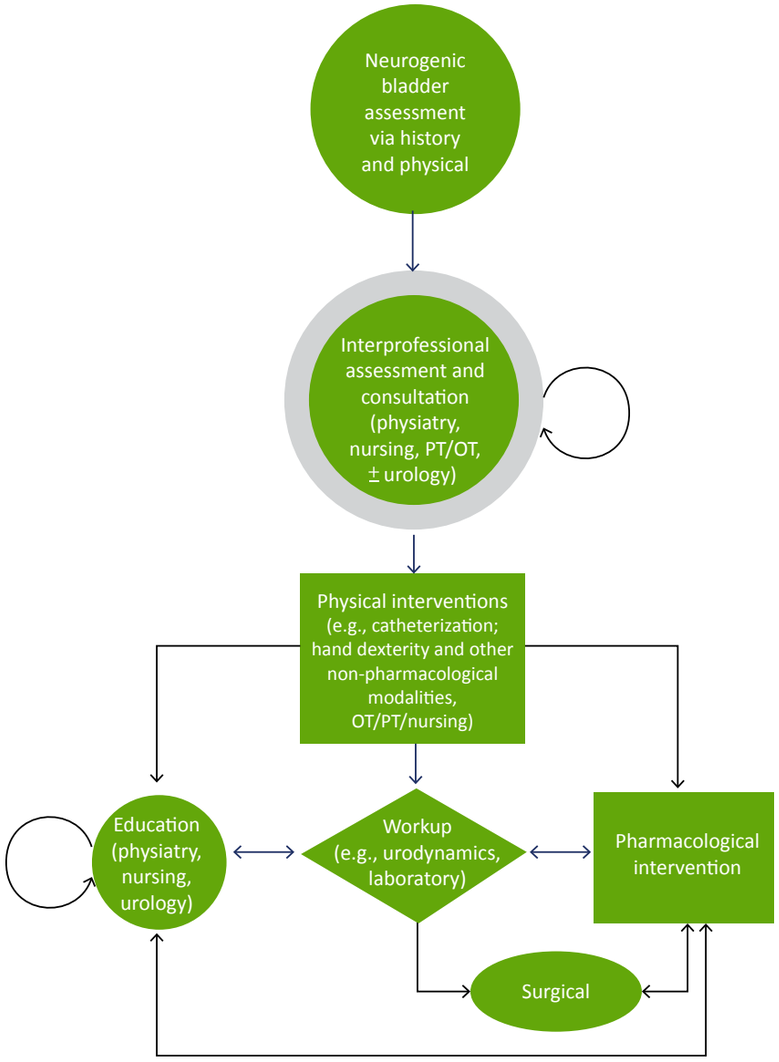
Testing to describe neurogenic bladder function should be done in the first few months following injury. The optimal timeline for this varies, in Canada, but generally, the individual should be out of spinal shock. Therefore, some sites wait until the three month point, before baseline testing. This baseline testing includes urodynamics, ultrasound of kidney and bladder, and determination of creatinine clearance, with a 24-hour urine collection.

After rehab discharge, an individual with SCI should ideally undergo bladder function testing - annually, for the first five years and then every second year, thereafter. Tests offered from site to site vary, depending on testing resources and any follow-up program. Minimally, ultrasound imaging (see Figure 5.0) and a kidney function test should be done. Monitoring for renal failure using serum creatinine testing is generally unreliable in individuals with SCI because less creatinine is made, as a result of reduced muscle mass. Even in the case of failing kidneys, serum creatinine may not be significantly elevated beyond the normal reference range. Thus, 24-hour urine collection for creatinine clearance is recommended. Regular follow-up urodynamic testing is preferably done as well, but may not be acceptable to individuals (with some preservation of sensation), who can perceive rectal and urethral catheter insertion as invasive.

For those with long-term indwelling catheters, annual screening starting one decade, post-injury (or five years post-injury, for high risk individuals, such as smokers), should be done via cystoscopy to monitor for possible development of bladder cancer. Regular follow up should also include an inquiry for new onset of complications, bladder maintenance routine, frequency of UTIs, incidents of incontinence, urodynamic testing, and review of ongoing and available treatments. Significant symptoms of overactive bladder, such as problematic urgency, frequency and need for frequent catheterizations, should prompt investigations to rule out UTIs, followed by introduction of anticholinergic medications (as indicated). These two interventions are mainstays of first-line treatment for incontinence. If neither of these interventions are effective or tolerated, botulinum toxin injected in the bladder muscle (detrusor) can be used, or surgical bladder augmentation considered. Surgical considerations are generally deferred for at least one year, to observe natural recovery of bladder function.

One site reports not having an RN dedicated to bladder management activities, and four sites report lacking specific physiatric and urologic relationships, for the bladder management program. The spectrum of service for management of overactive bladder is shown in Figure 3.0.

FIGURE 3.0 SIMPLIFIED SCHEMATIC OF THE INTERPROFESSIONAL, MULTI-MODAL DELIVERY OF BLADDER CONTINENCE PROGRAMS, POST-SCI.



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Neurogenic Bladder Dysfunction Assessments Currently in Use

BLADDER MANAGEMENT ASSESSMENT TOOLS IN CURRENT USE:

- Bladder diaries [92/53%]
- Urodynamics [83/58%]
  - Post-void Residual [100/67%]
  - Maximum Detrusor Volume [83/42%]
  - Reflex Detrusor Volume [58/33%]
- Cystoscopy [75/33]%
- Creatinine Clearance [67/42%]
- Renal Perfusion Scans [33/0%]
- Renal and Bladder Ultrasound [25/25%]

Bladder diaries can be helpful in select circumstances. However, the current authors suggest that this is not necessary in routine clinical practice, due to the administrative burden. It's interesting to note that although 58% of sites routinely perform a urodynamic assessment, 75% of sites report having the equipment available, and 95% report having sufficient equipment for their needs. However, only 25% report its routine use.

Similarly, although renal and bladder ultrasounds are only performed routinely in 25% of the sites, 92% report having the service available, within their organization (67% onsite), and 92% of sites deem the service to be adequate overall. Reasons for this discrepancy between available resources and utilization are unclear, and may include individual tolerance of assessment, limited access to a urologist or physiatrist to

order/interpret the results, or inadequate understanding of the clinical importance or necessity for these tests. It appears from the data gathered that urodynamic evaluation should be available when clinically indicated, in a majority of the sites (see Figure 4.0). In addition, there is an apparent lack of attention to long-term surveillance, in a majority of sites.

Considering data suggests that urodynamic evaluation is available when indicated, inadequate physiatry resources may be the reason for the lack of long-term bladder follow up in Canada. Specifically, inadequate long-term tracking mechanisms of individuals with SCI, inadequate knowledge of the need for these individuals to have regular testing, or inadequate appointment adherence are likely the reasons that such repeated testing is not carried out longitudinally.

FIGURE 4.0 PERCENT OF CANADIAN SCI CENTRES REPORTING AVAILABILITY OF DIAGNOSTIC SERVICES

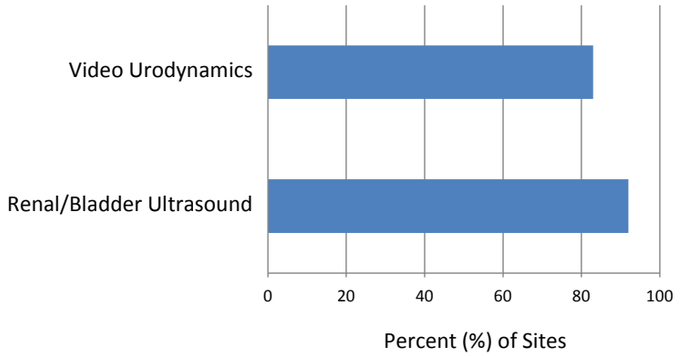
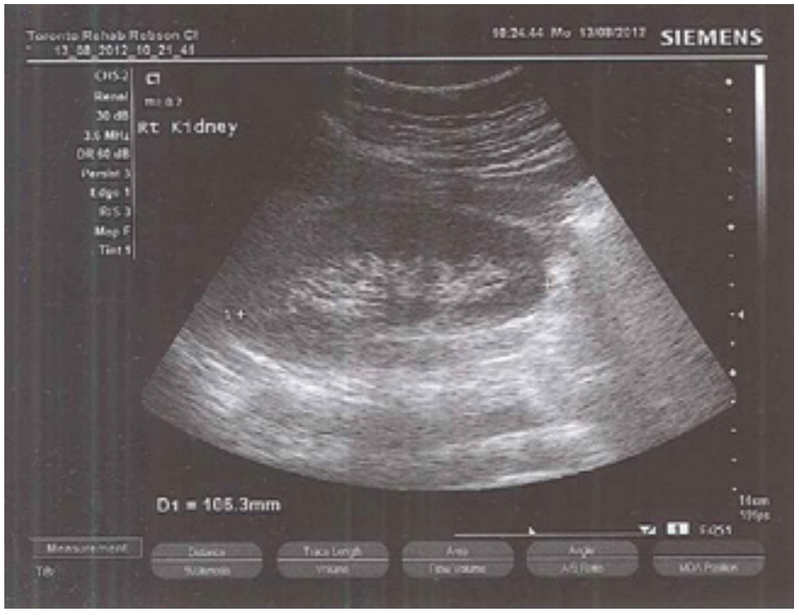


FIGURE 5.0 ULTRASOUND



Published (Peer-reviewed) Canadian SCI Experts Rank Among the Best in the World

1. Jerzy Gajewski, MD (Urology), Halifax: Director of Functional Urology Program at Dalhousie University with clinical and research interests in voiding dysfunction, neurogenic bladder, incontinence, interstitial cystitis and erectile dysfunction.

2. Gregory Bailly, MD (Urology), Halifax: Most interested in female urology, incontinence, urethral reconstruction, erectile dysfunction and prostate disease.

3. Magdy Hassouna, MD (Urology), Toronto: Primary research interest is in neuro-urology, with special emphasis on the use of neurostimulation to modulate the functions of the urinary bladder. Clinical interests include voiding dysfunction and male erectile dysfunction.

4. Sendor Herschorn, MD (Urology), Toronto: His clinical and research interests include urinary incontinence, overactive bladder, erectile dysfunction and female urological issues. Along with many peer-reviewed publications in bladder function, Dr. Herschorn has been invited to speak on this subject, worldwide.

5. Patrick Potter, MD (Physiatry), London: A physiatrist with a long-standing interest in bladder function, and a publication history in peer-reviewed SCI journals.

6. Jean-Guy Vézina, MD (Urology), Québec City: Primary research interest is associated with advances in penile vibrator stimulation (PVS) and oral midodrine for the enhancement of self-ejaculation in spinal cord injured (SCI) men to self-ejaculate.

7. Karen Ethans, MD (Physiatry), Winnipeg: A physiatrist who has pioneered bladder management strategies including, but not limited to, bolulinum toxin injections. Dr. Ethans has participated in numerous bladder management-related clinical trials, as well as related peer-reviewed publications.

SPOTLIGHT BEST PRACTICE ORGANIZATION

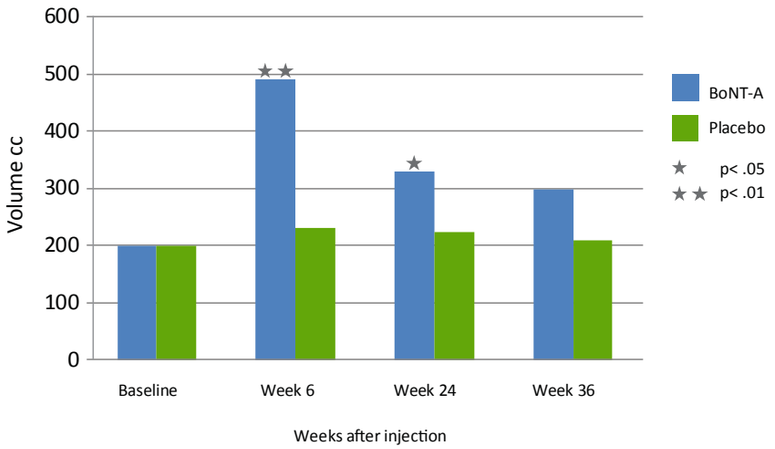
SPINAL CORD INJURY PROGRAM –

Health Sciences Centre Winnipeg, Winnipeg Regional Health Authority, Winnipeg, Manitoba.

In Winnipeg, there is a long-term, interdisciplinary approach to neurogenic bladder management. SCI physiatrists conduct testing and management follow up every year, for the first five years and every two years, thereafter. Any specific problems requiring urodynamic evaluation are assessed, with physiatrist-ordered tests; and a neuro-urologist is consulted for any concerns requiring cystoscopy evaluation and management, botulinum toxin injection or surgical management. The physiatrists and neuro-urologist have published on the use of anti-cholinergics in SCI, participated as strong recruiters in the botulinum toxin trials, and collaborate well together.

Winnipeg's interdisciplinary neurogenic bladder management team are at the cutting edge of treatments. Pictured here is the team at work providing botulinum toxin injections, with the aid of a cystoscope into the bladder via the urethra. This recent Health Canada approved treatment is well supported by the literature for use in overactive bladders with a low risk of side effects.

FIGURE 6.0 VOLUME AT MAXIMUM DETRUSOR PRESSURE DURING FILLING (ML). CANADIAN TRIAL RESULTS OF USE OF BOTULINUM TOXIN, ONTO THE DETRUSOR IN NEUROGENIC BLADDER.
REPRODUCED FROM HERSCHORN ET AL.[2] © 2011 AMERICAN UROLOGICAL ASSOCIATION EDUCATION AND RESEARCH, INC. REPRINTED WITH PERMISSION.



Where We Need to Go and Where We are Headed

Currently, there are four published clinical practice guidelines, and at least nine key references to provide evidence-based recommendations; as well as a variety of validated assessment tools, used in the management of neurogenic bladder. Despite the availability of these resources, there are many key clinical issues that relate to the need for rehabilitation leadership, in best practice implementation (BPI). The top two priority areas needed to optimize clinical care are:

1. Use of botulinum toxin therapy for the detrusor muscle
Due to recent publication of Level 1 evidence demonstrating the efficacy of intravesicular botulinum toxin studies (see Figure 6.0),[2,3] Health Canada approval for intravesicular botulinum toxin was obtained, in December 2011. However, the processes and timelines for adoption of this therapy, in provincial formularies, are unclear (estimated timeline is 2017). There is a need to advocate for access to intravesicular botulinum toxin for those who have failed intermittent catheterization, and conventional anticholinergic medications. Further definition of an adequate trial of conventional treatment is needed.

2. Long-term self-management is key to life-long bladder health
To achieve this, there needs to be coordinated, interdisciplinary follow up and management of individuals with neurogenic overactive bladder. Follow up and management include ongoing patient education on the effects of neurogenic bladder, and the need for appropriate management; management of secondary complications of neurogenic overactive bladder, and assessment of the need for surgical referral, for issues such as continent catheterizable stomas - with or without bladder augmentation.

In addition to working towards resolution of these clinical issues, knowledge innovation is required for bladder continence, post-SCI, as follows:

1. Newer-generation anticholinergics need to be further addressed in the SCI population Those available require better funding (e.g., M3 receptor antagonists) uniformly, across Canada. Presently unfunded are sustained-action anticholinergics, with more acceptable side effects (e.g., less dry mouth).

2. The use of botulinum toxin needs further evaluation, especially in the area of sphincter management There is a lack of quality studies to date.[4] Although the effectiveness of detrusor injections for incontinence management is well investigated, long-term use of botulinum toxin for detrusor muscle injections needs further evaluation, including effects on issues other than incontinence (e.g., frequency of catherizations, medication use, intervals of treatment, dosage). Funding issues also need to be resolved, as this is largely unfunded, in Canada, at present.

3. Education is a key component to life-long bladder continence
The question of what information should be delivered, in what format, by whom and when, can only be answered by designing studies to systematically evaluate interdisciplinary education programs, for bladder continence.

The implementation of best practices, in a structured and measureable framework (once evidence is available), is key to resolving these top clinical issues. A common barrier to best practice implementation is the lack of funding to allow for interventions requiring external resources, such as pharmaceuticals on the formulary for SCI, and appropriate health professionals to provide the evidence-based best practice interventions.

In order to ensure that any practice is effective, an agreement on measures of performance is needed. In an evolving healthcare environment that promotes continuous quality improvement (CQI), accreditation at the level of Distinction for SCI through Accreditation Canada might be achievable with the quality indicators shown in the following table.

SUGGESTED BEST PRACTICE INDICATORS ARE:

BEST PRACTICE INDICATORS	HOW IS IT MEASURED?	WHO MEASURES IT? WHERE?	WHEN IS IT IDEALLY MEASURED?
1. The organization conducts an initial bladder function assessment, at admission, that includes urgency/ frequency and urodynamics (including cystometry, urethral pressure profile, post-void residuals).	Counts	Program	Quarterly
2. The organization implements documented protocols and procedures to maintain and sustain bladder function and kidney health, annually for five years, and every second year thereafter.	Counts	Program	Annual
3. The organization educates staff on neurogenic overactive bladder and management strategies.	Counts	Program	Quarterly
4. Prior to discharge, 100% of patients receive, understand and apply bladder management methods, as provided through a structured and individualized educational program (one-on-one or group workshops, demonstrations, technique practice and written materials), mediated by SCI specialist health professionals.	Counts	Program	Annual
5. The organization monitors its success in maintaining and sustaining bladder continence, and incorporates data into continuous, rapid quality-improvement cycles for inpatients. Incidence of deteriorating renal function long term is monitored.	Incidence/ Prevalence	Program	Quarterly

Anticipated Outcomes of a Culture of BPI and Knowledge Innovation through Establishment of Accreditation Canada's SCI Distinction Program (AC-DSCI):

If a neurogenic bladder and renal healthcare policy platform exists to facilitate BPI, knowledge innovation and AC-DSCI compliance (as the ultimate goal for SCI rehabilitation), these are the anticipated results:

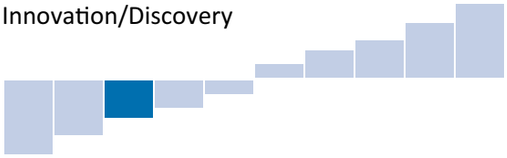
- Standardized and consistent best practices across continuum of care, including acute care, subacute rehabilitation and long-term follow up
- Improved quality of life of all individuals, including those living in the community
- Improved renal and bladder health for those living in the community
- Enabled individual self-management
- Decreased healthcare costs
- Increased economic contribution of individuals and in the community.

REPORT CARD: Bladder Continence

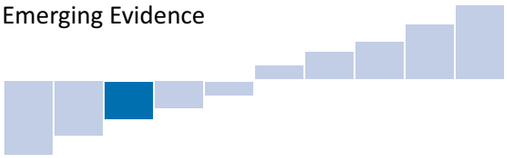
Extreme left below median: ***insufficient***
Extreme right above median: ***optimal***

KNOWLEDGE GENERATION

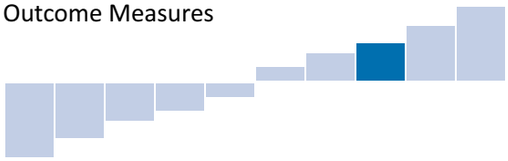
Innovation/Discovery



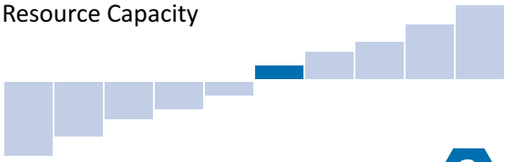
Emerging Evidence



Outcome Measures



Resource Capacity



2020 PRIORITY 3

CLINICAL APPLICATION

Integrative Care

Effective Practice
(Evidence and Outcomes)

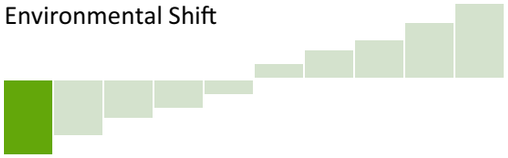
Equity Practice

Capacity

2020 PRIORITY 2

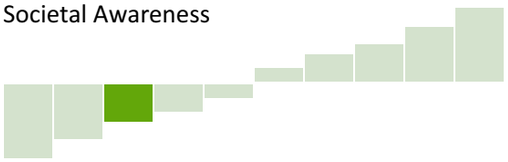
POLICY CHANGE

Environmental Shift

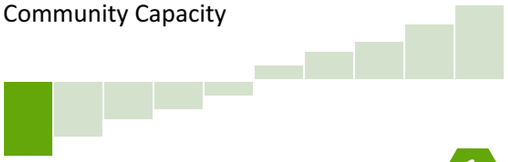


Change Agents

Societal Awareness



Community Capacity



2020 PRIORITY 1

TAKE HOME MESSAGE:

Ensuring systematic follow up and surveillance of individuals with SCI, in order to capture urologic problems prior to the onset of renal dysfunction/failure, is essential; and an important policy priority that needs to be incorporated into future Accreditation Standards.

Funding of newer devices, medical and surgical therapies including hydrophilic catheters, M3 receptor antagonists, intravesicular botulinum toxin and continent stomas, are a priority.

RESOURCES

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Bowel Continence

K Smith, MD; C Balioussis, PhD; C Craven, MD; and the E-Scan Investigative Team

***Bowel continence*, in the context of individuals with spinal cord injury (SCI), can be interpreted as efficient and effective bowel evacuation, occurring at socially appropriate times, and without adverse effects on health or quality of life.**

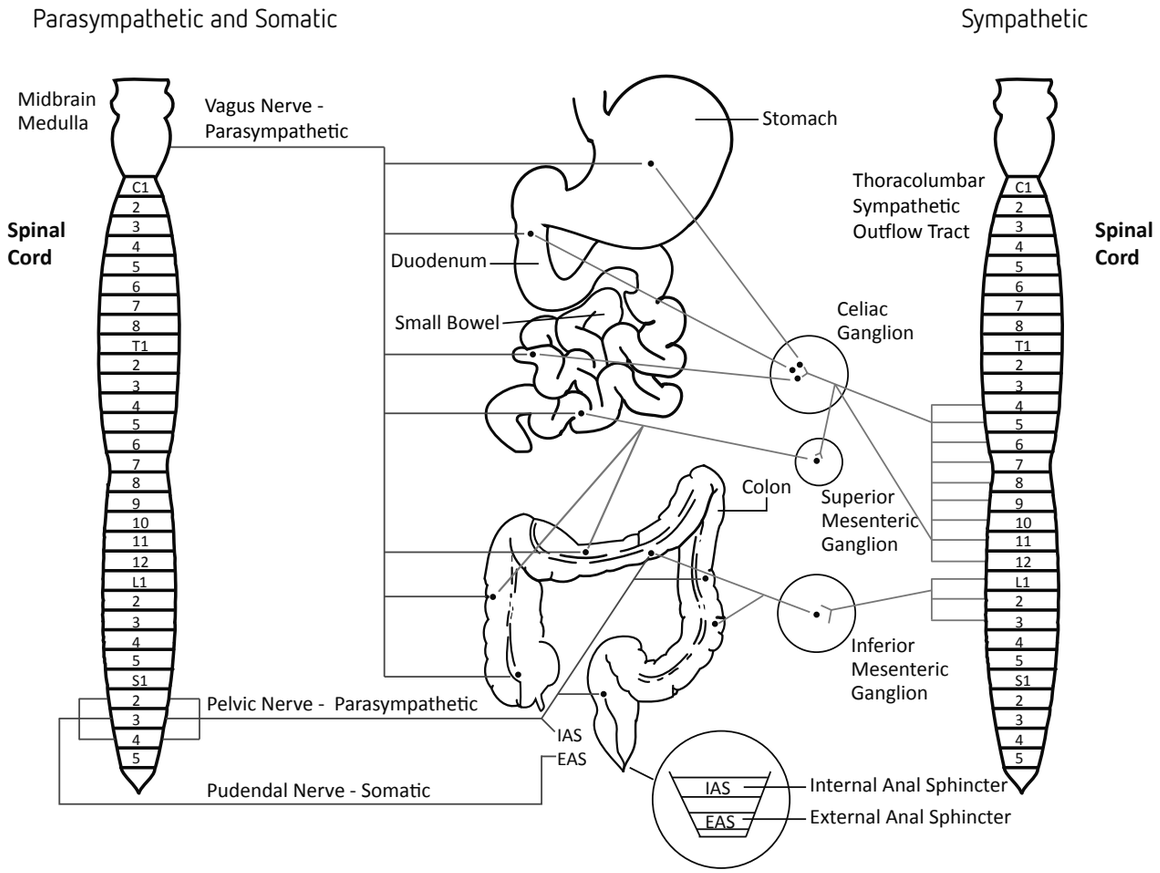
Neurogenic Bowel Dysfunction (NBD) care is based on an overall *bowel program*, which outlines the full treatment plan. The goal of the bowel program is to eliminate impaction or incontinence, resulting in efficient and timely bowel evacuation, at a socially appropriate time, and to prevent secondary complications.[1]

Individuals after SCI require an effective *bowel program* and *bowel care* to achieve continence, and to avoid the two most common patterns of bowel dysfunction: constipation or incontinence.

A bowel program typically includes adequate fluid intake, diet, oral and rectal medications (to avoid adverse effects on bowel function, or to facilitate bowel function), activity levels, personal assistance and equipment required for scheduled bowel care. Bowel care is the regular routine followed to ensure emptying of stool, from the left colon and rectum.

In a non-injured population, normal stool frequencies range from three times a week, to three times a day. Again, in a non-injured population, constipation is defined by the Rome III criteria, which includes stool frequency of less than three times per week, hard dry stools, sensation of incomplete evacuation, straining and sensation of anorectal obstruction.[2] Fecal incontinence is defined as the continuous or recurrent uncontrolled passage of fecal material (more than 10 ml), for at least one month, in an individual over age three.[3]

FIGURE 1.0 SCHEMATIC OF NERVOUS INNERVATION OF THE BOWEL. REPRODUCED FROM BERGMAN.[4] © 2000 JOHN WILEY & SONS LTD. REPRINTED WITH PERMISSION.



Effects of SCI on Bowel Function

SCI or disease results in many unique consequences and complications in bowel evacuation, due to the effect of varying levels and degrees in paralysis of voluntary muscle, impairment of sensory afferent nerves and autonomic function. NBD is experienced by individuals, with any injury or disease to the nervous system responsible for bowel function, especially those with SCI or disease, multiple sclerosis and spina bifida (see Figure 1.0 on previous page).

The main functions of the colon are storage, propulsion and defecation of feces/stool. The colon also supports the growth of symbiotic bacteria, and resorbs fluid and electrolytes, short-chain fatty acids and bacterial metabolites. Colonic motility is regulated by systemic factors including neural inputs, hormonal, metabolic and drug effects; and local factors such as diet, laxatives, bacterial endotoxins and bile acids.

Colonic motility refers to local mixing peristaltic and propulsive movements and superimposed gastrocolic, rectocolic and rectoanal reflexes. Neural influences are from the intrinsic (Auerbach's and Meissner's plexuses) or extrinsic neural plexuses (parasympathetic, sympathetic and somatic nervous system). The intrinsic plexus influences gut wall contraction and secretion of digestive juices. The parasympathetic nervous system stimulates the gut wall, and the sympathetic nervous system relaxes the gut wall, the ileocecal valve and the internal anal sphincter. The somatic nervous system influences the external anal sphincter, pelvic floor and abdominal wall muscles.

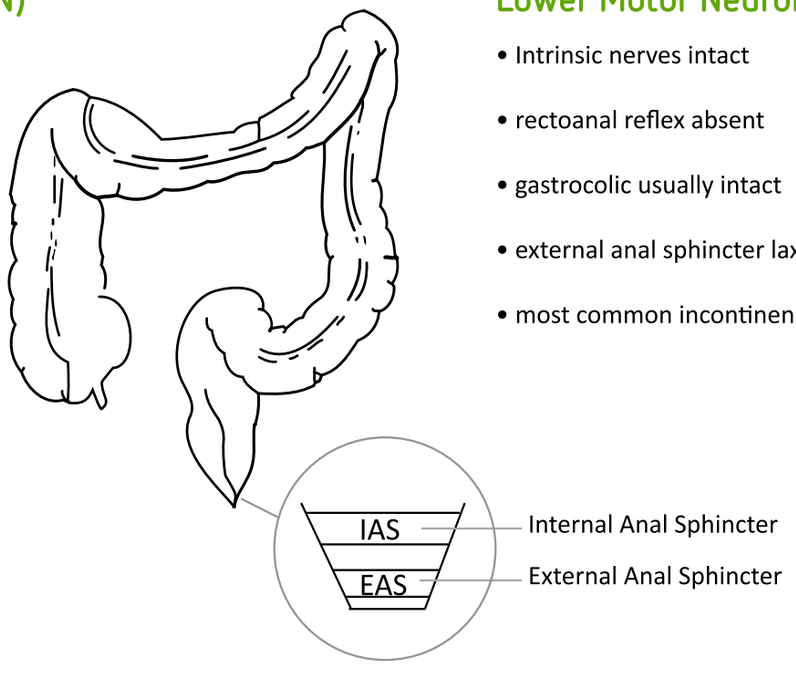
Several investigators have studied bowel activity following SCI,[5-11] with varying results in heterogeneous populations, with evolving clinical assessment tools to determine the level and extent of NBD. In general, these studies showed delayed colonic transit, especially in the left and sigmoid colon and impaired anorectal function. Recent studies of gastrointestinal transit times (GITT) report poor reproducibility for segmental studies, but overall colonic transit studies had reasonable reproducibility. With this limited reproducibility in mind, Faaborg et al.[12] found that GITT did not change significantly in two groups studied, at one and 19 years post injury, and again, twelve years later. This is particularly interesting and somewhat controversial, given that 30% of symptoms of NBD are reported to increase with duration of injury.[13]

Notwithstanding the above, some general statements can be made about common patterns of NBD, given the level of SCI. Injury above the sacral segments produces an *upper motor neuron (UMN) bowel*, with preserved intrinsic motility and reflex function, but lack of ability to influence the voluntary external anal sphincter, pelvic floor and abdominal muscles to assist with defecation. These individuals have a higher incidence of problems with constipation. Injury to the sacral segments results in a *lower motor neuron (LMN) bowel* with preserved intrinsic function, preserved gastrocolic reflex, but absent rectocolic and rectoanal reflexes; and lack of volitional anal sphincter or pelvic floor activity, but preserved abdominal wall muscles. Individuals with LMN injury have a higher incidence of problems with incontinence due to pelvic floor and anal sphincter weakness. Patients, with both upper and lower motor neuron bowel dysfunction, commonly experience bloating, abdominal pain and bleeding from hemorrhoids.

FIGURE 2.0 SCHEMATIC DRAWING OF UPPER AND LOWER MOTOR NEURON BOWEL DYSFUNCTION

Upper Motor Neuron (UMN)

- Intrinsic nerves intact
- Rectoanal and gastrocolic reflexes intact
- External anal sphincter spastic
- Cannot control external anal sphincter or abdominal muscles
- Most common constipation



Lower Motor Neuron (LMN)

- Intrinsic nerves intact
- rectoanal reflex absent
- gastrocolic usually intact
- external anal sphincter lax
- most common incontinence

SCI literature contains many descriptors of the type and extent of NBD - associated symptoms and adverse effects on health and quality of life. Gore[14] reported 87 complications of NBD function, in a review of 567 patients, with 45% (39/87) being fecal impaction. In addition, young patients in their 20's, with SCI, were found to have diverticulosis or changes in the bowel, usually found in the elderly. The largest and most recent is a survey of individuals with SCI, in the United Kingdom, by Dr Coggrave[15] highlighting the incidence of bowel care problems (Table 1.0). The Canadian experience is similar to this, as shown by the author's unpublished survey of 120 SCI patients, with NBD.

TABLE 1.0 PROBLEMS ASSOCIATED WITH NBD AND BOWEL CARE

REPRODUCED WITH PERMISSION FROM COGGRAVE[15] © 2009 INTERNATIONAL SPINAL CORD SOCIETY. REPRINTED WITH PERMISSION.

SYMPTOM	FREQUENCY	PERCENT (%)
Constipation	522	39
Hemorrhoids	485	36
Abdominal Distension	409	31
Abdominal Pain	268	20
Duration of Bowel Care > 60 minutes	185	14
Surgery to Bowel	130	10
Incontinence (at least monthly)	112	8
Autonomic Dysreflexia (AD) often/always	108	8
AD Often/always - lesions above T7 only	93	9.5
AD Occasionally - lesions above T7 only	348	36
No Flexibility in Routine	101	8
Anal Fissure	96	7
Rectal Prolapse	55	4
Other	58	4
TOTAL	2529	

Many individuals report such prolonged amounts of time to complete bowel routines that they perceived loss of social and vocational mobility, related to their bowel programs.[16] Thirty-nine - 62% of individuals with SCI - rate their NBD as more significant than the loss of mobility, with significant "interference with life".[17] Clinicians work with individuals with SCI to prevent or ameliorate these complications, through implementation of bowel care programs.

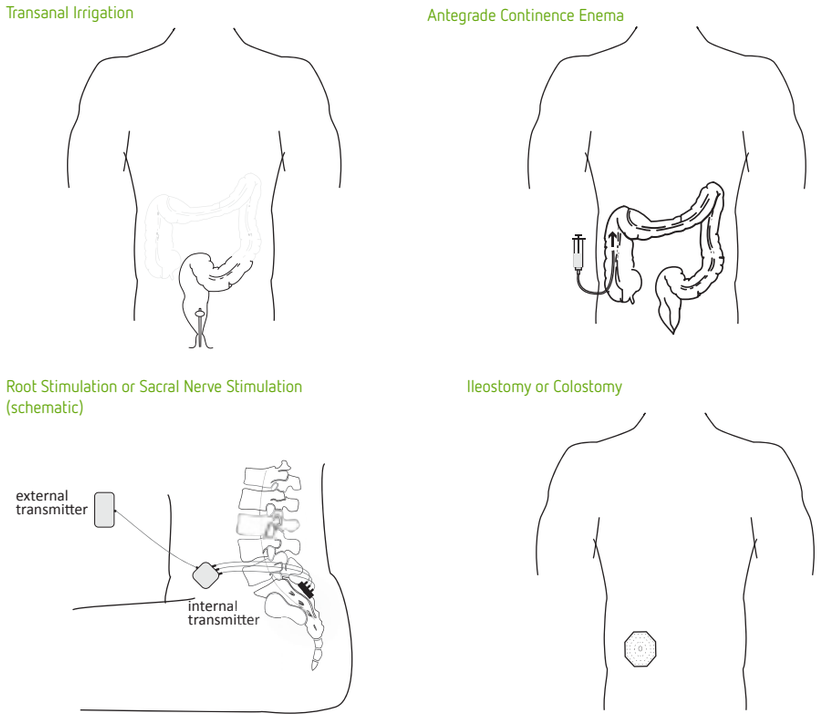
Care of Individuals with Neurogenic Bowel Dysfunction

Care for NBD includes the overall *bowel program* (diet, fluids, medications, activity level, assistance and equipment), and a bowel care routine. Physical interventions used for *bowel care* include taking advantage of the gastrocolic reflex, abdominal massage, digital rectal stimulation, digital evacuation and raising intra-abdominal pressure. Bowel care also utilizes stimulants, given rectally or orally. Despite all these conservative bowel care techniques, problems with bowel continence are frequent in individuals, following SCI.

In order to address some of these reported problems, a number of adjunctive, surgical and nonsurgical techniques have been employed (see Figure 3.0). These include:

- ***Transanal irrigation (TAI)*** - evacuation of feces aided by passing water (or other liquid) via the anus, with sufficient quantity to reach beyond the rectum
- ***Antegrade colonic irrigation*** - a surgical procedure where a catheterizable stoma is created in the proximal right colon and fluid is passed, through the colon, in an antegrade fashion to facilitate bowel evacuation
- ***Neuromodulation*** – surgically-implanted sacral anterior root stimulator or sacral nerve stimulator
- ***Stoma*** - surgical creation of colostomy or ileostomy. This is still infrequently done, but those who have one report improved satisfaction and reduced impact of NBD on quality of life.

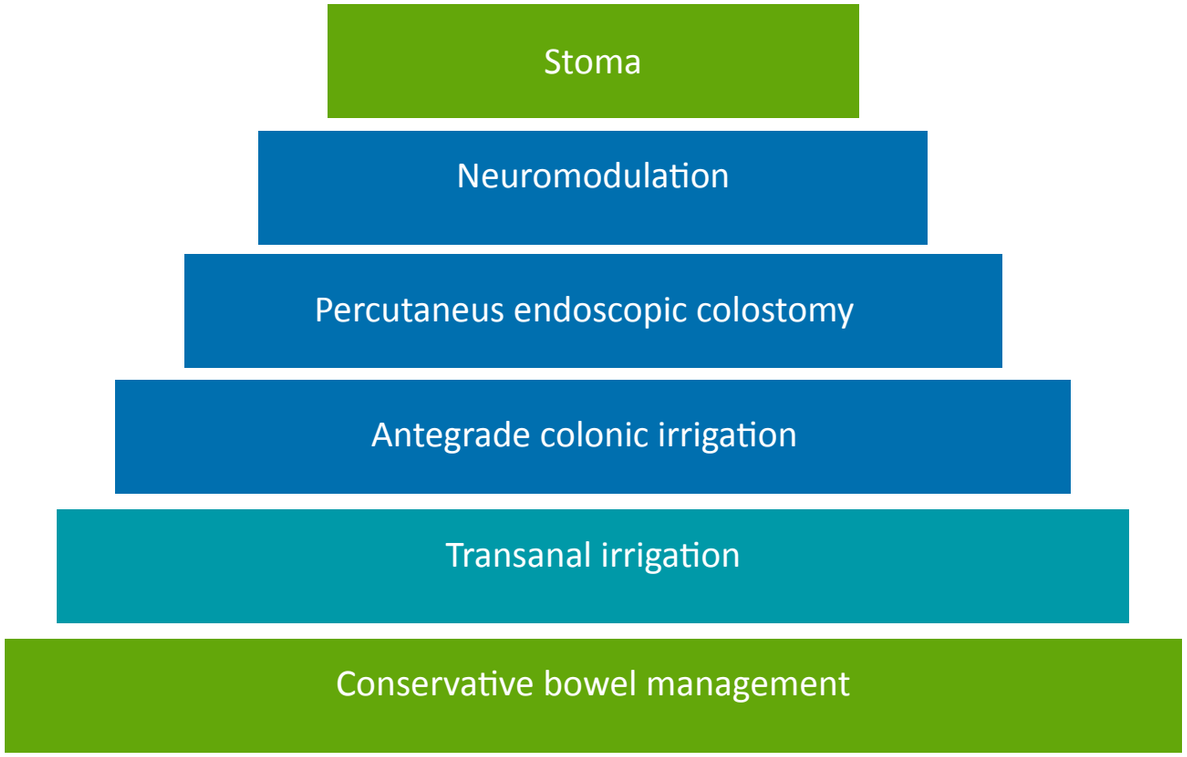
FIGURE 3.0 SCHEMATIC DIAGRAMS SHOWING TRANSANAL IRRIGATION, ANTEGRADE COLONIC IRRIGATION, NEUROMODULATION AND AN ILEOSTOMY.



THE CURRENT CLINICAL PRACTICE, SUGGESTED BY COGGRAVE (CREATED ORIGINALLY BY CHRISTENSEN, BAZZOCCHI, COGGRAVE, ET AL.[18]), AND SUPPORTED BY A DECISION ANALYSIS PUBLISHED BY FURLAN.[19]

FIGURE 4.0 CURRENT CLINICAL PRACTICE PARADIGM FOR NEUROGENIC BOWEL DYSFUNCTION

USED WITH PERMISSION FROM M. COGGRAVE. ORIGINAL SOURCE: CHRISTENSEN P, BAZZOCCHI G, COGGRAVE M, ET AL.[18]



Rethinking NBD Practice

WHERE DOES TAI FIT IN THE CURRENT SPECTRUM OF BOWEL CARE PROCEDURES?

Current evidence suggests using standard neurogenic bowel care procedures, based on the published Paralyzed Veterans of America guidelines. When the conservative measures recommended in the guideline are ineffective, before the availability of TAI, research reported by Furlan[19] would have suggested that individuals proceed with surgery called the Malone procedure (Appendicostomies), as the next logical treatment option. Christensen, Krogh and Coggrave suggest TAI should be introduced and evaluated, prior to considering any surgical intervention.

HOW DO WE PREVENT THE MORBIDITY ASSOCIATED WITH INEFFECTIVE BOWEL CARE?

Using the above paradigm, clinicians hope to eliminate the morbidity associated with NBD care. However, there is substantial regional disparity in practice and funding models across the provinces that often limit access to the newer NBD interventions. Multicentre studies of efficacy and effectiveness of these interventions are required to determine if the goal of reduced morbidity is being achieved.

In addition to the above treatment paradigm for management of NBD, there are two clinical scenarios, in which transanal irrigation has been reported to be clinically helpful:

1) In the acute rehabilitation setting, for select individuals having problems with conservative bowel management, but before all conservative treatments have been exhausted.

2) In the acute or chronic setting, to assist individuals with bowel preparation and cleanout, prior to colonoscopy.[20] This strategy avoids the use of large quantities of laxatives and potential for incontinence from unpredictable bowel movements, and reduces the potential for skin breakdown secondary to prolonged periods of time on the commode. There are published reports of the benefit of pulsed anal irrigation being used successfully in this clinical scenario, as well.

Current Practice

In a review of Canadian rehabilitation centres, with respect to bowel treatment protocols, six of 12 sites used the PVA Neurogenic Bowel Clinical Practice Guidelines as their source of information for neurogenic bowel management. Two of 12 had a uniquely articulated treatment protocol, five of 12 had an established standard of care, and three of 12 had a clinical practice guideline. This would suggest that there is an opportunity for knowledge translation, in the area of neurogenic bowel management, across Canadian rehabilitation sites.

The review also surveyed the sites regarding available equipment – specifically, the number of SCI-specific commode chairs, and the number of reclining commode chairs available, per patient. The number of chairs, in either category per patient, ranged from a low of .04 chairs/patient, to a high of .63 chairs/patient (mean .19 chairs/patient). More than half the sites felt that this was not an adequate supply of equipment to support bowel care.

Current Practice Bias and Dilemmas

The E-Scan data, with respect to current practice, are based on anecdotal reports from clinicians involved in the care of individuals with SCI. In addition to routine documenting of NBD, there is a need for documentation of the current NBD practice. Design and optimization of a conservative bowel care routine is within the scope of practice and abilities of all physiatrists, primary care physicians and nurses, given appropriate training. Unfortunately, the availability, interest and training of other colorectal experts, particularly surgeons, able to assess the appropriateness of, and to perform catheterizable stomas, implant stimulators or create stomas, is not uniformly available in Canada.

KEY PRACTICE REFERENCES

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Canadian Experts Likely to Influence NBD Practice, in the Next Five Years

1. Karen Ethans, MD (Physiatry) and Alan Casey, MD (Physiatry), Winnipeg: Physiatrists with evolving expertise in the implementation and evaluation of transanal irrigation.

2. Anthony Burns, MD (Physiatry), Toronto; Daphne St. Germain, RN, PhD, Québec: Leading a qualitative study regarding the lived experiences of persons with SCI and NBD to inform development of patient-focused NBD outcome measures.

3. Julio Furlan, MD (Neurology), Toronto: Developed a decision support tool to assist in the selection of surgical NBD intervention(s).

4. Paul Belliveau, MD (General Surgery), Kingston: Colorectal surgeon with an interest in neurogenic bowel function.

5. Karen Smith, MD (Physiatry); Margaret Power, RPN, Kingston: Acquired a significant volume of experience with TAI and NBD.

6. Nicole Mittman, PhD (Pharmacology), Toronto: Evaluating the economic burden of NBD care.

Key Clinical Questions

1. Can we prevent long-term bowel problems with early introduction of adjunctive bowel measures, in the acute and subacute phases of injury?

2. How do we customize bowel care for patients? Which intervention is appropriate for which client?

3. Are there ways to optimize some features of the adjunctive techniques? What is the ideal irrigation fluid, and optimal frequency for transanal irrigation?

4. How do we create adequate supports in primary care to allow for examination of patients, to determine the need for UMN versus LMN type bowel care? How do we enable appropriate training on initial design of bowel care programs, by primary care physicians, in order to reach the broadest number of individuals with NBD, in the community? There is ample evidence of the barriers to the provision of primary care, to individuals with SCI.[21] Some are knowledge barriers but there are also policy, system, physical and attitudinal barriers.

SPOTLIGHT BEST PRACTICE ORGANIZATION

PHYSICAL MEDICINE AND REHABILITATION PROGRAM –

St. Mary's of the Lake Hospital, Providence Care, Kingston

NBD has been a longstanding area of clinical and, more recently, a research interest of Dr. Karen Smith, who has been motivated by the huge social, physical and economic impact of NBD, on individuals with SCI. Dr. Smith and Margaret Power, RPN have led the early adoption of NBD procedures, such as pulsed anal irrigation and transanal irrigation. The volume of expertise acquired was born from a motivation to reduce the impact of NBD. Their early experience in implementing TAI has highlighted the need to address related issues, and to ensure successful implementation. Dr. Smith is currently looking at the policies and procedures required to facilitate broader use of these techniques. Example areas include policies that limit the scope of practice of techniques that go beyond the anal verge, infection control and occupational health and safety issues for staff, in community or institutional settings. This marriage of clinical interests with systematic investigation of the health service and health policy implications distinguished this program.

BEST PRACTICE INDICATORS

- Examination and documentation of type of bowel dysfunction, based on history and physical examination, with ancillary testing, only as required
- Design of a conservative bowel program to include education of patient and support personnel, and to incorporate patient goals
- Documentation of the results of bowel care
- Documentation of adverse results with evidence of redesign, reassessment and modification of bowel program and care, as appropriate. Documentation according to current best evidence of the consideration of adjunctive measures, as available.

Which Outcome Measures Should We Use?

1. ROUTINE DOCUMENTATION OF NBD IMPAIRMENTS

On a routine clinical basis, the basic clinical NBD data set should take 30 minutes to complete. For those with issues of NBD, completion of a bowel diary is indicated.

- International Neurogenic Bowel Data Set[22]
  The International SCI Bowel Function Basic and Extended Data Sets are the preferred outcome measure, in this population. Designed specifically for individuals with SCI, the data set includes the Cleveland Clinic, St. Marks and Neurogenic Bowel Dysfunction Scores, which can be calculated from the included data fields. Juul et al.[22] published results of a validation study demonstrating acceptable inter-rater reliability for most items.
- Autonomic Standards[23]
- Neurogenic Bowel Diary

FIGURE 5.0
BOWEL DIARY

Trained by: _____ Date: _____
Name of caregiver who trained on Peristeen

Date	Time (Start - Finish)	# of pumps	Water (ml)	Consistency (Bristol Scale)	Fecal Incontinence	Abdominal pain	Medication	Comments
Mar 18	9:00-10:15	3	500	3	No	No	No	Bowel Empty

EXAMPLE

2. ADDITIONAL OUTCOME MEASURES/BOWEL FUNCTION MEASURES

- Modified American Society of Colon and Rectal Surgeons (ASCRS) Fecal Incontinence Score, Inflammatory Bowel Disease Questionnaire (IBDQ)
- Cleveland Clinic Incontinence (CCI) Score
- Cleveland Clinic Constipation Scoring System (CCCSS)
- Mark's Fecal Incontinence Grading System (FIGS).

3. RESEARCH PRIORITIES

Basic science advancements are needed to inform clinical practice, and to answer the following questions:

- What is happening to smooth muscle in the bowel with time, post injury?
- There are conflicting results regarding the impact of level and completeness of lesion, and degree of autonomic dysfunction, on the pattern and severity of bowel impairment. What happens to any preserved colonic motility, with time post injury, and why? Are these age-related changes or changes specific to time post injury?
- Does the degree of autonomic dysfunction predict bowel function following SCI?
- Does the rectoanal inhibitory reflex diminish over time?
- Can we develop physiologic tests of bowel function (beyond manometry and colonic motility)?
- How would recruitment of smooth muscle physiologists assist in the exploration of these issues, and what new knowledge would they contribute to the field?

4. POLICY PRIORITIES

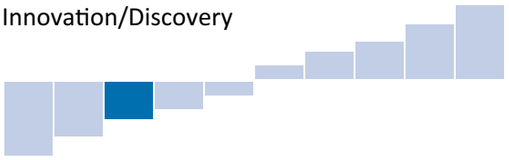
- Develop attendant care funding and policy with respect to scope of practice to support optimal bowel care
- Determine/clarify whose scope of practice should include provision of interventions beyond the anal verge. This is especially a problem for clients in hospital or dependent on an agency for delivery of bowel care, in the community
- Advocate for appropriate disability supports that include funding of bowel medications, standard care items (i.e. Magic Bullet®, polyethylene glycol) and appropriate equipment
- Advocate for changes in the disability supports benefits for individuals with disability to include funding for transanal irrigation, similar to the funding provided for colostomy supplies
- Align current best practice for optimizing bowel care with the private and public funding for required assistive care, equipment, medications and supplies
- Reflect the complexity and intensity of service, required in the care of individuals of SCI, in the reimbursement for involved health care professionals.

REPORT CARD: Bowel Continence

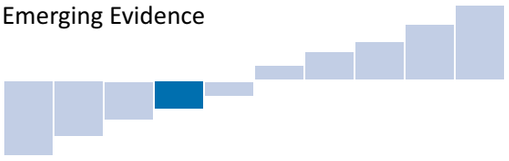
Extreme left below median: ***insufficient***
Extreme right above median: ***optimal***

KNOWLEDGE GENERATION

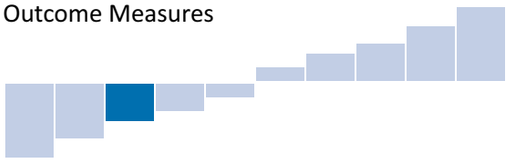
Innovation/Discovery



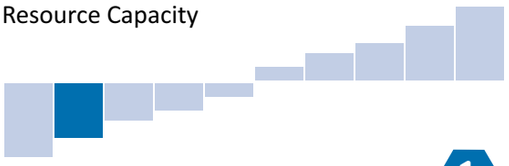
Emerging Evidence



Outcome Measures



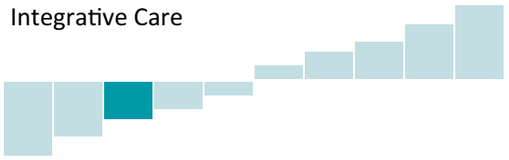
Resource Capacity



2020 PRIORITY 1

CLINICAL APPLICATION

Integrative Care



Effective Practice
(Evidence and Outcomes)

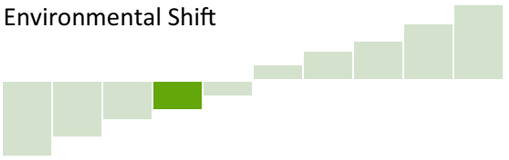
Equity Practice

Capacity

2020 PRIORITY 2

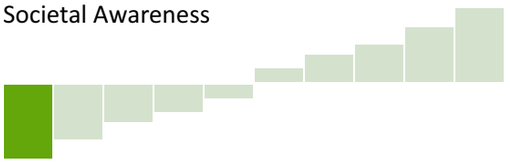
POLICY CHANGE

Environmental Shift

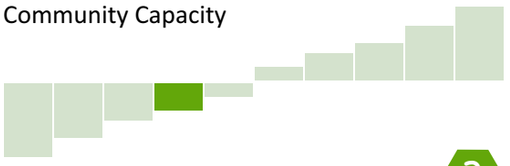


Change Agents

Societal Awareness



Community Capacity



2020 PRIORITY 3

TAKE HOME MESSAGE:

TWO URGENT PRIORITIES EXIST TO ENSURE OPTIMAL BOWEL CARE IS AVAILABLE TO INDIVIDUALS WITH SCI:

- Access to funding for NBD procedures and physical supplies, for the majority of those on social assistance (disability support programs)
- Resolution of health policy barriers with regard to supplies, provision of adequate volume and frequency of attendant care, equipment (commodes, TAI, nerve stimulation devices) or primary and specialist care because of funding, system or attitudinal barriers.

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Reaching, Grasping and Manipulation

MC Verrier, MHSc; S Kalsi-Ryan, PhD; N Desai, MSc; and the E-Scan Investigative Team

Upper limb function is vital to everyone. The ability to lean over a table, to grasp a pen and position it in order to sign one's name, is critical to one's independence – and a great challenge to individuals with spinal cord injury (SCI). Reaching, grasping and manipulation are the important components of upper limb function that allow individuals to use the sensorimotor integrity of their arm and hand, to perform activities that meet their personal needs, and to explore and participate in their external environment, in meaningful ways.

For those with tetraplegia, how to optimize upper limb recovery, or replace function by an alternative means, is a major rehabilitation focus. Even small gains in function are extremely critical for these individuals, because they translate into some degree of independence.

Individuals with tetraplegia use their upper limbs to perform functions that able-bodied individuals would do with their hands. Often, these upper limbs also replace functions of other body parts. For example, leg function for walking is often replaced by wheelchair propulsion and weight bearing activities, such as transfers in and out of bed or on and off the toilet. In some instances, use or overuse of the upper limbs, causes secondary complications, such as degeneration of the rotator cuff, which leads to shoulder pain, restriction in movements and, ultimately, decreased function longitudinally. Therefore, improvement and maintenance of upper limb function, across an individual's lifespan is a priority and, according to individuals with tetraplegia,[1] one of the most significant factors in improving quality of life. Best practices in rehabilitation for upper limb function must be robust and encompass both primary rehabilitation and secondary prevention.

Many factors require consideration, when providing best practices in assessment and therapeutic interventions for upper limb rehabilitation for individuals with SCI, beyond the neurological their status (Figure 1.0). Reaching, grasping and manipulation are inherently complex and exquisite movements, and integration of many determinants ensures that movements result in improved quality of life.

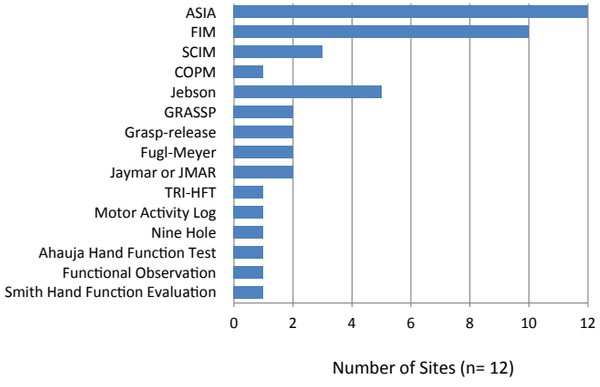
FIGURE 1.0 A MODEL OF FACTORS THAT REQUIRE CONSIDERATION WHEN IMPLEMENTING UPPER LIMB REHABILITATION.

Current Practice: Specialized Assessment of Upper Limb Function in Individuals with SCI

Assessment of upper limb function in SCI rehabilitation is undertaken using multiple approaches to measure different constructs at the impairment, activity or participation levels. These measures are often used for different purposes, and to test different outcomes.[2] As seen in Figure 2.0 (top portion of figure), all sites use the International Standards of Neurological Classification of Spinal Cord Injury (ISNCSCI) that account for upper limb motor function and sensation (with the exclusion of the palmar surface of the hand). Eleven of 12 sites use the Functional Independence Measure (FIM) and three of 12 sites, the Spinal Cord Independence Measure (SCIM). Both FIM and SCIM incorporate upper limb function, in the context of activities of daily living. The Canadian Occupational Performance Measure (COPM) – designed to detect change in an individual's self-perception of occupational performance, over time – is used in only one site.

The bottom portion of Figure 2.0 illustrates the paucity and heterogeneity of psychometrically robust upper limb assessments in use. Given the importance of upper extremity function to individuals with tetraplegia, the frequency of formal assessment is concerning. With the exception of the Jensen, the rest of the ten upper limb assessments (many of which incorporate reaching, grasping and manipulation), are formally used in two or less sites, making it very difficult to measure patient outcomes comprehensively, over time and across sites. Most of the measures are not specific to SCI, and with the uniqueness of the sensorimotor deficits and the therapeutic interventions, this is problematic when defining best practice.

FIGURE 2.0 FREQUENCY OF SITES REPORTING ROUTINE USE OF GLOBAL ASSESSMENTS WITH UPPER LIMB ELEMENTS (TOP), AND SITES REPORTING ROUTINE USE OF SPECIFIC HAND FUNCTION ASSESSMENTS (BOTTOM).



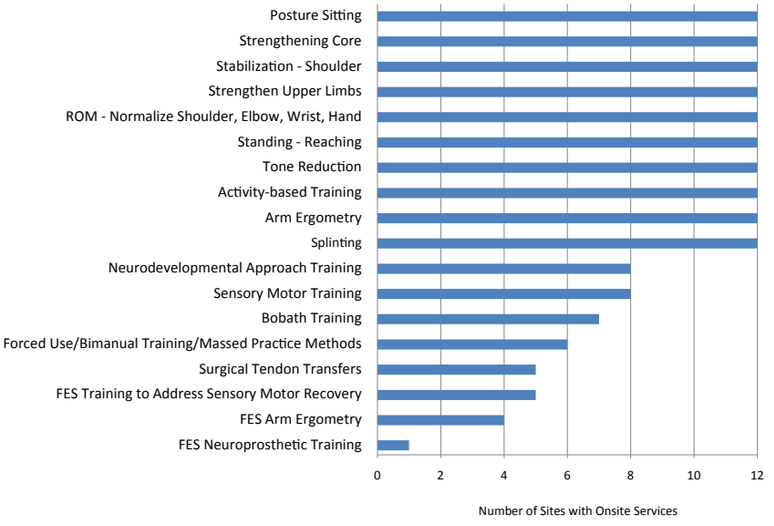
The Graded and Redefined Assessment of Strength, Sensibility and Prehension (GRASSP),[2,3] a new upper limb measure developed specifically for assessment of impairment of the upper limb for individuals with tetraplegia, is being tested for responsiveness and Minimal Clinical Important Difference (MCID), in four SCI rehabilitation sites in Canada and six, in Europe. Results from the study will be important to determine its use as a routine clinical assessment as part of occupational therapy or physical therapy best practice. Details about GRASSP can be found at www.sci-grassp.org.

Current Practice: Therapeutic Approaches for Upper Limb Rehabilitation in Individuals with SCI

In all 12 E-Scan sites, current upper limb rehabilitation includes splinting, muscle strengthening and tone reduction as part of standard practice, as well as the use of functional activities that require enhanced postural and motor control (Figure 3.0). Important indicators regarding patient outcomes, based on these interventions, have been documented in detail, in the upper limb chapter of Spinal Cord Injury Rehabilitation Evidence (SCIRE).[4] SCIRE chapter authors state that "Restorative therapy interventions need to be associated with meaningful change in functional motor performance and incorporate technology that is available in the clinic and at home".

Without formally measuring specific upper limb functional outcomes, both outside the rehabilitation setting and longitudinally, the evidence for effectiveness of the multitude of approaches will elude rehabilitation service providers and funders. It is clear that FIM and SCIM are insufficient to characterize the upper limb functions important to individuals with tetraplegia, particularly in the neurorecovery phase. Both the Toronto Rehab Hand Function Test (TRI-HFT) and the GRASSP measure show potential for addressing this void. A combination of the key elements in these measures would likely suffice, but this issue requires additional item reduction and psychometric validation.

FIGURE 3.0 FREQUENCY OF THE USE OF APPROACHES TO UPPER LIMB REHABILITATION



Current Practice: Customized Approaches for Upper Limb Rehabilitation in Individuals with SCI

Prosthetic and orthotic services to support splinting, as a therapeutic approach, are reported in 11 sites; but only four sites have formalized Rehabilitation Engineering expertise as part of SCI rehabilitation services. Engineering application, coupled with occupational therapy and physical therapy, is becoming important. Improvements in upper limb function, during rehabilitation, are accomplished by using emerging technologies to facilitate the natural recovery of upper limbs (such as Functional Electrical Stimulation Therapy[5] or FEST) or assisted reaching, grasping and manipulation using robotics[6]; or supportive, in-home technology approaches.[7] These relatively new approaches are being tested along with other assessments, in Canada and internationally.

Tendon transfers are being performed in five sites only. With the lack of cross-provincial healthcare, Canada has areas where individuals cannot get access to surgeons, with expertise in tendon transfer. This may be, in part, due to changes in consumer willingness to undergo surgical intervention, including tendon transfer and interphalangeal or finger joint fusions; and the delisting of elective procedures of this nature, in some jurisdictions. Clearly, retention of relevant expertise, and a focus on the service void, requires national reflection.

There are several novel and exciting approaches, being developed in Canada to enhance individual participation in therapy, and provide new ways to evaluate outcomes:

Armeo Therapy Concept, being tested at ICORD by John Steeves and at Toronto Rehabilitation Institute-UHN by Milos Popovic, is proposed to improve the efficiency of therapy treatments. Exercises are self-initiated, self-directed, functional and intense, and incorporate arm weight support, augmented feedback and accurate monitoring of the individual's recovery.

ReJoyce, developed in Edmonton by Arthur Prochazka, is a therapeutic workstation that allows a clinician to work with individuals as they participate in arm-hand function therapy sessions, in the clinic or remotely in their own home. Computer software uses various "games" to guide the individual through a series of upper limb and hand exercises. Most importantly, the ReJoyce workstation features a set of spring-loaded manipulanda, each of which represents a typical grip posture required during one of many tasks of daily life. Outcomes of these interventions are automatically logged by the ReJoyce Arm-Hand Function Test, which uses recordings from ReJoyce systems and integrates them into a measure of the upper limb function.

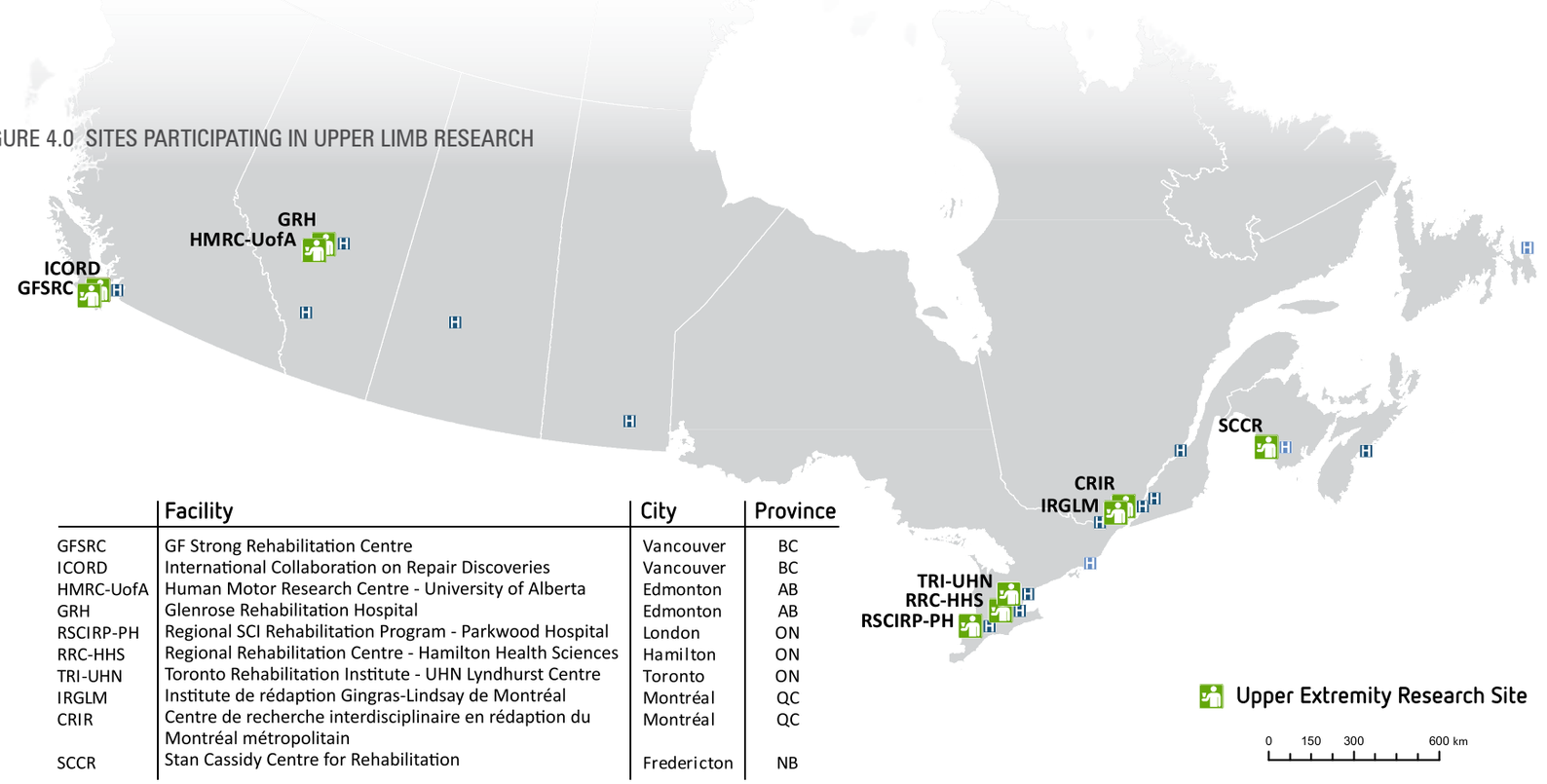
Compex Motion electric stimulator, developed by Milos Popovic, provides FES-designed stimulation protocols to generate power (palmar grasp and lateral pinch), and precision grasps (opposition with two and three fingers) on demand. The stimulation sequence (protocol) for power and precision grasps is customized for each individual, using the fully-programmable stimulator. The approach is being used successfully in the rehabilitation phase to supplement training during recovery.

These approaches form the foundation of current evolving upper limb research in multiple Canadian sites (Figure 4.0).

Current Prevention and Management of Upper Limb Secondary Conditions in Individuals with SCI

Upper limb pain and injury, following SCI, are secondary conditions that affect individuals with both tetraplegia and paraplegia. The Consortium for Spinal Cord Medicine (CSCM) developed Clinical Practice Guidelines, in 2005, for both individuals and healthcare providers.[8] Under the categories of Evaluation, Management, and Prevention and Treatment, the Consortium created 35 recommendations for the prevention and management of secondary upper limb complications, based on clinical and epidemiological evidence.[8] A user guide for individuals with SCI accompanies the guideline. Some aspects have been implemented at E-Scan sites but adherence to these guidelines has not been formally evaluated. The authors suggest that the guidelines be adopted in Canada, and become part of the Accreditation Canada Standards for SCI.

FIGURE 4.0 SITES PARTICIPATING IN UPPER LIMB RESEARCH



	Facility	City	Province
GFSRC	GF Strong Rehabilitation Centre	Vancouver	BC
ICORD	International Collaboration on Repair Discoveries	Vancouver	BC
HMRC-UofA	Human Motor Research Centre - University of Alberta	Edmonton	AB
GRH	Glenrose Rehabilitation Hospital	Edmonton	AB
RSCIRP-PH	Regional SCI Rehabilitation Program - Parkwood Hospital	London	ON
RRC-HHS	Regional Rehabilitation Centre - Hamilton Health Sciences	Hamilton	ON
TRI-UHN	Toronto Rehabilitation Institute - UHN Lyndhurst Centre	Toronto	ON
IRGLM	Institute de rédaption Gingras-Lindsay de Montréal	Montréal	QC
CRIR	Centre de recherche interdisciplinaire en rédaption du Montréal métropolitain	Montréal	QC
SCCR	Stan Cassidy Centre for Rehabilitation	Fredericton	NB

Key Clinical Issues: What is Needed for Best Practice?

1. Optimize sensorimotor plasticity in the early phase of injury
Little is known about the effect of sensory deprivation of the hand, early post-SCI, and what effect amplification of sensory input might have on recovery. For best practice, in terms of assessment, it is essential to capture palmar sensation on the surface of the hand, and to monitor changes in sensation systematically over the course of rehabilitation.

2. New paradigms for providing sensory stimulation to the hand
Opportunities for active exploration of the hand need to be developed and embedded into the therapeutic intervention early on post-injury, coupled with detailed assessment.

3. Training in the application of new therapeutic paradigms
Training to implement newer therapy modalities (such as functional electrical stimulation, as an adjunct training technique, during inpatient rehabilitation) to ensure more informed application and to enhance patient outcomes, should be implemented across the country and/or at national meetings where therapists gather to learn new best practices.

4. Restoration and comprehensive management of upper limb spasticity
Adequacy of maintaining and restoring upper limb function, as specified in CSCM clinical practice guidelines, should be the gold standard for practice, in all sites across Canada. Particular monitoring of elbow extension should be undertaken, on a routine basis, to ensure adequacy for transfers.

5. Determine minimal clinical important difference (MCID)
As MCID often drives length of stay, access to care and clinical decision-making, indicators for MCID should be determined, based on neurological status. Appropriate services, across the continuum of care, should be put in place, including assistive technology to ensure adequacy of therapeutic interventions.

Key Research Priorities

1. Determine the metrics of rehabilitation therapy that promote enhanced recovery. Based on the current animal literature, there is controversy about the right time to optimize recovery, as well as the dosage of the intervention to be given. A research focus on the metrics of early intervention needs to be developed to ensure that the right parameters are optimized, at the right times, post-injury.

2. Test new therapeutic approaches with the sub-acute population.
For most research, the focus has been directed towards the chronic SCI population, based on the concept that natural recovery has already occurred. Carefully designed studies are required to evaluate interventions which enhance the natural recovery, combined with current standard of care.

3. Develop a model to incorporate and monitor the effects of the upper limb rehabilitation component, in future clinical trials. With the emergence of new, basic science approaches to promote neurorecovery, a model is needed to account for the rehabilitation component when assessing primary and secondary outcomes, longitudinally.

SPOTLIGHT BEST PRACTICE ORGANIZATION

BRAIN AND SPINAL CORD REHAB PROGRAM –

Toronto Rehabilitation Institute (TRI), University Health Network, Toronto

Interactive practice at the Lyndhurst Centre is focused on client-centered care, during inpatient rehabilitation, and with the chronic population where both are involved in ongoing clinical studies. Researchers, occupational therapists, physical therapists, engineers, physiatrists and neurosurgeons work together to discuss the best approaches to enhance upper limb function, design and validate new assessment measures (GRASSP and TRI-HFT), and conduct clinical trials on the implementation of new therapies (such as FEST).

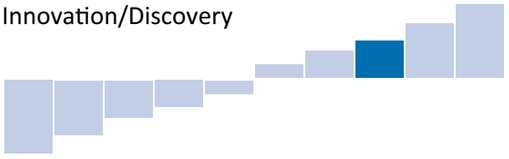
This team approach is being translated into practice provincially, nationally and internationally, which assists with capacity building, everywhere. Lyndhurst Centre is part of the Academic Health Science Complex at the University of Toronto, where the development of these activities benefits from the focused training and studies of professional master's students and graduate students (from the Rehabilitation Science Program), who contribute maximally to moving forward best practices for upper limb rehabilitation. Best practices are facilitated by members of the team who network routinely with other international colleagues at national and international conferences, through training workshops.

REPORT CARD: Reaching, Grasping and Manipulation

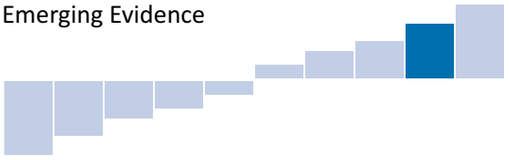
Extreme left below median: ***insufficient***
Extreme right above median: ***optimal***

KNOWLEDGE GENERATION

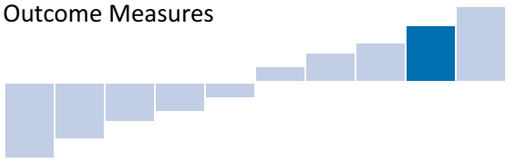
Innovation/Discovery



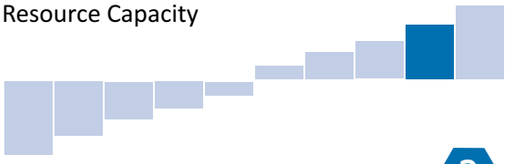
Emerging Evidence



Outcome Measures



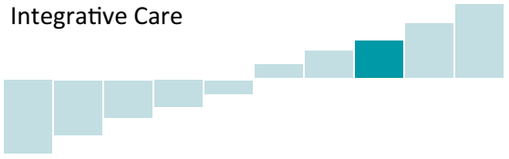
Resource Capacity



2020 PRIORITY 3

CLINICAL APPLICATION

Integrative Care



Effective Practice
(Evidence and Outcomes)

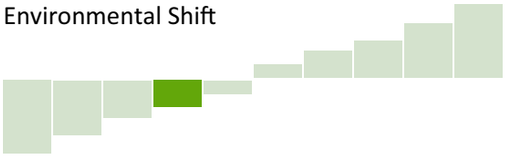
Equity Practice

Capacity

2020 PRIORITY 1

POLICY CHANGE

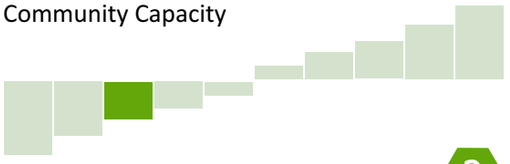
Environmental Shift



Change Agents

Societal Awareness

Community Capacity



2020 PRIORITY 2

TAKE HOME MESSAGE:

Canadian rehabilitation health professionals and engineers lead internationally, with the design of novel and meaningful assessments, and the development of new therapeutic approaches to enhance recovery of upper limb function, for individuals with tetraplegia. Adoption of these approaches nationally would enhance rehabilitation services for individuals with tetraplegia.

Secondly, priority attention should be given to developing rehabilitation strategies to address shoulder injuries for individuals who depend on their upper limbs for transfers and wheelchair propulsion. Development of a nationally focused, integrated team of researchers and clinicians would be a logical first step.

RESOURCES

1. Snoek GJ. Survey of the needs of patients with spinal cord injury: impact and priority for improvement in hand function in tetraplegics. *Spinal Cord*. 2004;42(9):526-32.

2. Kalsi-Ryan S, Verrier MC. A synthesis of best evidence for the restoration of upper extremity function in people with tetraplegia. *Physiother Can*. 2011;63(4):474-89.

3. Kalsi-Ryan S, Curt A, Fehlings MG, Verrier MC. Assessment of the hand in tetraplegia using the graded redefined assessment of strength sensibility and prehension (GRASSP): impairment versus function. *Top Spinal Cord Inj Rehabil*. 2009;14(4):34-46.

4. Connolly SJ, Mehta S, Foulon BL, Teasell RW, Aubut JL. Upper limb rehabilitation following spinal cord injury. In: Eng JJ, Teasell RW, Miller WC, et al., eds. *Spinal Cord Injury Rehabilitation Evidence*. Version 4.0. Vancouver, BC; 2012.

5. Popovic MR, Kapadia N, Zivanovic V, Furlan JC, Craven BC, McGillivray C. Functional electrical stimulation therapy of voluntary grasping versus only conventional for patients with subacute incomplete tetraplegia: a randomized clinical trial rehabilitation. *Neurorehabil Neural Repair*. 2011;25(5):433-42.

6. Stienen AH. *Development of Novel Devices for Upper-Extremity Rehabilitation* [dissertation]. Enschede, The Netherlands: University of Twente; 2009.

7. Kowalczewski J, Chong SL, Galea M, Prochazka A. In-home tele-rehabilitation improves tetraplegic hand function. *Neurorehabil Neural Repair*. 2011;25(5):412-22.

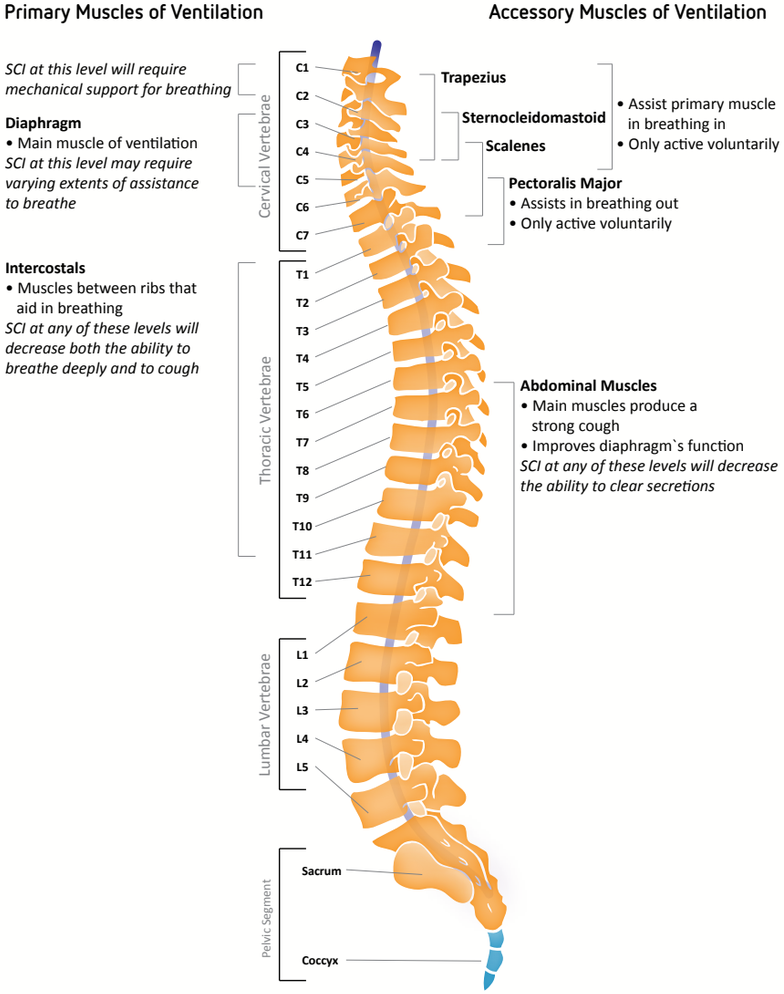
8. Paralyzed Veterans of America Consortium for Spinal Cord Medicine. Preservation of upper limb function following spinal cord injury: a clinical practice guideline for healthcare professionals. *J Spinal Cord Med*. 2005;28(5):434-70.

Independence in Breathing

D Tsui, MScPT; R Vaughan, RRT; VK Noonan, PhD; C O'Connell, MD; C Craven, MD; and the E-Scan Investigative Team

Promoting independence in breathing after spinal cord injury (SCI) involves maximizing respiratory function, through timely and comprehensive assessment and treatment. SCI can cause paralysis or weakness of respiratory muscles, including the diaphragm, abdominal muscles responsible for coughing, and upper airway muscles responsible for speech, swallowing and clearing secretions (Figure 1.0). The number and extent of respiratory impairments depends upon the level of injury (Figure 1.0)[1,2]

FIGURE 1.0 INNERVATION OF PRIMARY AND ACCESSORY MUSCLES OF VENTILATION EXPLAINS MANY OF THE RESPIRATORY PROBLEMS OBSERVED IN INDIVIDUALS WITH SCI.



The result is changed effectiveness of the respiratory system and muscles responsible for ventilation.[3]

Ventilation is the process by which oxygen and gas enter and leave the lungs. Hence, clinical manifestations of respiratory muscle dysfunction can range from an inability to maintain effective spontaneous ventilation, ineffective cough (with decreased clearance of secretions and debris), recurrent infections and poor gas exchange, to limited muscle endurance with respiratory fatigue (Figure 2.0).[2,4]

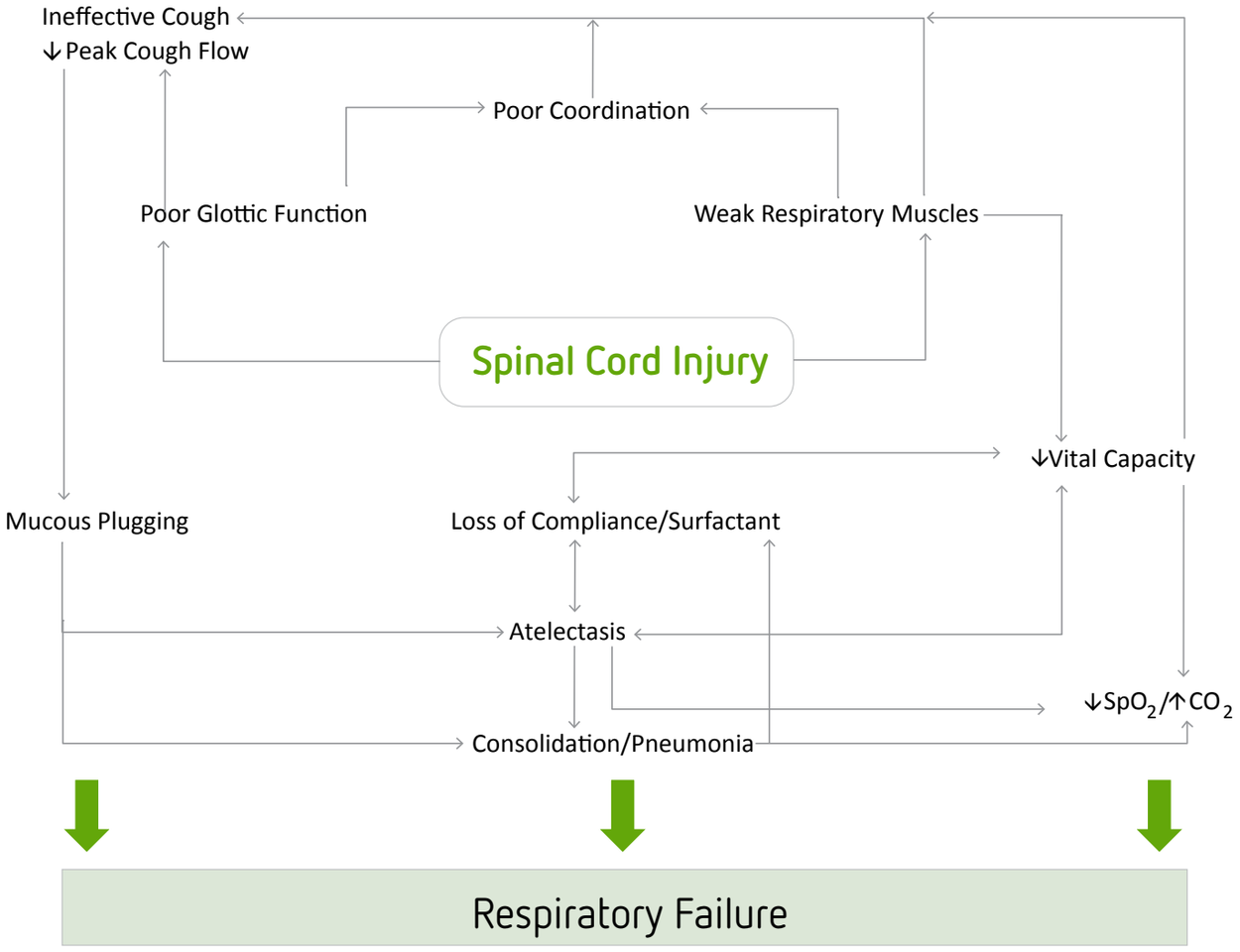
Furthermore, individuals with SCI are at risk of developing sleep-disordered breathing, and the prevalence of obstructive sleep apnea ranges from 15-83%.[5] *Obstructive sleep apnea* is a breathing disorder characterized by recurrent collapse of the upper airway during sleep, which can lead to desaturation, hypoxemia, sleep fragmentation and excessive daytime sleepiness.[1,5] Undetected sleep apnea increases the risk of stroke and heart attack after SCI.[6] Obstructive sleep apnea is most common in elderly men with high tetraplegia, and a large neck circumference.[7]

Regardless of the degree of respiratory dysfunction, rehabilitation respiratory care should provide individualized interventions to optimize bronchial hygiene, chest mobility and respiratory performance.[4] Specific goals of respiratory rehabilitation are to prevent complications (e.g., pneumonia, atelectasis), maximize recovery of respiratory muscles, and increase respiratory endurance, so that individuals with SCI can fully participate in rehabilitation.

Incidence of respiratory complications (such as pneumonia, pulmonary edema, pulmonary embolism, aspiration, and ventilatory failure) range from 36 to 83%.[3,8-13] Respiratory complications are the leading causes of morbidity and mortality in the SCI population.[3,8-13]

Most importantly, 11% of early deaths, in the first month after SCI, are due to respiratory complications.[14]

FIGURE 2.0 POTENTIAL RESPIRATORY CONSEQUENCES OF SCI



Evidence-based or best practices should be the standard of rehabilitation respiratory care to prevent early death and long-term complications, and to optimize health in individuals with SCI.

Current Key Clinical Questions

1. What are the current resources for respiratory care at Canadian SCI rehabilitation centres? Can all sites support best practice for independence in breathing?

2. Is there equal and fair access to rehabilitation regardless of the respiratory support required?

3. What is the current respiratory rehabilitation management for individuals with high tetraplegia who have ventilation dependency?

Current Practice: Rehabilitation Management of Respiratory Dysfunction Post-SCI

Service Providers: Maximizing respiratory function in rehabilitation requires interprofessional collaboration, within a team of healthcare professionals, that includes physicians (physiatrists, respirologists, infectious disease specialists, otolaryngologists), respiratory therapists, pulmonary function technicians, physiotherapists, nurses, occupational therapists, pharmacists, speech language pathologists, dietitians, registered practical nurses, physiotherapy assistants and occupational therapy assistants (Figures 3.0 and 4.0). For individuals who require ventilation, respiratory management will require additional interprofessional care, especially by respiratory therapists, nurses, occupational therapists and wheelchair vendors (Figures 3.0 and 4.0).

FIGURE 3.0 ONSITE HEALTHCARE PROFESSIONALS INVOLVED IN RESPIRATORY CARE WITHIN INPATIENT SCI REHABILITATION PROGRAM

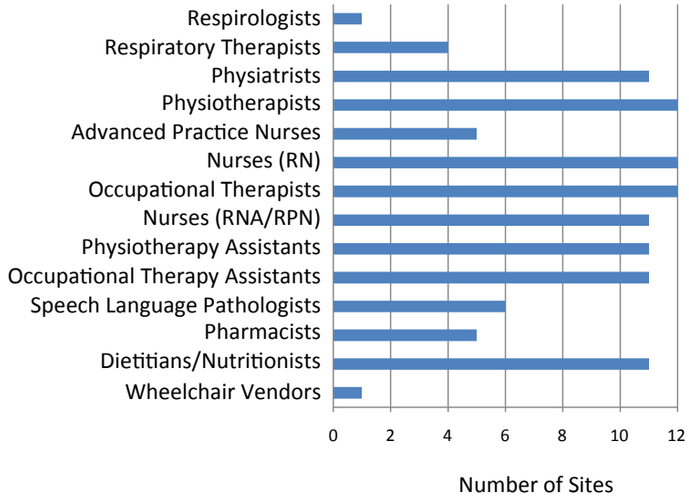
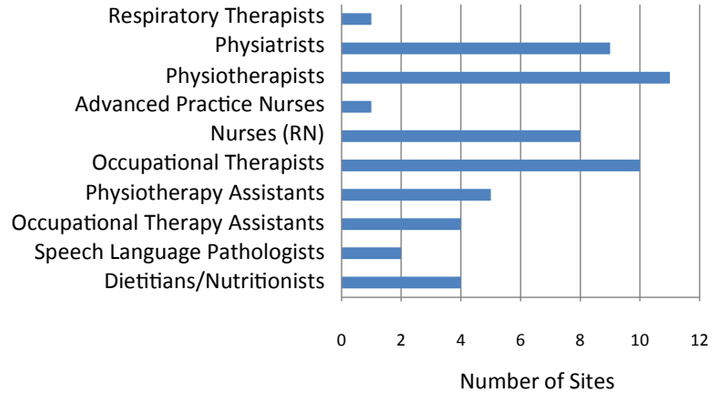


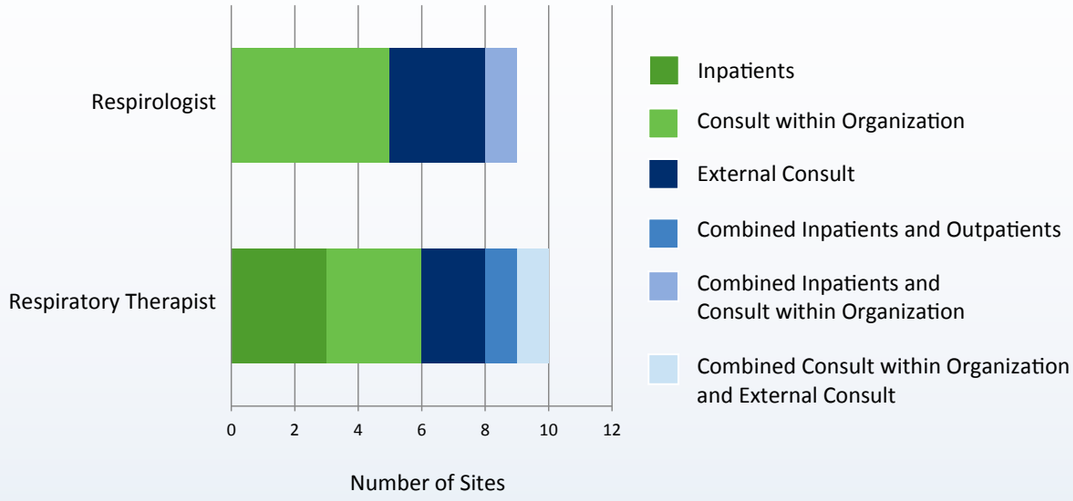
FIGURE 4.0 ONSITE HEALTHCARE PROFESSIONALS INVOLVED IN RESPIRATORY CARE WITHIN OUTPATIENT SCI REHABILITATION PROGRAM



All 12 E-Scan sites offer some extent of respiratory care, and three sites confirm admission of individuals with SCI who are ventilator dependent. While nine sites have an affiliated respirologist, only one site has an onsite respirologist who is dedicated to care of inpatients. Respiratory therapists provide service at 10 sites: dedicated to inpatient service at three sites, dedicated to both inpatient and outpatient services at one site, and on a consult basis at six sites (Figure 5.0).

All sites have physiotherapists (Figure 3.0). However, the extent of respiratory care provided by physiotherapists is unclear. Similarly, the involvement of other members of the rehabilitation team in providing respiratory care and the specific details of such care is unknown. It appears from the E-Scan validation process that although regulated healthcare professionals (RN, PT, OT, etc.) are practicing within the sites, an inadequate portion of their time and resources is allocated to optimizing respiratory care.

FIGURE 5.0 CAPACITY FOR RESPIROLOGY AND RESPIRATORY THERAPY CARE



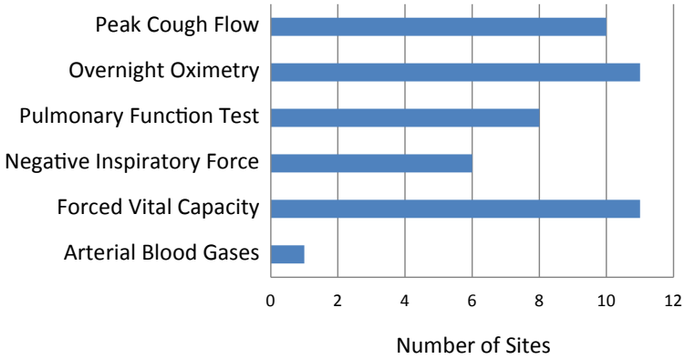
Assessments and Outcome Measures

Comprehensive assessment of respiratory status is integral to providing optimal care in rehabilitation. This should include respiratory history and physical examination, vital signs, pulmonary function (spirometry in supine and sitting), maximum insufflation capacity, peak cough flow, overnight oximetry (including transcutaneous carbon dioxide, if available) and sleep studies, ventilatory muscle strength, chest x-ray and arterial blood gases.[15-18]

Screening assessments should be conducted at rehabilitation admission for individuals with SCI at level L1 and above, with follow-up assessments conducted as necessary, based upon screening assessment results. Specific tests or assessments performed should be based on the individual's level of SCI and respiratory impairments.[19]
Canadian rehabilitation sites vary in their capacity to conduct comprehensive respiratory assessments. Most sites report being able to conduct overnight oximetry (11/12) and peak cough flow (10/12) assessments (Figure 6.0). While eight of 12 sites report using pulmonary function tests to assess respiratory function, there is considerable variation in the information specifically used from this test (Figure 6.0). Most sites (11/12) used forced vital capacity, while only half used negative inspiratory force (Figure 6.0).

In Canadian rehabilitation sites, respiratory assessments are conducted by a variety of healthcare professionals (Figure 7.0). While many assessments are done by respirologists (19%), respiratory therapists (18%) and physiotherapists (18%), other care providers (e.g., nurses, respiratory technicians, pulmonary function test technicians, and physiatrists) also conduct a substantial proportion of respiratory assessments (Figure 7.0). These results suggest that capacity for performing respiratory assessments can be increased through appropriate training of available clinicians.

FIGURE 6.0 OUTCOME MEASURES –
CURRENT CAPACITY TO CONDUCT COMPREHENSIVE ASSESSMENTS



Capacity to perform respiratory assessments, or availability of a diagnostic service, does not always coincide with utilization of the specific assessment or diagnostic service. Of the eight sites that report capacity to assess arterial blood gases, only one site report using this outcome measure (Figures 6.0 and 8.0). Such lack of utilization may be appropriate (e.g., good clinical judgment, availability of alternative assessments), but the data does not give reasons for the extent of utilization. In relation, current data also does not allow identification of respiratory outcome measures that are routinely used in Canadian rehabilitation centres.

FIGURE 7.0 HEALTHCARE PROFESSIONALS CONDUCTING RESPIRATORY ASSESSMENTS

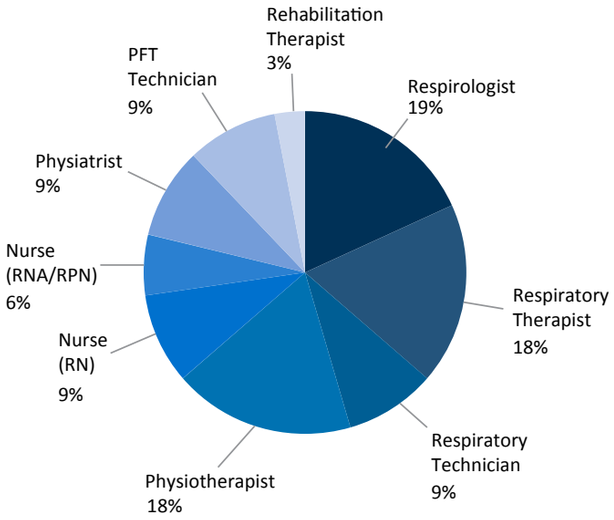
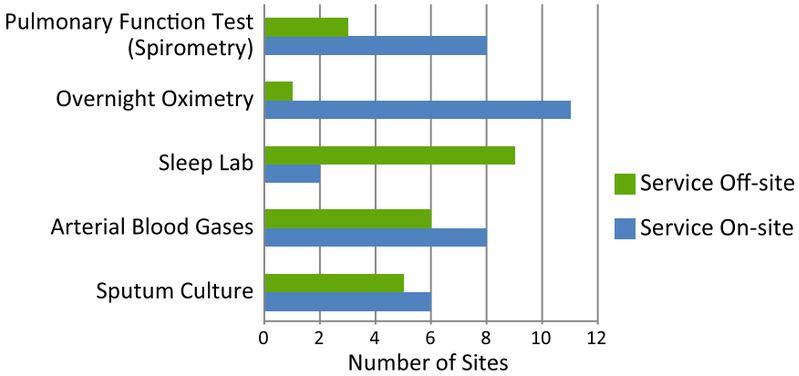


FIGURE 8.0 CURRENT CAPACITY TO CONDUCT SPECIFIC RESPIRATORY ASSESSMENTS



Interventions and Specialized Equipment

Current, best available evidence of rehabilitation interventions to maximize respiratory function, in individuals with SCI, is summarized by Clinical Practice Guidelines (CPGs) and systematic reviews.

1. Respiratory management following spinal cord injury: a clinical practice guideline for healthcare professionals. 2005.[15]

2. Respiratory Management. In: Spinal Cord Injury Rehabilitation Evidence. Volume 3.0. 2010.[1]

3. Physiotherapy secretion removal techniques in people with spinal cord injury: a systematic review. 2010.[20]

4. Home mechanical ventilation: a Canadian Thoracic Society clinical practice guideline. 2011.[18]

THE FOLLOWING RESPIRATORY INTERVENTIONS ARE SUPPORTED BY LEVEL 1 OR 2 EVIDENCE [1, 20, 21]:

- Exercise training
- Specific training of respiratory muscles – normocapnic hyperpnoea concomitant inspiratory and expiratory muscle training
- Pharmaceutical interventions - bronchodilators
- Interdisciplinary tracheostomy review and management team
- Abdominal binding
- Secretion removal techniques - mechanical insufflation/exsufflation with manual respiratory kinesitherapy
- Neuromuscular electrical stimulation – abdominal muscles and pectoralis major.

THE FOLLOWING RESPIRATORY INTERVENTIONS ARE STRONGLY RECOMMENDED[18]:

- Weaning protocol with progressive ventilator-free breathing
- Non-invasive ventilation preferred over invasive ventilation

- Regular lung volume recruitment, manually assisted cough and mechanical insufflation-exsufflation, for airway clearance.

There is considerable disparity among Canadian rehabilitation sites in the use of best-available evidence summaries. Few sites report using guidelines or systematic reviews to inform management of respiratory dysfunction. Four of 12 sites (33%) report using the Paralyzed Veterans of America's (PVA) Consortium for Spinal Cord Medicine guideline, and three of 12 sites (25%) report using the Rick Hansen Institute's Spinal Cord Injury Rehabilitation Evidence review. At the time of the Rehabilitation E-Scan survey, the Canadian Thoracic Society guideline was not yet published, so its current utilization by rehabilitation sites is yet to be determined.

There is also disparity in Canadian rehabilitation sites' capacity to provide evidence-based respiratory care. For example, level 2 evidence, and strong recommendation support use of mechanical insufflation/exsufflation to remove secretions, but only seven of 12 sites (58%) have a mechanical insufflator-exsufflator available for clinical care (Table 1.0).[1,18]

TABLE 1.0 AVAILABILITY OF EQUIPMENT FOR RESPIRATORY CARE

VENTILATORY EQUIPMENT	AVAILABLE FOR CLINICAL CARE
Ventilator – BiPAP	7/12 (58%)
Ventilator – CPAP	7/12 (58%)
Ventilator – Volume	5/12 (42%)
Ventilator – Pressure	3/12 (25%)
Insufflator- Exsufflator	7/12 (58%)
Suction Units	12/12 (100%)

Similarly, the PVA's guideline recommended continuous positive airway pressure (CPAP) therapy for individuals with obstructive sleep apnea, but only seven of 12 sites (58%) have the equipment necessary to provide care (Table 1.0).[15]

The most disparate aspect of Canadian SCI respiratory rehabilitation can be found in the care of Canadians with high tetraplegia who are ventilator-dependent. Most Canadian rehabilitation sites are not equipped with ventilators (Table 1.0). Even though most sites report availability of environmental controls for individuals with high tetraplegia (Table 2.0), only three sites confirm admission of individuals with SCI who are ventilator-dependent. One site accepts out-of-province individuals who are ventilator-dependent.

TABLE 2.0 AVAILABILITY OF MOBILITY AIDS AND ENVIRONMENTAL CONTROLS FOR INDIVIDUALS WITH HIGH TETRAPLEGIA

ENVIRONMENTAL CONTROLS	AVAILABLE FOR CLINICAL CARE
Sip and Puff Controller	12/12 (100%)
Shoulder Switches	9/12 (75%)
Hands free in room – Call Bells	10/12 (83%)
Hands free in room – Phones	9/12 (75%)
Hands free in room – Head Master	8/12 (67%)
Hands free in room – Environmental Controls	9/12 (75%)

In many regions of the country, Canadians with SCI who are ventilator-dependent are unable to access specialized SCI rehabilitation. These individuals may receive respiratory rehabilitation at sites that do not provide SCI rehabilitation, and may not receive care from clinicians with expertise in SCI. This can limit access to interventions, such as phrenic nerve pacing and diaphragm pacing, which offer alternatives to mechanical ventilation (level 4 evidence).[1,18]

SPOTLIGHT BEST PRACTICE ORGANIZATION

SPINAL CORD INJURY REHABILITATION PROGRAM –

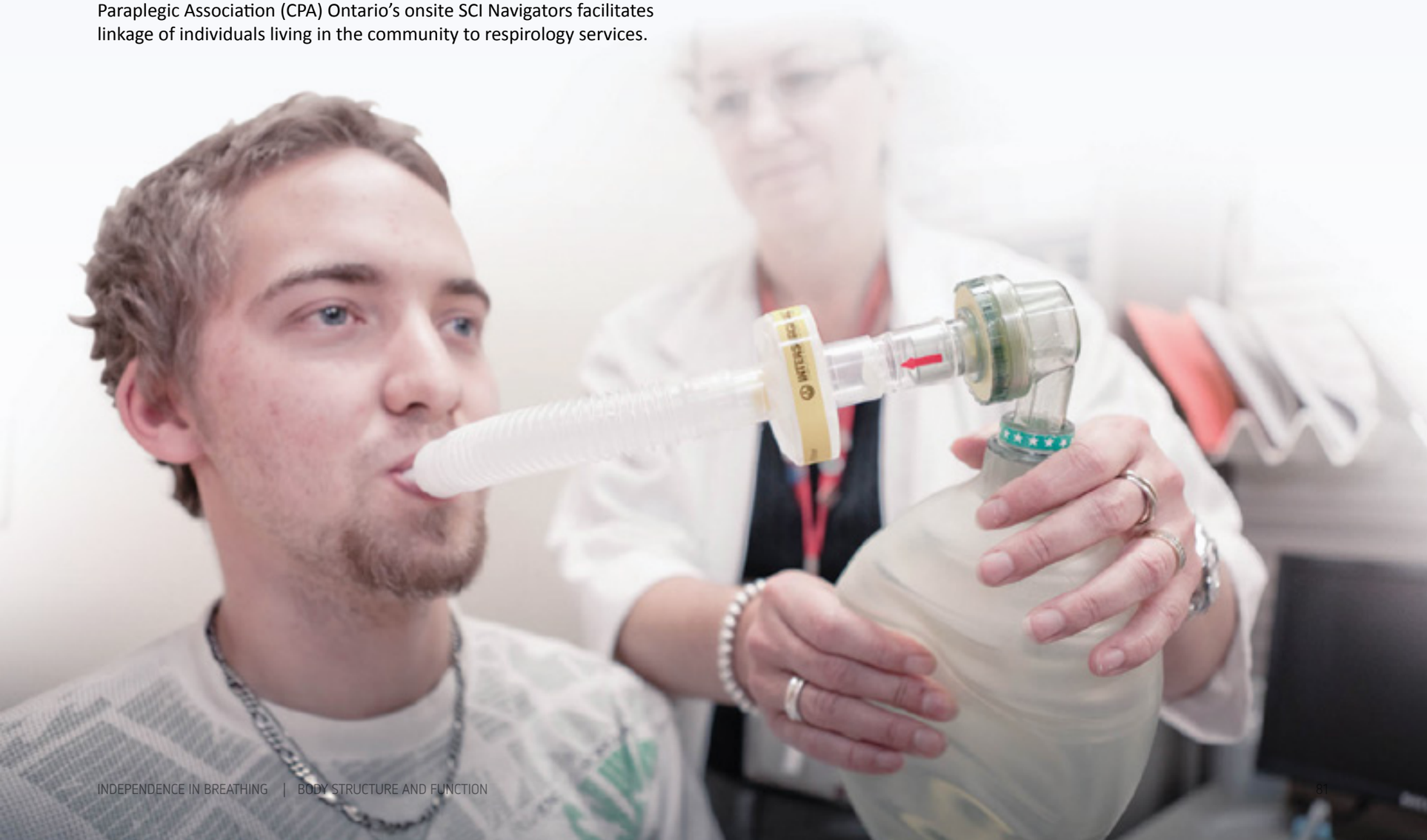
Hamilton Health Sciences Regional Rehabilitation Centre – Hamilton, Ontario

This SCI rehabilitation site's clinical expertise and extent of respiratory care deserves mention. Their interprofessional team approach to respiratory care includes dedicated respiratory therapists, a respirologist, and a pulmonary function technician. Respiratory therapists are on site during business hours, and respiratory therapists from acute care are available on call 24/7.

Individuals with SCI at the level of L1 or above are routinely screened for respiratory impairments, including sleep-disordered breathing. Both inpatients and outpatients undergo full respirology assessments, including evaluation for invasive and non-invasive ventilation, lung volume recruitment and secretion clearance. After discharge, follow-up care is provided at the respirology outpatient clinic, which also accepts referrals of other community-dwelling individuals with SCI, outside of their traditional catchment area. Collaboration with Canadian Paraplegic Association (CPA) Ontario's onsite SCI Navigators facilitates linkage of individuals living in the community to respirology services.

This site has a considerable range of respiratory equipment, including auto-titrate CPAP devices, bi-level and volume ventilator devices, mechanical insufflator-exsufflators, overnight oximetry equipment and software, and a pulmonary function laboratory. Respiratory therapists facilitate access to Ontario's Assistive Devices Ventilation Program, and have expertise in education regarding long-term ventilation. Instruction in respiratory health is regularly provided in education classes, and print and online materials are available to all individuals with SCI.

Uniquely, the Regional Rehabilitation Centre is physically joined to, and closely integrated with, the acute care spine site. This proximity allows acute care services to provide and/or support respiratory care (e.g., Rapid Assessment of Critical Events Team, Diagnostics, Infectious Diseases, Otolaryngology, Internal Medicine, Cardiology) and facilitates comprehensive respiratory management.



Emerging Expertise with Unique Solutions

The Stan Cassidy Centre for Rehabilitation, in Fredericton, New Brunswick, is a newer site of the Rick Hansen SCI Registry (joining after E-Scan data collection), and unique because it is in a different city to the hospitals that deliver acute SCI care. Their approach to respiratory management is interprofessional and evidence based. Onsite nursing, physiotherapy and physiatry are complemented with access to respiratory therapy, from industry and regional hospitals; and team members work with private industry, to conduct level three sleep studies, and to initiate non-invasive ventilation for individuals with SCI, as inpatients and outpatients. A local surgeon is trained in implantation of diaphragmatic pacing systems (two individuals have undergone a trial with the device), and mechanical insufflation-exsufflation and lung volume recruitment techniques are routine.

Roadmap: Optimal Assessment and Treatment to Maximize Respiratory Function

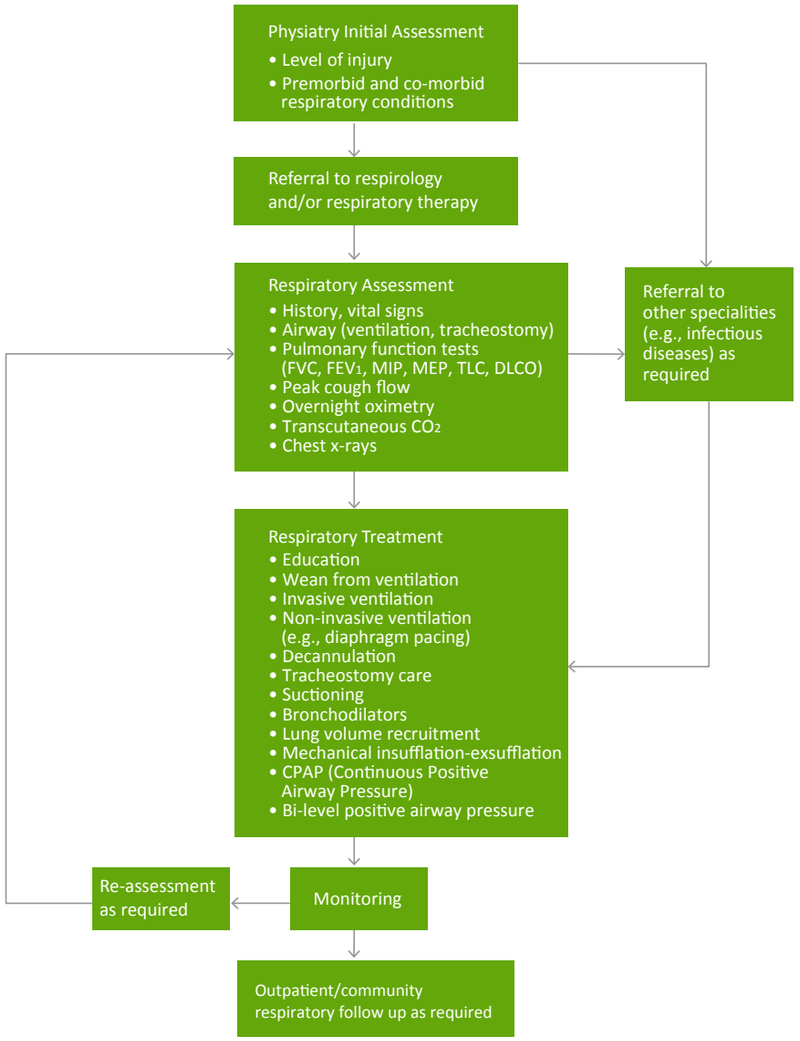
Based on the literature and the E-Scan of Canadian rehabilitation sites, there is an urgent need to:

- Ensure the performance of a standardized respiratory assessment upon admission to rehabilitation, that includes pulmonary function (spirometry in supine and sitting), peak cough flow, maximum insufflation capacity and overnight oximetry, for all individuals with SCI at level L1 and above

- Implement best practice interventions, including lung volume recruitment/volume augmentation techniques, cough assist techniques, CPAP or BiPAP®; and consider promising interventions to increase respiratory muscle force, including respiratory muscle training, and neuromuscular electrical stimulation

- Provide specialized, inpatient SCI rehabilitation for individuals with SCI who are ventilator-dependent.

FIGURE 9.0 PROPOSED MODEL OF RESPIRATORY CARE



BEST PRACTICE INDICATORS

1. Documented assessment for all individuals with SCI and a NLI above L2, by a respirologist and/or respiratory therapist, during inpatient admission, and follow-up care for those with respiratory impairment.

2. Perform routine respiratory assessments using standardized outcomes, prior to, or at the time of, rehabilitation admission. At a minimum, these include:

- History of Respiratory Complications
- Chest X-Ray
- Pulmonary Function Test
- Peak Cough Flow
- Maximum Insufflation Capacity
- Overnight Oximetry

3. Tertiary rehabilitation sites provide respiratory care, with specialty equipment (documented in good working order) used by appropriately trained staff. Equipment should include:

- Mechanical Insufflator-Exsufflator
- Manual Resuscitation Bag with Adapters
- Ventilators for Invasive and Non-invasive Ventilation: CPAP; BiPAP®; Pressure-Volume Ventilators
- Inspiratory Muscle Trainers

- Oxygen and Suction
- Heated Molecular Humidity
- Abdominal Binders

4. Conduct follow-up respiratory assessments as indicated, throughout the individual's lifetime.

5. Admit individuals with ventilator dependence to inpatient SCI rehabilitation, and provide interprofessional care to optimize the method of ventilation, and maximize potential for spontaneous breathing.

References to Guide Clinical Practice

CLINICAL PRACTICE GUIDELINES:

- Respiratory management, Consortium for Spinal Cord Medicine.[15]
- Home mechanical ventilation, McKim et al.[18]

SYSTEMATIC REVIEWS:

- Respiratory management, Sheel et al.[1]
- Secretion removal techniques, Reid et al.[20]

BOOK CHAPTERS:

- Respiratory evaluation, Wetzel.[17]
- Respiratory dysfunction in SCI, Baydur and Sassoon.[2]
- Management of respiratory dysfunction, Wetzel.[4]
- Sleep disorders in SCI, Epstein and Brown.[5]

Canadian Content Experts Likely to Influence Practice in the Next Five Years

1. Graham Jones, MD (Respirology), Hamilton: Respirologist and intensivist at Hamilton Health Sciences. Provides consultations and follow-up care for inpatients and outpatients with SCI. Expertise in cardiorespiratory assessment, exercise counselling and ventilatory management of individuals with SCI.

2. Douglas McKim, MD (Respirology), Ottawa: Respirologist and Medical Director of Respiratory Rehabilitation Services/CANVent (Canadian Alternatives in Non-Invasive Ventilation) Program, and the Ottawa Sleep Centre. The CANVent Program develops weaning strategies in critical care, and educates healthcare professionals about non-invasive airway clearance strategies, to enable individuals with SCI to participate in rehabilitation. He is the lead author of the 2011 Canadian Thoracic Society Clinical Practice Guidelines on Home Mechanical Ventilation and co-investigator of CIHR-funded projects to study long-term ventilation.

3. Colleen O'Connell, MD (Physiatry), Fredericton: Physiatrist with expertise in respiratory management in SCI and other neurologic conditions, particularly in non-invasive ventilation. Member of the Canadian Home Mechanical Ventilation Guidelines Committee, to assist with regional dissemination and implementation of the guideline.

4. Jeremy Road, MD (Respirology), Vancouver: Respirologist at Vancouver General Hospital and Medical Director of the Provincial Respiratory Outreach Program for individuals on home-assisted ventilation; part of the research team that piloted diaphragm pacing in Canada,and Co-Chair of the Canadian Thoracic Society Home Mechanical Ventilation Committee. He will assist with regional dissemination and implementation of the guideline.

5. Andrea Townson, MD (Physiatry), Vancouver: Physiatrist with research interests in high tetraplegia, ventilator dependency and fatigue. Experienced in the care and management of individuals with high tetraplegia.

6. Renata Vaughan, RRT, Hamilton: Respiratory Therapist at Hamilton Health Sciences Regional Rehabilitation Centre and Clinical Coordinator at the Michener Institute of Applied Health Sciences. Teaches others about respiratory care of individuals with SCI, based on 22 years of experience in SCI rehabilitation, long-term ventilation and non-invasive secretion clearance techniques.

Research Implications

- Focus strongly on knowledge translation and best practices implementation to achieve a high standard of respiratory care, across the country.

- Create guidelines regarding rehabilitation assessment of respiratory function, in individuals with SCI, and a systematic method of evaluating utilization.

- Conduct an economic analysis of the value, and cost of implementing respiratory best practices during SCI rehabilitation, to be informative and useful for health policy improvements.

Health Policy Implications

- SCI rehabilitation should be accessible to all Canadians with SCI in a fair and equitable way. If future analyses of Canadian healthcare data show that respiratory status affects access to specialized SCI rehabilitation, the role of health policy in ensuring appropriate access must be considered

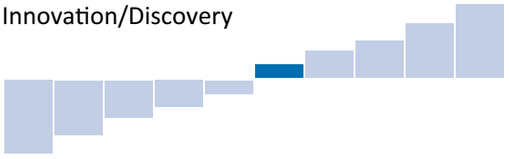
- Health policies that change the SCI continuum of care (e.g., shortened acute care stay, admission to community hospitals with limited expertise in SCI care prior to rehab, or shortened rehabilitation stay) can affect respiratory health outcomes of individuals with SCI, and need to be evaluated.

REPORT CARD: Independence in Breathing

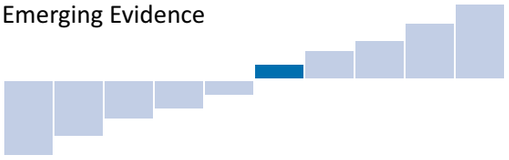
Extreme left below median: ***insufficient***
Extreme right above median: ***optimal***

KNOWLEDGE GENERATION

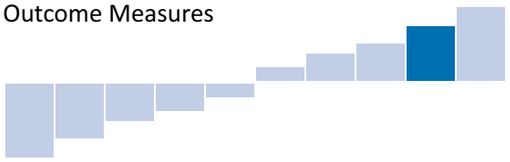
Innovation/Discovery



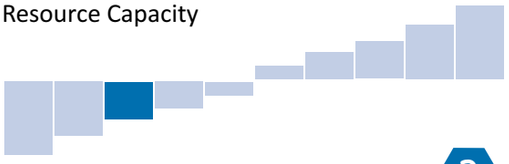
Emerging Evidence



Outcome Measures



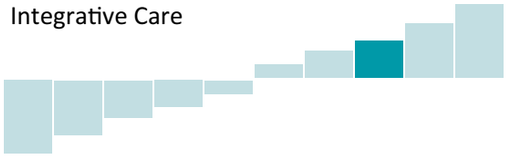
Resource Capacity



2020 PRIORITY 3

CLINICAL APPLICATION

Integrative Care



Effective Practice
(Evidence and Outcomes)

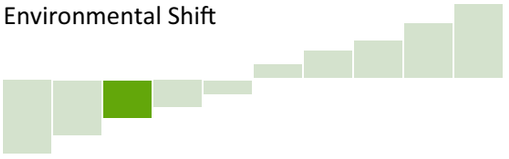
Equity Practice

Capacity

2020 PRIORITY 1

POLICY CHANGE

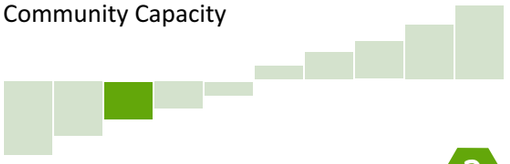
Environmental Shift



Change Agents

Societal Awareness

Community Capacity



2020 PRIORITY 2

TAKE HOME MESSAGE:

Respiratory complications are leading causes of morbidity and mortality for individuals with SCI. Routine and standardized respiratory assessments must be conducted during inpatient rehabilitation, and evidence-based therapies must be provided as a standard of care to all individuals with respiratory impairments after SCI, throughout their lifetime.

RESOURCES

1. Sheel AW, Reid WD, Townson A, Ayas N. Respiratory management. In: Eng JJ, Teasell RW, Miller WC, et al., eds. *Spinal Cord Injury Rehabilitation Evidence*. Volume 3.0. Vancouver, BC; 2010:1-46.

2. Baydur A, Sassoon CSH. Respiratory dysfunction in spinal cord disorders. In: Lin VW, ed. *Spinal Cord Medicine: Principles and Practice*. 2nd ed. New York, NY: Demos Medical Publishing; 2010:215-29.

3. Winslow C, Rozovsky J. Effect of spinal cord injury on the respiratory system. *Am J Phys Med Rehabil*. 2003;82(10):803-14.

4. Wetzel JL. Management of respiratory dysfunction. In: Field-Fote EC, ed. *Spinal Cord Injury Rehabilitation*. Philadelphia, PA: F.A. Davis; 2009:337-92.

5. Epstein LJ, Brown R. Sleep disorders in spinal cord injury. In: Lin VW, ed. *Spinal Cord Medicine: Principles and Practice*. 2nd ed. New York, NY: Demos Medical Publishing; 2010:230-40.

6. Chung SA, Jairam S, Hussain MRG, Shapiro CM. How, what, and why of sleep apnea. *Can Fam Physician*. 2002;48:1073-80.

7. Stockhammer E, Tobon A, Michel F, et al. Characteristics of sleep apnea syndrome in tetraplegic patients. *Spinal Cord*. 2002;40(6):286-94.

8. Tollefsen E, Fondenes O. Respiratory complications associated with spinal cord injury. *Tidsskr Nor Laegeforen*. 2012;132(9):1111-5.

9. Hartkopp A, Bronnum-Hansen H, Seidenschnur AM, Biering-Sorensen F. Survival and cause of death after traumatic spinal cord injury: a long-term epidemiological survey from Denmark. *Spinal Cord.* 1997;35(2):76-85.

10. Hagen EM, Rekand T, Gilhus NE, Gronning M. Traumatic spinal cord injuries – incidence, mechanisms and course. *Tidsskr Nor Laegeforen*. 2012;132(7):831-7.

11. Devivo MJ, Kartus PL, Stover SL, Phillip RD, Fine R. Cause of death for patients with spinal cord injury. *Arch Intern Med*. 1989;149(8):1761-6.

12. Jackson AB, Groomers TE. Incidence of respiratory complications following SCI. *Arch Phys Med Rehabil.* 1994;75(3):270-5.

13. Lemons VR, Wagner FC Jr. Respiratory complications after cervical spinal cord injury. *Spine*. 1994;19(20):2315-20.

14. Reines HD, Harris RC. Pulmonary complications of acute spinal cord injuries. *Neurosurgery*. 1987;21(2):193-6.

15. Consortium for Spinal Cord Medicine. *Respiratory management following spinal cord injury: a clinical practice guideline for healthcare professionals*. Washington, DC: Paralyzed Veterans of America; 2005:1-49.

16. Biering-Sorensen F, Krassioukov A, Alexander MS, et al. International spinal cord injury pulmonary function basic data set. *Spinal Cord*. 2012;50(6):418-21.

17. Wetzel JL. Respiratory evaluation of individuals with spinal cord injury (bonus chapter). In: Field-Fote EC, ed. *Spinal Cord Injury Rehabilitation*. Philadelphia, PA: F.A. Davis; 2009:1-32. http://davisplus.fadavis.com/landing_page.cfm?publication_id=2319. Accessed June 26, 2012.

18. McKim DA, Road J, Avendano M, et al. Home mechanical ventilation: a Canadian Thoracic Society clinical practice guideline. *Can Respir J*. 2011;18(4):197-215.

19. Clough P, Lindenauer D, Hayes M, Zekany B. Guidelines for routine respiratory care of patients with spinal cord injury: a clinical report. *Phys Ther*. 1986;66(9):1395-1402.

20. Reid WD, Brown JA, Konnyu KJ, Rurak JM, Sakakibara BM, SCIRE Research Team. Physiotherapy secretion removal techniques in people with spinal cord injury: a systematic review. *J Spinal Cord Med*. 2010;33(4):353-70.

21. Cheng PT, Chen CL, Wang CM, Chung CY. Effect of neuromuscular electrical stimulation on cough capacity and pulmonary function in patients with acute cervical cord injury. *J Rehabil Med*. 2006;38(1):32-6.

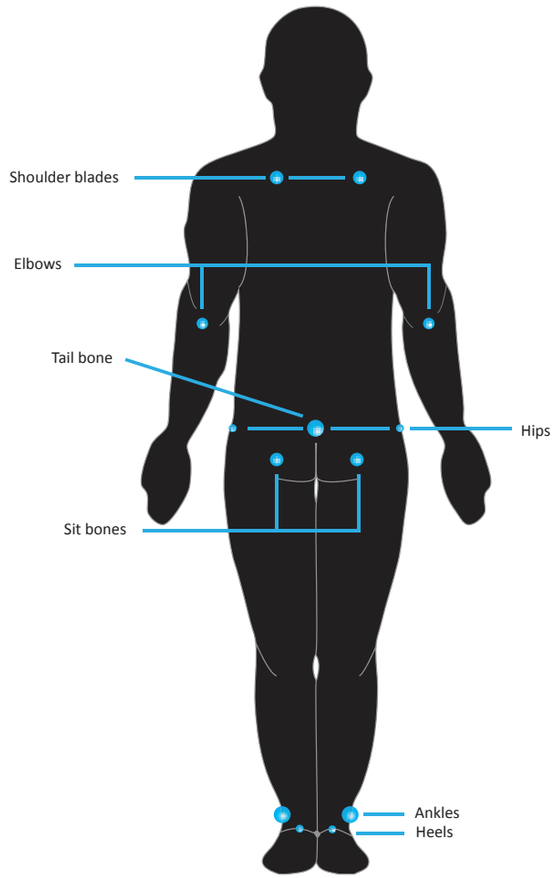
Skin Integrity

J Hsieh, MSc; DL Wolfe, PhD; E Nussbaum, PhD; H Flett, MSc; C Craven, MD; and the E-Scan Investigative Team

Maintaining skin integrity after spinal cord injury (SCI) involves the prevention and management of pressure ulcers in areas of the body where sensation is often diminished or absent. A pressure ulcer is a localized injury to the skin and/or underlying tissue (e.g., deep tissue), typically over a bony prominence (Figure 1.0). It is caused by pressure, or pressure in combination with shear and/or friction, moisture and a variety of other contributing factors.

Pressure ulcers often result in functional limitations and disruption of an individual's life. In addition, re-hospitalization, significant fluid and protein loss and, in severe cases, osteomyelitis, myonecrosis, necrotizing fascitis, sepsis and death can result from untreated pressure ulcers. As there is a 95% lifelong pressure ulcer prevalence rate for individuals with SCI, rehabilitation plays a critical role in maintaining skin integrity and overall health.

FIGURE 1.0 COMMON PRESSURE ULCER RISK AREAS.
USED WITH PERMISSION FROM THE SPINAL CORD INJURY UNIVERSITY (SCI-U) WEBSITE.[1]



Although prevention and implementation of evidence-based best practices can reduce costs associated with treating pressure ulcers by 90%,[2,3] annual incidence and prevalence rates among individuals with SCI remain high at 30%.[4,5]

Current Practice: Prevention and Management of Pressure Ulcers Post-SCI

Facilitating skin integrity in a rehabilitation setting requires coordinated interprofessional care by assistive device authorized personnel - case coordinators/managers, dietitians, doctors (family, hospitalist, physiatrist, plastic surgeon, infectious disease specialist), nurses (registered, registered nursing assistant/registered practical, advanced practice), occupational therapists (OTs), physiotherapists (PTs), pharmacists, social workers, peer support workers and wheelchair vendors - provided in a variety of settings including inpatient and outpatient, transition, rehabilitation and community (Figure 2.0, next page). Although all SCI rehabilitation facilities across Canada provide skin and wound management services, the extent of the services provided varies due to diversity in the interprofessional team makeup, the spectrum of treatments provided, the seven published guidelines and variety of unpublished care pathways. There is a 'disconnect' between the available evidence, and the challenges of interprofessional care delivery that often results in care providers reverting to solo practice.

Figure 2.0 illustrates how typical interprofessional skin and wound management services should be delivered, Figure 3.0 describes the spectrum of interprofessional representation across organizations. Seven tertiary rehabilitation sites (58%) report a minimum skin integrity team comprised of a nurse, an OT and a physiatrist. The other disciplines are represented at one or two sites, except for PT, which is represented at five sites; and three sites report additional contributions from an enterostomy therapist, plastic surgeon, psychiatrist, hospitalist or an infectious disease specialist.

FIGURE 2.0 THE SPECTRUM OF SERVICES AVAILABLE TO PREVENT AND MANAGE PRESSURE ULCERS AMONG INDIVIDUALS WITH SCI

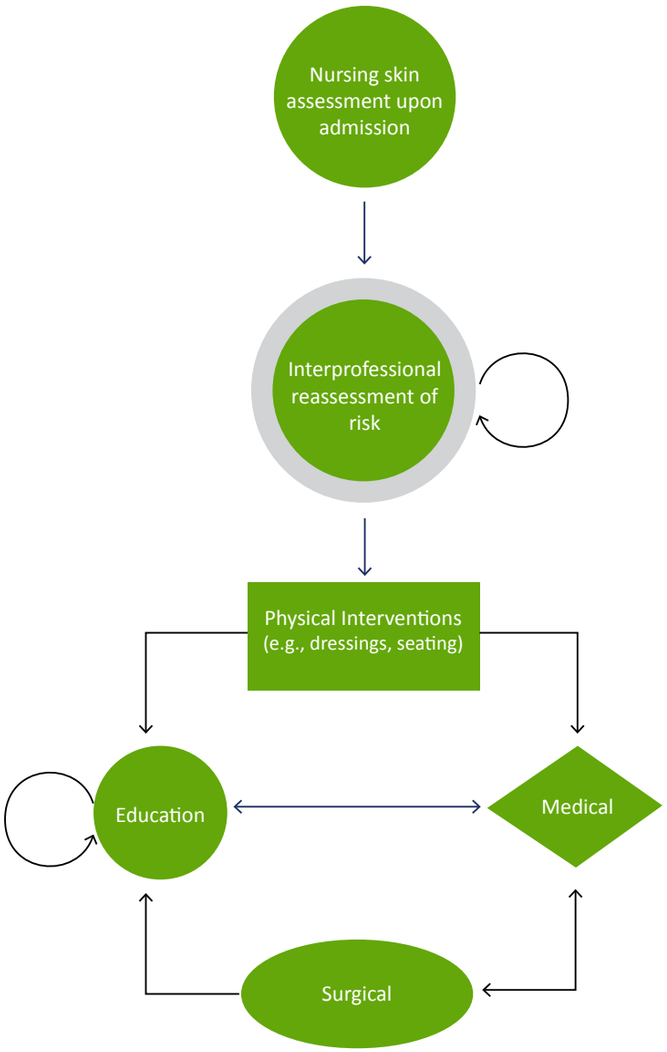
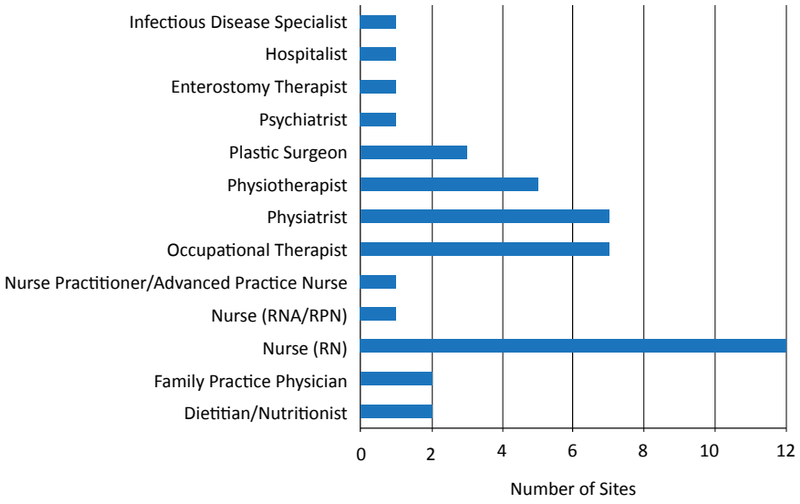


FIGURE 3.0 DISTRIBUTION OF HEALTHCARE PROFESSIONALS PROVIDING SKIN INTEGRITY SERVICES IN TERTIARY SCI REHABILITATION CENTRES ACROSS CANADA



Current Canadian SCI Pressure Ulcer Practice Profile

CLINICAL PRACTICE GUIDELINES

1. Houghton PE, Campbell KE, and BPG Panel members. *Canadian Best Practice Guidelines for the Prevention, Assessment and Treatment of Pressure Ulcers in Individuals with Spinal Cord Injury*; Rick Hansen Institute (RHI) and the Ontario Neurotrauma Foundation (ONF); 2012. (Contact phoughto@uwo.ca for more information)

2. European Pressure Ulcer Advisory Panel and National Pressure Ulcer Advisory Panel. *Prevention and treatment of pressure ulcers: quick reference guide.* Washington, DC: National Pressure Ulcer Advisory Panel; 2009. http://www.epuap.org/guidelines/Final_Quick_Prevention.pdf. Accessed May 29, 2012.

3. Paralyzed Veterans of America (PVA) Consortium for Spinal Cord Medicine Clinical Practice Guidelines. *Pressure ulcer prevention and treatment following SCI: A clinical practice guideline for healthcare professionals.* 2000;1-77.

4. Registered Nurses Association of Ontario (RNAO). *Nursing Best Practice Guideline: Risk Assessment and Prevention of Pressure Ulcers*; 2005. http://rnao.ca/bpg/guidelines/risk-assessment-and-prevention-pressure-ulcers. Accessed May 31, 2012.

5. Ovington LG. Dressings and adjunctive therapies: AHCPR guidelines revisited. *Ostomy Wound Manage*. 1999;45(Suppl 1A):94S-106S.

CARE PATHWAYS OR LOCAL PROTOCOLS

Most sites (92%) report having a treatment protocol or a pressure ulcer standard of care (33%), but only 50% report using one of the published CPGs (e.g., RNAO or PVA), emphasizing the disconnection between previously published CPGs and current practice implementation.

PRACTICE REFERENCES

1. Regan M, Teasell RW, Keast D, Aubut JL, Foulon BL, Mehta S. Pressure ulcers following spinal cord injury. In: Eng JJ, Teasell RW, Miller WC, et al., eds. *Spinal Cord Injury Rehabilitation Evidence*. Version 3.0. Vancouver, BC; 2010. http://www.scireproject.com/rehabilitation-evidence/pressure-ulcers. Accessed May 29, 2012.

2. Black J, Baharestani M, Cuddigan J, et al. National pressure ulcer advisory panel's updated pressure ulcer staging system. *Urol Nurs*. 2007;27:144-150.

3. Keast DH, Parslow N, Houghton PE, Norton L, Fraser C. (2006). Best practice recommendations for the prevention and treatment of pressure ulcers: Update. *Wound Care Canada*. 2006;22-32.

4. Mortenson WB, Miller WC. Scales for assessing the risk of developing a pressure ulcer in individuals with SCI. *Spinal Cord*. 2008;46:168-75.

Wound Assessments

1. A variety of wound assessment tools are in use [any use%; routine use%] by sites for:

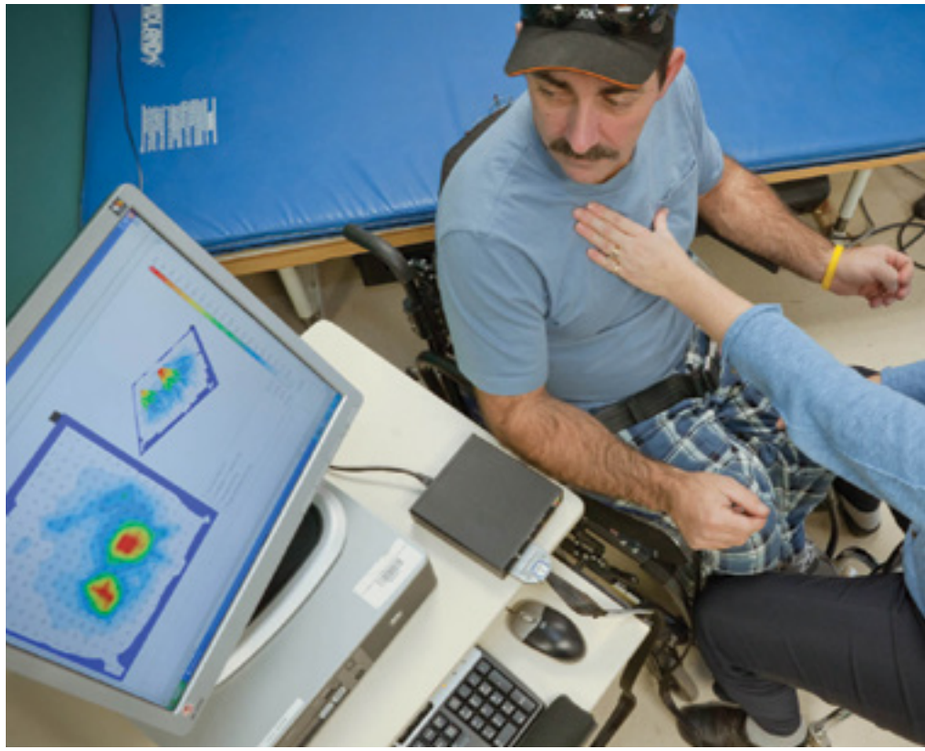
a. Characterization and/evaluation of pressure ulcers:

- Bates Jenson Wound Assessment Tool (BWAT) [0%;0%]
- Pressure Ulcer Stages (1989). *National Pressure Ulcer Advisory Panel (NPUAP)* (http://npuap.org/positn6.htm) [50%; 25%]
- High definition diagnostic ultrasound assessment (see below) of deep tissue integrity (further validation of tool is required) [8%; 8%]
- Cardiff Wound Impact Scale (CWIS) [8%; 0%]
- Wound tracer [42%; 0%]
- Measure [42%; 17%]
- Photograph [8%; 0%]

b. Prediction of who will develop a pressure sore:

- Braden Scale [92%;50%]
- Spinal Cord Injury Pressure Ulcer Scale Measure [0;0%]
- Pressure maps [8%;0%]
- Site-specific assessment tool [1%;8%]

Interestingly, no sites report routine use of pressure maps for SCI inpatients. All sites, however, either own or have access to – with 67% reporting adequate access to – pressure-mapping equipment, despite controversy over pressure map data interpretation.[6]



There is considerable controversy over the optimal process for, and role of, pressure mapping within wheelchair seating prescription.

Many confounding factors related to the individual (intrinsic, extrinsic, and physiological characteristics), their assessment position, injury duration and the physical attributes of the equipment itself, contribute to the controversies related to routine clinical use and interpretation of pressure mapping data. Interrater reliability studies suggest that pressure mapping is only reliable for areas of maximum pressure and that, in the quest for adequate pressure distribution, sole reliance on visual interpretation of pressure maps may lead to inappropriate cushion provision.

There is a 'disconnect' between access to pressure mapping devices, and their routine use in prevention and management of pressure sores in Canada, that merits further enquiry (see photo of pressure mapping process above).

Novel Therapies for Pressure Ulcer Prevention and Management

1. PREVENTION

Smart-e-Pants
www.scialberta.ca/study/smart-e-pants:
For individuals with SCI who have lost the use of their legs, surface electrical stimulation of the buttocks can enable contractions in their gluteus muscles. These contractions provide mechanical and vascular stimulation which relieve pressure around bones, thereby reducing the risk of developing pressure ulcers.

Sensimat
www.toronto-fes.ca/sensimat:
The Sensimat is a cushion that aims to prevent pressure development by monitoring the individual's buttock-to-cushion interface pressures and posture. The intent is for the cushion to notify the individual regarding when and how best to do pressure relief.

2. MANAGEMENT

Two sites (London and Toronto) report access to local research expertise in the management of non-healing pressure ulcers, with UV light therapy and electrical stimulation.[7] Electrical stimulation therapy (EST) provides low-level current via surface electrodes to the pressure ulcer wound bed. Hypothesized mechanisms for improved wound healing by EST include protein synthesis, cell migration, and increased wound angiogenesis and tissue oxygenation (see photo of EST). In Toronto, the healing potential of low-intensity laser irradiation, for individuals with chronic pressure ulcers, has recently been evaluated.

Electrical stimulation therapy (EST) provides low-level current via surface electrodes to the pressure ulcer wound bed. Hypothesized mechanisms for improved wound healing by EST include protein synthesis, cell migration, and increased wound angiogenesis and tissue oxygenation.

Ultra Violet Light C (UVC) is a non-invasive treatment that promotes healing of chronic wounds by eradicating pathogens,[8] and producing vasodilation in dermal blood vessels while stimulating epidermal cell proliferation. A randomized, double blind, placebo-controlled trial of UVC for pressure ulcers, in individuals with spinal cord injury, has demonstrated that UVC significantly improves healing of Stage 2 pelvic ulcers.[9]

Despite preliminary Level I evidence of their efficacy, further dissemination and uptake of EST and UV light therapy is urgently needed for those with non-healing wounds, living in the community. This will be possible with the acquisition of knowledge, skills and capacity for science of implementation.

Canadian SCI Experts in Skin Integrity rank among the best in the world. Clinicians and scientists likely to influence practice in the next five years:

Cher Smith, OT; Peter Aikman, MD (Hospital Medicine); Roberta MacLean, RN; and Melanie Elerker, RN, Halifax: Contributors to the interdisciplinary SCI team at the Nova Scotia Rehabilitation Centre who provide expertise in the maintenance of skin integrity, in individuals with SCI.

Stéphane Côté, RN, Montréal: Years of first-hand experience and expertise in SCI skin integrity issues, and a resource for the SCI Rehabilitation program at IRGLM.

James Mahoney, MD (Plastic Surgery); Gary Sibbald, MD (Dermatology); Ethne Nussbaum (PT Research); Linda Norton, OT (W/C Vendor); Colleen McGillivray, MD (Physiatry); Cathy Craven, MD (Physiatry); Nicole Mittmann (Economics), Diane Leber, RN; Toronto: Published clinicians, researchers and skin integrity experts.

Dr. Pamela Houghton, PhD PT (Scientist), London: Published researcher working with supportive interdisciplinary research and clinical team of **Karen Campbell, RN (Scientist); David Keast, MD (General Practice); Chris Fraser (Dietitian/Consumer); Laura Titus, OT (Scientist); Sherry Green, RN,** who are well versed in SCI skin integrity knowledge generation for electrical stimulation healing, as well as prevention and management.

Dalton Wolfe, PhD (Neuroscience); Jane Hsieh, MSc (Scientist); Anna Kras Dupuis, RN MSc, London: Knowledge translation experts who are conduits of best practice adoption in SCI-related pressure ulcer prevention and management. **Dr. Wolfe** is principal investigator for a multi-centre feasibility study of in-home prevention and management of pressure ulcers in individuals with SCI, using the internet for care delivery.

Karen Ethans, MD (Physiatry) and Alan Casey, MD (Physiatry), Winnipeg: Actively participate in the pressure ulcer internet clinic multi-centre study and local pressure ulcer strategies, in collaboration with local patient advocacy groups.

Vivian Mushahwar, PhD (Biomedical Sciences), Edmonton: Internationally recognized for work in the development of Smart-e-Pants technology, shown to be effective in the prevention of skin breakdown, in individuals with SCI.

Mary Mark, RN, Edmonton: Nursing skin care expert.

Chester Ho, MD (Physiatry); Denise Hill, MD (Physiatry), Calgary: Published pressure ulcer clinician researchers who participate in the Internet Pressure Ulcer Clinic multi-centre study.

Cathy Flaman, PT; and Cheryl Oga, OT, Calgary: Skin integrity specialists.

Key Clinical Issues: What's Needed

Currently, there are seven clinical practice guidelines, and at least four key references that provide clinicians with evidence-based practices, in the prevention and management of pressure ulcers. Despite the diversity of healthcare providers and the plethora of resources, many issues relating to the need for rehabilitation leadership in best practice implementation (BPI) remain. Therefore, in order to optimize clinical care, these three priority areas must be addressed:

1. Establish process(es) for implementation of BPI related to the prevention and management of pressure sores.

2. Reach consensus on key modifiable risk factors (e.g., ischial pressures, blood flow, behavioural and psychosocial predictors), and take systematic actions to enable implementation of specific strategies to prevent pressure ulcer development, post-SCI.

3. Implement specific, effective pressure ulcer management (ultraviolet therapy and electrical stimulation therapy) educational strategies and methods, across all facilities in Canada that treat individuals with SCI.

Concurrently, to encourage self-management, research efforts need to expand into the realm of behaviour modification among individuals. This should begin in the inpatient setting prior to rehabilitation discharge and community living. This aim will be realized if the culture and capacity for BPI is developed across the continuum of care, particularly among community service providers (family physicians and visiting nurses), who deliver the majority of care over an individual's lifetime. To meet this goal, a *change environment* (e.g., awareness, readiness, funding) is required, to merge with health policy changes, and to address:

- The 95% lifetime prevalence of pressure ulcers among individuals with SCI
- Significant healthcare costs resulting from pressure ulcers ($2.1 billion/annum; Theta final report 2008[10]) and economic burden (loss of workforce contribution)
- Recurrence risks that increase with development of each pressure ulcer[5]
- Catastrophic impacts to quality of life and additional secondary health conditions as a result of pressure ulcers.

The primary barrier to implementation of a much-needed change environment is the current focus on acute care issues which pre-empts awareness of rehabilitative healthcare. Since pressure ulcers are usually first recognized during rehabilitation, pressure ulcer prevention and management is not prioritized in a field focused on acute care urgencies. There is a lack of awareness of the scope or importance of the problem in the media, community and among policy makers. For example, it is not well known that actor Christopher Reeve died of pressure ulcer complications.[11]

SPOTLIGHT BEST PRACTICE ORGANIZATION

REGIONAL SCI REHABILITATION PROGRAM – Parkwood Hospital, St. Joseph's Healthcare, London

The breadth of clinical and academic expertise in wound healing practice, at this site, is noteworthy. The SCI Rehabilitation Program has an interprofessional wound care team, a nursing-mediated wound coaching/training program, and a specialized wound-related feeding program. Key personnel affiliated with this site, including Drs Houghton, Campbell and Keast, are involved with the Canadian pressure ulcer guideline development project, and the program has developed an evidence-informed electrical stimulation therapy (EST) wound-healing protocol for chronic non-healing pressure sores. Parkwood is also leading a national pressure ulcer telehealth pilot project.

Innovations in wound care are the hallmark at Parkwood Hospital, due to interprofessional collaboration between researchers and expert clinicians. Researchers affiliated with partner organizations at the Lawson Health Research Institute and the University of Western Ontario have led the development of evidence resources such as *SCIRE* (www.scireproject.com), facilitating the subsequent development of the Canadian SCI Pressure Ulcer Clinical Practice Guideline (CPG). Leveraging these resources and partnerships, clinicians at Parkwood Hospital have established the role of EST in the management of chronic non-healing pressure sores. Efforts are underway to ensure EST is implemented throughout the community, and in the Ontario regional service catchment area.

In addition, Parkwood Hospital staff have taken a leadership role among six Canadian rehabilitation centres (Québec City, Montréal, Toronto, London, Edmonton and Calgary), within the SCI Knowledge Mobilization Network (KMN). The KMN is currently focused on implementing pressure ulcer prevention and management best practices, for individuals living with SCI. The KMN is funded collaboratively by RHI, ONF and the Alberta Paraplegic Foundation (APF), with local site implementation teams comprised of clinicians, administrators, patients, their support providers and other stakeholders.

Roadmap: Optimal Pressure Ulcer Prevention and Management

Healthcare policy relating to pressure ulcer prevention and management is urgently required. This process must begin with coordinated messaging directed at federal/provincial/regional governments, health authorities and funding agencies, from advocacy groups (APF, Canadian Paraplegic Association (CPA), Canadian Spinal Research Organization (CSRO), local health authorities, Ontario Neurotrauma Foundation (ONF), Rick Hansen Institute (RHI), Rick Hansen Foundation (RHF), Solutions Alliance and others). Awareness can be immediately leveraged through the planned and legacy activities of the RHF 25th Anniversary Campaign.

In addition, frontline clinicians and researchers can begin to improve pressure ulcer prevention and management practices through BPI, and by moving towards establishing centres of excellence, through Accreditation Canada (AC) BPI or performance measures (PM).

TABLE 1.0 ACCREDITATION CANADA COMPLIANCE TEST

ACCREDITATION CANADA 2011 (FEBRUARY) BPIs ALSO IDENTIFIED THE FOLLOWING TESTS FOR COMPLIANCE	HOW IS IT MEASURED?	WHO MEASURES IT? WHERE?	WHEN IS IT IDEALLY MEASURED?
1. The organization conducts an initial pressure ulcer risk assessment at admission, using a standardized risk-assessment tool.	Counts**	Program*	Quarterly
2. At regular intervals, the organization reassesses each client for risk of developing pressure ulcers.	Counts	Program*	Quarterly
3. The organization implements documented protocols and procedures to prevent the development of pressure ulcers. These include interventions to prevent skin breakdown and reduce pressure, as well as those that focus on repositioning, managing moisture, maximizing nutrition, and enhancing mobility and activity.	Counts	Program	Quarterly
4. The organization educates staff on risk factors and strategies for the prevention of pressure ulcers.	Counts	Program*	Quarterly
5. The organization monitors its success in preventing the development of pressure ulcers, and makes improvements to its prevention strategies and processes.	Pressure Ulcer Incidence/ Prevalence	Program*	Quarterly

** Counts – To name or list the units of a group or frequency of date/event, one by one, in order to determine the total.

* Program – Within the local participating SCI rehabilitation programs.

TABLE 2.0 RHI, ONF, APF AND KMN ACTIVITIES ON BPIs IN SCI PRESSURE ULCERS TO INFORM ACCREDITATION CANADA STANDARDS

RHI, ONF, APF AND KMN BPIs AND PMs (AS OF 2011/07/23) FOR PRESSURE-ULCER PREVENTION IN SCI	HOW IS IT MEASURED?	WHO MEASURES IT? WHERE?	WHEN IS IT IDEALLY MEASURED?
1. Overall, SCI pressure ulcer prevention and management program PMs are evaluated by: • The percentage of designated staff who have completed Continuing Medical Education (as appropriate for each implementation target) pertaining to pressure ulcer risk assessment, and structured and individualized education methods; and report completion of orientation and annual continuing medical education (CME) thereafter • The percentage of designated staff with demonstrated competence in performing pressure ulcer risk assessment, and conducting structured and individualized education.	Counts	Program	Annual
2. SCI pressure ulcer risk assessment best practice PMs are evaluated by: • The percentage of individuals with a documented review of their pressure ulcer risk assessment (conducted at regular intervals and when they've experienced a change in status) • The percentage of individuals who indicate that they have been informed of the results of their pressure ulcer risk assessment.	Counts	Program	Annual
3. SCI pressure ulcer education best practice PMs are evaluated by: • The percentage of individuals who report scores ≥ 7/10 (on a Likert scale where 0 = disagree; 10 = agree), to indicate that a structured and individualized education program provided adequate education regarding pressure ulcer prevention and management strategies.	Counts	Program	Annual

Anticipated Results of BPI and AC Distinction

IF A PRESSURE ULCER PREVENTION AND MANAGEMENT HEALTHCARE POLICY PLATFORM WERE ESTABLISHED TO FACILITATE BPI AND AC DISTINCTION ADHERENCE, THE FOLLOWING RESULTS ARE ANTICIPATED:

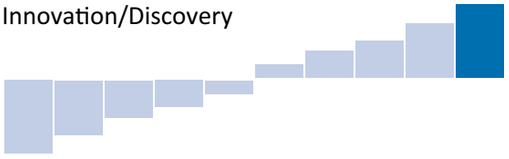
- Standardized and consistent best practices, across the continuum of care
- Improved quality of life for all individuals, including those living in the community
- Precursor to individual self-management
- Decreased healthcare costs
- Increased economic contribution by individuals with SCI, in the community.

REPORT CARD: Skin Integrity

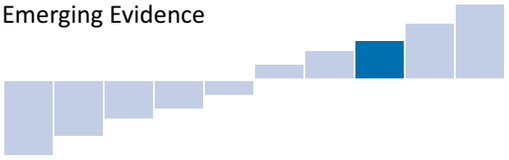
Extreme left below median: ***insufficient***
Extreme right above median: ***optimal***

KNOWLEDGE GENERATION

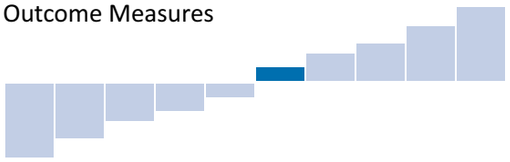
Innovation/Discovery



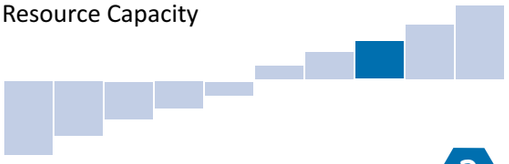
Emerging Evidence



Outcome Measures



Resource Capacity



2020 PRIORITY 3

CLINICAL APPLICATION

Integrative Care

Effective Practice
(Evidence and Outcomes)

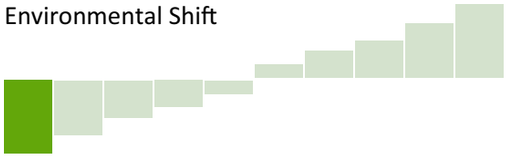
Equity Practice

Capacity

2020 PRIORITY 2

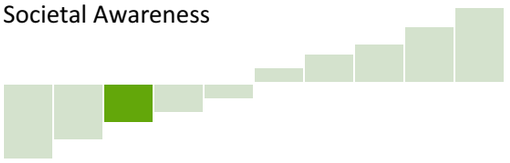
POLICY CHANGE

Environmental Shift

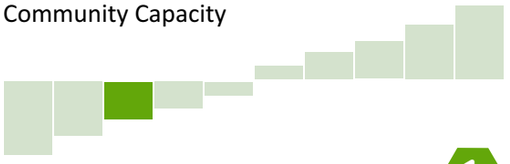


Change Agents

Societal Awareness



Community Capacity



2020 PRIORITY 1

TAKE HOME MESSAGE:

Strong, published evidence currently exists for electrical stimulation enhanced wound healing.[7] Given the impact to an individual's quality of life and health, and associated healthcare cost savings, the logical step would be to promote enhanced wound healing through electrical stimulation, as routine clinical practice. However, policy changes are required to ensure this compelling evidence is applied to practice. Policy changes, within institutional and funding sectors, are required to ensure funding for equipment acquisition and education/training of interprofessional skin integrity teams. In addition, a culture of best practice implementation is the essential foundation to allow for timely uptake of evidence, for interventions that improve health outcomes.

RESOURCES

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Optimizing Spasticity

J Hsieh, MSc; L Satkunam, MD; K Ethans, MD; S Kalsi-Ryan, PhD; C Craven, MD; and the E-Scan Investigative Team

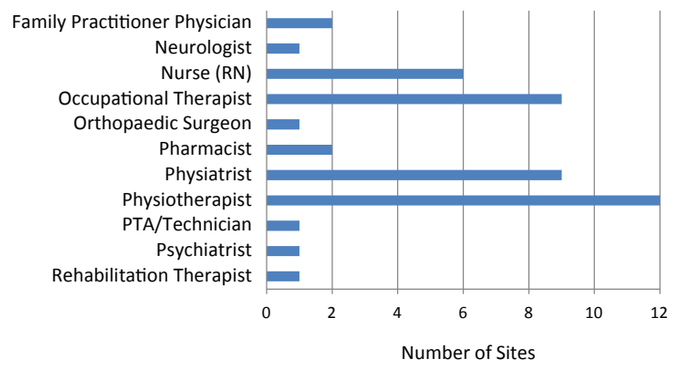
Spinal cord injury (SCI)-related spasticity is caused by damage to the spinal cord nerve pathways that control muscle movement. This type of damage is the reason for abnormal increases in muscle tone or stiffness that may lead to unwanted movement, discomfort, pain and interference with activities of daily living. Left uncontrolled, spasticity can be the cause of fixed joints (contractures) and injuries, as a result of sudden, awkward movements.

The impact of spasticity varies with the extent of the insult to the spinal cord. Spasticity commonly precipitates secondary health conditions, leading to emotional and environmental integration issues, if left unmanaged.[1] The increased muscle tone, related to spasticity, can have a negative and/or positive impact on an individual, often with both positive and negative effects occurring in the same individual. As an example, spasticity can sometimes be beneficial for mobility and transfers, but can also be a source of pain, hygiene difficulties, seating problems or sleep disturbance. As well, spasticity can have gender-specific effects such as enhancement/detraction of sexual activity in males and females, respectively.[2,3]

Forty-one percent of individuals with spasticity, secondary to SCI, report that it is one of the major medical obstacles to community and workplace re-integration.[4,5]

Assessments of spasticity-related treatment goals must be customized for each individual, their impairment and ability to overcome functional impairments[6] (given consideration of the potential protective attributes of spasticity, such as the prevention of skeletal muscle atrophy[7]), and type II diabetes risk reduction.[8] *Optimizing spasticity* is best achieved through incremental application of the least invasive and most cost-efficient treatments, [9] while objectively measuring clinical- and patient-reported outcomes in multiple domains of everyday life.[10]

FIGURE 1.0 DISTRIBUTION OF HEALTHCARE PROFESSIONALS PROVIDING SERVICES FOR THE OPTIMIZATION OF SPASTICITY, IN TERTIARY SCI REHABILITATION CENTRES, ACROSS CANADA.

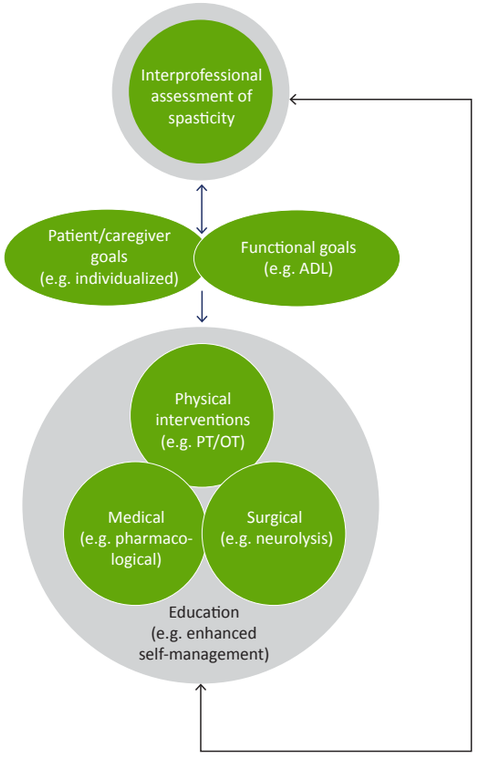


Current Practice: Optimizing Spasticity Post-SCI

Building on the concept of incremental application of the least invasive treatment options, physical (PT) and occupational therapy (OT) are initiated early during rehabilitation, and continue indefinitely, through post-discharge care - either formally through professional follow up or informally through self-management and/or personal caregivers. Physiatrists and family medicine practitioners offer pharmacotherapies, which are thought to be the most efficient treatment for velocity-dependent components of spasticity. Surgery and neurolysis are options for the treatment of focal spasticity. An individualized combination of treatment options is often the preferred method of management towards optimization, organized by an interprofessional team comprised of PTs, OTs, doctors (physiatrists, general practitioners and surgeons), nurses and pharmacists. Some institutions report access to additional professionals such as a neurologist, a psychiatrist, orthotist and OT and/or PT assistants. Figure 1.0 illustrates that, although all rehabilitation facilities report spasticity management services, interprofessional staffing models vary across organizations, with the most consistent management models including PT/OTs, physiatrists and nurses.

Current Canadian Practice Profile: Optimizing Spasticity after SCI

FIGURE 2.0 A SIMPLIFIED ILLUSTRATION OF THE INTERRELATIONSHIPS BETWEEN SERVICES THAT PROVIDES AN OVERVIEW OF THE SPECTRUM OF MULTI-MODAL SERVICES AVAILABLE TO OPTIMIZE SPASTICITY, POST-SCI.



KEY PRACTICE REFERENCES

No SCI specific clinical practice guidelines (CPGs) are available.

1. Walker HW, Kirshblum S. Spasticity due to disease of the spinal cord: pathophysiology, epidemiology, and treatment. In: Brashear A, Elovic E, eds. *Spasticity: Diagnosis and Management.* New York, NY: Demos Medical Publishing; 2010:313-40.

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CARE PATHWAYS OR LOCAL PROTOCOLS

All sites report that spasticity optimization is managed on site with 58% (7/12) using a treatment protocol, and 17% (2/12) having a standard of care. Interestingly, 33% (4/12) report using a CPG, although chapter authors did not find peer-reviewed published CPGs.

Assessments

1. Number of sites reporting use of wound assessment tools [any use/routine use] for:

a. Characterization and/evaluation of spasticity

- Modified Ashworth and Ashworth [100/42%] and [25/0%]
- Penn Spasm Frequency and Severity Scale (SFSS) [58/8%]
- Visual Analogue Scale (VAS) for spasticity [42/8%]
- Pendulum [33%] for research purposes only
- Other measures such as Goal Attainment Scaling (GAS), Tardieu Scale, Range of Motion (ROM) measurement and Numeric Rating Scale are noted by a single site, with only ROM measurement and the Numeric Rating Scale for spasticity used routinely at one site.
- Interestingly, the Spinal Cord Assessment Tool for Spasticity (SCATS) and SCI Spasticity Evaluation Tool (SCI-SET), available in the peer-reviewed published literature (albeit in the early stages of psychometric validation), have not yet been adopted, even for research purposes.

Due to the multidimensional nature of spasticity, no single outcome measure can encapsulate the extent of spasticity impact, for a holistic approach to treatment. Consensus has not yet been achieved for the determination of clinically meaningful, feasible and effective outcome measures. *Currently, a multidimensional test battery is likely the way forward, the intent of SCATS and SCI-SET.*

Practice leaders from sites with dedicated spasticity clinics, use numeric rating scale/visual analogue scales (NRS/VAS) to document the functional implication of spasticity, and to describe spasticity severity. The goal attainment scale is used to evaluate achievement of the stated rehabilitation goals, prior to intervention.

SPOTLIGHT BEST PRACTICE ORGANIZATION

SPINAL CORD INJURY PROGRAM – Health Sciences Centre Winnipeg Winnipeg Regional Health Authority, Winnipeg

Winnipeg has an interdisciplinary approach to long-term spasticity management, with two SCI physiatrists leading a multidisciplinary management program. Treatments are always goal directed and patient focused, with input from the patients, caregivers and team members, prior to defining realistic and obtainable goals. These range from education provided by the nurse or pharmacist, and physical modalities from the OT and PT; orthosis provision by the orthotist, to medical therapy offered by the physiatrist, or other team members. This centre has extensive clinical experience using a range of medical therapies - from oral medications to botulinum toxin and, more recently, phenol (in select cases) and intrathecal pumps. The intrathecal baclofen pump program has been running for over two decades, and is unique because pump therapy is offered to select geographically remote patients, through provision of different types of pumps. Newer techniques such as Saebo splints and Bioness FES have also been incorporated into the program service delivery models. The program is supported by active clinical research in this area, and evaluation of the efficacy of numerous drug therapies (in the past) including baclofen, cyproheptadine, tizanidine, fampridine, intrathecal baclofen and, most recently, cannabinoids.

Canadians Likely to Influence Practice in the Next Five Years

1. Chris Boulias, MD (Physiatry), Toronto: Explores the interrelationship between pain and spasticity.

2. Allan Casey, MD (Physiatry), Winnipeg: Extensive experience in the long-term management of individuals with an Intrathecal pump.

3. Cathy Craven, MD (Physiatry), Toronto: Evaluates the psychometric properties of a new method for quantifying spasticity using a shape–tape.

4. Karen Ethans, MD (Physiatry), Winnipeg: Extensive experience with a variety of pumps, and an expert mentor for colleagues across the country.

5. Monica Gorassini, PhD (Physiology), Edmonton: Explores the role of intrathecal 5-Hydroxytryptophan (5-HT).

6. Jane Hsieh, MSc, Toronto: Extensive experience leading implementation of multicentre trials to evaluate the efficacy of fampridine, among individuals with chronic SCI, that can be used to inform future multi-site initiatives.

7. Tom Miller, MD (Physiatry), London: Leads the development of a new spasticity outcome measure.

8. Lalith Satkunum, MD (Physiatry), Edmonton: Explores muscle anatomy and the implications for service delivery, and is developing an iPad application of a visual analogue scale to document spasticity frequency and severity.

9. Christine Short, MD (Physiatry), Halifax: Assists with the evaluation of the role of fampridine to augment gait performance, among individuals with incomplete SCI and significant spasticity.

Emerging Practices for the Optimization of Spasticity in SCI

1. Botulinum toxin for the augmentation of gait in individuals with motor incomplete SCI.

2. The role of cannabinoids as alternate or adjunct therapy, for spasticity.

3. Dalfampridine (4-aminopyridine), establishing research protocols to demonstrate treatment efficacy and effectiveness.

4. Elimination of the regional disparity in Baclofen pump provision.

5. The role of whole body vibration to reduce spasticity.

6. The role of Functional Electrical Stimulation (FES) and exoskeletons to reduce spasticity.

7. Constraint-induced movement therapy, including evidence describing the frequency and intensity of range of motion, stretching exercises and serial casting.

8. Identification of an optimal outcome measure or standard battery of measures, to inform treatment of spasticity, in a holistic fashion.

9. Determination of the adverse sequelae of early Baclofen administration, during subacute rehabilitation.

10. The role of 5-HT in modulation of spinal reflexes that reduce muscle tone.

Roadmap: Optimizing Spasticity, Post-SCI

Clinical Practice Guidelines (CPGs) for standardized best practices, in the optimization of spasticity treatment, are required. A decent foundation or body of literature already exists, as does the expertise to create an SCI-specific CPG. Missing is funding for such an activity and, therefore, a coordinated request, directed at government and non-governmental (NGO) funding agencies, would provide an immediate way forward. The ultimate goal would be to standardize best practices, with best practice indicators, to objectively measure improvements in patient outcomes.

SUGGESTED BEST PRACTICE INDICATORS ARE:

BEST PRACTICE INDICATORS	HOW IS IT MEASURED?	WHO MEASURES IT? WHERE?	WHEN IS IT IDEALLY MEASURED?
1. The organization conducts an initial spasticity assessment at admission, using a standardized assessment tool.	Counts**	Program*	Quarterly
2. The organization assesses each client for spasticity-related quality of life issues.	Counts**	Program*	Quarterly
3. The organization implements documented protocols and procedures to spasticity-related to quality of life.	Counts	Program	Quarterly
4. The organization educates patients and staff on risk factors for increased spasticity, and on strategies to minimize spasticity.	Counts	Program*	Quarterly
5. The organization monitors its successful spasticity-related, quality of life improvements.	Patient Reported Outcomes	Program*	Quarterly

** Counts – To name or list the units of a group or frequency of date/event, one by one, in order to determine the total.

* Program – Within the local participating SCI rehabilitation programs.

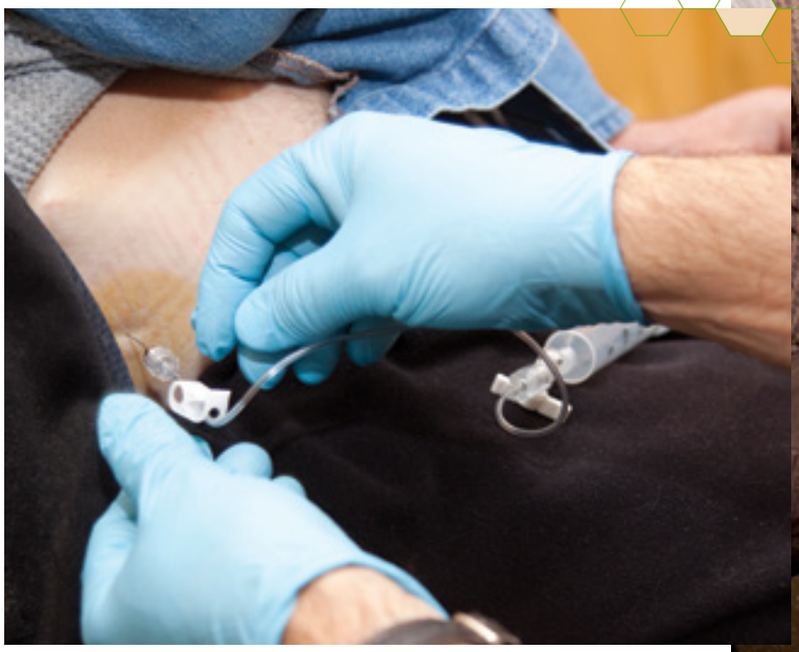
Anticipated Results of CPG-related Best Practice Implementation

IF A SCI SPASTICITY CPG WAS DEVELOPED AND IMPLEMENTED, THE FOLLOWING RESULTS ARE ANTICIPATED:

- Standardized and consistent best practices, across the continuum of care
- Improved quality of life of all individuals, including those living in the community
- Preparation for individual self-management, post-discharge
- Decreased healthcare costs
- Increased economic contribution by individuals with SCI, in the community.

Research Priorities

There is an urgent need to increase communication and knowledge transfer between scientists and clinicians, in the field of spasticity management.



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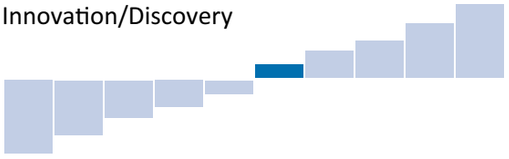
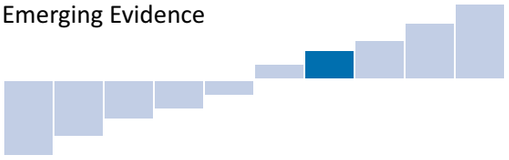
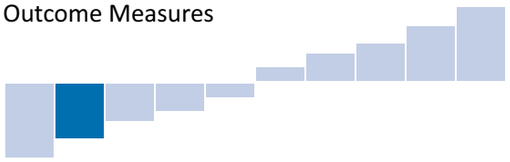
Innovation/Discovery



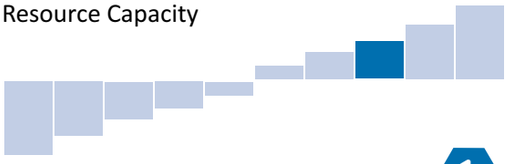
Emerging Evidence



Outcome Measures



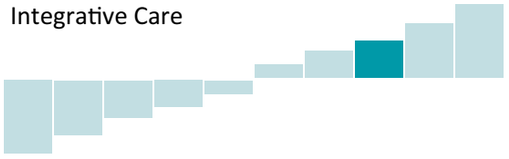
Resource Capacity



2020 PRIORITY 1

CLINICAL APPLICATION

Integrative Care



Effective Practice
(Evidence and Outcomes)

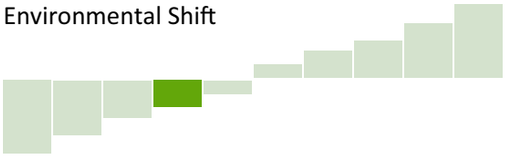
Equity Practice

Capacity

2020 PRIORITY 3

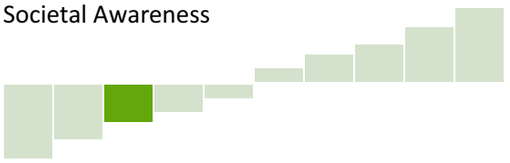
POLICY CHANGE

Environmental Shift

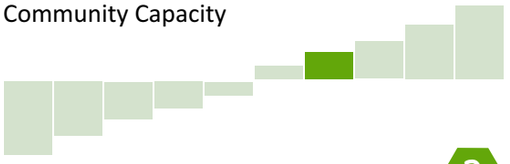


Change Agents

Societal Awareness



Community Capacity



2020 PRIORITY 2

TAKE HOME MESSAGE:

Development, psychometric validation and implementation of goal-directed outcome assessments of spasticity are a key priority.

Implementation of universal access to quality spasticity care, nationwide, including interdisciplinary, multimodal management and intrathecal pump provision, is needed.

RESOURCES

1. Krause JS. Self-reported problems after spinal cord injury: Implications for rehabilitation practice. *Top Spinal Cord Inj Rehabil*. 2007;12(3):35-44.

2. Anderson KD, Borisoff JF, Johnson RD, Stiens SA, Elliott SL. Long-term effects of spinal cord injury on sexual function in men: implications for neuroplasticity. *Spinal Cord*. 2007;45(5):338-48.

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Emotional Wellbeing

VK Noonan, PhD, PT; SL Hitzig, PhD; S Orenczuk, PsyD; P Bain, MSW, RSW; C Bradbury, C. Psych; C Craven, MD;
and the E-Scan Investigative Team

Emotional wellbeing is a state of mind in which the individual realizes his or her own abilities, is able to cope with the normal stresses of life, and can interact and contribute in the community. Enhanced emotional wellbeing can positively contribute to coping ability, self-esteem, productivity and longevity.[1]

For the purpose of the E-Scan, a broad perspective on emotional wellbeing has been maintained to highlight a continuum of emotional, social and physical functioning. On the extreme end of the continuum, depression and anxiety are clinical issues that commonly occur in reaction to significant life stressors. When individuals are dealing with a life-changing event, such as SCI, depression is not an inevitable outcome. However these individuals will often benefit from guidance and support, intended to improve their ability to cope and adjust to the changes in their lives.

A model by Elliot and Rivera[2] describes adjustment following SCI, and the determinants of psychological wellbeing and physical health. The model highlights how an individual's psychological and physical health is influenced by their environment, personal factors (e.g., age, gender) and personality. These components occur in a dynamic and interconnected continuum. There are opportunities to intervene - through improved resource allocation, health policy change or technology advancement - to ensure that individuals living with SCI can maintain high levels of emotional wellbeing, which in turn contributes to improvements in their quality of life.

FIGURE 1.0 DETERMINANTS OF PSYCHOLOGICAL WELLBEING AND PHYSICAL HEALTH.
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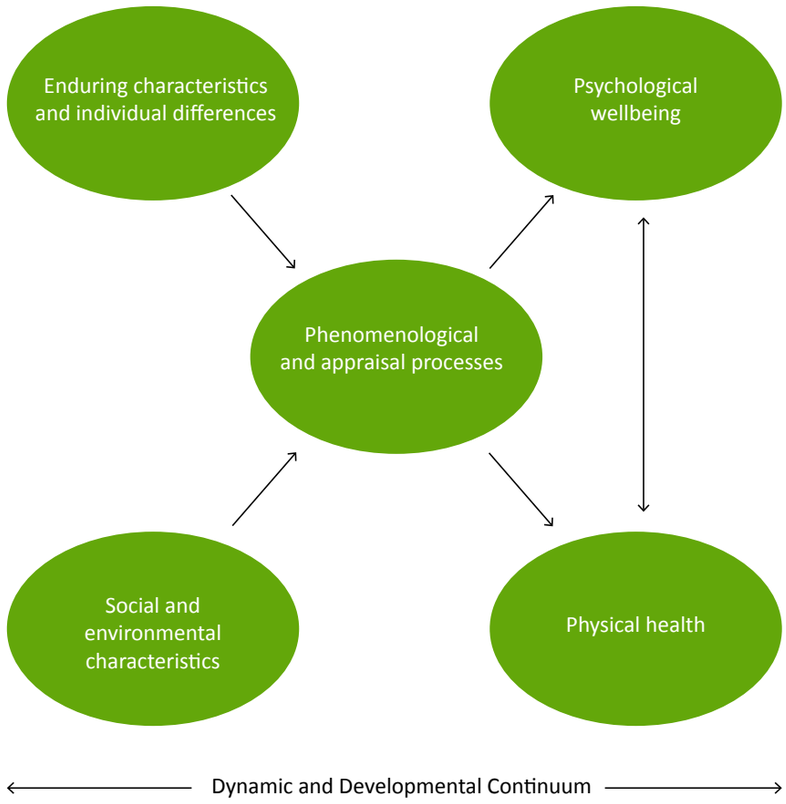


Current Practice: Addressing Emotional Wellbeing Following SCI

Current services for emotional wellbeing most often focus on the detection and treatment of depression. The incidence of depression among individuals with SCI ranges from 7% to 31%[3]; estimates vary due to differences in the definitions and methods used to assess depression.[4] Depression is four times more prevalent among individuals with chronic SCI living in the community, when compared to the general population.[5] In addition, emerging evidence suggests that those individuals are not being diagnosed or treated, indicating the need for more intensive depression screening.[6] Published research primarily reports on identifying symptoms of depression and anxiety.[7] However, a broader concept of 'emotional wellbeing' is required to address the unmet needs for individuals with SCI. There is a growing recognition that many suffer from post- traumatic stress disorder (PTSD), a type of anxiety disorder that can occur following a life-threatening event. PTSD has been reported in approximately 10% of individuals with longstanding SCI. Furthermore, PTSD is usually most prominent during the initial phase of post-SCI recovery, and primarily occurs with depressive disorders.[8] Use of substances such as alcohol, prescription medication or illicit drugs can also be a problem. Substance abuse prevalence rates are higher than 50%, in health conditions such as SCI, compared to the general population. Among individuals with SCI who drink alcohol, 40-50% are considered to be heavy drinkers.[9]

Using the International Classification of Functioning, Disability and Health (ICF)[10] as a conceptual framework, measuring emotional wellbeing should include not only assessing impairments in body functions, such as depression, but environmental factors (e.g., social support) and personal factors (e.g., lifestyle, social background, psychological characteristics), as well.

GEYH ET AL.[11] RECENTLY PROPOSED SEVEN RELEVANT DOMAINS TO CAPTURE PSYCHOLOGICAL SEQUELAE IN SCI, USING THE ICF THAT ARE RELEVANT TO THE CONCEPT OF EMOTIONAL WELLBEING. THESE INCLUDE:

1) Socio-demographic personal characteristics (e.g., age, sex)

2) Position in the immediate social and physical context (e.g., marital status)

3) Personal history and biography (e.g., post traumatic stress disorder)

4) Feelings (e.g., positive and negative affect)

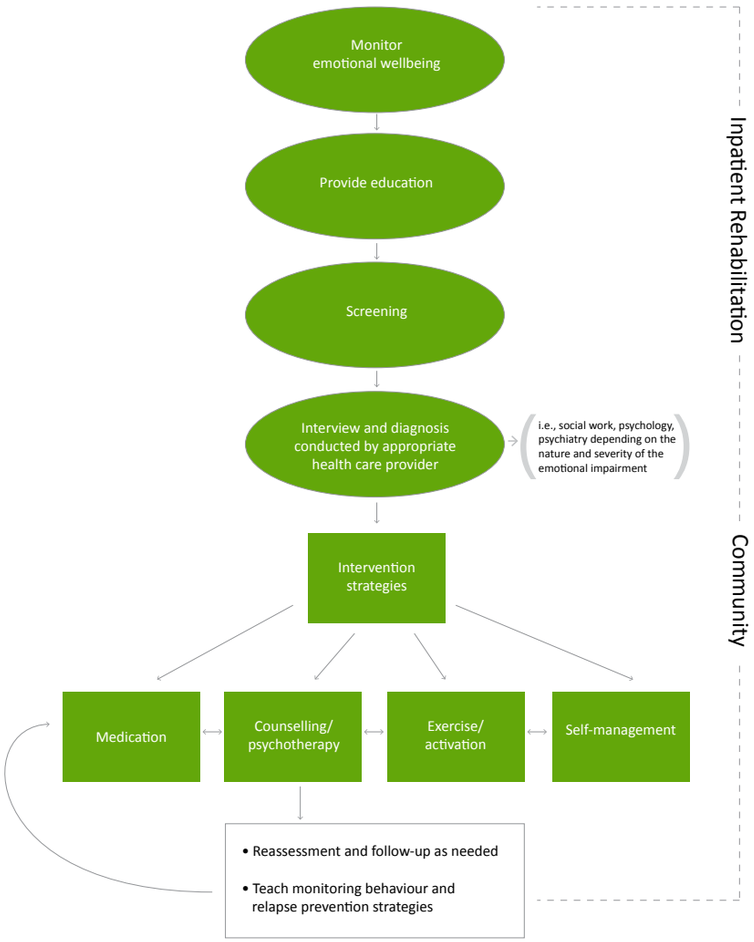
5) Thoughts and beliefs (e.g., perceived stress, locus of control, self-efficacy)

6) Motives (e.g., purpose in life)

7) Patterns of experience and behavior (e.g., coping, lifestyle factors – physical activity, substance use, personality factors).

Furthermore, there is a need to consider provision of emotional wellbeing services across the continuum of care, and to ensure access to services, following discharge from an inpatient rehabilitation setting. Individuals reporting clinically-significant levels of depression and anxiety at 12 weeks post SCI, are more likely to do so at 10 years post injury.[12] Given decreasing lengths of inpatient rehabilitation (e.g., six to eight weeks duration), it is essential that long-term follow-up programs are created to accurately identify problems with emotional wellbeing, assess resilience, and assist with the development of coping skills.

FIGURE 2.0: A DIAGRAM DEPICTING A POTENTIAL MODEL FOR FUTURE EMOTIONAL WELLBEING SERVICE PROVISION.



Current Canadian Emotional Wellbeing Practice Profile

HEALTHCARE PROFESSIONALS WORKING IN EMOTIONAL WELLBEING

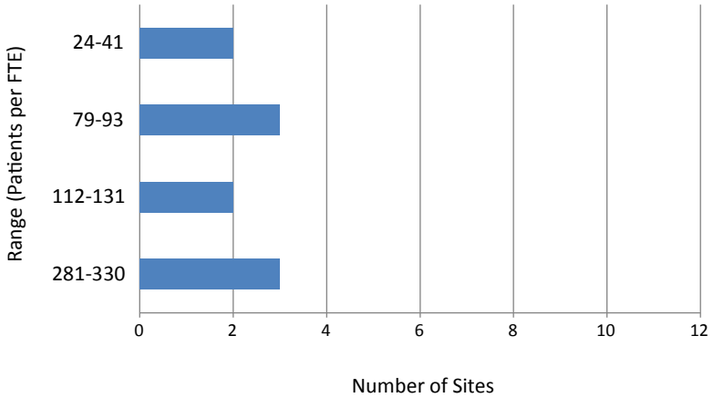
Teams that support the emotional wellbeing of individuals with SCI, and their families, include psychologists, psychometrists, psychiatrists, social workers, chaplains, physiatrists, family physicians, nurses, occupational and physical therapists, therapeutic recreation staff and peer counsellors. In Canada, most E-Scan sites report having psychology (12/12 sites), psychiatry (8/12 sites), social work (12/12 sites) spiritual services (11/12 sites); and peer-support coordinators (4/12 sites). However, there are differences in the adequacy and availability of these services for inpatient and outpatient rehabilitation (see Table 1.0).

TABLE 1.0 SERVICE PROVIDERS IN CANADA ADDRESSING EMOTIONAL WELLBEING

SERVICE PROVIDER	ONSITE: INPATIENT	ONSITE: OUTPATIENT	CONSULT
Psychologist	10/12 (83%)	5/12 (42%)	4/12 (33%)
Psychiatrist	0/12 (0%)	0/12 (0%)	8/12 (67%)
Psychometrist	4/12 (33%)	2/12 (17%)	3/12 (25%)
Social worker	12/12 (100%)	8/12 (67%)	1/12 (8%)
Chaplain/other	3/12 (25%)	0/12 (0%)	8/12 (67%)
Peer support coordinator	2/12 (17%)	1/12 (8%)	1/12 (8%)

Data from the E-Scan suggests an inadequate capacity to serve the emotional wellbeing needs, for individuals with SCI. For example, the number of inpatients with SCI served by full-time equivalent (FTE) psychologists, at participating sites, ranges from 24 per FTE to 330 per FTE (Figure 3.0).

FIGURE 3.0. NUMBER OF INPATIENTS WITH SCI PER FULL-TIME EQUIVALENT (FTE) PSYCHOLOGIST IN CANADA



USE OF GUIDELINES IN CANADIAN REHABILITATION SITES

Currently available emotional wellbeing guidelines to address the detection and management of depression in SCI:

1. Depression following spinal cord injury. A clinical practice guideline for primary care physicians. Washington, DC: Paralyzed Veterans of America (PVA); 1998.

2. Depression: What You Should Know. PVA. Available at http://www.scicpg.org/cpg_cons.htm.

3. University of Washington, Department of Rehabilitation. Available at http://sci.washington.edu/info/pamphlets/depression_sci.asp.

Even though guidelines are available for the treatment of depression, only one site reports use of a guideline, by the psychology/psychiatry service. The PVA guideline is not cited as a source by any of the E-Scan participating sites. One site report using the SCIRE Depression chapter, as a key reference.

USE OF ASSESSMENT TOOLS IN EMOTIONAL WELLBEING

Data from the E-Scan reveal that very few assessment tools are routinely used, in the area of emotional wellbeing, either clinically or for research purposes. The most common assessment tools are described in Table 2.0.

TABLE 2.0 TOOLS TO ASSESS EMOTIONAL WELLBEING IN CANADIAN REHABILITATION CENTRES

EMOTIONAL WELLBEING CONSTRUCT	ICF COMPONENT	ASSESSMENT TOOL	REPORTED USE OF TOOLS IN 12 CANADIAN SITES
Depression (Screening)	Body Functions	Beck Depression Inventory (BDI)	3/12 (25%)
		Centre for Epidemiological Studies Depression Scale (CESD)	1/12 (8%)
		Geriatric Depression Scale	2/12 (17%)
		Patient Health Questionnaire-9 (PHQ-9)	1/12 (8%)
Depression/Anxiety (Screening)	Body Functions	Depression and Anxiety Stress Scales (DASS)	1/12 (8%)
Anxiety (Screening)	Body Functions	State Trait Anxiety Inventory (STAI)	2/12 (17%)
Depression (Diagnosis)	Body Functions	Structured Clinical Interview for DSM Disorders (SCID)	1/12 (8%)
		Mini-International Neuropsychiatric Interview (M.I.N.I.)	1/12 (8%)
Post-Traumatic Stress Disorder	Personal Factors (Personal history and biography)	Post-Traumatic Stress Disorder (PTSD) Inventory	7/12 (58%)
Coping	Personal Factors (Patterns of experience and behavior)	Coping Inventory for Stressful Situations	1/12 (8%)
Substance Use - Alcohol	Personal Factors (Patterns of experience and behavior)	Michigan Alcohol Screening Test (MAST)	1/12 (8%)
		CAGE Questionnaire	1/12 (8%)

Canadian Experts Likely to Influence Practice in the Next Five Years

1. Patricia Bain, MSW RSW; and Sylvia Hycock, BHK BScOT Reg. (Ont); Toronto: Involved with the Community Reintegration Outpatient (CROP) service, which focuses on topics such as transition and adjustment, stress and pain management, at University Health Network – Toronto Rehab's Spinal Cord Rehabilitation Program.

2. Cheryl Bradbury, PhD (Clinical Psychology), Toronto: Expertise in the concurrent management of individuals, with traumatic brain injuries, and identifying the individual's need for emotional adjustment and wellbeing, following SCI.

3. Chris Davis, PhD (Psychology), Ottawa: Understanding the cognitive and emotional adaptations, following life-changing events such as SCI. Research on substance abuse issues, including patterns of use, and creating criteria to measure problematic substance use.

4. Sander Hitzig, PhD (Psychology), Toronto: Identifying factors and evaluating clinical programs that influence emotional wellbeing in people aging with SCI. This includes detailing the psychological benefits of therapeutic recreation programs (e.g., Toronto Rehab's Spinal Cord Rehabilitation Program Cottage Program), and therapeutic education services (e.g., Toronto Rehab's Community Reintegration Outpatient Service). Evidence collected from these evaluations will serve to address knowledge gaps, in these domains, while highlighting the importance of these programs, which could be implemented at different rehabilitation sites across the country.

5. Luc Noreau, PhD (Community Health), Québec City: Lead on the SCI Community Survey. This national survey identifies the needs of individuals with SCI in Canada, in areas such as SCI-specialized health-care, emotional counselling and peer support, at both a provincial and national levels; and can inform future clinical and policy initiatives.

6. Steven Orenczuk, PsyD, London: Expertise in adjustment to disability, as well as cognitive and vocational assessments.

7. Michael Sullivan, PhD (Psychology), Montréal: Holds a Canada Research Chair in Behavioural Health. Research involves understanding how thoughts or thought patterns can interfere with recovery, following an illness or disability. Findings provide insight into the psychological variables contributing to recovery and development of new treatments.

SPOTLIGHT BEST PRACTICE ORGANIZATION

BRAIN AND SPINAL CORD REHAB PROGRAM

– Toronto Rehabilitation Institute (TRI), University Health Network, Toronto

Toronto Rehab's Brain and Spinal Cord Rehabilitation Program offers a comprehensive service to address emotional wellbeing, at the individual and family level. The model of care offers a blend of profession-specific and interprofessional initiatives to maximize emotional coping, and to develop strategies during the recovery phase and/or living with a chronic condition. Leaders who developed the program are Patricia Bain, Social Worker and Dr. Cheryl Bradbury, Psychologist/Neuropsychologist. The care provided is interprofessional. Psychology, social work and chaplaincy services offer individual, couple, family/caregiver emotional counseling, and support. These professions address areas such as strengths, role transitions, interpersonal challenges, self-esteem, self-efficacy, losses/grief, stress, sexuality, etc. Therapeutic recreation also offers a number of opportunities such as the Cottage Program, a four-day cottage experience, where individuals with SCI can experience a number of leisure activities.

When appropriate, psychoeducation and support groups are offered to inpatients, and people living in the community with SCI at no cost. Notable group interventions offered in partnership with the Canadian Paraplegic Association Ontario (CPA Ontario) include:

CAREGIVER SUPPORT AND EDUCATION GROUP

Objectives of this program are to provide education regarding caregiving needs and issues, to provide practical and emotional support from a peer and professional perspective, to provide opportunities to share experiences and learn self-care strategies. Sessions are two hours in duration and run for six consecutive weeks.

HOLD ME TIGHT: CONVERSATIONS FOR CONNECTIONS

This is a relationship education group for all couples – happy, or distressed, where at least one person has a SCI or related condition. Couples attend an eight session program based on the theory and practice of Emotionally Focused Couples Therapy (EFT). EFT views the central problem in a distressed relationship as a loss of the secure emotional connection and the pattern of negative interactions that we (often unwittingly or unknowingly) get into with our partners. This interprofessional initiative is facilitated by social work and a CPA Ontario Regional Services Co-ordinator with a background in social work.

WELLBEING FOLLOWING SCI (COMMUNITY REINTEGRATION OUTPATIENT PROGRAM OR CROP)

This interprofessional initiative is facilitated by social work and occupational therapy. This therapeutic group was developed in recognition that adjusting and coping with the SCI experience is a lifelong process. Participants are given an education and resources manual containing readings and take home exercises for completion outside of the sessions. The sessions are 2.5 hours in duration, for 12 consecutive weeks, followed by a group outing.

STRESS MANAGEMENT

This group aims to help individuals understand the impact of stress following SCI. It encourages individuals to reflect on the effects of stress and their response, and introduces cognitive behavioural and other strategies to manage stress. Resources related to stress, and the adjustment and recovery process are also given. The sessions are two hours in duration, for five consecutive weeks and are co-facilitated by an inpatient and outpatient social worker.

YOGA PROGRAM

The program seeks to increase self-awareness through seated yoga interventions, to gain awareness of exercises that reduce pain and relieve stress in the body, and to demonstrate knowledge of the leisure benefits derived from seated yoga. This is an eight week, one hour per week, seated yoga intervention available to both inpatients and outpatients at no cost. The program benefits are formally evaluated by Dr. Sander Hitzig (Scientist) and Nicole Leong (Therapeutic Recreationist).

Roadmap: Where Do We Need to Go?

Based on an E-Scan scoping review, there is a need to enhance clinical care and to ensure that standardized assessments are performed for emotional wellbeing, during inpatient rehabilitation, and then annually, in the community (or earlier, based on the clinical team's discretion).

Kalpakjian et al.[13] conducted a systematic review of depression measures, and stated that more work assessing the psychometric properties (validity, reliability, responsiveness) in SCI, is needed before one measure can be recommended for use in clinical practice. In the review, the Patient Health Questionnaire-9 (PHQ-9) was identified as a good candidate, based on existing research, and its current use by the National SCI Statistical Centre Database (within the US Model SCI Systems). The authors suggest inclusion of a standardized assessment tool, especially when non-psychology personnel see individuals with SCI. However, Kalpakjian et al.[13] caution that, before screening programs are implemented, resources (i.e., psychologists, psychiatrists, or other mental health personnel) are required for further evaluation and treatment, for those individuals who are identified as at risk, based on the results of their screening assessment.

The recommendation to conduct regular routine screening (Table 3.0) aligns with *Actionable Nuggets* (www.actionnuggets.ca), a best practice implementation project in which continuing medical education credits are available to primary care physicians, through the Canadian Medical Association planned for Spring 2013. Specifically, Actionable Nugget #14 states "Conduct annual screening for depression in patients with SCI, using the PHQ 3/9".

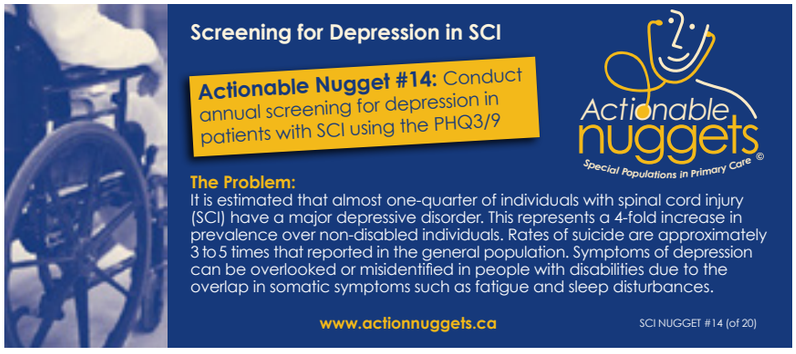


TABLE 3.0 BEST PRACTICE INDICATORS FOR EMOTIONAL WELLBEING

BEST PRACTICE INDICATORS FOR EMOTIONAL WELLBEING	YES	NO
1. Conduct a screening assessment for emotional wellbeing on all individuals with SCI, during inpatient admission; and further assess, depending on results (e.g., diagnosis depression, if positive screen).		
2.Re-assess emotional wellbeing, prior to discharge into the community.		
3. Provide ongoing follow up annually, following discharge (or earlier, based on the clinical team's discretion).		

Recommended, required and optional assessment tools are provided in Table 4.0 and, where possible, selected from the Spinal Cord Injury Rehabilitation Evidence Outcome Measures Toolkit (www.scireproject.com). Additional assessments were selected based on published articles[11,14] and expert opinion. In cases where there is no clear consensus, options have been provided. Ideally, all sites should align their practice and use the same assessment tools. It is important to acknowledge that many of these assessments are designed for healthy individuals, with emotional distress. Often, they may include somatic symptoms that are difficult to distinguish from the consequences of SCI (e.g., numbness and tingling). The overlap between somatic signs and symptoms of emotional distress, and spinal cord-related impairments, may falsely inflate the individual's overall score. More research is needed on the psychometric properties of these instruments, when applied to individuals with SCI.

TABLE 4.0 RECOMMENDED ASSESSMENT TOOLS FOR BEST PRACTICE INDICATORS

EMOTIONAL WELLBEING CONSTRUCT	ICF COMPONENT	ASSESSMENT TOOL	CLINICAL UTILITY
RECOMMENDED REQUIRED ASSESSMENTS			
Depression	Body Function	Depression Anxiety Stress Scales (DASS)-21 or Patient Health Questionnaire-9 (PHQ-9)	• Screening • Follow up
Anxiety Disorders	Body Function	DASS-21 or General Anxiety Disorder-7	• Screening • Follow up
Depression and Anxiety	Body Function	Structured Clinical Interview for DSM Disorders (SCID) or Mini-International Neuropsychiatric Interview (M.I.N.I.)	• Diagnosis • Follow up
Post-Traumatic Stress Disorder	Personal Factors (Personal history and biography)	Primary Care, Post-Traumatic Stress Disorder	• Screening • Follow up
Substance Use - Alcohol	Personal Factors (Patterns of experience and behavior)	CAGE Questionnaire	• Screening
Substance Use - Opioids	Personal Factors (Patterns of experience and behavior)	Opioid Risk Tool	• Screening
RECOMMENDED OPTIONAL ASSESSMENT			
Coping	Personal Factors (Patterns of experience and behavior)	Spinal Cord Lesion Coping Strategies Questionnaire or Ways of Coping	• Screening • Follow up
Self-Efficacy	Personal Factors (Thoughts and beliefs)	General Self-Efficacy Scale or Moorong Self-Efficacy Scale	• Screening • Follow up
Personality	Personal Factors (Patterns of experience and behavior)	Personality Assessment Inventory or Ten-Item Personality Inventory	• Screening
Social Support	Environmental Factor	Short Form Social Support Questionnaire	• Screening • Follow up

Table 5.0 contains citations for the assessment tools presented or discussed in this chapter. It is important to note that many of the tools presented are generic and may be administered, scored and interpreted by any member of the rehab team, while others require discipline–specific expertise to administer, score and interpret.

TABLE 5.0 RESOURCES FOR EMOTIONAL WELLBEING ASSESSMENTS TOOLS

(CONTAINS REFERENCES FOR TOOLS DESCRIBED IN TABLE 2.0, AND THE 'REQUIRED TOOLS' IN TABLE 4.0)

ASSESSMENT TOOL	CITATION
Beck Depression Inventory (BDI)	Beck AT, et al. *Arch Gen Psychiat.* 1961;4:561-71.
CAGE Questionnaire	Ewing JA. *JAMA.* 1984;252:1905-7.
Centre for Epidemiological Studies Depression Scale (CESD)	Radloff LS. *Appl Psych Meas.* 1977; 1(3):385-401.
Coping Inventory for Stressful Situations (CISS)	Engler NS, Parker JDA. *Coping Inventory for Stressful Situations (CISS): Manual (Revised Edition).* Toronto, ON: Multi-Health Systems; 1999.
Depression and Anxiety Stress Scales (DASS)	Brown TA, et al. *Behav Res Ther.* 1997;35:79-89.
General Anxiety Disorder-7	Spitzer RL, et al. *Arch Intern Med.* 2006;166(10):1092-7.
Geriatric Depression Scale	Yesavage JA, et al. *J Psychiatr Res.* 1982; 17(1):37-49. Sheikh JI, et al. *Clin Gerontol.* 1986; 5(1/2):165-73.
Michigan Alcohol Screening Test -(MAST)	Selzer ML, *Am J Psych.* 1975;3:176-81.
Mini-International Neuropsychiatric Interview (M.I.N.I.)	Sheehan DV, et al. *J Clin Psychiat.* 1998;59(Suppl. 20):22-33; quiz 34-57.
Opioid Risk Tool	Webster LR, Webster RM. *Pain Med.* 2005;6(6):432-42.
Patient Health Questionnaire-9 (PHQ-9)	Kroenke K, et al. *J Gen Intern Med.* 2001;16(9):606-13. Kroenke K, et al. *Psych Annals.* 2002; 32:509-21.
Post-Traumatic Stress Disorder Inventory (PTSD)	Solomon Z, et al. *Isr J Psychiatry Relat Sci.* 1993;30(2):110-5.
Primary Care Post Traumatic Stress Disorder Screen (PC-PTSD)	Prins A, et al. *Prim Care Psychiatr.* 2003;9:9-14.
State Trait Anxiety Inventory (STAI)	Spielberger CD, et al. *Manual for the State-Trait Anxiety Inventory.* Palo Alto, CA: Consulting Psychologists Press, Inc.; 1983.
Structure Clinical Interview for DSM Disorders (SCID)	First MB, et al. *Structured Clinical Interview for the DSM-IV Axis I Disorders, Clinician Version (SCID-CV).* Washington, DC: American Psychiatric Press, Inc.; 1996.

Future Clinical Directions

- Conduct research to determine which interventions and resources are most effective for treating psychological distress/depression, in individuals with SCI
- Develop clinical practice guidelines for areas of emotional wellbeing, including screening and treatment of post-traumatic stress disorder and/or substance abuse.

Future Research

- Determine which affective and cognitive factors (e.g., self-efficacy, coping styles, mood, etc.) best predict emotional wellbeing, following SCI
- Examine the impact of poor versus optimal emotional wellbeing, following SCI, on various outcomes in both rehabilitation (e.g., motivation to participate in therapy, functional independence, etc.) and community settings (e.g., pain, quality of life, development of secondary complications)
- Examine the impact of mediating factors, such as pre-existing emotional sequelae, family history, social-supports and access to resources (geographic location); motor vehicle insurance funding for private resources and ability to advocate for services
- Develop and validate assessments among individuals with SCI, to improve accuracy of diagnosis and the ability to monitor outcomes.

Future Policy Initiatives

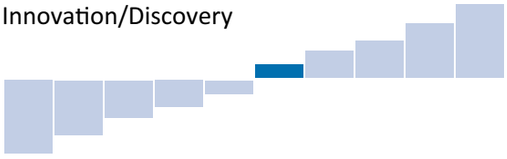
- Ensure access to care, for individuals with SCI, who have depression or require intervention to optimize their emotional wellbeing.

REPORT CARD: Emotional Wellbeing

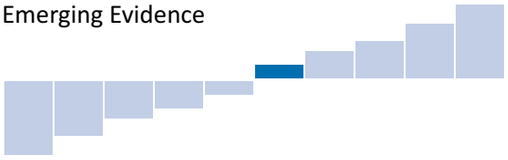
Extreme left below median: ***insufficient***
Extreme right above median: ***optimal***

KNOWLEDGE GENERATION

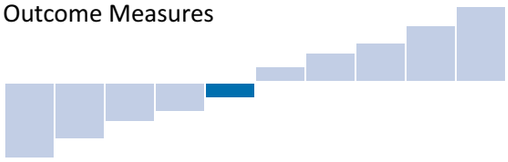
Innovation/Discovery



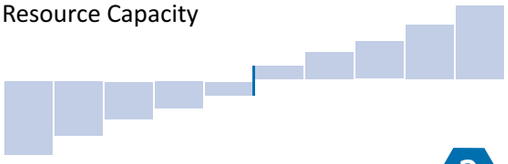
Emerging Evidence



Outcome Measures



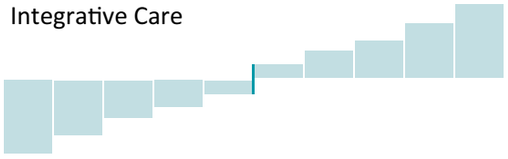
Resource Capacity



2020 PRIORITY 3

CLINICAL APPLICATION

Integrative Care



Effective Practice
(Evidence and Outcomes)

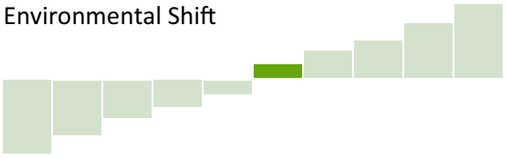
Equity Practice

Capacity

2020 PRIORITY 1

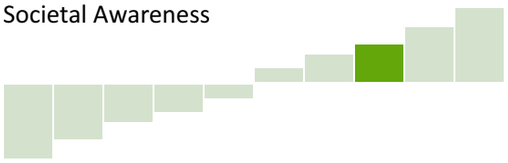
POLICY CHANGE

Environmental Shift

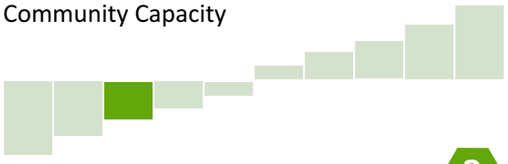


Change Agents

Societal Awareness



Community Capacity



2020 PRIORITY 2

TAKE HOME MESSAGE:

People with SCI face a number of challenges to maintain emotional wellbeing, which could potentially spiral into a clinical issue, like depression. A standardized assessment for emotional wellbeing, conducted during inpatient rehabilitation, re-evaluated prior to discharge and then annually in the community, should be part of Accreditation Canada Standards. For this standard to be effectively implemented, additional healthcare resources, for this area, are critical.

RESOURCES

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2. Elliott TR, Rivera P. Spinal cord injury. In: Nezu A, Maguth C, Geller P, eds. *Handbook of psychology: Health psychology.* Volume 9. Hoboken, NJ: John Wiley & Sons, Inc; 2003:415-35.

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11. Geyh S, Muller R, Peter C, et al. Capturing the psychologic-personal perspective in spinal cord injury. *Am J Phys Med Rehabil.* 2011;90(Suppl):S79-S96.

12. Pollard C, Kennedy P. A longitudinal analysis of emotional impact, coping strategies and post-traumatic psychological growth following spinal cord injury: a 10-year review. *Brit J Health Psychol.* 2007;12:347-62.

13. Kalpakjian CZ, Bombardier CH, Schomer K, Brown PA, Johnson KL. Measuring depression in persons with spinal cord injury: a systematic review. *J Spinal Cord Med*. 2009;32(1):6-24.

14. Geyh S, Nick E, Stirnimann D, et al. Self-efficacy and self-esteem as predictors of participation in spinal cord injury – an ICF-based study. *Spinal Cord*. 2012;50(9):699-706.

Ameliorate Neuropathic Pain

C Short, MD; C O'Connell, MD; C Craven, MD; and the E-Scan Investigative Team

Neuropathic pain (NeP) - reported in about 40% of individuals with spinal cord injury (SCI) - is a common and severe type of pain resulting from damage to the spinal cord and or peripheral nerves.[1] This damage causes abnormal, painful sensations in the body, even when there is no identifiable or visible cause of the pain.

NeP can occur anywhere in the body below the level of injury, and develop in any individual with SCI, regardless of the level (cervical, thoracic or lumbar) or extent of cord damage (completeness of injury).[2-6] Individuals with NeP often report painful sensations of heat, cold, and electric-like shocks, and even normal sensations - like a breeze or light touch - can cause severe pain (Figure 1.0). This type of pain can be so horrible that individuals indicate they are willing to trade a cure for their paralysis, for pain relief. In addition to NeP, individuals with SCI also suffer from soft tissue and joint pain. As a result, two-thirds will develop chronic pain.

Pain has many negative effects: social isolation, unemployment, decreased function, decreased quality of life, depression and even suicide.[7-10] Musculoskeletal pain seems more manageable with our current treatments, while NeP is much more difficult to control. Individuals with SCI, and NeP rarely experience spontaneous remission.[6] In fact, over time, pain increases in 47% of these individuals, and decreases in only 7%.[6]

Seventy-seven percent of individuals with SCI indicate that pain always interferes with one or more of their daily activities. Pain affects sleep in 40%, exercise in 35%, and work in 34% of those who are employed.[7] Eleven percent of people report that pain, rather than loss of function, is the main factor preventing them from engaging in work.

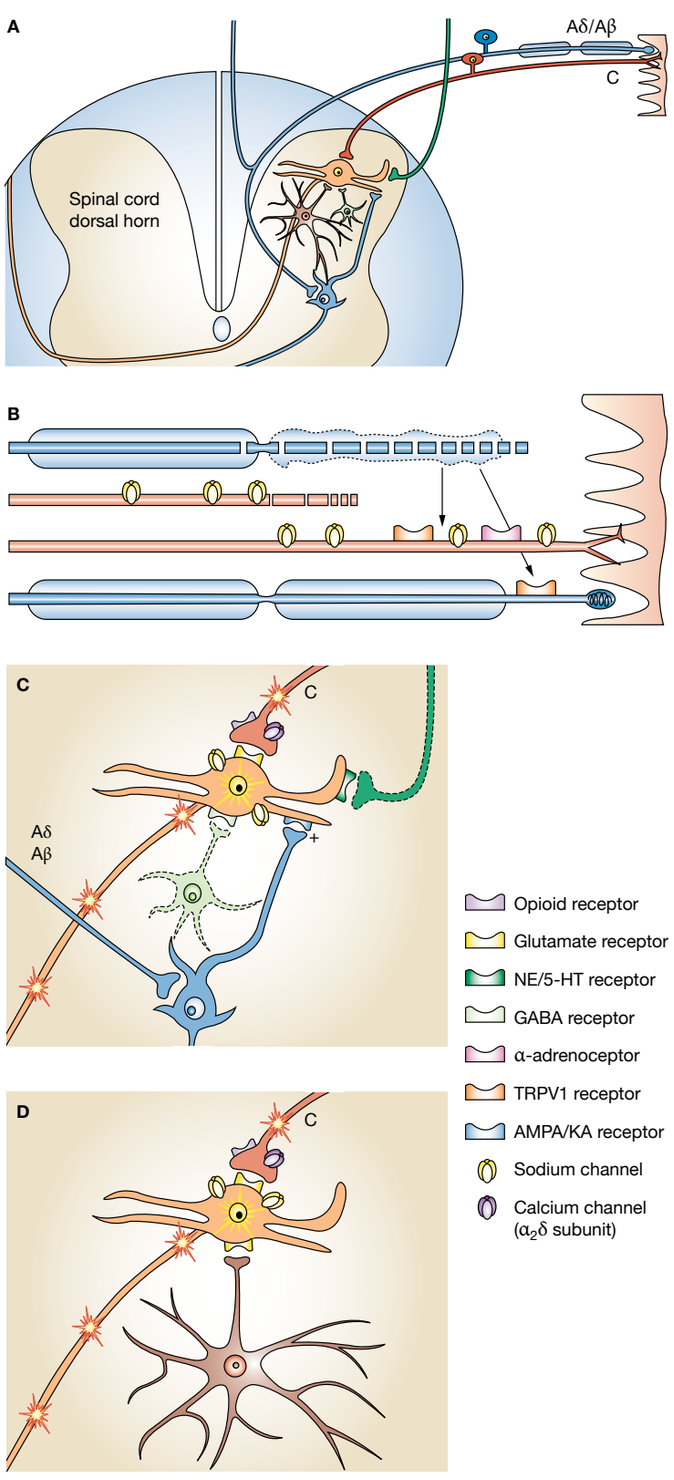

FIGURE 1.0 EVENTS THAT LEAD TO DEVELOPMENT OF NEP, FOLLOWING SCI. WHEN A PERIPHERAL NERVE OR A CENTRAL NERVE PATHWAY FOR PAIN IS DAMAGED, IT CAN TRIGGER UPREGULATION OF PAIN RECEPTORS, PERIPHERALLY AND CENTRALLY, LEADING TO PERSISTENT ABNORMAL PAIN SENSATIONS. IT CAN ALSO TRIGGER CHANGES IN THE BRAIN AND SPINAL CORD THAT LEAD TO NON-PAINFUL STIMULI BECOMING PAINFUL.

There have only been a small number of experimental studies addressing the efficacy of pain treatments, in the SCI population, despite the high prevalence of pain and its major impact on their lives. As a result, little progress has been made in developing truly effective treatments. Table 1.0 lists current evidence-based treatments.

TABLE 1.0 EVIDENCE BASE FOR TREATMENT OF NEUROPATHIC PAIN AFTER SPINAL CORD INJURY (ADAPTED FROM SCIRE VERSION 4).[9]

TREATMENT	LEVEL OF EVIDENCE	TREATMENT EFFICACY
PHARMACOLOGIC INTERVENTIONS - ORAL AND TOPICAL		
Pregabalin	Level 1	+
Gabapentin	Level 1	+
Lamotrigine* for incomplete SCI only	Level 2	+
Amitryptyline* post-SCI patients, with depression and pain only	Level 1	+
Tramadol	Level 1	+
Topical capsaicin for radicular pain post SCI	Level 4	+
Levetiracetam	Level 1	-
Valproic acid	Level 1	-
Trazodone	Level 1	-
Mexilitene	Level 1	-
PHARMACOLOGIC THERAPY – INTRAVENOUS ADMINISTRATION		
Intravenous alfentanil* for short-term relief	Level 1	+
Intravenous morphine for mechanical allodynia* for short-term relief	Level 1	+
Intravenous ketamine* for short-term relief of allodynia	Level 1	+
Intrathecal lidocaine * for short-term pain relief	Level 1	+
PHARMACOLOGIC THERAPY - INTRATHECAL		
Intrathecal morphine plus clonidine	Level 2	+
Intrathecal baclofen for dysesthetic pain	Level 1	+
Intrathecal clonidine	Level 1	-
NON-PHARMACOLOGIC THERAPY		
Heat and massage	Level 4	+
Accupuncture and electroacupuncture	Level 4	+
Regular exercise	Level 1	+
Hypnosis	Level 4	+
Cognitive behavioural pain management with pharmacological treatment	Level 2	+
Visual imagery	Level 4	+
Transcranial electrical stimulation	Level 1	+
Cognitive behavioural pain management alone	Level 2	-
SURGICAL THERAPY		
Spinal cord stimulation	Level 4	+
Dorsal root entry zone ablation	Level 4	+

From the available evidence on maximizing the success of pain management after SCI, it is important to apply a team-based approach that combines both pharmacologic and non-pharmacologic therapies. In addition, some researchers are exploring ways to prevent neuropathic pain before it develops.

Current Clinical Practice

Twelve E-Scan sites provided data regarding pain management practices. All sites report access to pain management services, for inpatients; and 10 sites report access for outpatients. Most of these programs are onsite or within the organization, with three of 12 external to the organization. Services within the organization are important to ensure accessibility and timely access. Nine of twelve sites report adequate wait times. Despite universal access to pain management services, only seven of 12 sites report those services to be adequate. Since early intervention is critical to successful pain management, this pattern is a concern.

Few sites report routine use of any type of standardized assessments, for either diagnosis or treatment of pain. The most common tool - used in seven of 12 sites, but only routinely at five - is the visual analog scale (VAS) for pain. Simple and easy to use, this is a well-validated tool for getting baseline assessments for pain, and for determining response to treatment. The Brief Pain Inventory (BPI) and the Multidimensional Pain Inventory (MPI) - also well validated for pain assessment and follow up, with the added benefit of a function component - are only used by three of 12, and four of 12 sites, respectively. In the diagnosis of neuropathic pain, less than half the sites use any validated tools. Five of twelve sites report using the DN4 questionnaire, and one-twelfth report using the S-LANSS. To improve post-SCI management of NeP in Canada, it is imperative that sites possess the knowledge and tools to ensure a uniform approach to diagnosis, assessment and follow up.

Related to treatment guidelines for managing NeP, only three of 12 sites follow a standard of care, and only three of 12 sites follow any kind of clinical practice guidelines. Spinal Cord Injury Rehabilitation Evidence (SCIRE) - a Canadian, evidence-based document for SCI rehabilitation care - contains an excellent guide for management of pain after SCI (www.scireproject.com).[9] A summary of these pharmacologic management recommendations was published in 2010.[11] Another excellent, non-Canadian publication has been written by Siddall.[12] Only one of 12 sites report routine use Siddall's guidelines, and only two of 12 sites report using the SCIRE systematic review to guide practice. Next steps, for enhancing treatment of NeP, require uptake and implementation of current evidence and clinical practice guidelines.

Outcomes/Assessments

Below is a succinct list of some of the more frequently used and appropriately validated tools (*validated in SCI population) for assessment of NeP). It does not include all the possible pain assessment and outcome tools available for the diagnosis of neuropathic pain.[13]

- DN4 neuropathic pain diagnosis questionnaire, based on history and physical exam
- Leeds Assessment for neuropathic symptoms and signs (LANSS)*, based on history and physical exam
- Self-report Leeds Assessment for neuropathic symptoms and signs (S-LANSS)*, as above, but based on individual self-assessment.

Assessment and Follow Up Evaluation of Pain Severity

- **Visual Analog Scale (VAS)** - Consists of one horizontal or vertical line, usually 10 centimeters in length, anchored with verbal descriptors of "no pain" and "pain as bad as it could be." The individual with pain marks the line, on the scale, at the point of pain severity. The VAS may also be used as a verbal analog scale, in which the respondent anchors 0 as "no pain", and 10 or 100 as "worst pain possible" (or other descriptor).
- **VAS: Faces Pain Scale** - As above but presenting facial expressions (ranging from happy to increasing degrees of unhappiness) for the individual to circle, to best reflect pain level.
- **Numeric Rating Scale (NRS)** - A variation of the VAS scale where each 10 millimeters on the scale is given a number, for the individual to rate from 0 (no pain) to 10 (the worst pain experienced).
- **McGill Pain Questionnaire (MPQ)** - Measures different qualities of the subjective pain experience, with three classes of words (a total of 78) that describe the sensory, affective and evaluative aspects of pain; and a five-point pain intensity scale (present pain intensity [PPI]). A shorter, less time-consuming form of the MPQ also measures different qualities of the subjective pain experience, using 15 words from the original questionnaire: 11 sensory words and four affective words.

Assessment and Follow up Evaluation of Pain Severity and Its Impact on Function

- **Brief Pain Inventory (BPI)** - A brief, relatively simple, self-administered questionnaire, to address the relevant aspects of pain: history, intensity, timing, location and quality; as well as the pain's ability to interfere with the individual's function.
- **West Haven-Yale Multidisciplinary Pain Inventory (MPI)** - This tool has multiple scales, like the BPI, to measure severity and interference of pain, individual responses to pain, and its impact on daily activities.

Current Guidelines Used in Practice

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- Multidisciplinary Association of Spinal Cord Injury Professionals. *Guidelines for the Management of Neuropathic Pain in Adults Following Spinal Cord Injury*. 2nd ed. Middlesex, UK: Spinal Cord Injury Centre, Royal National Orthopaedic Hospital; 2008. http://www.mascip.co.uk/guidelines.aspx. Accessed August 16, 2012.
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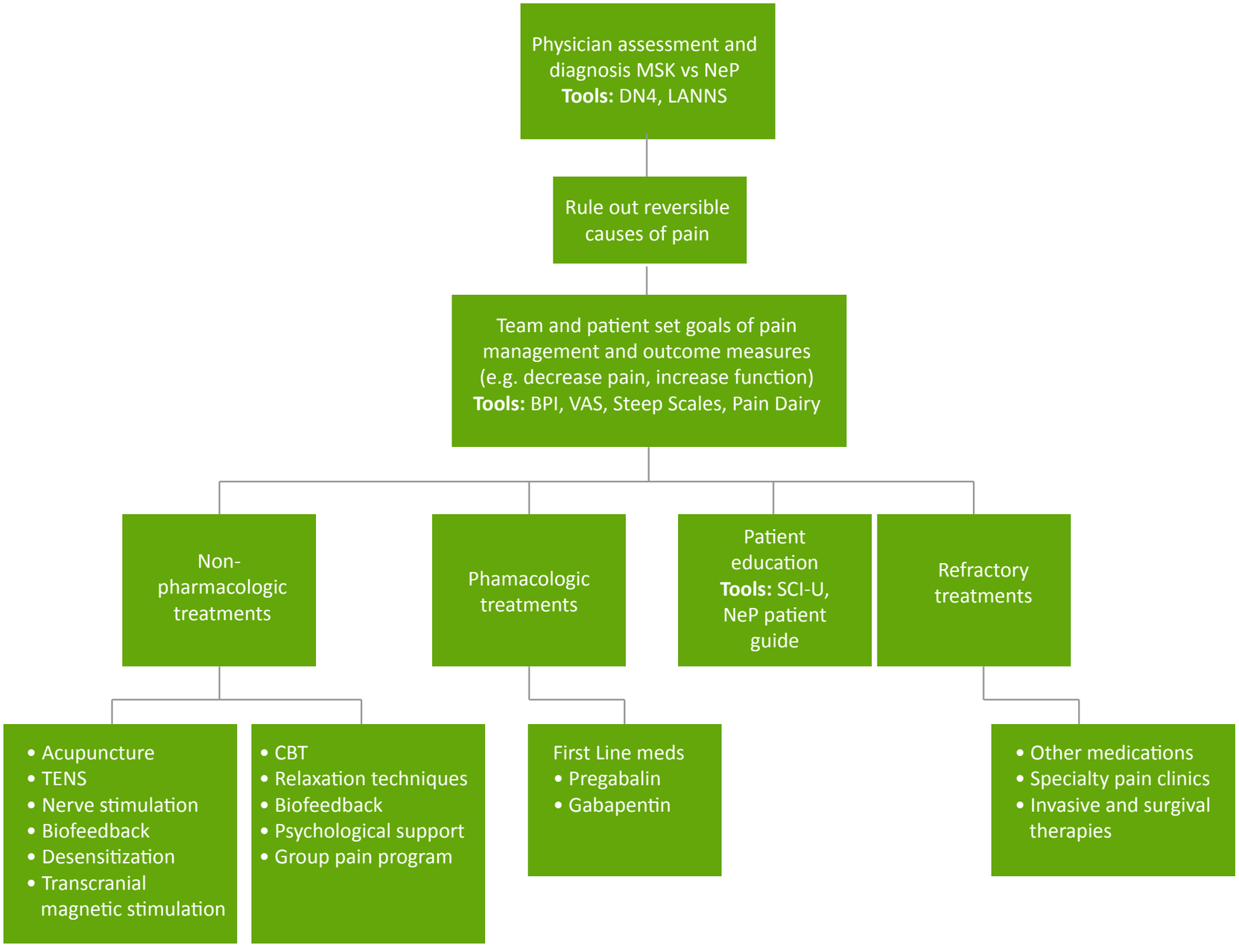
- National Pain Centre. Canadian Guideline for Safe and Effective Use of Opioids for Chronic Non-Cancer Pain — Part B: Recommendations for Practice, Version 5.5 Canada: National Opioid Use Guideline Group (NOUGG);2010. http://nationalpaincentre.mcmaster.ca/opioid/. Accessed August 16, 2012.

Ideal Practice and Flow Diagram

A systematic approach is important to diagnose and treat NeP. Figure 2.0 below illustrates a typical algorithm for this approach. First, a physician or other clinician, experienced in pain assessment and diagnosis, must assess the person. Once it is established that pain is present, it is important to differentiate whether the origin is nociceptive/musculoskeletal or neuropathic, or both. This will help to guide investigation and treatment choices. Assessment includes ruling reversible causes for pain in or out (e.g., missed fractures, post-traumatic syringomyelia, peripheral nerve damage). Once NeP is identified, the treating team needs to negotiate goals with the individual, and select the measures used to appropriately assess response to treatment. There are a number of well-validated tools for baseline and follow-up assessment of pain and function. Treatment will generally be multimodal, and involve a combination of pharmacologic and non-pharmacologic options. Individual education is critical to treatment success, and surgical options are generally reserved for refractory cases.

FIGURE 2.0 TYPICAL ALGORITHM FOR A SYSTEMATIC APPROACH TO DIAGNOSE AND TREAT NEP.



SPINAL CORD REHABILITATION PROGRAM

**Nova Scotia Rehabilitation Centre,
Queen Elizabeth II Health Sciences Centre, Capital Health,
Halifax**

The SCI Neurorehabilitation Program in Halifax attributes its current success in managing pain after SCI - an integral part of inpatient and outpatient rehabilitation - on a good interdisciplinary team for SCI management. Individuals with special interest in pain management collaborate with the district pain management unit, and local neurosurgeons with experience in the surgical management of NeP. This collaborative group meets regularly to review and support the most complex and challenging cases, to enable group momentum and to prevent provider burnout.

Pain management is a continuum: from acute SCI, through inpatient rehabilitation, and into the community setting. While the program, like many, uses a pharmacologic-based approach, it continually strives to accrue funding, manpower and support to maximize non-pharmacologic management of neuropathic pain. One key example is an interdisciplinary chronic pain self-management program, run by a team of experts (in psychology, physiotherapy, occupational therapy, social work and vocational counselling), and available to groups of individuals with chronic pain conditions, over a six-week period. The SCI Neurorehabilitation team does inpatient pain management, and SCI physicians (physiatry, anaesthesia and neurosurgery), post discharge, with outpatient team members (nursing, OT and PT).

One reason for the program's success is the team's philosophy to never say, "We have nothing else to offer you".

The team believes, "Hope goes a long way to sustain those suffering from chronic pain, and to know there is always something else to try, carries them a long way".

Recognized Content Experts Likely to Influence Practice in the Next Five Years

1. Ian Beauprie, MD (Anaesthesia), Halifax: Interventional pain management.

2. Robert Brownstone, PhD MD (Neurosurgery), Halifax: Neurosurgical interventions for pain management.

3. John Clark, MD (Anesthesiology), Halifax: Chronic pain management and pain policy in Canada.

4. Cathy Craven, MD (Physiatry), Toronto: Exploring the role of vitamin D in pain management.

5. Karen Ethans, MD (Physiatry), Winnipeg: Clinical management of NeP.

6. Andrea Furlan, PhD MD (Physiatry), Toronto: Implementation of the Canadian Narcotic Guidelines.

7. Sander Hitzig, PhD (Psychology), Toronto: Psychosocial factors influencing the development and maintenance of SCI-related chronic pain.

8. Mojgan Hodaie, MD (Neurosurgery), Toronto: Sacral stimulation, dorsal rhizotomy, deep brain stimulation.

9. Judi Hunter, PhD (Physiotherapy), Toronto: Development of a thermal grill to enable bedside assessment of neuropathic pain.

10. Howard Intrater, MD (Anaesthesia), Winnipeg: Interventional pain management.

11. Lin Jacques, MD (Neurosurgery), Montréal: Surgical management of NeP.

12. Joel Katz, PhD (Clinical Psychology), Toronto: Promotion of a biopsychosocial approach (e.g., pain phenotypes, mood, environmental factors) for understanding mechanisms that contribute to the development and maintenance of pain, post-SCI, and the transition to chronicity.

13. Kris Kumar, MD (Neurosurgery), Regina: Surgical management of NeP.

14. Eldon Loh, MD (Physiatry), London: Musculoskeletal and soft tissue pain in SCI.

15. Mary Lynch, MD (Psychiatry), Halifax: Pharmacological management of NeP.

16. Jason McDougall, PhD, Calgary: Basic research into NeP.

17. Dan Marsh, PhD (Physiology), Halifax: Animal models for prevention of NeP.

18. Dwight Moulin, MD (Neurology), London: Leading expert in chronic NeP management.

19. Colleen O'Connell, MD (Physiatry), Fredericton: Evaluating the role of cannabinoids in management of pain.

20. Andy Parrent, MD (Neurosurgery), London: Surgical management of NeP

21. Phillip Peng, MD (Anaesthesia), Toronto: Interventional pain management.

22. Linda Rapson, MD (Acupuncture), Toronto: Leading a trial evaluating the efficacy of acupuncture for treatment of NeP, among individuals with subacute SCI; and exploring the role of vitamin D in pain management.

23. Jana Sawynok, PhD (Pharmacology), Halifax: Basic research in NeP.

24. Christine Short, MD (Physiatry), Halifax: Studying the prevention of neuropathic pain in animal and human models. Evaluating the role of cannabinoids in management of NeP.

25. Eldon Tunks, MD (Psychiatry), Hamilton: Novel approaches to the pharmacologic management of NeP.

26. Mark Ware, MD (Anesthesia), Montréal: Clinical research and health policy implementation related to cannabinoids for treatment of pain.

Evaluating the Impact of SCI-related Chronic Pain on Quality of Life and Community Participation

BEST PRACTICE INDICATORS

A centre of excellence for pain management after SCI should have:

1. An interdisciplinary team with team member interest and experience in managing pain after SCI, including a physiatrist and, possibly other pain specialists (neurosurgery, anaesthesiology).

2. Established, collaborative relationships with chronic pain programs, within facilities/regions.

3. Timely access to a pain specialist and pain management programs (e.g., self management programs, acupuncture, CBT).

4. Routine pain assessments using standardized assessment and outcome tools (e.g., *DN4, LANNS, BPI, ORT, Health Related QOL, etc.*).

5. An evidence-based approach to patient treatment, with developed pathways that maximize both non-pharmacologic and pharmacologic treatments (using *Guidelines for the management of NeP*, including SCIRE).

6. Evidence-based tools to evaluate treatment efficacy and patient adherence (e.g., *Canadian guidelines for opiate use in treatment of non-cancer pain*).

7. Funding available to rehab team members to support CPD activities related to pain management (e.g., to attend key conferences, share new knowledge through grand rounds or journal club, or for visiting content experts).

Clinical Care Priorities

1. Further research in neuropathic pain prevention.

2. Enhanced pain management in SCI by ensuring national standards for adequate access to evidence-based therapies (e.g., funding across Canada for approved therapies for neuropathic pain in spinal cord injury, like Pregabalin).

3. Better education for healthcare professionals on the importance of managing neuropathic pain in SCI.

4. Timely access to experts in pain management, including SCI.

5. Better education for patients
(e.g., Spinal Cord Injury University, SCI-U).

Research Priorities

1. Clinical trials for evidence-based pharmacological and non-pharmacologic management of neuropathic pain, and preventing NeP in SCI, is essential to strengthen current therapies, to better understand treatments and their timing, and to lead to the greatest success in pain management. Research priorities should include:

   a. Non-pharmacologic: A single centre or small, multicentre trial to further explore the role of acupuncture in the treatment of NeP in SCI; and a large, group-based protocol for evaluation of the value of CBT programs (e.g., group-based pain management), for individuals with post-SCI pain.

   b. Pharmacologic: Clinical trials to assess the efficacy and tolerability of cannabinoids (e.g., nabilone and/or sativex), for NeP in SCI; a pilot study to explore the role of topical agents in the management of NeP, in focal distribution; and clinical trials to look at the efficacy of oral opiates in managing NeP, after SCI.

2. Development of a better understanding of the pathophysiology of pain development (e.g., PET or functional MRI studies in SCI individuals, with and without NeP); and animal models of NeP, post-SCI, where novel medications could be tried.

Health Policy Priorities

1. Eliminate regional disparities and financial barriers for access to evidence-based treatments.

2. Educate policy makers on the importance of good pain management. The E-Scan data sets show large disparities in access to pain specialist clinicians, for all disciplines, including physicians. Mandated universal application of available evidence-based therapies for NeP, though accreditation, is recommended.

Research Priorities

1. Pilot study to explore the role of topical agents in the management of neuropathic pain, in focal distribution.

2. Further research on the prevention of NeP, wherever possible.

3. Better SCI pain management by ensuring national standards for adequate access to evidence-based therapies, education for healthcare professionals on the importance of managing neuropathic pain in SCI, better education for individuals (e.g., SCI-U), and timely access to experts in SCI pain management.

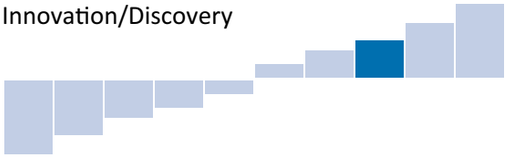
Knowledge generation is progressing well, with a growing number of research projects and collaborative research groups. However, funding is lacking, necessitating strong advocacy for a change in policy, to better support research and clinical care for individuals with pain, after SCI. To prepare, work is needed on clinical application (to ensure provision of a national, unified, evidence-based approach to managing NeP after SCI), and the identification of barriers.

REPORT CARD: Ameliorate Neuropathic Pain

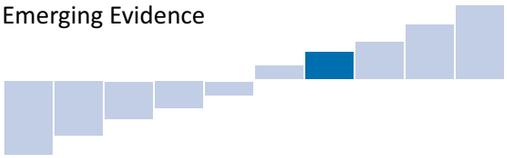
Extreme left below median: ***insufficient***
Extreme right above median: ***optimal***

KNOWLEDGE GENERATION

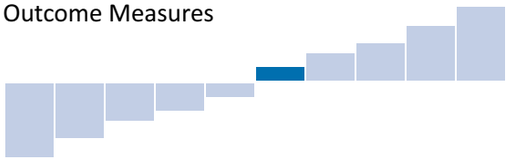
Innovation/Discovery



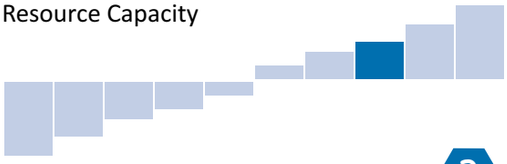
Emerging Evidence



Outcome Measures



Resource Capacity



2020 PRIORITY 3

CLINICAL APPLICATION

Integrative Care

Effective Practice
(Evidence and Outcomes)

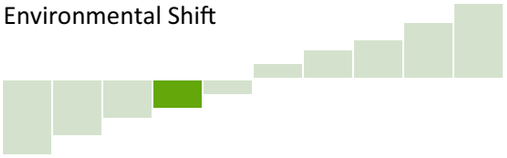
Equity Practice

Capacity

2020 PRIORITY 1

POLICY CHANGE

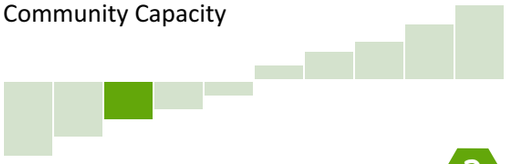
Environmental Shift



Change Agents

Societal Awareness

Community Capacity



2020 PRIORITY 2

TAKE HOME MESSAGE:

Neuropathic pain is an under-recognized complication of SCI that has profoundly negative impacts on function and quality of life. Significant regional disparity in the approach to treatment and early intervention requires the involvement of interdisciplinary teams, using an evidence-based approach. For this to happen, funding and support is needed for team development, standardized outcomes and research into effective clinical management.

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Skeletal Integrity

C Craven, MD; L Blencowe, MSc; AS Burns, MD; I Côté, MD; LM Giangregorio, PhD; and the E-Scan Investigative Team

Skeletal Integrity **refers to whether an individual with spinal cord injury (SCI) has adequate bone architecture and alignment to allow for participation in his or her choice of rehabilitation interventions and leisure pursuits.**

Sublesional Osteoporosis (SLOP) is a disease process unique to individuals with SCI, characterized by excess bone resorption and deterioration in lower extremity bone density and bone architecture, which leads to a lifetime of increased risk of lower extremity fragility fracture (see Table 1.0). Common problems following SCI that influence skeletal integrity include SLOP and related fragility fractures, heterotopic ossification, scoliosis, kyphosis and Charcot joints. This chapter discusses the prevention, detection and treatment of SLOP and fracture management, among individuals with SCI.

PHOTO COURTESY OF RICH VANDERWAL

TABLE 1.0 DEFINITION OF SUBLESIONAL OSTEOPOROSIS (SLOP).

AGE RANGE	DEFINITION
Men ≥ 60 years or postmenopausal women	Hip or knee region T score ≤ -2.5
Men < 59 years or premenopausal women	Hip or knee region Z score < -2.0 with ≥ 3 risk factors for fracture
Men or women age 16–90	Prior fragility fracture and no identifiable etiology of osteoporosis, other than SCI

T score is the number of standard deviations (SD) BMD above or below gender-specific young adult mean peak bone mass.

Z score is the number of SD BMD above or below that, expected for individuals of the same age and gender.

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Among individuals with motor complete SCI, there is a characteristic 3%-4% per month decline in hip and knee region bone mineral density (BMD), in the first year after injury. Typically, BMD of the hips, thigh bone (distal femur), and shin bone (proximal tibia) are 28%, 37% to 43%, and 36% to 50% below that of gender-matched peers, at 12 to 18 months post injury. There is disagreement whether this decline in BMD continues with chronic injury, or stabilizes after the initial injury. The result of these processes is a lifetime-increased risk of lower extremity fragility fracture. A *fragility fracture* is one that results from mechanical forces which would not ordinarily cause fracture in a healthy young adult (see Figure 1.0).

Distal femur and proximal tibia fragility fractures prevail in the SCI patient population, with 25% to 46% of chronic SCI patients developing fragility fractures. Torsional stresses on the legs, during a transfer, or compressive forces at the knee, during a low velocity fall, are frequent causes of distal femur and proximal tibia fractures.

FIGURE 1.0 MOST COMMON SITES OF FRACTURE AFTER SCI IN DESCENDING ORDER OF FREQUENCY, AND COMMON FRACTURE RISK FACTORS, AFTER SCI.

Yes	FRACTURE RISK FACTORS CHECKLIST
☐	Age at injury < 16 years[2]
☐	Alcohol intake > 5 servings/day[3]
☐	BMI < 19[4]
☐	Duration of SCI ≥ 10 years[5]
☐	Female[5,6]
☐	Motor complete (AIS A-B)[7]
☐	Paraplegia[8]
☐	Prior fragility fracture
☐	Family history of fracture[9]

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Much of what we know about sublesional osteoporosis comes from published data describing changes in bone mineral density, among men with motor complete SCI. Less is known about women, those with incomplete injuries, and/or non-traumatic SCI.

Dual x-ray absorptiometry (DXA) testing of the spine and hip region is the gold standard for the detection of osteoporosis and individuals, with high fracture risk, in the general population.

However, for individuals with SCI, assessment of knee region BMD best predicts knee region fracture risk.[5, 10] BMD *fracture thresholds* are values below which fractures begin to occur, whereas *fracture breakpoints* are values at which the majority of fractures occur. aBMD (aerial BMD measured via DXA) and vBMD (volumetric BMD measured via peripheral quantitative computed tomography) knee region values for fracture threshold, and fracture breakpoint are identified in Table 2.0.

TABLE 2.0 BMD THRESHOLDS FOR FRACTURE AND FRACTURE BREAKPOINT.

NAME	VALUE	DEFINITION
Fracture threshold	$\leq$ 0.78 g/cm^2 (aBMD) $<$ 114 mg/cm^3 (vBMD-femur) $<$ 72 mg/cm^3 (vBMD-tibia)	Knee region BMD values below which fragility fractures occur
Fracture breakpoint	$<$ 0.49 g/cm^2 (aBMD)	Knee region BMD values at which the majority of fragility fractures occur

BMD = bone mineral density; aBMD = areal BMD; vBMD = volumetric BMD.

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Current Practice: SLOP and Fracture Risk following SCI

Individuals with SCI who require intervention, related to their Skeletal Integrity, fall into one of three categories:

- Those newly injured, for whom we wish to prevent SLOP, and regional declines in lower extremity bone mass (prevention).
- Those with established low BMD of the hip and knee regions, and significant risk of fragility fracture who require therapy (treatment).
- Those who have sustained a lower extremity fracture and require post- fracture care (management).

Canadian authors have published a proposed paradigm to guide clinical decision making, regarding the detection of SLOP and treatment of individuals with high fracture risk, based on the data contained in available systematic reviews, key references available to inform practice and expert consensus. Diagnosis of SLOP involves a combination of health screening, assessment of lifestyle and nutrition factors, in addition to BMD and fracture risk assessment (see Figure 3.0). In the absence of a formal clinical practice guideline, clinical uncertainty has led to regional disparity in practice, among SCI clinicians.

Health Status

Secondary causes of osteoporosis are prevalent in individuals with SCI, and can exacerbate or even mask SLOP. The health evaluation process should include a detailed medical history to identify secondary causes of low BMD, unrelated to SCI; review of current and prior medications known to adversely affect bone mass, and serum and urine screen for secondary causes of osteoporosis, amenable to medical intervention. Hypothyroidism, renal insufficiency, vitamin D deficiency (with or without secondary hyperparathyroidism), and hypogonadism are frequently identified, and have established treatments.

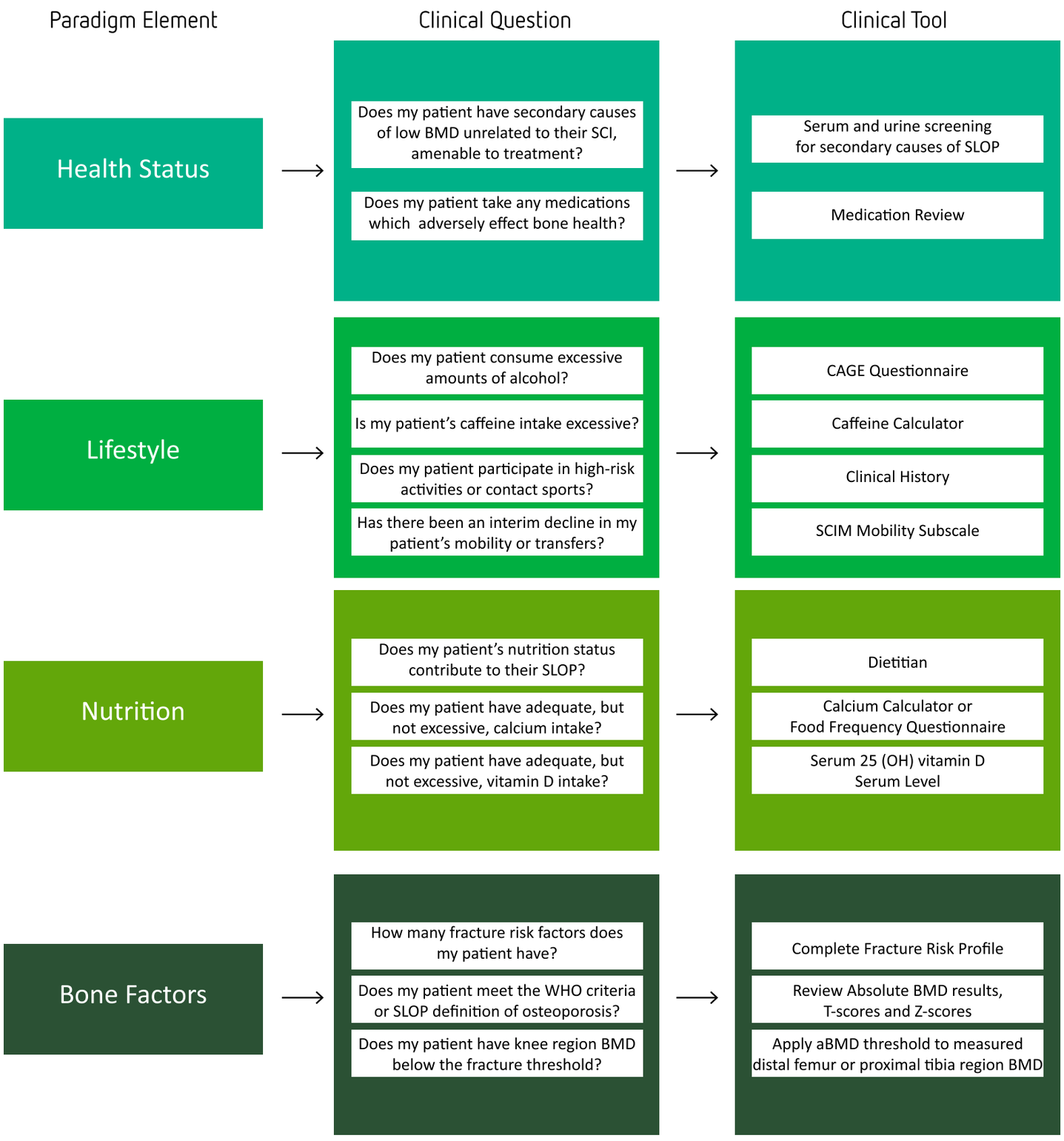
Lifestyle

Lifestyle behaviours requiring intervention can be identified through simple questions regarding daily or weekly caffeine and alcohol intake, and smoking history. Smoking cessation, reduced caffeine intake (< three servings per day) and restricted alcohol intake (< two servings per day, and no more than nine servings of alcohol per week for women, and no more than 14 per week for men) are prudent behavioural intervention targets.

Many individuals with SCI participate in contact or high-risk sports, with numerous physical and psychological benefits that also pose a potential fracture risk. Counselling regarding use of protective gear, and the need to have a high index of suspicion for fracture when regional swelling is evident after a collision/fall, should be provided.

FIGURE 3.0 PARADIGM FOR DETECTION OF SUBLESIONAL OSTEOPOROSIS AND ASSESSMENT OF INDIVIDUAL FRACTURE RISK.

REPRINTED FROM CRIT REV PHYS REHABIL MED, 20(4), CRAVEN BC, GIANGREGORIO LM, ROBERTSON LA, DELPARTE JJ, ASHE MC, ENG JJ, SUBLESIONAL OSTEOPOROSIS PREVENTION, DETECTION AND TREATMENT: A DECISION GUIDE FOR REHABILITATION CLINICIANS TREATING PATIENTS WITH SPINAL CORD INJURY, P. 290, COPYRIGHT (2008), WITH PERMISSION FROM BEGELL HOUSE, INC.



Individuals aging with SCI frequently develop functional declines, in their mobility, resulting in changes in gait, use of mobility aids, and deteriorating transfers. Careful review of functional abilities and transfer techniques is essential to prevent future fragility fractures. Discussion of strategies to reduce the risk of falls, in the home, has a particularly high yield for those with AIS C and D impairment.

Nutrition

A 30% prevalence of vitamin D deficiency is reported among individuals with SCI, and dietary intakes of calcium are often insufficient, below 660 mg per day. Serum screening and assessment of dietary adequacy is necessary to ensure optimal, but not excessive, calcium and vitamin D intakes, through diet or supplements. Dietary sources of calcium are preferred over supplements, due to the reported cardiovascular risks associated with supplementation. A dietary calcium intake of 1,000 mg per day, in divided doses, is recommended for individuals with SCI and SLOP, without a prior history of renal or bladder stones. Serum screening is important for identifying individuals with deficiency, and facilitates titration to an appropriate serum level. While a serum vitamin D level of 75nmol/L is desirable for fracture prevention, in the general population, a serum level ≥ 100nmol/L is optimal for bone health, as well as cancer and cardiovascular disease prevention, among individuals with SCI. Once optimal calcium and vitamin D intakes are achieved, additional rehabilitation or pharmacologic intervention may be considered, in those with an elevated fracture risk.

Bone Density Testing

Despite established methods for assessing health status, lifestyle, nutrition and BMD via DXA following SCI, there is variation in access to services, and considerable variation in their utilization. Figure 4.0 illustrates access to skeletal integrity services, across Canada. While most sites have access to bone density testing (onsite or offsite), the majority (n = 8 sites) do not assess knee region BMD, and indicate no established treatment protocol or standard of care. Four sites report use of a common knee region DXA protocol developed at Toronto Rehab. Despite the availability of multidisciplinary staff in most centres, few sites provide interdisciplinary care, skeletal integrity services are almost exclusively provided by physiatrists throughout the country (Figure 5.0).

FIGURE 4.0 OVERVIEW OF NATIONAL ACCESS TO SKELETAL INTEGRITY-RELATED SERVICES.

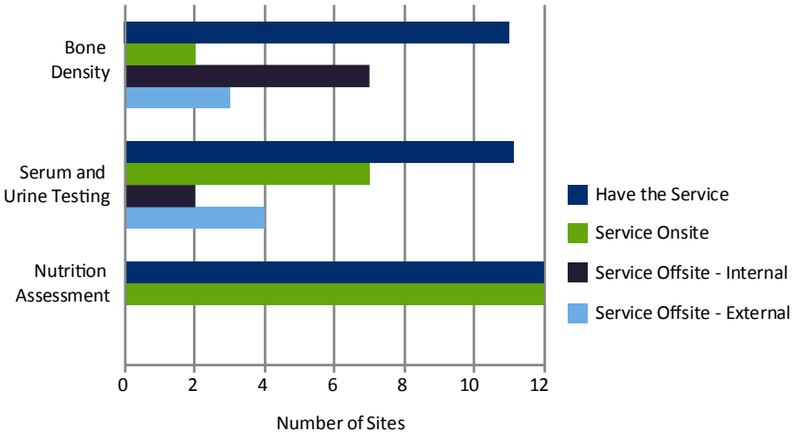
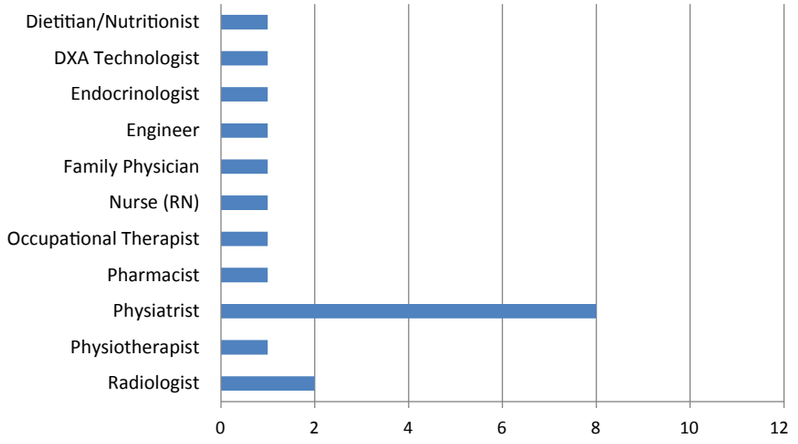


FIGURE 5.0 OVERVIEW OF ACCESS TO HEALTHCARE PROFESSIONALS WITH SKELETAL INTEGRITY EXPERTISE.



Evaluating Treatment Effectiveness

To be valid, changes in BMD, from serial scans, must be equivalent to or exceed the least significant change (LSC) of the densitometer. The International Society of Clinical Densitometry (ISCD) recommends monitoring the treatment response, among osteoporotic patients, with DXA measures of BMD, every one to two years, at the same facility, with the same densitometer, using the same acquisition and analysis protocols.[11] LSC is the least amount of BMD change considered statistically significant, and is calculated by multiplying the precision error by 2.77. In clinical practice, an increase in BMD, above the LSC, is considered effective therapy; while a decrease, below the LSC, is considered non-response to therapy.[12] Non-response to therapy should prompt a review of treatment adherence, followed by consideration of therapy cessation or alternate therapy.

Selecting Therapy

Once an individual with low BMD of the hip or knee region (Z score ≤ -2.0) and an increased risk of lower extremity fragility fracture (≥ 3 risk factors) is identified, the clinician must should consider treatment. For all SLOP therapies, increases in BMD are assumed to be a suitable surrogate outcome for fracture risk reduction, when assessing the effectiveness of SLOP therapy - with "optimal therapy" resulting in an increase in knee region BMD, above the fracture threshold. To date, no SLOP treatment trial has been adequately powered to address fracture risk reduction, among individuals with SCI. The E-Scan survey provides insufficient data to allow us to do anything more than comment on trends in therapy selection. Recent systematic reviews summarize the drug and rehabilitation interventions available for SLOP prevention and treatment.

Preventing SLOP

Evidence for pharmacological prevention of SLOP after subacute SCI includes several randomized controlled trials (RCT) (see Table 3.0). These studies vary in the choice of of pharmacological intervention, primary outcome measure, duration of follow up, sample sizes and impairment groups. In the majority of studies, bisphosphonate therapy given early post injury reduced the degree of decline, in hip and knee region bone mass, when compared with a control group. Shapiro and colleagues[13] tested the effect of once-yearly IV Zoledronate, with significant improvements reported in BMD at the hip, at six months, that returned to baseline values at 12 months. The control group, on the placebo treatment, lost bone over the 12 months. Bubbear et al.[14] also showed that a once-yearly IV Zolendronate infusion ameliorated deterioration in bone mass, at the spine and hip, over 12 months. Investigators also highlighted the added benefits of a once-yearly IV administration of bisphosphonate, to eliminate issues surrounding poor patient adherence, and the adverse gastrointestinal effects associated with oral bisphosphonate therapies. Although there is evidence that bisphosphonates may reduce bone resorption, current medications do not entirely preserve lower extremity BMD.

TABLE 3.0 SUMMARY OF SLOP BISPHOSPHONATE PREVENTION TRIALS

AUTHOR, YEAR	COMPOUND	RELATIVE POTENCY	PEDro	N	DURATION	BMD
Bubbear, 2011	Zolendronate	≥ 5000	6	14	12/12	+
Craven, 2008	Risedronate	5,000	11	34	12/12	-
Gilchrist, 2007	Alendronate	1000	7	31	12/12	+
Gilchrist, 2007	Alendronate	1000	7	31	12/12	+
Bauman, 2005	Pamidronate	100	10	14	12/12	-
Nance, 1999	Pamidronate	100	13*	24	6/12	+
Pearson, 1997	Etidronate	1	8	13	4.5/12	+AIS D/ - AIS A-C
Chappard, 1995	Tiludronate	10	9	20	3/12	Biopsy
Minaire, 1978	Clodronate	10	7	21	3.5/12	+
Minaire, 1981	Clodronate	10	10	21	3.5/12	Biomarker

Treatment of SLOP

Level 1b evidence supports alendronate for treatment of SLOP, among individuals with chronic motor complete paraplegia (Table 4.0). Using a randomized, open-label design, Zehnder et al.[15] evaluated the effectiveness of alendronate 10 mg daily, and calcium 500 mg daily, versus calcium 500 mg daily (alone) for 24 months on BMD, after SCI. The study cohort consisted of 55 men with motor complete SCI (para/tetraplegia, AIS A or B), living in Switzerland. Injury duration ranged from one month to 29 years, post SCI, with group means of 10 years, post injury. The primary outcome was a change in tibia epiphysis aBMD, from baseline. Key findings included an 8.0% decline in tibia epiphysis BMD, in the control group, and relative maintenance of tibia epiphysis BMD (-2.0%), in the treatment group ($p < .001$). Thus, individuals with SLOP and motor complete injury (AIS A or B) may be treated with alendronate (70 mg weekly), calcium, and vitamin D supplements.

Alendronate should be used with caution, in individuals with spinal cord lesions at or above T6, as esophageal dysmotility is common after SCI, and increases the risk of esophageal erosions. Alendronate may also elicit atrial fibrillation, among individuals with SCI above T6, and a propensity for autonomic dysfunction.

No clinical trials, to date, evaluate drug treatments of SLOP, among individuals with motor incomplete injuries (AIS C and D). Recent p-QCT data, describing changes in lower extremity cortical and trabecular volumetric BMD, over time, suggest there is a therapeutic window, two to eight years post injury, during which antiresorptive therapies, like the bisphosphonates, are most likely to be effective for SCI patients.

TABLE 4.0 SUMMARY OF BISPHOSPHONATE TREATMENT TRIALS

AUTHOR, YEAR	COMPOUND	RELATIVE POTENCY	PEDro	N	DURATION	BMD
Zehnder, 2004	Alendronate	1000	7	65	24/12	+
Bauman, 2005	Vitamin D	N/A	10	40	24/12	+
Moran de Brito, 2005	Alendronate	1000	6	19	6/12	No significant change

Non-Drug Rehabilitation Therapies for SLOP

Rehabilitation therapies for SLOP focus on muscle contraction, stimulation and/or weight bearing activities, intended to simulate typical mechanical stresses on the bone, in order to activate bone formation. Common SLOP rehabilitation interventions include functional electrical stimulation (FES), electrical stimulation (ES), standing and walking, body weight support treadmill training (BWSTT) and ultrasound. FES involves the use of surface or implanted electrodes to stimulate regional lower extremity muscle contractions, to facilitate standing, ambulation or cycle ergometry, with the goal of increasing regional BMD. FES cycle ergometry (FES-CE) requires a series of electrodes placed over the hamstrings, quadriceps and gluteal muscles of the legs, to simulate a cycling pattern (Figure 6.0). Weight-bearing activities include either passive standing (tilt-table or standing frame, Figure 7.0) or active standing, with or without FES, to assist with knee extension. Relative contraindications, for these therapies, include a subluxed or dislocated hip, hip and knee flexion contractures totalling > 30 degrees combined, nonunion of lower extremity fractures, and a strong hip flexor synergy.

A systematic review by Biering-Sorensen et al.[16] provides a detailed evaluation of the non-pharmacological interventions for prevention of SLOP, and highlights the lack of efficacy of rehabilitation interventions. Among individuals with chronic SCI and SLOP, rehabilitation interventions may be ineffective, due to prolonged suppression of osteocyte and osteoblast activity. It is also plausible that insufficient mechanical stresses and short durations of therapy have resulted in the modest treatment effects, to date.

Unfortunately, the therapeutic effects observed with Electrical Stimulation (ES) and Functional Electrical Stimulation (FES) are isolated to the area stimulated and return to baseline within months of stopping therapy. Up to now, no rehabilitation intervention has led to sustained increases in hip or knee region BMD, in chronic SCI subjects with SLOP. FES cycle ergometry or passive standing may be offered to individuals as SLOP treatment - provided patients understand it is a lifetime prescription, as the therapeutic benefits abate, with therapy cessation. Rehabilitation interventions may be offered as SLOP treatment options, provided their potential risks and limited efficacy have been discussed, prior to initiation. Clinical decision making regarding the relative efficacy of therapy is further complicated by many studies that have enrolled participants, with both acute and chronic injuries, making it difficult to identify interventions as primarily for SLOP prevention or treatment.

FIGURE 6.0 FES CYCLE-ERGOMETRY.

FIGURE 7.0 PASSIVE STANDING USING A STANDING FRAME.

TABLE 5.0 SUMMARY OF REHABILITATION INTERVENTIONS.

AUTHOR, YEAR	INTERVENTION	N	DURATION (MOS)	RESULT
STANDING				
Kaplan 1981	Standing	10	6 or 12-18	↑ Urinary calcium
Kunkel 1993	Standing	6	5	Neutral BMD
Needham Shropshire 1997	Standing/ Walking	16	2	No effect
ELECTRICAL SIMULATION (ES)				
Rodgers 1991	ES	12	3	Neutral BMD
FUNCTIONAL ELECTRICAL STIMULATION (FES)				
Pacy 1988	FES Cycling	4	?	Neutral BMD
Leeds 1990	FES Cycling	6	6	↑ No BMD change, formation markers, ↓ resorption markers
Hangartner 1994	FES Cycling	15	6-8	Neutral tibia
BeDell 1996	FES Cycling	10	13	↑ BMD
Mohr 1997	FES Cycling	12	?	↑ BMD (tibia), no treatment effect
Chen 2005	FES Cycling	30	6	↑ BMD (femur & tibia) ↓ BMD (hip)
Frotzler 2008	FES Cycling	11	12	↑ BMD (femur), neutral tibia
Ashe 2010	FES Cycling	3	6	↑ BMD (lower extremity)
WALKING				
Ogilvie 1993	Walking	4	Avg 5	↑ BMD (hip), no treatment effect at spine
Thoumie 1995	Walking	7	3-14 mos	No effect
BODY WEIGHT SUPPORT TREADMILL TRAINING (BWSTT)				
Giangregorio 2005	BWSTT	5	8	↑ BMD (femur & tibia)
Giangregorio 2006	BWSTT	14	12	Neutral BMD
Carvahlo 2006	BWSTT/ES	21	6	↑ Formation markers, ↓ resorption markers
Coupaud 2009	BWSTT with FES	1	2	↑ BMD and BMC (tibia)

The initiation of SLOP therapy necessitates repeat BMD testing to evaluate treatment effectiveness and periodic assessment of adherence. Non-response to drug or rehabilitation therapy should prompt therapy cessation or a trial of alternate therapy. Little is known about the efficacy of combination therapy although evolving research has begun to explore the therapeutic potential of a variety of intervention combinations.

Available Systematic Reviews

- Ashe MC, Craven C, Krassioukov A, Eng JJ. Bone health following spinal cord injury. In: Eng JJ, Teasell RW, Miller WC, et al., eds. *Spinal Cord Injury Rehabilitation Evidence.* Version 3.0. Vancouver, BC; 2010:1-26.
- Craven BC, Giangregorio LM, Robertson LA, Delparte JJ, Ashe MC, Eng JJ. Sublesional osteoporosis prevention, detection and treatment: a decision guide for rehabilitation clinicians treating patients with spinal cord injury. *Crit Rev Phys Rehabil Med*. 2008;20(4):277–321.
- Biering-Sorenson F, Hansen B, Lee BS. Non-pharmacological treatment and prevention of bone loss after spinal cord injury: a systematic review. *Spinal Cord*. 2009;47(7):508–18.

KEY REFERENCES TO INFORM PRACTICE

1. Papaioannou A, Morin S, Cheung AM, et al. 2010 clinical practice guidelines for the diagnosis and management of osteoporosis in Canada: summary. *CMAJ.*2010; 182(17):1864-73.

2. Bauman WA, Emmons RR, Cirnigliaro CM, Kirshblum SC, Spungen AM. An effective oral vitamin D replacement therapy in persons with spinal cord injury. *J Spinal Cord Med.* 2011;34(5):455-60.

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5. Hummel K, Craven BC, Giangregorio L. Serum 25(OH)D, PTH and correlates of suboptimal 25(OH)D levels in persons with chronic spinal cord injury [published online ahead of print June 19 2012]. *Spinal Cord*. 2012. http://www.nature.com/sc/journal/vaop/ncurrent/full/sc201267a.html. Accessed September 26, 2012.

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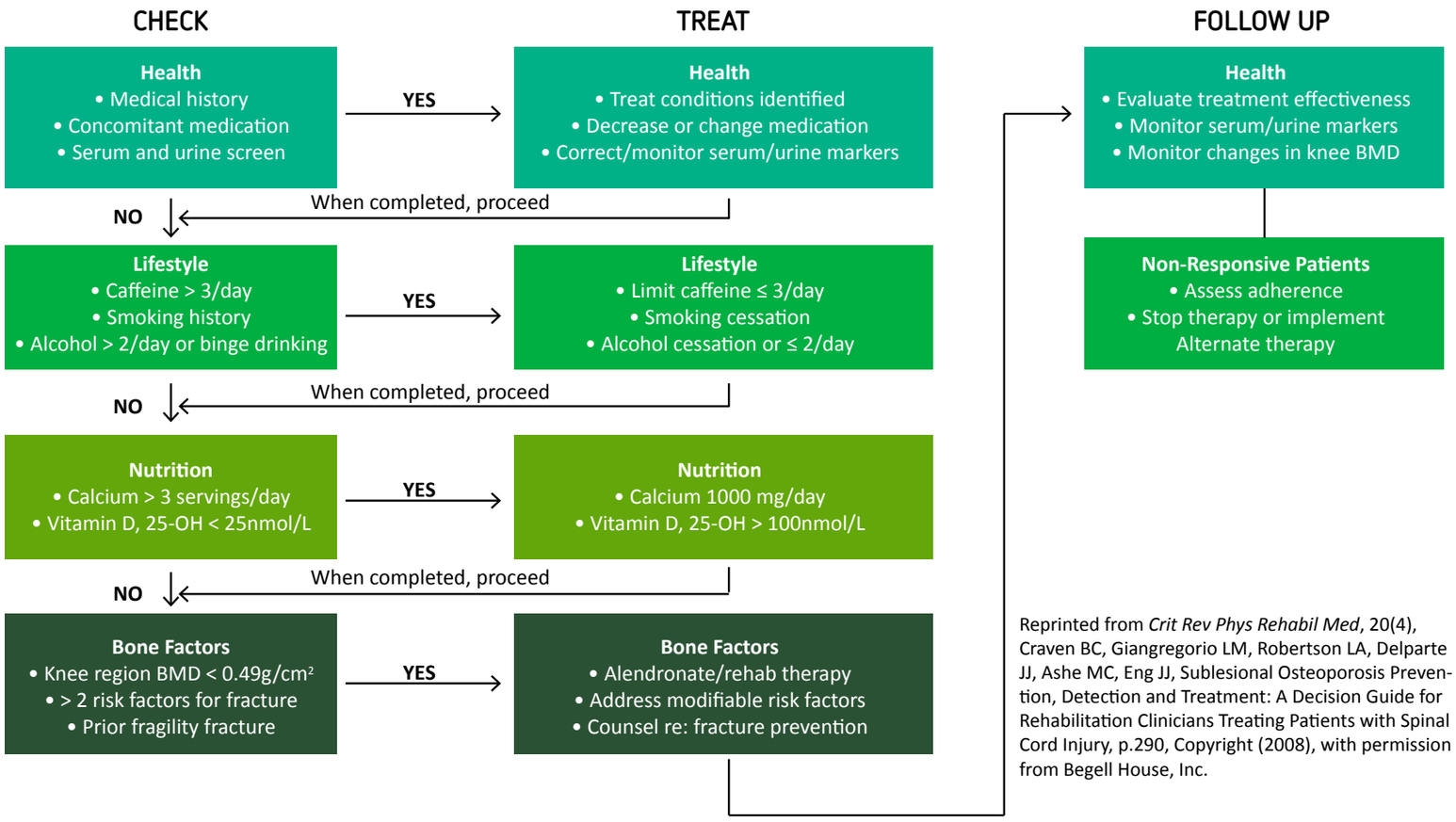
FIGURE 8.0 PROTOCOL FOR THE DIAGNOSIS, INITIATION AND EVALUATION OF TREATMENT EFFECTIVENESS FOR SLOP.



Reprinted from *Crit Rev Phys Rehabil Med*, 20(4), Craven BC, Giangregorio LM, Robertson LA, Delparte JJ, Ashe MC, Eng JJ, Sublesional Osteoporosis Prevention, Detection and Treatment: A Decision Guide for Rehabilitation Clinicians Treating Patients with Spinal Cord Injury, p.290, Copyright (2008), with permission from Begell House, Inc.

Evolving Evidence Likely to Influence SLOP Treatment

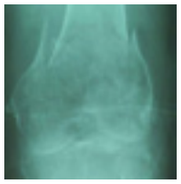
Battaglino RA, Lazzari AA, Garshick E, Morse LR. Spinal cord injury-induced osteoporosis: pathogenesis and emerging therapies [published online ahead of print September 16 2012]. *Curr Osteoporos Rep*. 2012.

- Evaluation of the efficacy of whole body vibration for treatment of SLOP (NCT00624988)
- Comparison of the efficacy of zoledronic acid and FES rowing to treat SLOP (NCT01426555)
- Pilot RCT confirming the efficacy of alendronate for treatment of SLOP (NCT01131884)
- Studies evaluating the efficacy of concurrent administration of drug and rehab interventions, on bone mass and bone architecture (e.g., rPTH and weight bearing (NCT00826228)
- Study evaluating the efficacy of two forms of LE ergometry for augmenting bone and muscle mass (NCT01244594).

Fracture Management

The majority of SCI individuals will sustain a lower extremity fracture, during their lifetime. Appropriate fracture management strategies are imperative to reduce morbidity. For those with distal lower extremity fractures requiring immobilization:

- Bivalve cast with malleolar windows to monitor skin



- Medication review to:
  - Optimize callous formation
  - Promote fracture healing
  - Treat established osteoporosis

- DVT (deep vein thrombosis) prophylaxis

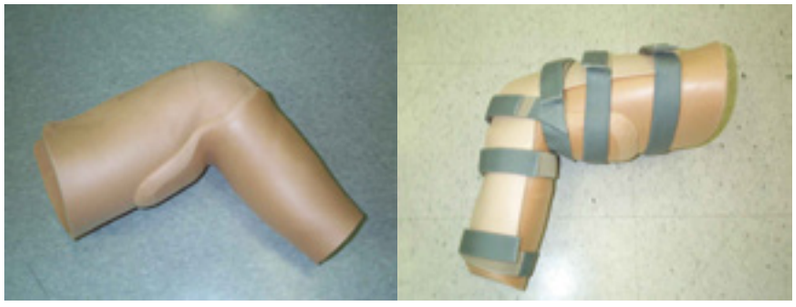
- Wheelchair adaptations to prevent pressure ulcers
  - Elevating leg rest
  - Power mobility

- Assess impact of immobilization device on transfers and self care
  - Provision of sliding board or lift
  - Increased attendant care supports

- Monitor emotional wellbeing

Fragility fractures after SCI frequently result in delayed union, nonunion or malunion. Ultrasound has been shown as an effective therapy to help speed healing. Elimination in variability of fracture management and post fracture care, employed across Canada, is an obvious intervention target.

FIGURE 9.0 SOFT SPLINTS THAT ALLOW FOR OPTIMAL MOBILIZATION WHILE SEATED ARE OFTEN PREFERABLE FOR PATIENTS WHO REQUIRE NON-OPERATIVE FRACTURE MANAGEMENT.



Canadian Content Experts Likely to Influence Practice in Next Five Years

1. Jonathan Adachi, MD (Rheumatology), Hamilton: Past President of Osteoporosis Canada, and member of the Scientific Advisory Council of the International Osteoporosis Foundation. Expertise in osteoporosis therapies, gluccocorticoid induced osteoporosis, non-invasive measurement of bone with dual energy x-ray absorptiometry, MRI and peripheral QCT, quality of life and health economics, as it relates to osteoporosis.

2. Anthony Burns, MD (Physiatry), Toronto: Runs a tertiary bone health clinicfor individuals with mobility impairments, and has expertise in the management of skeletal integrity across neurologic impairment groups.

3. Angela Cheung, MD (Internal Medicine), Toronto: Led a number of non-pharmacologic and pharmacologic clinical intervention trials, relevant to rehab service delivery.

4. Cathy Craven, MD (Physiatry), Toronto: involved in a longitudinal study of bone health and body composition, and has expertise in the conduct of trials evaluating drug therapy and rehabilitation interventions, for treatment of SLOP, contrasting the feasibility and diagnostic yield of knee region DXA versus PQCT.

5. Isabelle Côté, MD (Physiatry), Québec: Co-leads an interprovincial team examining the feasibility and test-retest reliability of knee region DXA, among SCI patients.

6. Lora Giangregorio, PhD (Kinesiology), Waterloo: Involved in a longitudinal study of bone health and body composition, and is leading refinement of pQCT measurement protocols. Member of the Scientific Advisory to Osteoporosis Canada, and has expertise in exercise interventions for individuals with vertebral fracture.

7. Susan Jaglal, PhD (Epidemiology), Toronto: Expertise in health services research, particularly in examining access to diagnostic services and appropriate therapy in high-risk and post-fracture populations; translation of service gaps into policy recommendations. Member of PHAC Osteoporosis Surveillance working group, and Principal Investigator for the evaluation of the Ontario Osteoporosis Strategy.

8. Nicole Mittmann, PhD (Pharmacology), Toronto: Expertise in the conduct of economic evaluations, co-leading a study to describe the direct medical costs of lower extremity fracture.

9. Alex Papaioannou, MD (Geriatrics), Hamilton: Past Chair, Scientific Advisory Council for Osteoporosis Canada, expertise in knowledge translation research,and focused the osteoporosis community on fracture risk reduction, through development of the 2010 Osteoporosis Canada guidelines.

10. Shabbir Alibhai, MD (Internal Medicine), Toronto: Expertise in the management of osteoporosis, in men with prostate cancer or on androgen deprivation therapy.

SPOTLIGHT BEST PRACTICE ORGANIZATION

BRAIN AND SPINAL CORD REHAB PROGRAM –

Toronto Rehabilitation Institute (TRI), University Health Network, Toronto

The clinical and research expertise of the clinicians and scientists, at this site, are recognized internationally. Members of the bone health team include two physiatrists, outpatient nurses, physical and occupational therapists, a dietitian, orthotist and two DXA technologists. Knee region bone density testing is routinely assessed using a standard protocol, for individuals with sub-acute or chronic SCI, through yearly assessments of bone health and fracture risk. The knee region bone density-testing protocols, developed here, have been shared with other sites and are routinely used in Hamilton, Québec City, Calgary and Toronto.

Physiatrists routinely review patients' health status, nutrition status, lifestyle factors, fracture risk factors and BMD results, when diagnosing SLOP, identifying fracture risk and selecting appropriate therapies. Pharmacological therapy, including oral or intravenous bisphosphonates and injectable medications (including monoclonal antibodies like danosamub and recombinant PTH), are routinely prescribed, in the outpatient setting. individuals have access to non-pharmacological SLOP therapies, including FES biking and passive standing. Individuals with fractures are supported and followed by the bone health team.

Post-fracture clinical services include provision or rental of elevating leg rests, medications to prevent bone loss and to augment fracture healing, interventions to assist with delayed union or nonunion fractures, and monitoring of skin, during and after application of fracture immobilizers; liaison with local orthopedic surgeons, and reconditioning after fracture healing or operative intervention.

Bone health research, at this site, spans from long-term, observational cohort studies, to clinical drug trials, and therapeutic device studies investigating novel treatment options. Research subjects have assisted Scientists in the determination of the efficacy of whole body vibration, FES therapy and oral bisphosphonate therapy, for treatment of SLOP. Local scientists are collaborating to prospectively evaluate the feasibility and diagnostic yield of knee region DXA versus pQCT, of the tibia.

BEST PRACTICE INDICATORS:

The following best practice indicators are provided to assist program leaders in conducting self evaluation of their skeletal integrity services. Does your organization routinely:

- ☐ Incorporate bone health objectives into rehab goals?
- ☐ Include bone health in your patient education modules?
- ☐ Screen for secondary causes of osteoporosis, unrelated to SCI at rehab admission?
- ☐ Provide diet and lifestyle counselling?
- ☐ Ensure adequate, but not excessive dietary calcium intakes?
- ☐ Ensure adequate, but not excessive intakes of vitamin D?
- ☐ Measure BMD (including the knee region) at rehab admission one and two years, post injury, to assess the effectiveness of SLOP prevention strategies?
- ☐ Offer Bisphosphonate therapy, early post injury, to AIS A-B patients to prevent SLOP?
- ☐ Discuss the role of rehab interventions to attenuate the decline in bone mass, early after injury?
- ☐ Routinely measure BMD at > five years, post injury, to discern SLOP treatment effectiveness and fracture risk?
- ☐ Provide patients with SLOP and high fracture risk access to drug and rehab therapies, for treatment of SLOP?
- ☐ Assess fall risk and/or need for functional upgrading to prevent falls?
- ☐ Ameliorate fracture risk through multidisciplinary team intervention?
- ☐ Provide post fracture care for patients, lower extremity fragility fracture?
- ☐ Provide rehab services for patient with SLOP-related complications: lumbar compression fracture, scoliosis, etc?
- ☐ Provide access to novel therapy, or evolving technology to augment bone mass?
- ☐ Evaluate effectiveness of SLOP interventions?
- ☐ Abandon ineffective therapy?
- ☐ Advocate for appropriate policy changes to support bone health service implementation?

Roadmap - Where Should We Go?

CLINICAL GOALS

- Universal access to DXA testing for individuals with subacute SCI followed by routine, annual knee region BMD measurement and fracture risk assessment, for individuals with chronic SCI

- Support development and implementation of bone health clinics, whose mandate includes the diagnosis and management of SLOP, fracture prevention and post-fracture treatment protocols, for individuals with SCI.

- Inclusion of Bone Health Assessment, including BMD interpretation and fracture risk appraisal, as SCI objectives in the core PMR residency training programs.

RESEARCH GOALS

- Identify a valid, cost-effective means of identifying individuals with high fracture risk.

- Priority funding of research projects which explore the pathophysiology of the muscle-bone unit, and its role in sustaining bone mass and maintaining skeletal integrity, is recommended

- Current osteoporosis intervention trials have identified increases in lower extremity BMD, as a proxy outcome for fracture reduction. Development and funding of multicentre clinical studies, with an adequate sample size, to evaluate treatment efficacy and fracture risk reduction as a primary goal, should be a community priority.

- Develop an authoritative understanding of the epidemiology and economic impact of SLOP, and fracture risk, after SCI

KEY POLICY GOALS

- Lobby for national diagnostic imaging accessibility standards to enable routine assessment of skeletal integrity.

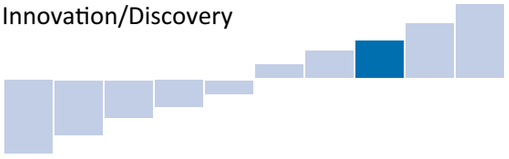
- Create DXA billing codes that reflect the time requirements and complexity of SCI patient assessment and management, to engage current, national osteoporosis experts in the assessment and management of individuals with SCI, SLOP and high fracture risk.

REPORT CARD: Skeletal Integrity

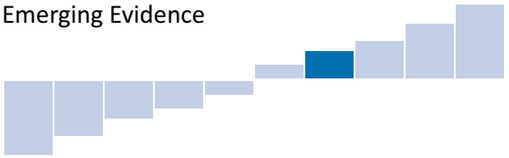
Extreme left below median: ***insufficient***
Extreme right above median: ***optimal***

KNOWLEDGE GENERATION

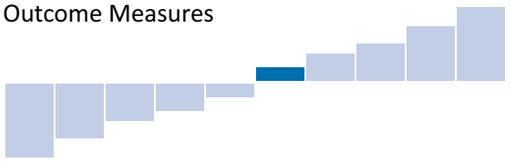
Innovation/Discovery



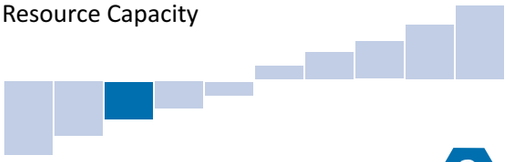
Emerging Evidence



Outcome Measures



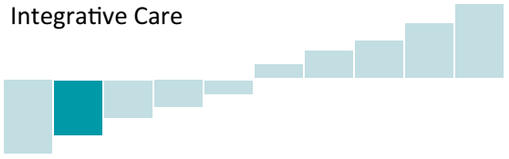
Resource Capacity



2020 PRIORITY 3

CLINICAL APPLICATION

Integrative Care



Effective Practice
(Evidence and Outcomes)

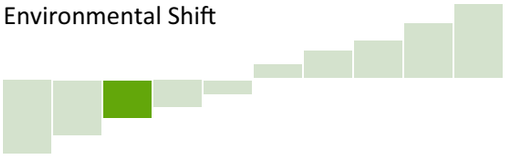
Equity Practice

Capacity

2020 PRIORITY 1

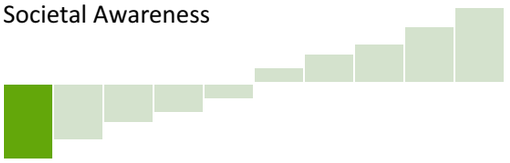
POLICY CHANGE

Environmental Shift

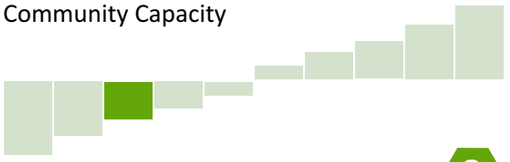


Change Agents

Societal Awareness



Community Capacity



2020 PRIORITY 2

TAKE HOME MESSAGE:

Priority funding should be given to support a multicentre prospective study to develop an authoritative understanding of the epidemiology of SLOP, enable identification of individuals with high fracture risk, and define the effectiveness of calcium and vitamin D supplements. Further knowledge translation efforts should focus on dissemination of a common knee region BMD test protocol.

RESOURCES

1. Craven BC, Robertson LA, McGillivray CF, Adachi JD. Detection and treatment of sublesional osteoporosis among patients with chronic spinal cord injury: proposed paradigms. *Top Spinal Cord Inj Rehabil*. 2009;14(4):1-22.

2. Parsons K, Lammertse D. Epidemiology, prevention and system of care of spinal cord disorders. *Arch Phys Med Rehabil*. 1991;72(Suppl. 4):S293-4.

3. Morse LR, Battaglino RA, Stolzmann KL, et al. Osteoporotic fractures and hospitalization risk in chronic spinal cord injury. *Osteoporos Int.* 2009;20(3):385-92.

4. Garland DE, Adkins RH, Kushwaha V, Stewart C. Risk factors for osteoporosis at the knee in the spinal cord injury population. *J Spinal Cord Med*. 2004;27(Suppl. 3):202-6.

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16. Biering-Sorensen F, Hansen B, Lee BS. Non-pharmacological treatment and prevention of bone loss after spinal cord injury: a systematic review. *Spinal Cord*. 2009;47(7):508–18.

Cardiovascular Integrity

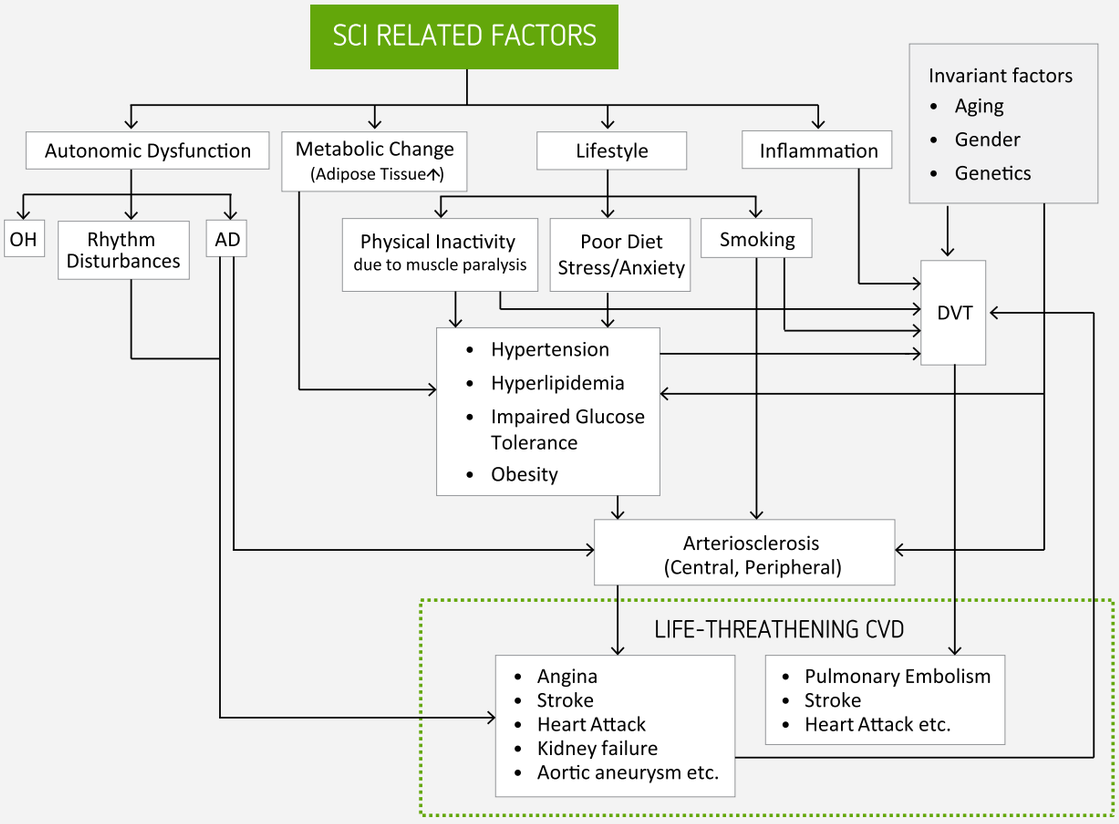
M Miyatani, PhD; A Krassioukov, MD, PhD; D Ditor, PhD; C Craven, MD; M Verrier, MHSc; and the E-Scan Investigative Team

The cardiovascular system, which includes the heart and blood vessels, is responsible for the transport of oxygen-rich blood, throughout the body. Changes in this system, after spinal cord injury (SCI), lead to an increased propensity for cardiovascular disease (CVD). CVD refers to any disease that affects the cardiovascular system, including heart disease, heart attack, heart valve disease, heart failure, peripheral vascular disease, hypertension, stroke and abnormal heart rhythms.

Maintaining *cardiovascular integrity*, in individuals with SCI, involves the prevention and management of CVD risk factors, linked to lifestyle changes and autonomic dysfunction, after injury. Development of CVD in individuals with SCI is not simple and results from the interactions of physiologic processes, such as gender, aging and genetic factors, and a variety of SCI-induced risk factors, such as lifestyle changes, stress and anxiety, autonomic dysfunction, metabolic changes and elevated inflammatory cytokines (Figure 1.0).[1,2] Common lifestyle changes, after SCI, include physical inactivity, poor nutrition and smoking, which contribute to alterations in cardiovascular integrity. Individuals with SCI develop virtually all the major lifestyle risk factors for CVD, as do the able bodied, over time, including abdominal obesity, lipid disorders and diabetes or glucose intolerance - with the exception of smoking.[3]

The autonomic nervous system regulates unconscious body functions including heart rate, blood pressure, sweating, temperature regulation, and metabolic and endocrine responses to stress. Autonomic dysfunction (or disorders of the autonomic nervous system) is extremely common in individuals with SCI above T6, leading to cardiovascular consequences: autonomic dysreflexia (AD),[4] orthostatic hypotension (OH)[5] and abnormal heart rhythms (arrhythmias). In addition, paralysis after SCI results in a series of metabolic consequences, which include increased abdominal and visceral obesity, reduced muscle mass, changes in muscle fibre type (preponderance of type II fibres), and activation of inflammatory and prothrombotic biomarkers. Appropriate assessments, intervention and/or management of these risk factors should reduce CVD-related mortality and morbidity, associated with these health conditions. Routine cardiovascular integrity screening is essential for primary and secondary prevention of CVD, improved quality of life, wellbeing and survival.

FIGURE 1.0 POTENTIAL MECHANISMS RESPONSIBLE FOR THE DEVELOPMENT OF CVD, AMONG INDIVIDUALS WITH SCI.



Autonomic Dysreflexia: Can be Dangerous if Not Recognized and Treated

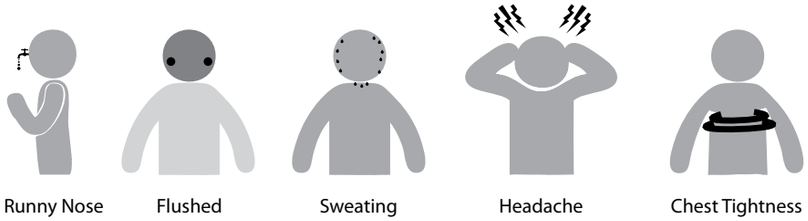
Autonomic Dysreflexia (AD) is a sudden 20-40 mmHg increase in blood pressure above baseline, in response to a noxious or non-noxious stimulus, below the level of the SCI (Table 1.0). AD is typically associated with a specific constellation of signs and symptoms, including headache, sweating, goose bumps, facial flushing above the level of the injury, and pallor below the level, a runny nose, and irritability or a sense of doom. Even small changes in blood pressure, combined with these symptoms, require urgent attention. Severe, prolonged AD is a life-threatening emergency and can result in stroke, angina, heart attack, seizure, retinal hemorrhage, arrhythmia or death, if not recognized. AD is easily managed, if recognized early and treated appropriately. An approach to the treatment of AD is outlined later in this chapter.

Major signs and symptoms of AD that individuals often present, within emergency departments, are reported in Figure 2.0.

TABLE 1.0 CAUSES OF AUTONOMIC DYSREFLEXIA

COMMON CAUSES OF AD		UNCOMMON CAUSES OF AD	
BODY SYSTEM	CAUSES	BODY SYSTEM	CAUSES
Bladder	Distension, Urinary Tract Infection (UTI), Detrusor Sphincter Dyssynergia	Urinary Tract and Genitals	Bladder or Kidney Stones, Epididymitis, Scrotal Compression, Coitus, Menses, Pregnancy
Bowel	Distension, Hemorrhoids	Skin	Pressure Sores, Burns, Blisters, Bites, Pressure from Tight, Hard or Sharp Objects
Skin	Constrictive Clothing/ Device, Pressure Sore, Ingrown Toenail	Musculo-skeletal	Heterotopic Bone, Fractures, Trauma
OTHER	CAUSES		
Tests/ Diagnostics Surgery/ Pregnancy (Iatrogenic)	Cystoscopy/Urodynamic Colonoscopy/Suctioning Vibrostimulation for Sperm Retrieval Uterine Contraction /Delivery of Children		

FIGURE 2.0 CONSTELLATION OF SIGNS AND SYMPTOMS OF AUTONOMIC DYSREFLEXIA



Orthostatic Hypotension

Orthostatic hypotension (OH) results in lightheadedness, dizziness, headache or fainting in response to an inadequate adaptation of blood pressure to changes in posture, typically when changing position from lying to sitting, or sitting to standing. OH is defined by a sudden 20mmHg drop in systolic blood pressure or a 10 mmHg drop in diastolic blood pressure, associated with changes in posture and altered cognition. This condition may be asymptomatic, and is often aggravated by exposure to hot conditions (weather, hot showers, or prolonged seating in a wheelchair).

Current Canadian Practice - CVD Prevention and Management

CURRENT AVAILABLE GUIDELINES TO SCREEN AND MANAGE CVD RISKS IN INDIVIDUALS WITH SCI

It is widely held that best practice involves the quantitative assessment of absolute CVD risk, followed by management, with therapeutic lifestyle changes (TLC) and pharmacotherapy. TLC are effective therapies used to reduce CVD risks or improve cardiovascular integrity, and include increases in physical activity, optimization of dietary intake and weight management strategies. Assessment of CVD risk becomes a critical link to achieve guideline-based primary and secondary disease prevention. Although current strategies for reducing CVD risk have not been customized for individuals with SCI, it is likely that the strategies designed for able-bodied individuals may be used or adapted for individuals with SCI. Current guidelines (for clinical practice and consumers) and currently available risk assessment tools are listed in Tables 2.0 to 4.0.

TABLE 2.0 GUIDELINES FOR PREVENTION AND MANAGEMENT OF LIFESTYLE-RELATED CVD RISK FACTORS

CVD

- Cragg JJ, Stone JA, Krassioukov AV. Management of cardiovascular disease risk factors in individuals with chronic spinal cord injury: an evidence-based review. *J Neurotrauma*. 2012;29(11):1999-2012.

OBESITY

- Lau DCW, Douketis JD, Morrison KM, et al. 2006 Canadian clinical practice guidelines on the management and prevention of obesity in adults and children. *CMAJ.* 2007;176(Suppl. 8):S1-13. http://www.cmaj.ca/cgi/content/full/176/8/S1/DC1. Accessed August 20, 2012.

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- Alberti KG, Zimmet PZ. Definition, diagnosis and classification of diabetes mellitus and its complications. Part 1: diagnosis and classification of diabetes mellitus provisional report of a WHO consultation. *Diabet Med*. 1998;15(7):539-53

- Expert Panel on Detection, Evaluation, and Treatment of High Blood Cholesterol in Adults. Executive summary of the third report of the national cholesterol education program expert panel on detection, evaluation, and treatment of high blood cholesterol in adults (Adult Treatment Panel III). *JAMA*. 2001;285(19):2486-97

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HYPERTENSION

- Daskalopoulou SS, Khan NA, Quinn RR, et al. The 2012 Canadian Hypertension Education Program recommendations for the management of hypertension: blood pressure measurement, diagnosis, assessment of risk, and therapy. *Can J Card*. 2012; 28(3):270-87.

PERIPHERAL VASCULAR DISEASE

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DEEP VEIN THROMBOSIS

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TABLE 3.0 GUIDELINES AND APPROACHES FOR PHYSICAL ACTIVITY AND NUTRITION

PHYSICAL ACTIVITY

- SCI Action Canada. *Physical Activity Guidelines for Adults with Spinal Cord Injury*. Hamilton, ON: McMaster University; 2011. http://www.sciactioncanada.ca/guidelines/ (see Physical Activity Chapter).

NUTRITION

- Health Canada. *Eating Well with Canada's Food Guide.* Health Canada; 2011. http://www.hc-sc.gc.ca/fn-an/food-guide-aliment/index-eng.php/
- Block G, Hartman AM, Dresser CM, Carroll MD, Gannon J, Gardner L. A data-based approach to diet questionnaire design and testing. *Am J Epidemiol*. 1986;124(3):453-69.
- Subar AF, Kirkpatrick SI, Mittl B, et al. The automated self-administered 24-hour dietary recall (ASA24): A resource for researchers, clinicians, and educators from the National Cancer Institute. *J Acad Nutr Diet*. 2012;112(8):1134-7. http://www.sciencedirect.com/science/article/pii/S2212267212005898 Accessed September 24, 2012.
- Academy of Nutrition and Dietetics (formerly American Dietetic Association). SCI: Nutrition Screening for Lipid Abnormalities. *Spinal Cord Injury Evidence-Based Nutrition Practice Guideline.* ADA Evidence Analysis Library; 2012. http://www.adaevidencelibrary.com/topic.cfm?cat=3485. Accessed August 21, 2012.

TABLE 4.0 GUIDELINES AND APPROACHES FOR AUTONOMIC DYSFUNCTION AND ORTHOSTATIC HYPOTENSION

AUTONOMIC STANDARD ASSESSMENT

- Alexander MS, Biering-Sorensen F, Bodner D, et al. International standards to document remaining autonomic function after spinal cord injury. *Spinal Cord.* 2009;47(1):36-43.

AUTONOMIC DYSREFLEXIA (AD)

- Consortium for Spinal Cord Medicine. Acute management of autonomic dysreflexia: adults with spinal cord injury presenting to healthcare facilities. *J Spinal Cord Med*. 1997;20(3):284-308.
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- Consortium for Spinal Cord Medicine. *Autonomic Dysreflexia: What You Should Know*. Washington, DC: Paralyzed Veterans of America; 1997. http://www.scicpg.org/cpg_cons_pdf/ADC.pdf. Accessed August 20, 2012.

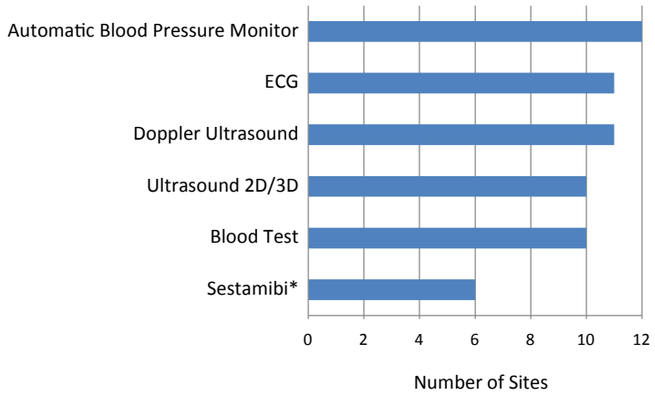
ORTHOSTATIC HYPOTENSION (OH)

- The Consensus Committee of the American Autonomic Society and the American Academy of Neurology. Consensus statement on the definition of orthostatic hypotension, pure autonomic failure, and multiple system atrophy. *Neurology*. 1996;46(5):1470.

What Cardiovascular Integrity Diagnostic Services are Available in Canada? Lifestyle-related CVD:

Although many SCI rehabilitation facilities, across Canada, possess CVD diagnostic devices (Figure 3.0), their use varies substantially: only three sites report routine conduct of these assessments, and two others report using them either as appropriate or sometimes. Physiatrists, pharmacists and nurses, at three of the 12 sites, routinely conduct assessment and management of CVD risk (e.g., blood glucose, lipid profile, blood pressure, weight monitoring, and smoking cessation counselling and intervention), for clinical purposes. One site routinely conducts CVD risk assessment, and another reports sporadic CVD risk assessment. Given the morbidity associated with CVD, this rate of service utilization is inadequate to diagnose and change the natural history of CVD, in this population. In terms of advanced CVD assessment, one site reports use of the ankle brachial index, as an index of peripheral vascular disease. One site reports long-term assessment of CVD risk, over time. Clearly, uptake of these assessments, nationally, is needed to reduce CVD-related morbidity and mortality. Nutritional assessments are conducted at several sites, but the extent of the practice varies. Five of 12 sites report that they routinely provide nutrition assessments. Six sites report conducting nutrition assessments (as indicated by using Food Frequency Questionnaires), a modified food record, and 24-hour recall, conducted by dietitians and nutritionists. Physical activity is one of the key factors associated with CVD risk (for assessment details see Physical Activity chapter).

FIGURE 3.0 AVAILABLE CVD DIAGNOSTIC TESTS AND EQUIPMENT



**Sestamibi: test to look at the blood supply to the muscle of heart and the function of the heart muscle.*

Autonomic Dysfunction Related to CVD

Management of AD varies and is often site dependent (Figure 4.0). The Paralyzed Veterans of America (PVA) Consumer Guide *Autonomic Dysreflexia: What You Should Know* (www.pva.org) has been used for patient education at most E-Scan sites (10 of 12). Within the sites, six reported using PVA guidelines routinely, and four sites report using them when deemed appropriate. Individuals with SCI are routinely provided with AD wallet-sized information cards summarizing the signs, symptoms and management of AD, to serve as a medical alert in an emergency room setting, after discharge from inpatient rehabilitation. Nurses, physiatrists, physiotherapists and/or urologists, at these sites, typically distribute wallet cards. GF Strong routinely distributes a customized AD card. Additionally, two sites use modified AD assessment tools, at their sites. Given the documented lack of knowledge (regarding the recognition and management of AD, among emergency service practitioners in tertiary health science centres reported in only three provinces - British Columbia, Manitoba and Ontario), the practice of carrying wallet cards is prudent and should be universal. Also, given that an *ABC of AD* certification course has been developed (by a collaboration of Canadian researchers and clinicians), promotion of AD training and certification among patients, family members, rehabilitation team members and emergency room personnel should be a key focus of continuing professional development, in rehabilitation and rehabilitation-related care settings.

Unfortunately, no sites report routine assessment of OH. OH can be assessed via sympathetic skin responses (SSR) and/or the Sit Up Test, a key element of the autonomic standards, and a recent addition to the International Standards for the Neurological Classification of Spinal Cord Injury (reference in Table 4.0). Only one of 12 sites reports conduct of the SSR, by a nurse or physical therapist. Assessment and management using testing of postural blood pressure, autonomic testing, bedside blood pressure monitoring, orthostatic blood pressure monitoring and/or 24-hour blood pressure monitoring are conducted. However, these approaches were reported to occur at only one site. This could be related to an error in reporting by individuals responsible for the E-Scan data collection, at each site or, alternatively, there are no formalized protocols established. Of concern is that, no matter the approach, basic blood pressure monitoring is not being internalized in SCI rehabilitation environments, with the likely consequence that the relationship of blood pressure to OH may not be readily recognized - unless the patient reports presyncope or syncope symptoms.

Approaches to Management of Autonomic Dysreflexia

Managing AD requires a consistent approach to ensure that the individual receives the appropriate management, in a timely manner. Figure 5.0 demonstrates a protocol that has been established, for when the patient presents with the signs and symptoms, which can be used for non-drug management. Rehabilitation programs routinely utilize these approaches.

FIGURE 4.0 PARALYZED VETERANS OF AMERICA GUIDELINE AND AD WALLET CARD UTILIZATION, ACROSS E-SCAN SITES

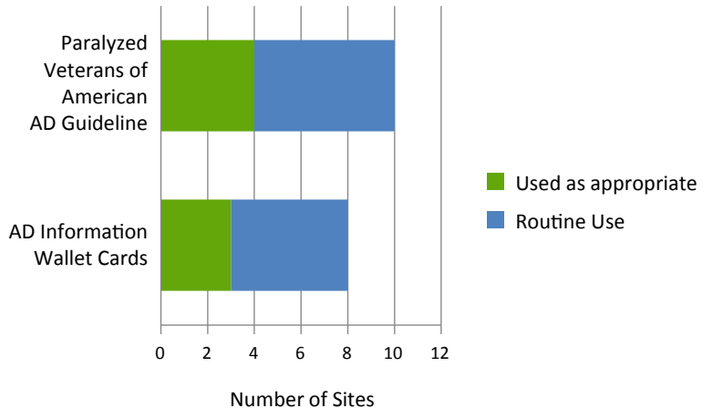
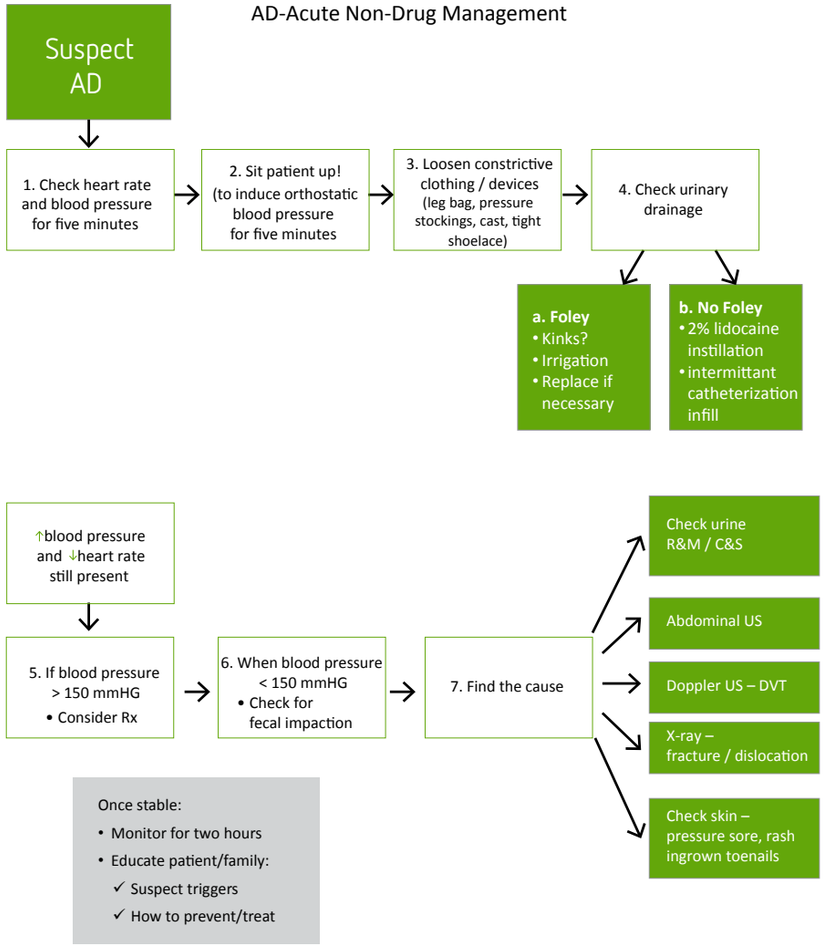


FIGURE 5.0 NON-DRUG AND PHARMACOTHERAPY OF AUTONOMIC DYSREFLEXIA



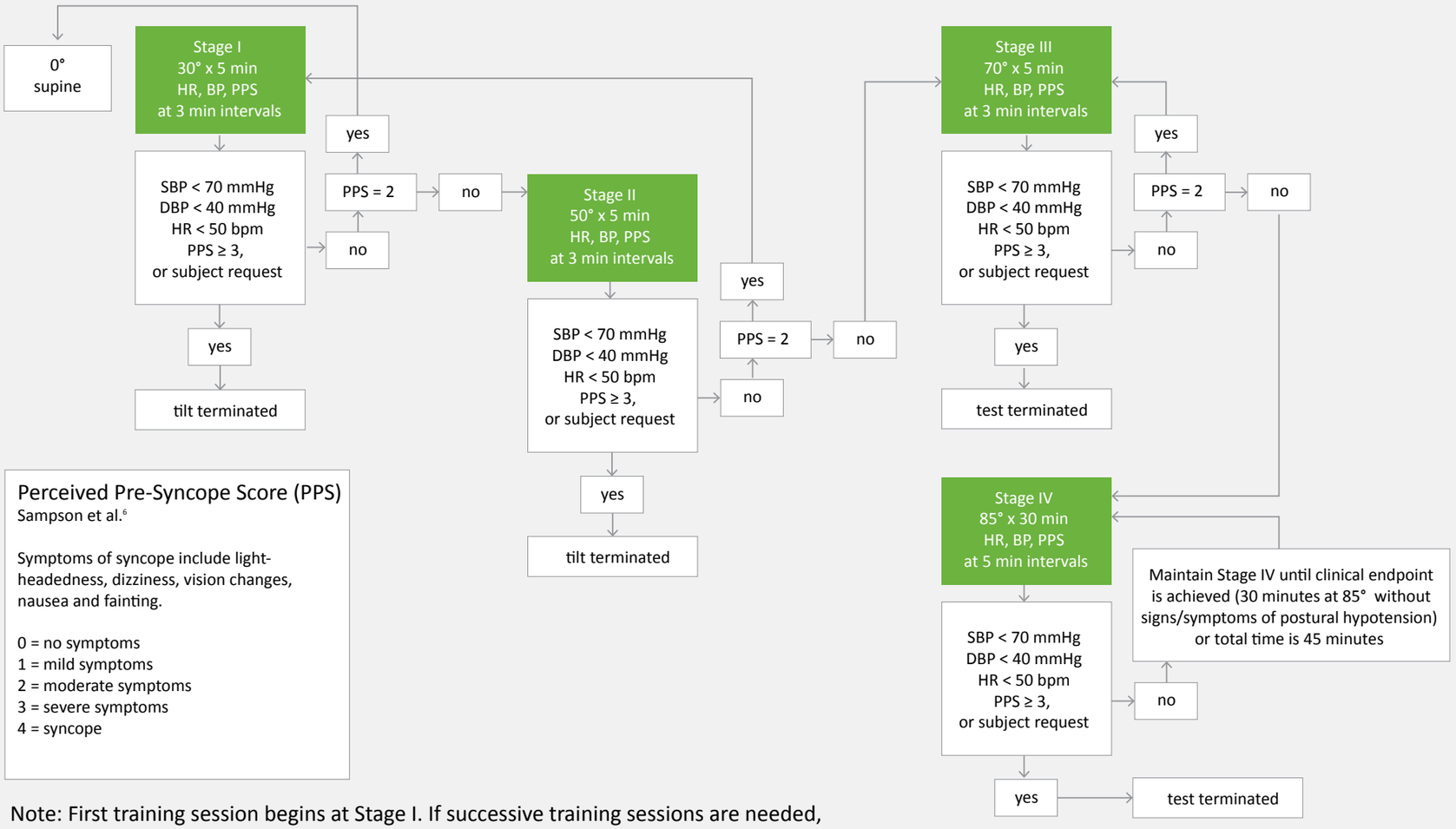
The PVA Guideline for management of AD is well established, and utilized by some programs, some of the time (Figure 4.0). Equally important is that healthcare providers, outside rehabilitation sites, recognize and have an approach for management of AD, when individuals with SCI present in emergency departments (or other medical care environments), where health professionals may be less familiar with AD. Individuals with SCI, who have received rehabilitation from some of the E-Scan sites, carry wallet cards. Again, this is not a universal practice and more attention to this approach, and other related knowledge translation efforts, would go a long way to ensure best practice, and to minimize adverse outcomes of untreated AD.

Approaches to Management of Orthostatic Hypotension

The Toronto Lyndhurst Centre tilt table protocol, a postural retraining method, is done at most sites (ten of the 12), either as appropriate (seven sites) or sometimes (three sites). Other OH-related assessments are done as appropriate (four sites), and sometimes (one site). In addition, the TLC tilt table protocol is used in an on-going research study, at one site. Use of the postural retraining protocol (Figure 6.0), in most sites, demonstrates how development of a specific protocol can lead to uptake of the approach, for the betterment of individuals and the field.

FIGURE 6.0 TORONTO LYNDHURST SITE POSTURAL RETRAINING PROTOCOL

REPRODUCED FROM CRAVEN BC, BUGARESTI JM, MCGILLIVRAY CF, ADACHI RJ, NANTAIS TC, PEPPER I. THE DEVELOPMENT AND EVALUATION OF A POSTURAL RETRAINING PROTOCOL FOR PERSONS WITH SPINAL CORD INJURY. *J SPINAL CORD MED.* 2002;25(1):S38B. © 2002 W.S. MANEY & SON LTD. REPRINTED WITH PERMISSION.



Note: First training session begins at Stage I. If successive training sessions are needed, begin at the last completed stage (i.e., stage maintained for 15 minutes and PPS < 2). The maximum number of training sessions is five.

CVD is now recognized as the leading cause of morbidity and mortality, after SCI. Further, AD (the autonomic dysfunction accompanying SCI, particularly), is recognized as a life-threatening condition and contributes to arterial disease. Nevertheless, less than half the E-Scan sites (five of 12) report that they conduct CVD risk assessments routinely/as appropriate - likely because of the tendency of SCI clinicians to attend more to neurologic assessments, and to diagnose and treat infectious conditions; and/or the paucity of longitudinal follow-up programs. However, CVD risk factor evaluation should be an integral part of routine clinical assessments, for all individuals with SCI, during inpatient rehabilitation and across their lifespan, after discharge into the community.

Cardiovascular Rehabilitation

Cardiac rehabilitation is also important for individuals diagnosed with heart disease. Participation in cardiac rehabilitation programs, which emphasize exercise, can lower chances of cardiac-related death by about 20 percent. Currently, eight of the 12 sites have some type of cardiac rehabilitation service for their patients, whether screening and/or assessment and services.

Metabolic Syndrome Screening

Metabolic syndrome is a term used to describe a group of conditions that puts individuals at higher risk of developing heart disease and/or type II diabetes. According to an American Heart Association/National Heart, Lung and Blood Institute scientific statement (AHA/NHLBI), metabolic syndrome is defined if there are any of three or more conditions (see Table 2.0). Criteria used for this assessment are seen in Table 5.0.

TABLE 5.0 SCREENING CRITERIA FOR METABOLIC SYNDROME

REPRODUCED FROM GRUNDY SM, CLEEMAN JI, DANIELS SR, ET AL. DIAGNOSIS AND MANAGEMENT OF THE METABOLIC SYNDROME: AN AMERICAN HEART ASSOCIATION/NATIONAL HEART, LUNG, AND BLOOD INSTITUTE SCIENTIFIC STATEMENT. *CIRCULATION.* 2005;112:2735-52. © 2005 AMERICAN HEART ASSOCIATION, INC. REPRINTED WITH PERMISSION.

Elevated waist circumference:	Men ≥ 40 inches (102 cm) Women ≥ than 35 inches (88 cm)
Elevated triglycerides:	≥ 150 mg/dL (1.7 mmol/L) or on drug treatment for elevated triglycerides
Reduced HDL cholesterol:	Men ≤ 40 mg/dL (1.03 mmol/L) Women ≤ 50 mg/dL (1.3 mmol/L) or on drug treatment for reduced HDL cholesterol
Elevated blood pressure:	≥ 130/85 mm Hg or on antihypertensive drug treatment, in a patient with a history of hypertension
Elevated fasting glucose:	≥ 100 mg/dL (5.6 mmol/L) or use of medication for hyperglycemia

However, according to the report by the SHAPE-SCI Research Group, metabolic syndrome definitions underestimate true CVD risks, in individuals with SCI,[7] and C-reactive protein (CRP) is a well-established constellation of CVD, in the general population. In fact, among individuals with SCI, CRP may be a potential factor to consider, in the development of SCI-specific screening tools, instead of using metabolic syndrome definitions. CRP cut points of 3.1-9.9, 1.0-3.0 and < 1.0mg/L indicate high, average and low heart disease risk.[8]

Cardiovascular Fitness Testing

It is well known that low cardiovascular fitness (VO_2peak: ml/kg/min), assessed by maximal exercise testing, is one of the key risk factors of CVD, in the general population. Like other sites in the country, Toronto's Lyndhurst Centre is currently working on a *clinical protocol*, for implementation of maximal exercise testing, using both arm and leg ergometry, among individuals with tetraplegia. Current results indicate that 10% of individuals (two of 20) experienced early termination of the test, before reaching their peak volitional effort; and 20% (five of 20) were unable to complete the test. Reasons for VO_2peak test termination were related to arm, leg and general fatigue; along with abdominal spasm, dyspnea, insufficient hand strength and shoulder pain. One individual reached physiological maximum. Establishing the VO_2 peak, duration (min) and power (kpm) parameters for test termination will assist the development of the much-needed testing protocols. It appears that maximal exercise testing can be attained in individuals with tetraplegia, by customization of the test protocols.

SUGGESTED ADAPTATIONS FOR EXERCISE TESTING AMONG INDIVIDUALS WITH TETRAPLEGIA

- ✔ Leg ergometry for those with AIS C or D impairment and LEMS > 20
- ✔ Reduced leg ergometry work loads of < 100kpm/min
- ✔ Reduced arm ergometry work loads of 30kpm/min
- ✔ Grip adaptations (e.g. velcro gloves)

Ongoing Cardiovascular Health-Related Research

Much of what we know about cardiovascular health and/or CVD, in individuals with SCI, has come from researchers in academic health science centers, in Canada (University of British Columbia, University of Toronto, McMaster University and Brock University), and their affiliated clinical rehabilitation programs (GF Strong, Centre for Health Promotion and Rehabilitation and TRI-UHN Lyndhurst Brain and Spinal Cord Rehab Program), where therapists, clinicians and scientists often interact regarding best practices (Table 6.0). These sites are forging ahead with new research on cardiovascular physiology, assessments and new interventions for optimizing cardiovascular health, in individuals with SCI. Additionally, researchers in these sites have been collaborating in attempts to minimize redundancy in research, and to enhance translation of research evidence to clinical practices.

Researchers and clinicians, in these institutes, have recently begun cardiovascular studies using pulse wave velocity assessments (a gold standard method to assess arterial stiffness), taking note of the clinical benefit of this method, as a novel assessment of CVD risk, in the SCI population.

TABLE 6.0 CURRENT CARDIOVASCULAR HEALTH RESEARCH, FOR INDIVIDUALS WITH SCI, IN CANADIAN REHABILITATION SITES

SITES	RESEARCH FOCUS	LEADS
UBC GF Strong ICORD	• Autonomic Dysfunctions (AD and OH) • Cardiovascular Health/Effects of Exercise • Targeted Education • Physical Activity and Heart Rate Levels	Andrei Krassioukov, MD, PhD Darren Warburton, PhD Janice Eng, PhD
TRI-UHN	• Associations between Arterial Stiffness and CVD Risk Factors • Physical Activity and Heart Rate Levels	Masae Miyatani, PhD Cathy Craven, MD, MSc Paul Oh, MD, PhD Molly Verrier, MHSc
McMaster University Centre for Health Promotion and Rehabilitation	• Effect of BWSTT on Cardiovascular Health • Exercise Guidelines for Cardiovascular Health • Effect of Exercise on Cardiovascular Health	Audrey Hicks, PhD Kathleen Martin Ginis, PhD Maureen MacDonald, PhD
University of Guelph	• Body Composition, Energy Expenditure and Chronic Disease Risk	Andrea Buchholz, PhD
Brock University	• Secondary Health Complications and Effect of Exercise on Cardiovascular Health	Dave Ditor, PhD

What is Required for Best Practice?

Many CVD risk factors are modifiable by changing lifestyle and/or pharmacotherapy, in the normal population, and can be transferred to individuals with SCI. Moreover, the management of CVD risks continues to be improved, as risk assessment tools become more accurate, and treatment interventions more effectively targeted. However, CVD is often asymptomatic and has, therefore, been undertreated. Facilitating cardiovascular integrity, in a rehabilitation setting, requires a coordinated CVD risk management system of health professionals (family practice physicians, physiatrists, cardiologists, nurses, dietitians, physiotherapists, occupational therapists, pharmacists and kinesiologists) and patient educators. As well, integrated strategies and best practice indicators, to achieve better CVD risk assessment and management, in Canada, for individuals with SCI, are warranted.

BEST PRACTICE INDICATORS

To address current gaps in practice, the following best practice indicators, for SCI cardiac rehabilitation, need to be developed:

- Individual education and consultation regarding lifestyle self-management (e.g., smoking, stress, diet, and physical activity), using e-learning approaches
- Lifestyle-related CVD risk assessment (e.g., hypertension, hyperlipidemia, obesity, diabetes) using standard validated protocols, at all annual follow-up visits, with a physiatrist
- Assessments of autonomic function, for individuals with tetraplegia, as a ***standard of care*** in all SCI rehabilitation sites, and incorporated into Canadian Accreditations Standards
- Wallet cards for recognizing AD as a standard practice, matching the prominence of medical alert wristbands
- Documentation in all health records to demonstrate that education has been provided to individuals for the management of AD, post discharge from rehabilitation
- Training on the signs of AD and OH, in the medical and health professional curricula (particularly emergency medicine), at all Academic Health Science Centres in Canada
- Standard guidelines for the provision of Cardiac Rehabilitation for the acute, sub-acute, rehabilitation and chronic phases of SCI, by Canadian Physiatry and Rehabilitation Medicine
- Training module for a standard CVD screening protocol for individuals with SCI, by SCI clinicians and researchers, for introduction at the 6th National Spinal Cord Conference, in 2014.

SPOTLIGHT BEST PRACTICE ORGANIZATION

SPINAL CORD INJURY PROGRAM – GF Strong Rehabilitation Centre, Vancouver Coastal Health, Vancouver

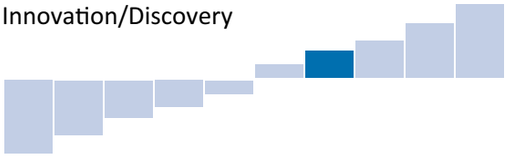
Dr. Andrei Krassioukov, Associate Director of Rehabilitation Research for ICORD, and his colleagues at UBC and GF Strong, Drs. Warburton, Eng and Townson, have been building a translational research enterprise with a focus on CVD, OH and AD. Their clinical research program spans from animal models to human studies to community applications (e.g., conducting research on AD during the 2012 Paralympic Games, where they assisted with education and research, as part of a cardiovascular clinic). As Principal Investigator, on a recently-awarded CIHR team grant, Dr. Krassioukov will work with four major SCI research and rehabilitation academic centres (Vancouver, Winnipeg, Toronto and Hamilton) to focus on cardiovascular health, in individuals with chronic SCI: locomotor training, education and knowledge translation - a first for Canadian spinal cord rehabilitation. The leadership on development of international standards, combined with a set of guidelines and education for addressing AD for clinicians, emergency room physicians and paramedics, shows how Vancouver is leading the way, both nationally and internationally, to put standards into practice. At GF Strong, in addition to completing an ASIA assessment, every individual is assessed for autonomic dysfunctions, using the new international standards for documentation of autonomic functions after SCI (ISAFSCI) that were approved in 2012 - a first for Canada.

REPORT CARD: Cardiovascular Integrity

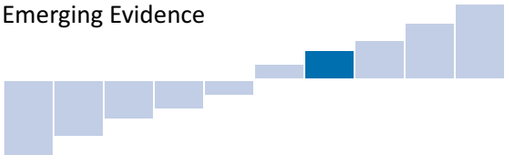
Extreme left below median: ***insufficient***
Extreme right above median: ***optimal***

KNOWLEDGE GENERATION

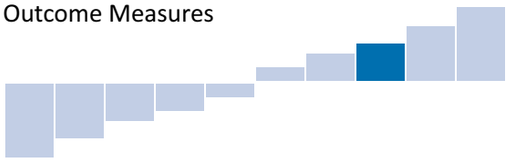
Innovation/Discovery



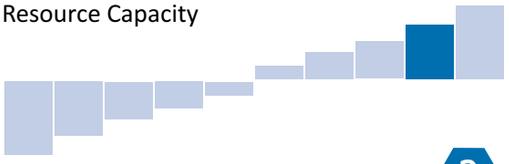
Emerging Evidence



Outcome Measures



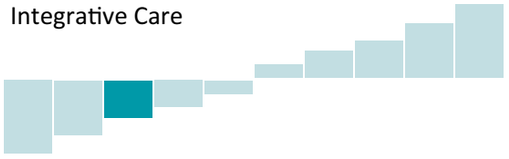
Resource Capacity



2020 PRIORITY 3

CLINICAL APPLICATION

Integrative Care



Effective Practice
(Evidence and Outcomes)

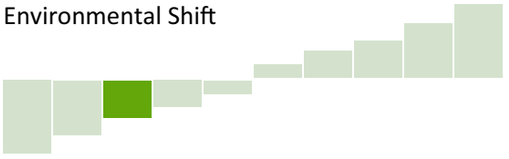
Equity Practice

Capacity

2020 PRIORITY 1

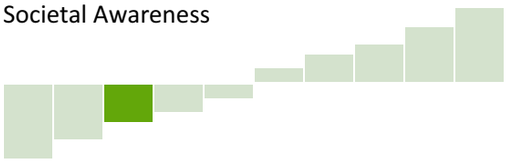
POLICY CHANGE

Environmental Shift

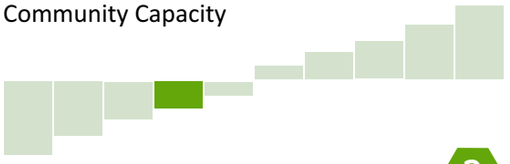


Change Agents

Societal Awareness



Community Capacity



2020 PRIORITY 2

TAKE HOME MESSAGE:

The prevention and rehabilitation of CVD, for individuals with SCI, is a major challenge due to the complexities of the added risk factors that SCI brings. The field is moving forward with SCI-specific research, but the practice, prevention and policy development lags behind. The immediate adoption of existing protocols for OH and AD testing, in all SCI rehabilitation sites, should be mandatory. The "customization" of care in cardiometabolic syndrome after spinal cord injury that has been suggested by Nash et al is embraced.[9] A well-constructed, integrated approach (including the creation of a national, interprofessional SCI CVD Working Group to deliver a strategic plan for the management of CVD, utilizing a concerted research-to-practice approach), is obligatory, if CVD-related morbidity and mortality, among Canadians with SCI, are to be reduced.

RESOURCES

1. Bauman WA, Spungen AM. Coronary heart disease in individuals with spinal cord injury: assessment of risk factors. *Spinal Cord*. 2008;46(7):466-76.

2. Myers J, Lee M, Kiratli J. Cardiovascular disease in spinal cord injury: an overview of prevalence, risk, evaluation, and management. *Am J Phys Med Rehabil*. 2007;86(2):142-52.

3. Warburton DER, Sproule S, Krassioukov A, Eng JJ. Cardiovascular health and exercise following spinal cord injury. In: Eng JJ, Teasell RW, Miller WC, et al., eds. *Spinal Cord Injury Rehabilitation Evidence*. Version 4.0. Vancouver, BC; 2012:1-43.

4. Krassioukov A, Blackmer J, Teasell RW, Eng JJ. Autonomic dysreflexia following spinal cord injury. In: Eng JJ, Teasell RW, Miller WC, et al., eds. *Spinal Cord Injury Rehabilitation Evidence*. Version 4.0. Vancouver, BC; 2012:1-31.

5. Krassioukov A, Wecht JM, Teasell RW, Eng JJ. Orthostatic hypotension following spinal cord injury. In: Eng JJ, Teasell RW, Miller WC, et al., eds. *Spinal Cord Injury Rehabilitation Evidence.* Version 4.0. Vancouver, BC;2012:1-21.

6. Sampson EE, Burnham RS, Andrews BJ. Functional electrical stimulation effect on orthostatic hypotension after spinal cord injury. *Arch Phys Med Rehabil.* 2000;81(2):139-43.

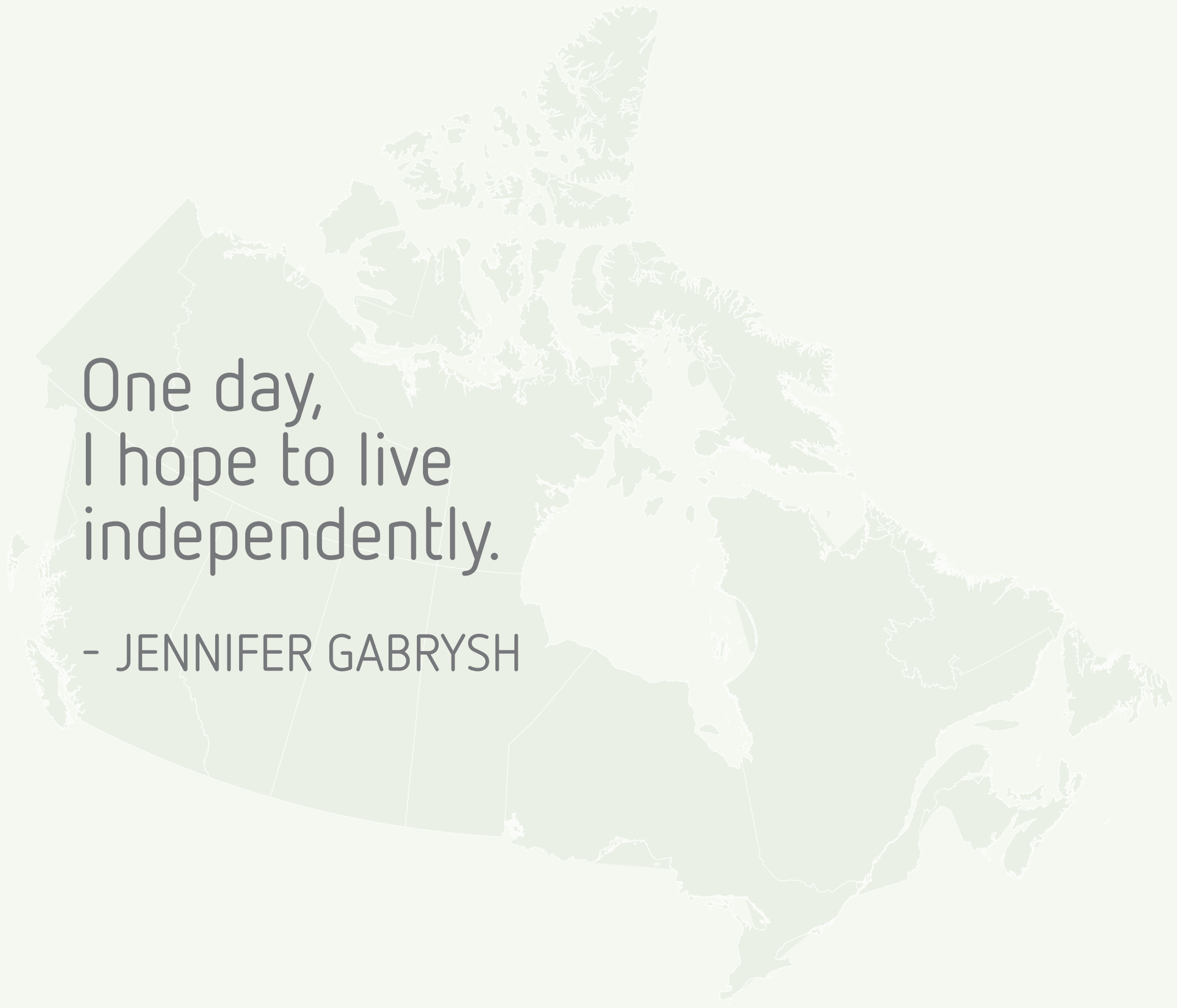
7. Finnie AK, Buchholz AC, Martin Ginis KA, and the SHAPE-SCI Research Group. Current coronary heart disease risk assessment tools may underestimate risk in community-dwelling persons with chronic spinal cord injury. *Spinal Cord.* 2008;46:608-15.

8. Pearson TA, Mensah GA, Alexander RW, et al. Markers of inflammation and cardiovascular disease. Application to clinical and public health practice: a statement for healthcare professionals from the Centers of Disease Control and Prevention and the American Heart Association. *Circulation*. 2003;107:499-511.

9. Nash MS, Cowan RE, Kressler J. Evidence-based and heuristic approaches for customization of care in cardiometabolic syndrome after spinal cord injury. *J Spinal Cord Med*. 2012;35(5):278-92.

Activity


ENVIRONMENTAL FACTORS
PERSONAL FACTORS
Activity
Household Mobility
Independent Bathing
Community Participation
Ameliorate Neuropathic Pain
Bowel Continence
Bladder Continence
Independent Eating
Informed Self Management
Walking
Wheeled Mobility
Recreation & Leisure Activity
Emotional Wellbeing
Cognitive & Behavioural Adjustment
Independent iADL
Employment & Vocation
Limit Metabolic Dysfunction
Spine Stabilization
Community Mobility
Utilize Technology
Postural Transitions & Balance
Skin Integrity
Independent Dressing
Accessible Housing
Skeletal Integrity
Immune Function
Independent Transfers
Sexual Health
Reaching, Grasping & Manipulation
Promote Neurorecovery
Driving
Physical Activity
Cardiovascular Integrity
Swallowing
Parenting
Independence in Breathing
Spirituality
Optimize Spasticity
Body Structure and Function
Participation



One day,
I hope to live
independently.

- JENNIFER GABRYSH

Wheeled Mobility

C Smith, MSc; L Titus, BScOT; DL Wolfe, PhD; C Craven, MD; RL Kirby, MD; and the E-Scan Investigative Team

Wheeled mobility refers to the skilled use of any personal device with wheels, by individuals with physical impairments such as spinal cord injury (SCI), in order to allow full participation in daily life (Figure 1.0).

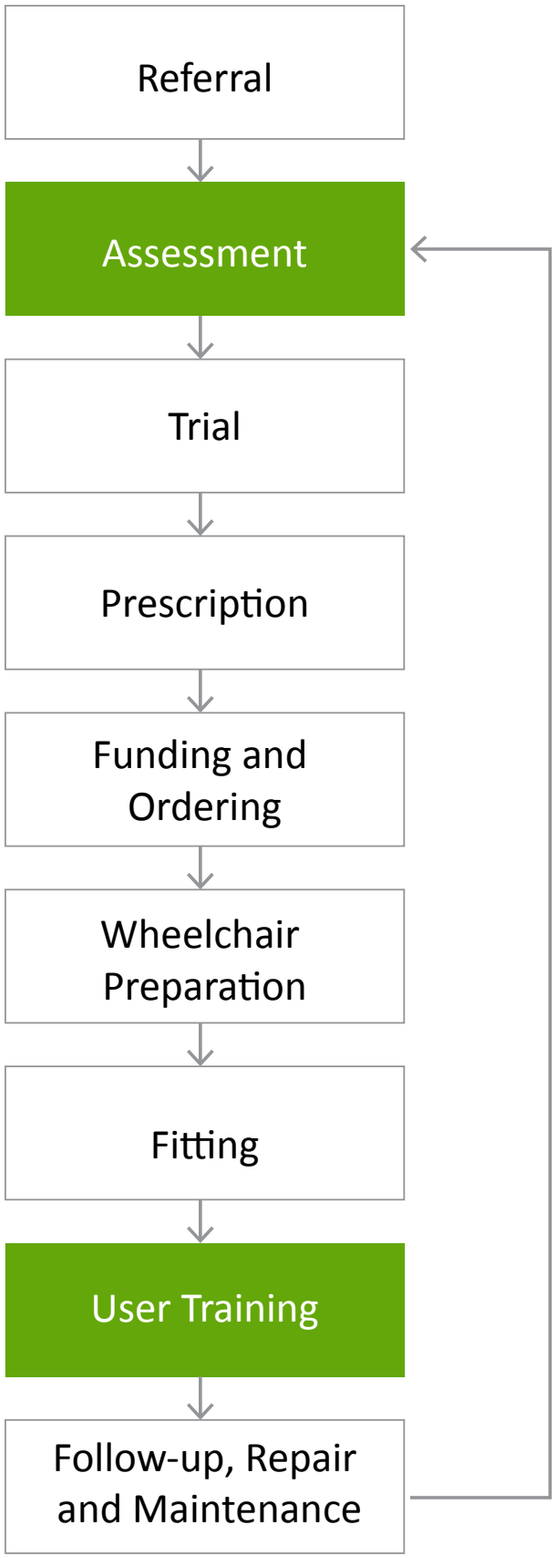
Effective wheeled mobility involves many functional and health-related aspects. In the context of the International Classification of Functioning, Disability and Health, mobility is a means of enabling an individual to overcome limitations on participating in an activity, despite SCI. To effectively overcome such limitations, the provision of an appropriate device is necessary.

Many aspects of mobility should be considered when making decisions about an appropriate device to enhance health, activity and participation. These include:

- Sitting in a supported and comfortable position, allowing the individual to sit still and to reach, during and when interacting with the environment
- Moving from place to place in the individual's home and community, either alone or with assistance
- Transferring between surfaces (e.g., from bed into a wheelchair), safely and efficiently
- Maintaining health (e.g., preventing pressure sores and/or shoulder pain).

FIGURE 1.0 POWER CHAIR AND INTERACTION WITH THERAPIST REGARDING KITCHEN MOBILITY

FIGURE 2.0 ESSENTIAL SERVICE PROVISION COMPONENTS.
BASED ON THE WHO WHEELCHAIR SERVICE TRAINING PACKAGE: BASIC MODULE.[2]



The wheelchair is the most commonly chosen mobility device and, arguably, the most important assistive device for individuals with SCI and lower limb paralysis. For functional mobility, an individualized approach to the wheelchair provision process is essential. Appropriate seating and mobility systems vary significantly, ranging from an ultra light-weight, rigid-framed wheelchair, mobilized by manually rolling the wheels, to a fully powered wheelchair, driven by breathing into a straw connected to a controller. It is essential that the wheelchair provided is customized for the individual's physical and functional needs. According to World Health Organization (WHO) guidelines,[1] a wheelchair is deemed appropriate when it:

- Meets the user's needs and environmental conditions
- Provides proper fit and postural support
- Is safe and durable
- Is available in the country, and
- Can be obtained, maintained and serviced, at an affordable cost.

Although other types of mobility devices such as Segways, scooters or standing wheelchairs have been investigated, manual or power wheelchairs are the most common wheeled mobility devices, in Canada. These consist of a mobility base (providing the means of movement) and seating components (the support for function, comfort and health maintenance). To determine appropriate seating and mobility characteristics, several practice components require assessment and prescription by the rehabilitation provider (which would benefit from further study), and by researchers (Figure 2.0).

Practice Components

SERVICE PROVISION COMPONENTS ARE:

1. Referral - Required for access to appropriate service providers, which includes an interdisciplinary team, when necessary.

2. Comprehensive Assessment - This cornerstone of mobility device provision includes the following physical and communication components:

- Identification of the wheelchair user's goals, needs and priorities, as well as those of caregivers or family.
- Determination of the influence of health status, function within the user's environment(s), and physical needs such as comfort, skin integrity and posture.
- Determination of the level of wheelchair skills (current abilities and needs) to inform seating and mobility component requirements, and skills training to optimize functional mobility.
- Analysis of findings to identify the parameters and characteristics of the seating components and mobility base, to best meet the user's functional mobility needs.

3. Trial/Simulation - Selection of specific equipment to trial, ideally in the user's environment(s). At least one trial is recommended and, often, several are needed. If specific equipment is unavailable, a simulation of the products and their orientation is required.

4. Prescription – The team (including the user) finalizes and documents final decisions, rationale and details of the seating components and mobility base.

5. Funding - Access and degree of funding varies across Canada, affected by age and SCI characteristics. Often, justification reports and letters of medical necessity are required.

6. Wheelchair Preparation - Once received, the seating and mobility system requires assembly and set-up by the supplier/vendor, guided by prescription specifications.

7. Fitting - Fine-tuning adjustments, such as centre of gravity and back support angles, are customized while the user sits in the new wheelchair, to ensure comfort, postural and functional needs are met.

8. User Training - It is critical that wheelchair users and caregivers have the knowledge and skills to use the seating and mobility system, safely and effectively (see Figure 3.0). Key areas for training include:

- Wheelchair handling, such as folding or propelling/driving, and managing obstacles.
- Transfer in and out of the wheelchair, on various surfaces (e.g., on and off the bed, in and out of the car).
- Regular activities (e.g., pushing up ramps or slopes, and over curbs).
- Maintenance, including cleaning and tire pressure
- Pressure sore prevention with cushion maintenance and safe, weight-shifting techniques.

9. Follow Up, Repair and Maintenance - Follow-up assessment and review of the training progress are required to ensure that the system operates as intended, with proper comfort, function and physiological supports. If modifications are required because of wear, changes in health or functional status, the assessment process begins, again.

FIGURE 3.0 USER TRAINING

Current Practice: Wheeled Mobility

WHEELED MOBILITY IN REHABILITATION

The ultimate goal of rehabilitation processes (outlined above and illustrated in Figure 2.0) is to assist the individual with SCI to achieve maximal independence, and to enable participation in activities he/she finds most important and meaningful.

SERVICE PROVIDERS

Every participating E-Scan site (n=12) reports multiple services directed toward wheelchair service provision, although other forms of wheeled mobility were not included, explicitly, in the survey questions. Each site indicates conducting some form of wheelchair skills training and having a specialized seating service. In general, these sites report having multiple service providers involved in service delivery.

Figure 4.0 A is a summary of service providers that deliver wheelchair skills training, with consistency of type noted, across the country. Data was collapsed across multiple categories of skills training, which ranged from training both users and caregivers in manual or power wheelchair skills, to training in varying environments or other challenges (e.g., inclines, stairs, confined spaces, doorways, different surfaces, curb cuts, obstacles), and on specific skills (e.g., forward and backward rolling, steering, wheelies).

OTs are involved at all sites (100%) and PTs, at all but one site (n=11, 91.7%) but in a lesser number of training categories. OT assistants, PT assistants, and general rehabilitation therapy assistants support these professionals at six (50%) sites. Nurses also conduct some aspects of skills training at four (33%) sites (most often involving caregiver training). Less frequently (one or two sites), physiatrists, kinesiologists, mobility equipment suppliers/vendors, clinical dietitians, therapeutic recreation specialists and researchers are involved in some aspects of wheelchair skills training.

For seating service delivery (Figure 4.0 B), all sites (n=12) report having OTs, and six sites (50%) report having PTs involved, in addition to other providers such as OT assistants, physiatrists, mobility equipment suppliers/vendors and/or external consultants. Although not indicated, within the data specific to seating service provision, eight (67.6%) sites report having personnel who provide assessment and/or authorization to funders for assistive devices; and rehabilitation engineers or technicians, at six (50%) of the sites. Where available, rehabilitation engineers typically act as technical resources to the therapists, to customize mobility device components (e.g., joysticks, wheelchair set up), to better meet individual needs.

FIGURE 4.0. HISTOGRAMS SHOWING NUMBER AND VARIETY OF PROFESSIONALS PROVIDING (4.0 A) WHEELCHAIR SKILLS TRAINING AND (4.0 B) SPECIALIZED SEATING SERVICES, ACROSS E-SCAN SITES.

FIGURE 4.0 A

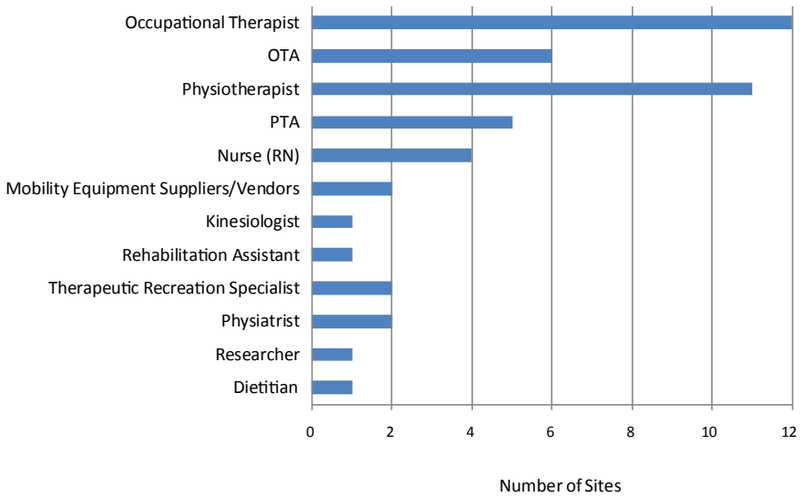
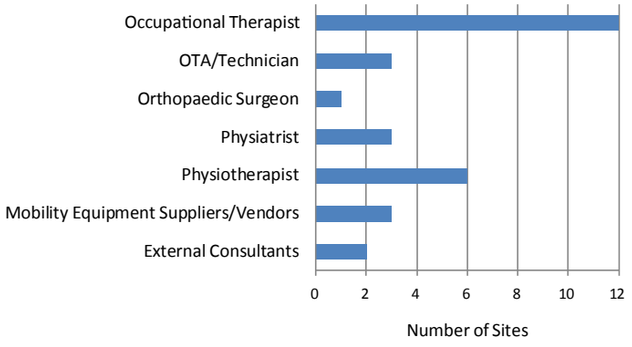


FIGURE 4.0 B



Clinical Protocols for Wheelchair Skill Development and Seating Services

Wheelchair skills training may encompass many distinct components, ranging from several discrete skills (for either manual or power wheelchair users), to generalization of skills, in a variety of environments, or in response to other challenges. In addition, training may be directed at the wheelchair user or future caregivers. Eight sites (66.7%) report a protocol to address at least some of these components. However, there is some uncertainty if the indicated protocols were standardized and validated, as there was much variability in reporting, across various components of wheelchair skills training. For most components, three sites (25%) indicate using the Wheelchair Skills Training Program.[3] However, up to six sites (50%) report applying this protocol to manual wheelchair skill development. Even fewer sites identify following clinical protocols, relative to their seating service delivery, and there was no protocol identified at some sites (n=2).

Additionally, nine sites (75%) identify using some form of wheelchair skills testing, as part of routine assessment, although it is unclear if this consists of non-standardized testing of this construct, or use of a validated tool, such as the Wheelchair Skills Test.[4] One site (8.3%) reports using the Wheelchair Outcome Measure tool to assess outcomes, from the client perspective, and two sites (16.7%) indicate ongoing informal testing associated with customization of power or manual chairs. The use of standardized tools is recommended for building consistent, competent practice across Canada, which ultimately affects the health and wellness of the person with SCI.

Adequacy of Service Provision

In general, most sites perceive that they have adequate service provision, for wheelchair skill development, as ten sites or greater (≥83.3%) report adequate wait times, and adequate overall service - with the minor exception of stair training, where nine sites (75%) report adequate overall service.

Seating service delivery was deemed less satisfactory, as seven sites (58.3%) report adequate wait times, and nine sites (75%) indicate adequate overall service.

Current Canadian Practice Profile

CLINICAL PRACTICE GUIDELINES, PROTOCOLS AND STANDARDS OF CARE

Several guidelines and protocols exist specifically for various aspects of wheeled mobility:

- Guidelines on the Provision of Manual Wheelchairs in Less-Resourced Settings.[1]

- Rehabilitation Engineering and Assistive Technology Society of North America (RESNA). *Wheelchair Service Provision Guide*. Arlington, VA: Rehabilitation Engineering and Assistive Technology Society of North America; 2011. http://www.resna.org/dotAsset/22485.pdf. Accessed August 22, 2012.

- Dalhousie University Faculty of Medicine and Capital Health. *Wheelchair Skills Program*. Halifax, NS: Dalhousie University; 2012. http://www.wheelchairskillsprogram.ca/eng/index.php. Accessed August 22, 2012.

Other relevant guidelines focus on practices associated with the critical roles that mobility and mobility devices play, in managing pressure and skin issues. For more information, please refer to the Skin Integrity Chapter:

- Houghton PE, Campbell KE, and BPG Panel members. *Canadian Best Practice Guidelines for the Prevention, Assessment and Treatment of Pressure Ulcers in Individuals with Spinal Cord Injury*; Rick Hansen Institute (RHI) and the Ontario Neurotrauma Foundation (ONF); 2012. (Please contact phoughto@uwo.ca for more information).

- Consortium for Spinal Cord Medicine. *Pressure ulcer prevention and treatment following spinal cord injury: a clinical practice guideline for healthcare professionals*. Washington, DC: Paralyzed Veterans of America; 2000:1-77.

Resources for Wheeled Mobility

- Assistive Technology and Seating Service at GF Strong. http://www.assistive-technology.ca/topics.html

- Rehabilitation Engineering Research Center on Wheeled Mobility (Mobility RERC), at the Center for Assistive Technology and Environmental Access (Georgia Tech). http://www.mobilityrerc.gatech.edu

- RESNA Position Papers on Clinical Practice are official statements by the organization that, based on the consensus of experts and evidence, summarizes current research and best-practice trends, most of which are relevant to wheeled mobility. http://www.resna.org/resources/position_papers.dot

- Connolly SJ, Miller WC, Trenholm K, et al. Wheeled mobility and seating equipment for the spinal cord injured individual. In: Eng JJ, Teasell RW, Miller WC, et al., eds. *Spinal Cord Injury Rehabilitation Evidence*. Version 4.0. Vancouver, BC; 2012. http://www.scireproject.com/rehabilitation-evidence/wheelchairs-and-seating-equipment. Accessed August 22, 2012.

- WheelchairNet is a community of people with a common interest in wheelchair technology, its improvement and successful application (the Rehabilitation Engineering Research Center on Wheeled Mobility at University of Pittsburgh). http://www.wheelchairnet.org

KEY PRACTICE REFERENCES

For frame selection:
1. Fitzgerald SG, Cooper RA, Boninger ML, Rentschler AJ. Comparison of fatigue life for three types of manual wheelchairs. *Arch Phys Med Rehabil*. 2001;82(10):1484-8.

For prevention of upper extremity injury:
Gagnon D, Nadeau S, Noreau L, Dehail P, Piotte F. Comparison of peak shoulder and elbow mechanical loads during weight relief lifts and sitting pivot transfers among manual wheelchair users with spinal cord injury. *J Rehabil Res Dev*. 2008;45(6):863-73.

For impact on quality of life:
Hosseini SM, Oyster ML, Kirby RL, Harrington AL, Boninger ML. Manual wheelchair skills capacity predicts quality of life and community integration in persons with spinal cord injury. [published online ahead of print June 6 2012]. *Arch Phys Med Rehabil*. 2012. http://www.archives-pmr.org/article/S0003-9993(12)00316-4/fulltext. Accessed October 4, 2012.

For wheelchair skills training:
MacPhee AH, Kirby RL, Coolen AL, Smith C, MacLeod DA, Dupuis DJ. Wheelchair skills training program: a randomized clinical trial on wheelchair users undergoing initial rehabilitation. *Arch Phys Med Rehabil*. 2004;85:41-50.

For prevention of pressure ulcers:
Sprigle S, Sonenblum S. Assessing evidence supporting redistribution of pressure for pressure ulcer prevention: a review. *J Rehabil Res Dev*. 2011;48(3):203-13.

ASSESSMENT TOOLS (ALL INTENDED FOR CLINICAL USE)

- Functional Tests for Persons Who Self-Propel a Manual Wheelchair (4FTPSMW) assists clinicians in assessing the effect of different postural supports (e.g., back support and seat cushions). [5]

- Tool for assessing mobility in wheelchair-dependent paraplegia through several motor tasks. [6]

- *Wheelchair Circuit* is used to assess skill and performance associated with tempo, technical skill and physical capacity. [7]

- *Wheelchair Outcome Measure* (WhOM) is a client-specific wheelchair intervention measurement tool, based on the ICF. [8]

- *Wheelchair Skills Test* is a comprehensive measure representative of the range of skills regularly needed by wheelchair users and/or caregivers, varying from the most basic to the very difficult. [9] Version 4.1.60; Accessed May 31, 2012. http://www.wheelchairskillsprogram.ca/eng/testers.php

- The *Wheelchair Use Confidence Scale* is an outcome measure designed to assess confidence in wheelchair use. The WheelCon-P and WheelCon-M are for use with power and manual wheelchair users, respectively. [10]

Leaders in Wheeled Mobility

1. Jennifer Birt, BMR OT, Winnipeg: Develops and implements best practices for wheelchair seating and pressure management, for the SCI population, into clinical practice and the individual's daily life.

2. Dany Gagnon, PhD PT, Montréal: Creates best practices by developing an understanding of how individuals with SCI transfer between surfaces, and the related impact on their bodies.

3. R Lee Kirby, MD (Physiatry), Halifax: Expands the knowledge base of wheelchair skills testing and training, for manual and power wheelchair users and caregivers, world-wide.

4. Bill Miller, PhD (Epidemiology & Biostatistics), Vancouver: Understands the determinants and social impacts of wheelchair use and develops and evaluates measurement tools.

5. Linda Norton, BScOT MScCH, Toronto: Advances understanding of wheelchair mobility and related topics for clinicians through her role as a national educator and clinician.

6. Jan Polgar, PhD OT, London: Develops outcome measures and practice models for an individualized approach to assistive technology assessment (AT), and evaluates the factors of integrating assistive technology, into daily life.

7. Paula Rushton, PhD (Biomedical Sciences), Montréal: Develops tools to assess and understand wheelchair confidence of manual and power wheelchair users.

8. Cher Smith, MSc OT, Halifax: Advances wheelchair skills training in clinical application, education and research.

9. Laura Titus, BScOT PhD (candidate), London: Determines barriers and facilitators for using power tilt for pressure management, and influences clinical practice related to the daily needs of power mobility users.

10. CanWheel Research Team, Canada: Fourteen clinical researchers and basic scientists work with over 20 trainees, as a cross country team, using five key research projects to provide a comprehensive, systematic and unified approach to enhance the mobility of older adult wheelchair users. www.canwheel.ca.

SPOTLIGHT BEST PRACTICE ORGANIZATION

SPINAL CORD REHABILITATION PROGRAM –

Nova Scotia Rehabilitation Centre, Queen Elizabeth II Health Sciences Centre, Capital Health and Dalhousie University Wheelchair Research Team

The Nova Scotia Rehabilitation Centre (NSRC), in Halifax, provides inpatient and outpatient rehabilitative services to adults through videoconferencing and outreach. The Spinal Cord Rehabilitation Program services include physiatry, occupational and physical therapy, orthotics, recreation, speech language, vocational counselling, social work, and spiritual and medical care. With a strong commitment to evidence-informed approaches to health and wellness, throughout the continuum of care, there is a significant focus on mobility.

The NSRC's Mobility Centre, used by walkers and wheelers, incorporates indoor obstacles, a GAITRite System and the Wheelchair Skills Program (WSP). The WSP - a free resource to users - uses a set of assessment and training protocols, and includes the Wheelchair Skills Test (WST), the Wheelchair Skills Training Program (WSTP), as well as related materials developed by a team of clinicians and researchers.

Described as a "low tech, high impact" intervention by Nenad Kostanjsek of the World Health Organization, the WSP was started in 1996, by the Wheelchair Research Team, at Dalhousie University and Capital District Health Authority. The WSP is fully integrated within the service delivery associated with the NSRC Spinal Cord Rehabilitation Program, and is currently being used, or considered for use, at several other SCI rehabilitation programs, across Canada and other parts of the world.

Differences in the WSP, in comparison with other measurement tools and training approaches, include a focus on both the wheelchair user and the caregiver, the inclusion of manual and powered wheelchairs, a foundation in motor skills, biomechanics and ergonomics literature, the process and sequencing of the training; and ongoing, scientific evaluation of the program.

http://www.wheelchairskillsprogram.ca.

Key Clinical Issues: A Roadmap for SCI Rehabilitation and Wheeled Mobility

There is significant disparity in wheeled mobility practice across Canada. Several sites are not systematically addressing wheeled mobility, in a manner consistent with available best practice protocols. Substantial challenges also exist in acquiring adequate and timely funding for equipment, and to accommodate the changing needs of individuals, with respect to wheeled mobility options. These challenges vary across jurisdictions, and reflect differences in policy, resources and service delivery models.

In addition, many challenges are associated with effective follow up and ongoing assessment, training and customization to meet the changing needs of individuals living in the community, over time. Initially, clinicians prescribe wheeled mobility devices to best serve both immediate and long-term needs, by considering several factors (e.g., functional ability, safety, risk for complications, personal goals). However, individuals with SCI often undergo significant changes, within the first few years of injury, as they adjust to their disability. This may be accompanied by a re-shaping of life goals, new leisure or vocational pursuits or changes in health and wellness (e.g., secondary complications). Individuals may also return to communities that lack the resources available in SCI-specialist facilities.

Effective systems may not be in place to assess, train or customize a new solution to address this service delivery gap. Three key clinical priorities, consistent with enhanced rehabilitation practice, would improve programming in wheeled mobility:

1. Reduce disparity through implementation of a standardized approach to wheelchair skills training and assessment, across Canada.

- Implementation of the WHO guidelines (including the WSP), in programs not currently offering these services systematically, would standardize service delivery. Some resourcing may be required to assist equipment funding and training, at these sites.

2. Reduce disparity through a professional certification program which requires a minimum standard.

- A certification system, similar to RESNA's and informed by WHO guidelines and standards, would include information on training, follow up and maintenance, and be offered for basic, intermediate, and complex levels of certification attainment.

3. Augment ongoing follow-up services to ensure programs better meet the changing needs of individuals with SCI.

- Rehabilitation programming needs to facilitate ongoing service delivery to all individuals, even to those who return to remote communities. This may be accomplished through various service models and requires changes in both policy and clinical application levels. Reimbursement models need to be revised to enable this follow up with wheelchair users – part of which may be facilitated via telehealth applications. However, initial rehabilitation efforts should be directed to encourage a self-management perspective. This approach empowers the individual, and instills an awareness of the benefits of ongoing review to inform modifications to training/practice regimens, or existing wheeled mobility devices. Creation of appropriate tools and resources, during initial rehabilitation, may enhance adherence and facilitate a return to specialized services.

Each of these priorities could be enabled, in part, by inclusion in the Accreditation Canada framework (especially in the context of a specialized SCI "Program of Distinction"). Further development work is important to establish essential best practice indicators that support assessment and monitoring, in clinical practice settings. Table 1.0 identifies possible practice indicators.

TABLE 1.0 BEST CLINICAL PRACTICE INDICATORS FOR WHEELED MOBILITY

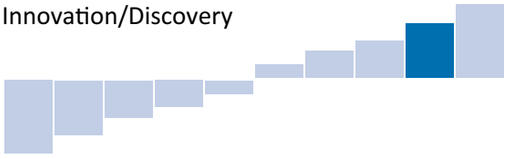
BEST PRACTICE INDICATORS	HOW IS IT MEASURED?
1. The program adheres to a standardized and validated protocol for wheelchair skills training (e.g., Wheelchair Skills Training Program[3]), in all suitable individuals.	Patient records document assessment and training procedures.
2. Each patient requiring a mobility device has a documented assessment of physical, functional and environmental needs that informs wheelchair selection and procurement.	Patient records document assessment findings, analysis and plan.
3. The program follows the WHO Guidelines for Manual Wheelchair Provisions in Less-Resourced Settings,[1] thereby enabling equal access to trained personnel, appropriate equipment, and short- and long-term follow-up.	Patient records document specific steps, outlined in WHO Guidelines.

REPORT CARD: Wheeled Mobility

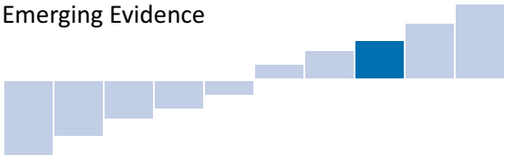
Extreme left below median: ***insufficient***
Extreme right above median: ***optimal***

KNOWLEDGE GENERATION

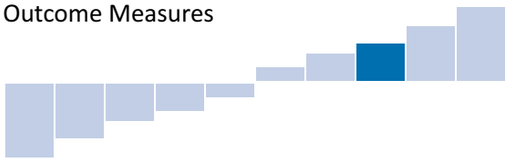
Innovation/Discovery



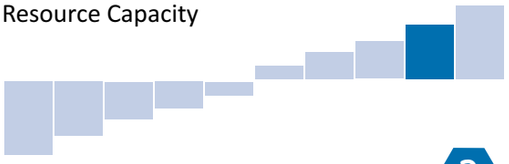
Emerging Evidence



Outcome Measures



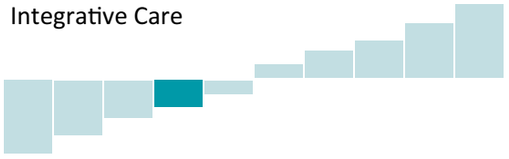
Resource Capacity



2020 PRIORITY 3

CLINICAL APPLICATION

Integrative Care



Effective Practice
(Evidence and Outcomes)

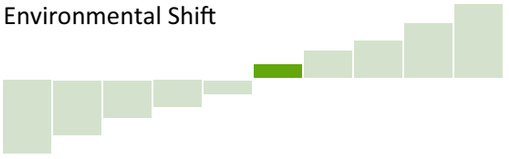
Equity Practice

Capacity

2020 PRIORITY 1

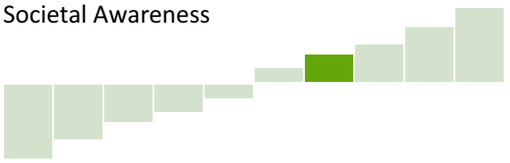
POLICY CHANGE

Environmental Shift

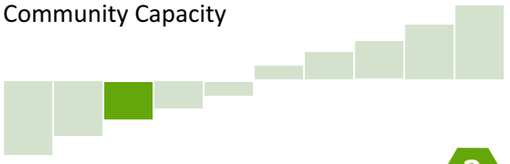


Change Agents

Societal Awareness



Community Capacity



2020 PRIORITY 2

TAKE HOME MESSAGE:

Practice disparity and resulting patient outcomes, associated with wheeled mobility, can be improved through implementation of the Wheelchair Skills Program, and the creation of a minimum standard for wheelchair provision. Enhanced follow-up services are needed to better meet the changing mobility needs of individuals living, and aging, with SCI.

RESOURCES

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6. Harvey LA, Batty J, Fahey A. Reliability of a tool for assessing mobility in wheelchair-dependent paraplegia. *Spinal Cord*. 1998;36(6):427-31.

7. Kilkens OJ, Post MW, van der Woude LH, Dallmeijer AJ, van den Heuvel WJ. The Wheelchair Circuit: reliability of a test to assess mobility in persons with spinal cord injuries. *Arch Phys Med Rehabil.* 2002;83(12):1783-8.

8. Mortenson WB, Miller WC, Miller-Polgar J. Measuring wheelchair intervention outcomes: Development of the Wheelchair Outcome Measure. *Disabil Rehabil Assist Technol*. 2007;2(5):275-85.

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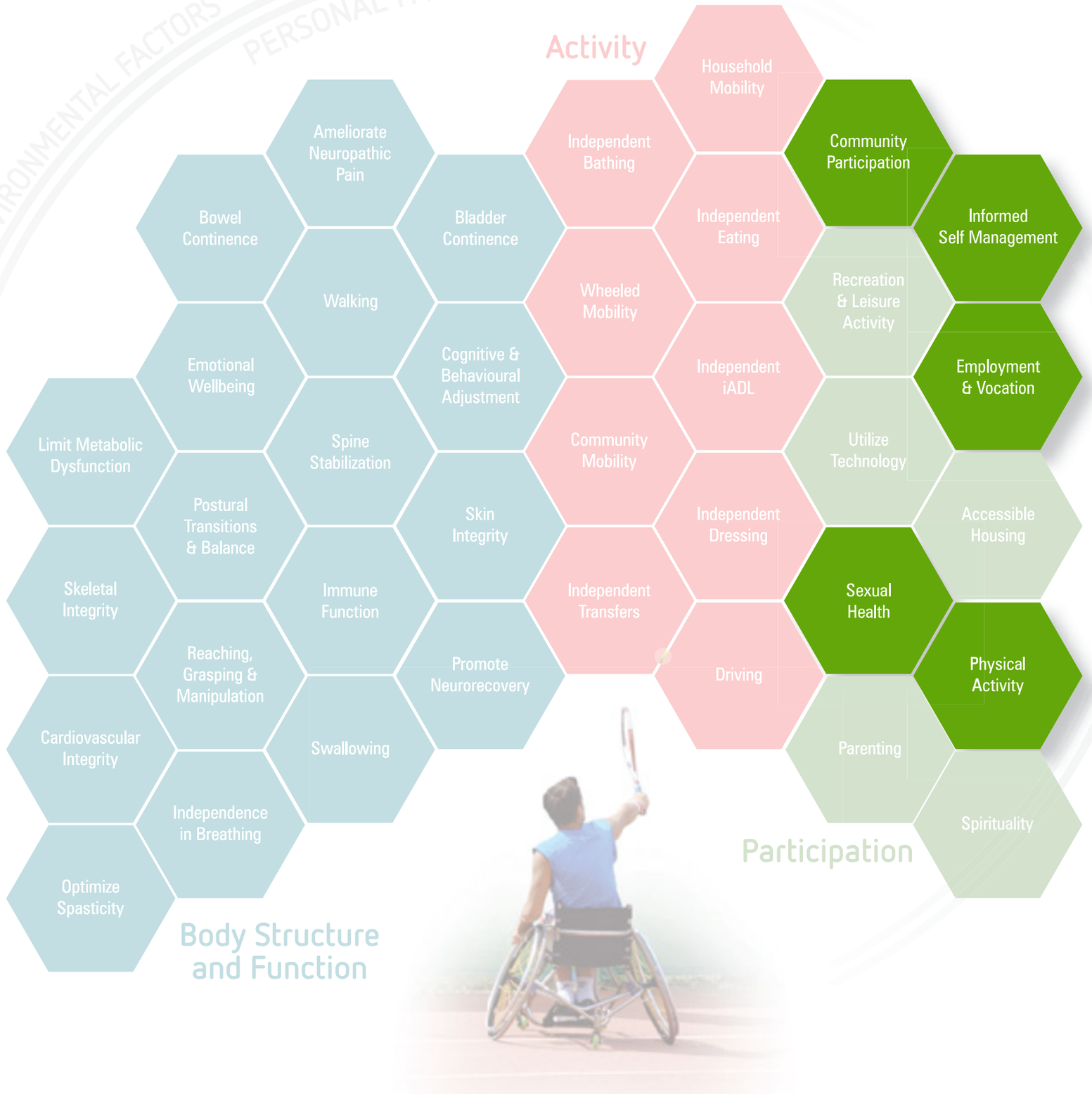
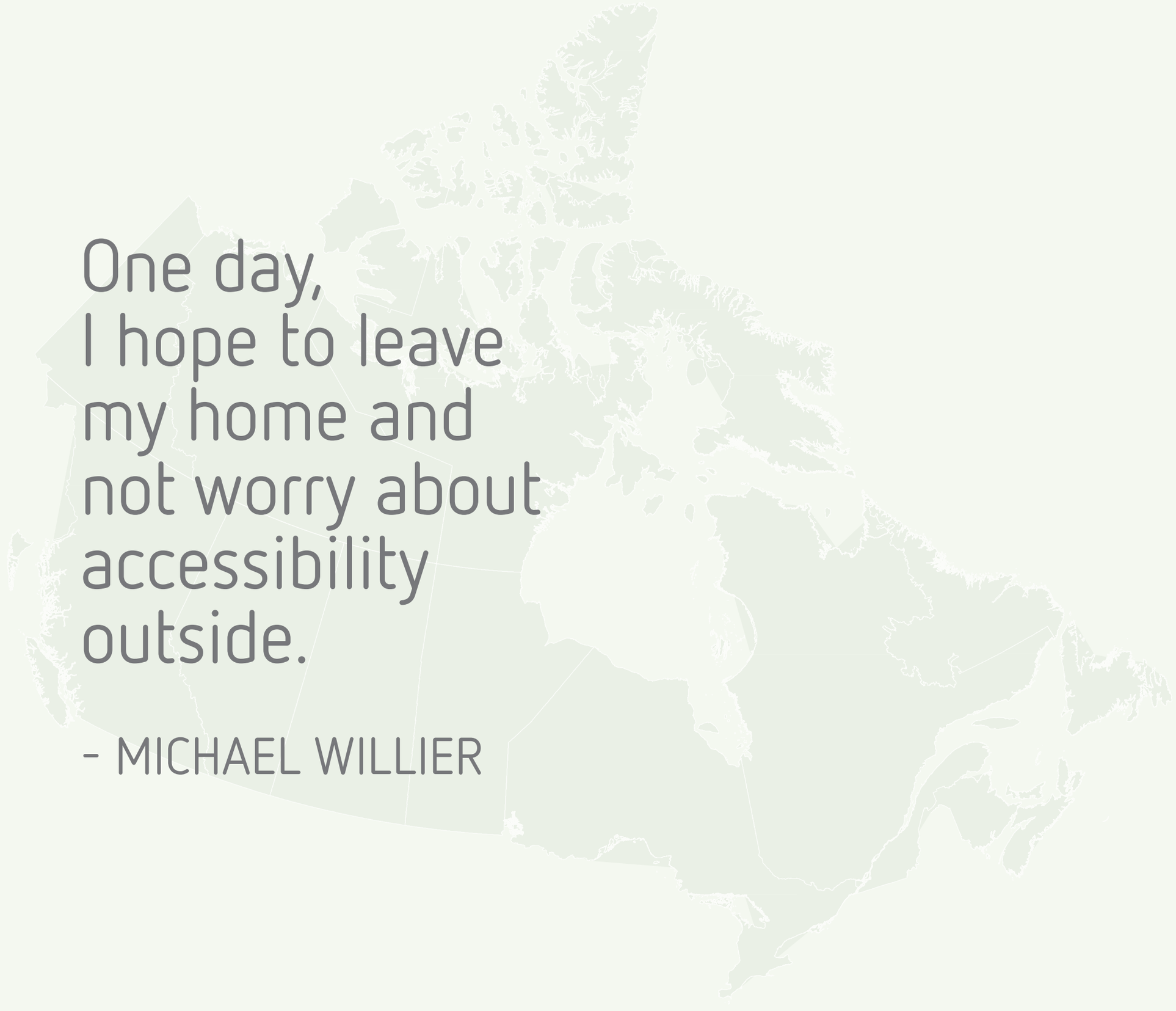
10. Rushton PW, Miller WC, Lee Kirby R, Eng JJ, Yip J. Development and content validation of the Wheelchair Use Confidence Scale: a mixed-methods study. *Disabil Rehabil Assist Technol.* 2011;6(1):57-66.

Participation





One day,
I hope to leave
my home and
not worry about
accessibility
outside.

- MICHAEL WILLIER

Sexual Health

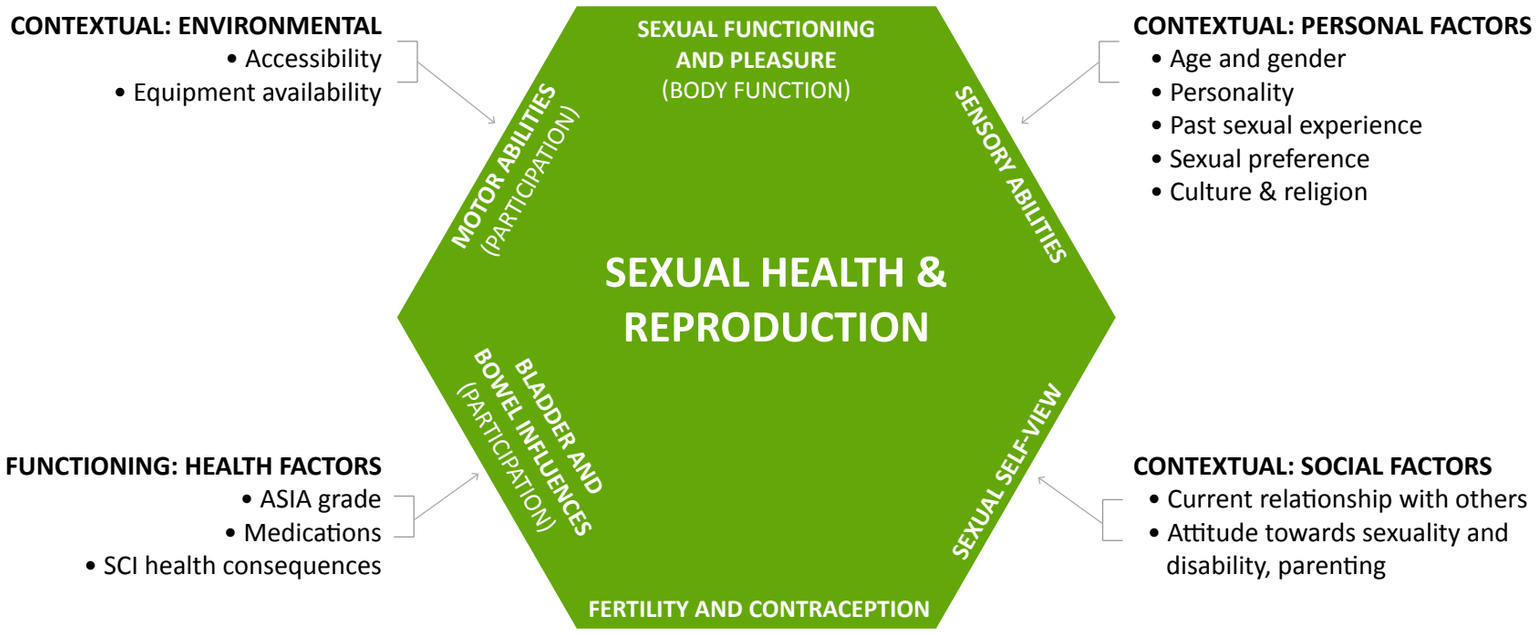
S Elliott, MD; F Courtois, PhD; K McBride, BScN; D Ditor, PhD; C Craven, MD; and the E-Scan Investigative Team

The World Health Organization (WHO) defines Sexual Health as a state of physical, emotional, mental and social wellbeing in relation to sexuality. Sexual health rehabilitation requires a positive and respectful approach to sexuality, sexual relationships, and reproductive wishes, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. In this context, sexuality encompasses sex, gender identity and gender roles, sexual orientation, eroticism, pleasure, intimacy and reproduction.

The impact of SCI has a profound and lifelong impact on every aspect of an individual's life. After SCI, sexuality and the need for sexual health and fertility rehabilitation often does not get specific attention through evidence-based clinical practice. Despite current knowledge and research, in the area of sexual functioning, discomfort by both patients and professionals has resulted in limited attention to sexual health, within Canadian rehabilitation service delivery.

Sexual functioning is complex, encompassing physical, emotional, behavioural and social areas - all of which are influenced by factors such as health, culture and attitude.[1] Given the biopsychosocial nature of sexuality, and the profound impact of SCI, it is not surprising that individuals with SCI rate sexual functioning as either the first or second priority, with respect to quality of life, on needs surveys.[2,3] Given the International Classification of Function (ICF) model for health, the model in Figure 1.0 illustrates the relationships between all aspects of an individual's life and their sexual health.

FIGURE 1.0 MODEL OF SEXUAL HEALTH, REPRODUCTION AND RELATED FACTORS.
ADAPTED FROM ELLIOTT SL[4] AND USED WITH PERMISSION.



Common Sexual Health Problems

Following SCI, an individual faces physiological, emotional, and interpersonal changes that impact his or her sexual health. These changes manifest differently for men and women, and if not addressed, can have a profound impact on an individual, beyond their sexual health needs. These unattended concerns cause immense fears of "loss of manhood" or "womanhood" – and the fears often lead to despair, unwillingness to comply with strenuous rehabilitation programs and, most importantly, to impaired interpersonal relationships and family and social dysfunction.

COMMON PROBLEMS THAT INDIVIDUALS FACE AFTER SCI, RELATED TO SEXUAL HEALTH, ARE:

- Altered body self-image
- Sexual dysfunction (erection, ejaculation, lubrication, orgasm)
- Cardiovascular consequences with sexual activity
- Management of bowel and bladder routine around sexual practices
- Positioning for sexual activities
- Spasticity management
- Expressing intimacy with self and others
- Accessibility issues (physical barriers, social stigmas)
- Fertility and contraceptive issues.

Typically, the combination of these issues, integrated with personal morals, ethics and societal perspectives, will influence the sexual health of an individual following SCI. A comprehensive approach is necessary to understand the issues, assess accurately and provide comprehensive care.

Current Practice

COMPREHENSIVE SEXUAL HEALTHCARE

The current models of sexual health services in Canada are predominantly limited to addressing erectile dysfunction and anejaculation in men with SCI, with the exception of the interdisciplinary programs in British Columbia and Québec, which address a variety of sexual health and fertility issues. These models (10/12) are insufficient to meet the breadth and depth of consumer needs related to sexual health. The current model, utilized by the Sexual Health Rehabilitation Service, in Vancouver, has been used to comprehensively manage the multidisciplinary needs seen with sexual and fertility rehabilitation, via a Sexual Rehabilitation Framework approach, applicable to several disciplines (Figure 2.0).[4]

FIGURE 2.0 SEXUAL REHABILITATION FRAMEWORK

Sexual Health Action List

Sexual Area	Consequences	Actions
Sexual Drive/Interest		
Sexual Functioning Abilities		
Bladder & Bowel Function		
Motor & Sensory Influences		
Factors Specific to SCI		
Fertility & Contraception		
Sexual Self View & Self Esteem		
Partnership Issues		

The Spectrum of Services

This framework outlines the clinical areas which require review when addressing an individual's sexual health, and expands beyond specific genital functioning. This realistic approach is appropriate during inpatient rehabilitation and/or outpatient follow up, depending on the readiness of the individual.

Current sexual health services are generally guided by research. However, the majority of research comes from case reports and observational studies, with limited Level I evidence, from clinical trials or systematic reviews. Further confounding the application of research-to-care are social norms and ethical considerations.

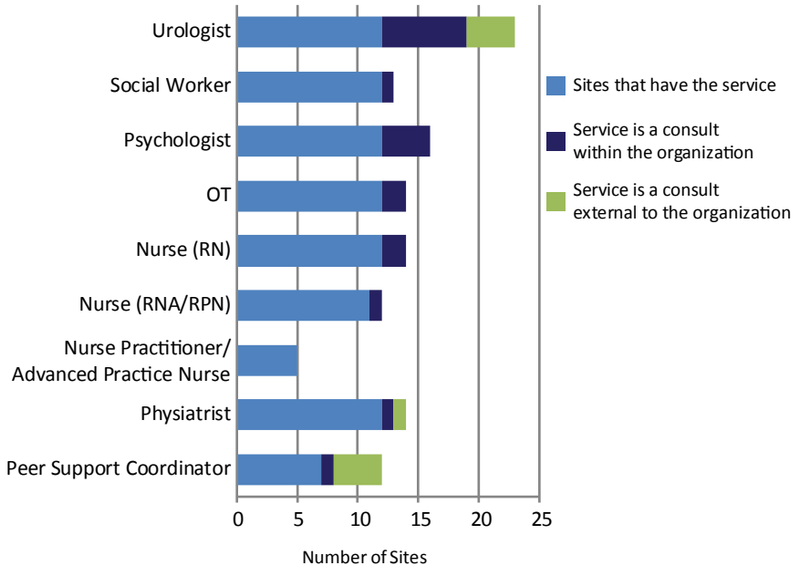
Clinical Practice: Where Are We Now?

Within Canada, clinical care varies, and expertise in addressing the sexual health and reproductive needs, of both men and women, are limited to a few key rehabilitation centers. Facilitating good clinical care for sexual health requires an interdisciplinary team whose role is briefly outlined in Table 1.0. (This list is intended to facilitate discussion but is not exhaustive.)

TABLE 1.0 THE ROLE OF VARIOUS DISCIPLINES IN SEXUAL HEALTH PROVISION

DISCIPLINE	ROLE IN SEXUAL HEALTH PROVISION
Medicine (Physiatry, Sexual Medicine, Urology, Gynecology, Psychiatry)	Medical treatment for sexual dysfunction and fertility, treatment of associated urinary and bladder incontinence, prevention and management of AD, routine gynecologic and urologic screening.
Nursing	Education and support re: effect of SCI and related issues on sexuality and relationships (includes management of bowel/bladder/spasticity/AD/medication side effects).
Occupational Therapy	Adaptation of sexual devices, positioning assistive devices.
Physical Therapy	Movement, positioning.
Psychology and Sexology (Relationship Therapy, Sex Education, Sex therapy)	Sex education, sex therapy.
Social Work	Adjustment to living with disability, applications for independent living environment and attendant services.
Recreational Therapy	Opportunities for engagement in social/sport activities, thereby facilitating social, psychological adjustment.

FIGURE 3.0 LIMITED ACCESS TO EXPERTISE IN SEXUAL HEALTH ACROSS THE COUNTRY



Current Canadian SCI Sexual Health Services

E-Scan data reveals that 12/12 sites report having a fertility/ sexual health service, 11 of which are onsite. Standards of care, in these sites, are heterogeneous, with variability in identification of key practice protocols. Five sites report having a treatment protocol; three, a standard of care; and three, a clinical practice guideline. Four sites report using other sources including a research protocol, SCI Reference Manual, GF Strong Sperm Retrieval Guidelines, and sexual device manual for persons with disability – *PleasurABLE*.[5]

Sources for the protocols identified included expert clinicians (Courtois et al.[6]; PVA guidelines; GF Strong's Internal Standards for Vibratory Stimulation, Electroejaculation and Erectile Dysfunction, and the SCIRE Sexual Health chapter.[7]

The E-Scan data suggests consistent availability of interdisciplinary service providers, within healthcare facilities, but limited specific expertise in sexual health services, in terms of sexual health knowledge, clinical skills and expertise, by those service providers. Furthermore, teams are rare. Most centers have a designated sexual health individual, with limited formal training outside their respective discipline, and are subject to high expectations in terms of service delivery and relevant expertise. Figure 3.0 illustrates the limited accessibility of expertise in sexual health, across Canada. Table 2.0 displays the sexuality and fertility outcomes used in clinical practice reported by providers in the E-scan sites.

TABLE 2.0 SEXUALITY ASSESSMENTS, OUTCOMES, AND TREATMENTS

MEASURE	SITES THAT USE THE MEASURE	SITES THAT USE THE MEASURE FOR CLINICAL PURPOSES	SITES THAT USE THE MEASURE FOR RESEARCH PURPOSES
FERTILITY			
Serum Screening for Hypogonadism	7/12	7/12	0
Sperm Count	8/12	8/12	0
Pelvic Ultrasound	7/12	7/12	0
SEXUALITY			
International Index of Erectile Function (IIEF)	4/12	3/12	1/12
Assessment of Sexual Potential and Treatment of Sexual Dysfunctions in Men and Women with SCI	1/12	1/12	1/12
Rehab Team Assessment	1/12	1/12	0
Female Sexual Function Index	1/12	0	1/12
Clinical Questions	1/12	1/12	0
Locally Generated Scale	1/12	1/12	0

Current Clinical Practice Guidelines in Use

1. Consortium of Spinal Cord Medicine and Paralyzed Veterans of America. Clinical Practice Guideline. Sexuality and reproductive health in adults with spinal cord injury: a clinical practice guideline for healthcare professionals. *J Spinal Cord Med*. 2010;33(3):281-336.

2. Consortium of Spinal Cord Medicine and Paralyzed Veterans of America. *Sexuality and reproductive health in adults with spinal cord injury: What you should know. A guide for people with spinal cord injury.* Washington, DC: Paralyzed Veterans of America; 2011.

3. Alexander MS, Brackett NL, Bodner D, Elliott S, Jackson A, Sonksen J; National Institute on Disability and Rehabilitation Research. Measurement of sexual functioning after spinal cord injury: preferred instruments. *J Spinal Cord Med.* 2009;32(3):226-36.

4. Vancouver Coastal Health Authority. *Supporting Sexual Health and Intimacy in Care Facilities: Guidelines for Supporting Adults Living in Long-Term Care Facilities and Group Homes in British Columbia, Canada*. Vancouver Coastal Health Authority; 2009. These guidelines are the result of an international literature search and clinical, ethical and legal expertise on this subject. Sponsored by the Public Health Agency of Canada. http://www.vch.ca/media/FacilitiesLicensing_SupportingSexualHealthandIntimacyinCareFacilities2.pdf

CURRENT KEY PRACTICE REFERENCES

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11. Brackett NL, Ibrahim E. Fertility after spinal cord injury. In: Field-Fote DC, ed. *Spinal Cord Injury Rehabilitation*. Philadelphia, PA: F.A. Davis; 2009:531-47.

12. Courtois F, Charvier K, Leriche A, et al. Perceived physiological and orgasmic sensations at ejaculation in spinal cord injured men. *J Sex Med*. 2008;5(10): 2419-30.

13. Courtois F, Charvier K, Vézina JG, et al. Assessing and conceptualizing orgasm after a spinal cord injury. *BJU Int*. 2011;108(10):1624-33.

14. Courtois F, Rodrigue X, Côté I, et al. Sexual function and autonomic dysreflexia in men with spinal cord injuries: How to treat. *Spinal Cord*. 2012 Aug 7. doi: 10.1038/sc.2012.83. [Epub ahead of print]

Other Key Sources: *PleasurAble*

A manual about sexual devices for individuals with disability, which presents considerations for mobility/sensation alterations, practicality of use, etc. Developed by two Master's OT students and Drs' Elliott and Krassioukov with input from Sexual Health Clinicians. http://www.dhrn.ca/files/sexualhealthmanual_lowres_2010_0208.pdf

Assessments Currently in Use

1. International Index of Erectile Function (IIEF)
2. Female Sexual Function Index (FSFI)
3. Sensations Perceived at Ejaculation
4. Emotional Quality of the Relationship Scale (EQR)
5. Knowledge, Comfort, Approach and Attitude towards Sexuality Scale (KCAASS)
6. Sexual Attitude and Information Questionnaire
7. Sexual Interest, Activity and Satisfaction (SIAS) and Sexual Activity and Satisfaction (SAS) Scales
8. Sexual Interest and Satisfaction Scale (SIS).

Canadians Likely to Influence Practice in the Next Five Years

1. Stacy Elliott, MD (Sexual Medicine), Vancouver: Development of international clinical guidelines for provision of sexual health and intimacy (http://www.ncbi.nlm.nih.gov/pubmed/20737805); participant in international autonomic standards for sexual function (references 4 and 5); SCIRE evaluation (reference 1); assistance with guidelines for supporting adults living in long-term care facilities (http://www.vch.ca/media/FacilitiesLicensing_SupportingSexualHealthandIntimacyinCareFacilities2.pdf) revision and distribution of sexual device manual – *PleasurAble* (http://www.dhrn.ca/files/sexualhealthmanual_lowres_2010_0208.pdf); development of a pregnancy, labour and delivery manual for women with spinal cord injury; research and development of sexual sensory substitution device(s); production of commercial male and female vibrators developed by BCIT/ICORD; reduction of autonomic dysfunction associated with sperm retrieval; current development/evaluation of on-line introduction to sexual health rehabilitation courses for healthcare professionals (http://www.bcit.ca/health/industry/sexualrehab.shtml), starting fall 2012.

2. Frederique Courtois, PhD (Sexology), Montréal: Sexual Sensations, Pleasure And Orgasm Following Spinal Cord Injury, pharmacotherapy to facilitate ejaculation and orgasm.

3. Dave Ditor, PhD (Kinesiology), St Catharine's, Ontario: Understanding cardiovascular risk during sexual activity and autonomic factors which impede sexual satisfaction.

4. Shaniff Esmail, MScOT PhD (Human Ecology), Edmonton: Sexual health education guidelines, sexuality and disability, and educator.

5. Andrei Krassioukov, MD (Physiatry), Vancouver: Clinical expertise on cardiovascular effects of sexual function after SCI; validation of the autonomic standards for describing sexual function.

6. Mark Nigro, MD (Urology), Vancouver: Fertility, erectile dysfunction and anejaculation, and bladder care, related after spinal cord injury.

7. Kate McBride, RN (Sexual Health); and Sexual Health Clinicians, Vancouver: Coordinator and clinicians of the Sexual Health Rehabilitation Service, Vancouver Coastal Health, in British Columbia; sexual health and intimacy among individuals in long term institutions; development of on-line sexual health competency programs for healthcare professionals, nationally and internationally; psychoeducational intervention targeting sexual function and body image among women with SCI.

8. Bernard Leduc, MD (Physiatry), Montréal: Anejaculation and fertility after spinal cord injury.

9. Cory Silverberg, Sexuality Educator, Toronto/Washington, DC: AASECT-certified disability expert who writes the blog: www.Sexuality.about.com. Topic areas include sex and technology, sexual pleasure, and sex and disability, sexual politics, education, culture, and health. Author of *What Makes a Baby*, which helps parents tell children a story about where they came from, in a way that acknowledges the help that some parents get to bring a child into their lives. http://www.kickstarter.com/projects/1809291619/what-makes-a-baby.

SPOTLIGHT BEST PRACTICE ORGANIZATION

SEXUAL HEALTH REHABILITATION SERVICE (SHRS) AND VANCOUVER SPERM RETRIEVAL CLINIC (VSRC) –

GF Strong Rehabilitation Centre and Blusson Spinal Cord Research Centre, Vancouver Coastal Health, Vancouver, British Columbia

The Sexual Health Rehabilitation Service (SHRS) and the Vancouver Sperm Retrieval Clinic (VSRC) - part of the Blusson Spinal Cord Centre, home of ICORD and the Brenda and David McLean Integrated Spine Clinic - provide a combination of clinical, education and research expertise and services.

These services, informed by an integrated research agenda, are recognized as a model of sexual rehabilitation and fertility care. The SHRS and VSRC serve approximately 400 clients each year, including individuals with SCI, and provide group patient/family education, sometimes in collaboration with peer services such as SCI-BC.

VSRC provides sexual health rehabilitation through medical therapies and emotional support. Unique interventions include formal sexual desire and function assessment, and treatment in the hospital setting for men (erectile dysfunction, anejaculation and anorgasmia), and women (arousal disorders and orgasmic dysfunction). The team of sexual health clinicians, a sexual medicine physician and a urologist offer fertility counseling, education and medical interventions, related to ejaculatory dysfunction. Since opening in 1985, over 100 live births have been reported (a similar success rate to other non-SCI fertility clinics). The VSRC is unique in that it provides comprehensive couple care and management in one setting: it is a provincial resource for the education of healthcare providers, students, researchers and individuals interested in sexuality and disability.

Founded in 1975 by Dr. George Szasz, the SHRS is recognized, nationally and internationally, as a forerunner in clinical practice, education delivery, and research in the area of sexuality and disability/chronic illness. A provincial tertiary care, consultative interdisciplinary service, the SHRS provides brief intervention therapy for patients with neurological disabilities and/or disorders, and their families; and offers numerous in-services, patient and clinician educational materials.

With increasing evidence that sexual health needs of patients are poorly addressed, and a global interest in training and education, the team has developed (in partnership with the British Columbia Institute of Technology and the Rick Hansen Institute), unique courses in Sexual Health Rehabilitation, available online in September 2012.

Specialized knowledge is disseminated through peer-reviewed journals, book chapter contributions, rehab textbooks and on-line modules for SCI-University; as well as contributions to guidelines for the Paralyzed Veterans Association and Vancouver Coastal Health, and a book on sexual health education for children with physical disabilities, for The Sex Information and Education Council of Canada.

The SHRS is committed to the development of the body of sexual health knowledge through reflective practice, clinical practice guidelines, outcome measures and research. Recent research has focused on investigating the use of a sensory substitution device to facilitate the sexual rehabilitation of men with SCI, the development of vibrostimulation devices for enhancing sexual pleasure of men and women with SCI, the validation of sexual health outcome criteria on the ASIA exam, and the adaptation of an established psychoeducational tool for women with SCI, with low desire and body self-esteem.

Success is attributed to SHRS founder Dr. Szasz, and Drs. Nigro and Elliott, the Sexual Health Clinicians, and partnerships and affiliations (with BC Centre for Sexual Medicine, UBC Physiatry, Urology and Gynecology departments; ICORD, SCI-BC, BC Institute of Technology, the Rick Hansen Institute, BC Ministry of Health and Public Health Agency of Canada, and others). Client care, education and research are informed by patient experiences, as well as interdisciplinary experience and current research.

BEST PRACTICE INDICATORS

- Routine introduction of sexual health/fertility services during inpatient rehab
- Access to a multidisciplinary team available to address sexual health needs
- Access to sexual health services after discharge from inpatient rehabilitation
- Evidence of documentation of a sexual health assessment
- Documentation of sexual health goal setting
- Documentation of sexual health goal attainment
- Documentation of guideline adherence or implementation
- Opportunities to revisit sexual health goals/goal attainment.

Principles for Future Advancement of Sexual Healthcare

KEY CLINICAL PRIORITIES

Currently, there is no standard of care in sexual rehabilitation and fertility, although there are excellent sites throughout North America and Europe that have similar approaches and intercommunicate. Three areas which require particular attention, and are best supported through evidence, are suggested:

1. Maintain a client-centered focus towards addressing sexual health for people with SCI. While paying particular sensitivity to gender, culture and social expectations, readiness to address sexuality and fertility, and a motivation to return to sexual practices, must be respected.

2. A comprehensive sexual health history and physical, and a multidisciplinary approach is required to maintain an individual's sense of sexual wellbeing, quality of life and fertility potential. This includes risks and benefits of medical treatments, along with consideration of associated health issues, including autonomic dysreflexia.

3. Implementation of sexual rehabilitation principles
1) Maximizing physiology 2) adapting to remaining limitations, and 3) being open to new experiences, requires both the client and the healthcare provider to place appropriate attention on mental, physical and accessibility considerations, regarding sexuality.[8] Some guides are available for the socialization aspects of sexuality, for the use of medical interventions, and for innovative use of equipment and devices.

Barriers to full implementation of such guidelines, and to those referenced in this chapter are vast, including the various societal and ethical norms seen across Canada. A comprehensive education and training program for sexual health clinicians, in the area of sex and disability, would be one way to address such gaps in care. (In British Columbia, Dr. Stacy Elliott, her colleagues and other educators and academics, will be contributing to the development of a sexual health training program for individuals with disability). The intent of a training curriculum would be to close the gap between what is known in sexual health rehabilitation, and what is used in clinical practice, and to do so through an accessible route, such as online training, with supervision at designated sites. This would allow further dissemination of knowledge and practical application of client care, across Canada, and provide the ability to do much needed research, in the area of sexual and fertility rehabilitation.

Key Policy Priorities

THERE ARE MANY POLICY-RELATED IMPLICATIONS NECESSARY TO SUPPORT THE IMPLEMENTATION OF SEXUAL HEALTH GUIDELINES AND CLINICAL PRACTICE EXPECTATIONS.

1. Fund and allocate resources to support a multidisciplinary approach to sexual healthcare, for all people with SCI, throughout the continuum of care.

2. Incorporate sexual health programs for healthcare professionals, throughout academic training institutions and into clinical practice. Create formal, sexual health clinician training programs that include classroom instruction and hands-on training, in a supervised environment, by an accredited body for healthcare professionals.

3. Provide client's right for privacy and protection of confidentiality, throughout the care received within facilities, as it relates to sexual health. Develop policies that recognize and respect the client's rights for privacy and autonomy for sexual activity, in care facilities.

Key Research Priorities

RESEARCH PRIORITIES IN SEXUAL HEALTH TO SUPPORT THE ADVANCEMENT IN CARE, IN CLINICAL PRACTICE:

1. Bridge the gap between what is known about sexual health rehabilitation in the SCI continuum of care and the implementation of the few existing guidelines.

2. Funding to advance research in sexual sensation, orgasm and pleasure.

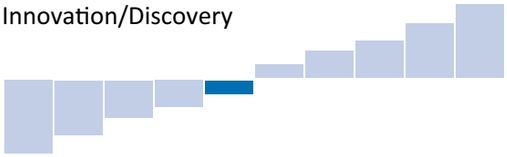
3. Develop and evaluate assistive techniques, from psychological to mechanical, to facilitate sexual sensation and arousal.

REPORT CARD: Sexual Health

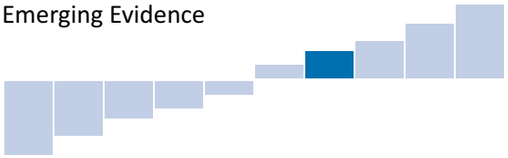
Extreme left below median: ***insufficient***
Extreme right above median: ***optimal***

KNOWLEDGE GENERATION

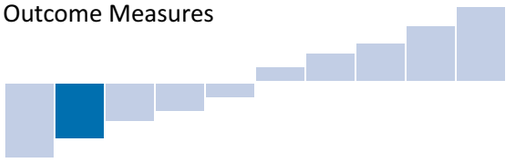
Innovation/Discovery



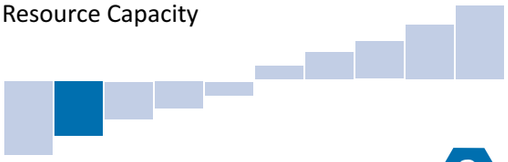
Emerging Evidence



Outcome Measures



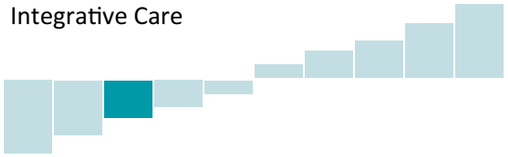
Resource Capacity



2020 PRIORITY 3

CLINICAL APPLICATION

Integrative Care



Effective Practice
(Evidence and Outcomes)

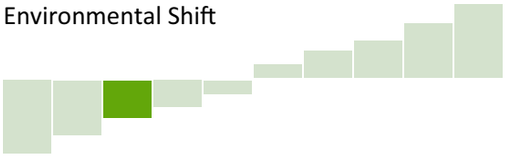
Equity Practice

Capacity

2020 PRIORITY 2

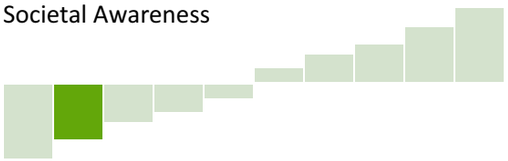
POLICY CHANGE

Environmental Shift

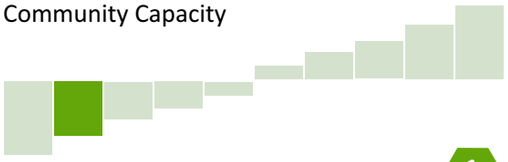


Change Agents

Societal Awareness



Community Capacity



2020 PRIORITY 1

TAKE HOME MESSAGE:

Sexual health is a validated, primary priority for individuals with SCI. However, resistance to these high-priority sexual needs has resulted in adverse consequences. There is currently a colossal disconnect between the capacity to provide sexual health service and clinical demands. Recognition of Sexual Health, as a rehab priority, needs to be embedded in national health service policies.

RESOURCES

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Informed Self-Management

DL Wolfe, PhD; S Mills, MEd; J Shepherd, MBA; C Craven, MD; and the E-Scan Investigative Team

Self-management comprises the interventions, training and skills provided to individuals with spinal cord injury (SCI) that support them in effectively managing all aspects of their lives (see Figure 1.0).

This represents all meaningful aspects of life (relevant to the individual). Some of the typical strategies for enhancing self-management include methods for problem solving, self-monitoring, goal setting, action planning and enhancement of self-efficacy, in conjunction with education.

Much of the current programming related to self-management has its basis in the conceptual framework of Wagner et al.'s Chronic Disease Model[1] and, therefore, has been applied, most frequently, to "typical" chronic diseases – most specifically, to the conditions of diabetes, arthritis and cardiovascular disease. Recent efforts have been undertaken to translate these approaches to SCI (e.g., Ontario Neurotrauma Foundation-funded initiative of the Stanford Patient Education Centre approach to self-management, Lorig et al.[2]). A common model of self-management support is the Five-A model, summarized by Glasgow et al.[3] and shown in Figure 2.0.

FIGURE 2.0. FIVE A'S MODEL OF SELF-MANAGEMENT SUPPORT.
© JOINT COMMISSION RESOURCES: IMPLEMENTING PRACTICAL INTERVENTIONS TO SUPPORT CHRONIC ILLNESS SELF-MANAGEMENT. JOINT COMMISSION JOURNAL OF QUALITY AND SAFETY, 29(11):563-74, 2003.[3] REPRINTED WITH PERMISSION.

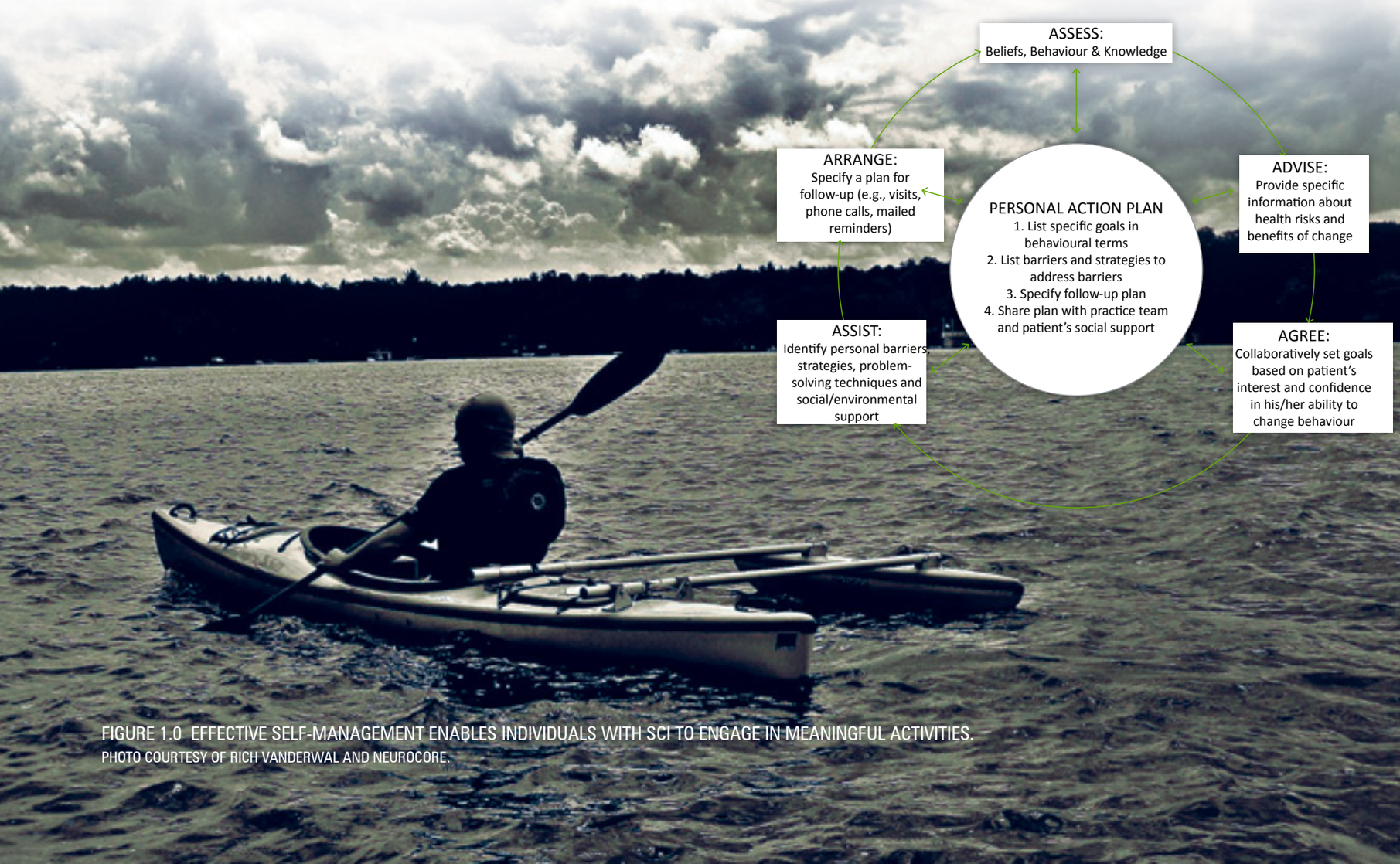


FIGURE 1.0 EFFECTIVE SELF-MANAGEMENT ENABLES INDIVIDUALS WITH SCI TO ENGAGE IN MEANINGFUL ACTIVITIES.
PHOTO COURTESY OF RICH VANDERWAL AND NEUROCORE.

SEVERAL KEY FEATURES, INHERENT IN THIS MODEL, ARE COMMON TO GENERAL APPROACHES TO SELF-MANAGEMENT EDUCATION, AND INCLUDE THE FOLLOWING:

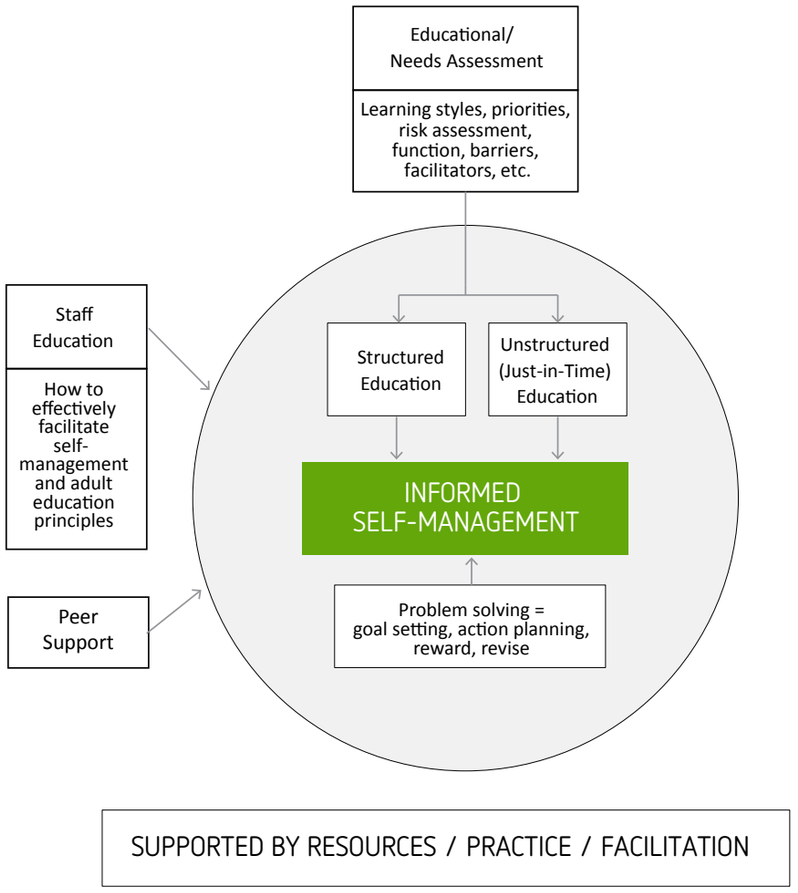
1. **Assessment, including the persons beliefs, knowledge, barriers and facilitators.**
2. **Facilitation of goal setting and problem solving.**
3. **Development and execution of an action plan.**
4. **Follow-up plan.**

The goal of self-management education is consistent with that of rehabilitation (i.e., to empower the individual to manage their health and daily activities toward successful community integration). However, although some rehabilitation programs have integrated a few of the approaches noted above, this philosophy has rarely been integrated systematically and comprehensively, within current rehabilitation service delivery. Most rehabilitation processes are goal directed and involve collaborative goal setting, problem solving and action planning. In contrast, the primary objective of informed self-management is to instil this set of strategies and skills, within individuals with SCI, so that they can effectively manage their own health, irrespective of the specific challenges or goals at hand.

Figure 3.0 illustrates an idealized model of self-management programming within rehabilitation service delivery, depicting the current spectrum of services with typical practice patterns, and adds key self-management principles. Much of the current variation in informed self-management practice stems from the variability in adoption of these principles.

Most typically, SCI rehabilitation programs have developed some structured form(s) of patient education, as well as unstructured educational delivery methods, each of which are intended to inform and equip the individual to effectively self-manage their health and daily activities, following discharge. Some programs also provide similar programming, within an outpatient or community outreach model.

FIGURE 3.0 SPECTRUM OF REHABILITATION SERVICES ASSOCIATED WITH ENABLING INFORMED SELF-MANAGEMENT IN INDIVIDUALS WITH SCI



Current Practice: Facilitating Informed Self-Management in Individuals with SCI

EDUCATION UNIVERSAL THROUGHOUT REHABILITATION

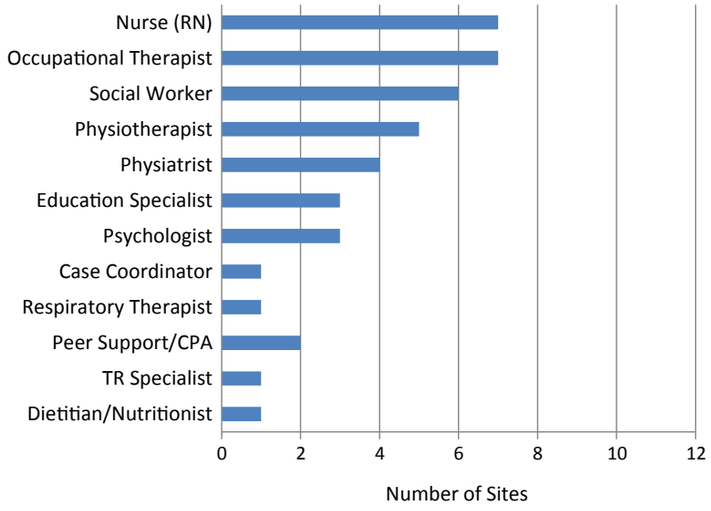
It has been noted that education is the "essence" of SCI rehabilitation,[4] borne out by results of the E-Scan. Informed self-management is potentially facilitated through structured programs of patient education, in rehabilitation settings, often delivered in group formats (see Figure 4.0) and augmented by unstructured, informal "just-in-time" education delivery. In general, most rehabilitation providers understand and appreciate their role in delivering this "just-in-time" education – although, by its very nature, there is likely to be little standardization or assurance that the information and skill development, associated with this form of educational delivery, is as effective as possible.

FIGURE 4.0 GROUP GARDENING

WHO PROVIDES SCI PATIENT EDUCATION IN CANADA?

Every participating E-Scan site offers specific services directed to patient education or to promoting adjustment to disability, with the majority of sites indicating services associated with both practice areas. These practices are viewed as interdisciplinary, with nine sites reporting multiple providers. Figure 5.0 shows a summary of the most prevalent provider types delivering education-related services. There is some variation, across the country, with respect to who is involved in delivering education with nurses, psychologists, social workers, PTs, OTs and physiatrists taking key roles, within an interdisciplinary team. There are also several sites (n=7) that partner with offsite or community personnel to deliver these programs, with case coordinators/managers, personnel from SCI Canada, consumers providing peer support, and teachers all playing a role.

FIGURE 5.0 PREVALENT PROVIDER TYPES DELIVERING EDUCATION-RELATED SERVICES



CURRENT PRACTICE AND RESOURCES USED IN EDUCATION PROGRAMS

An in-depth inventory of educational practice was not conducted as part of the Rehabilitation E-Scan. However, several practices and educational resources were noted by E-Scan respondents, which the authors supplemented with others recognized across the country. In general, most programs conduct structured patient education sessions, which often consist of didactic seminar-style sessions, with an opportunity for questions/answers on a series of topics deemed relevant to individuals undergoing SCI rehabilitation (e.g., intro to SCI, skin care, bowel and bladder care). These sessions are typically conducted by a rotating group of healthcare providers (see Figure 5.0) and include multimedia resources (e.g., Powerpoint).

For the most part, sites seemed satisfied with their educational programming. Only three sites identified that they felt that their services in this area were not "adequate" and needing improvement. Notably, six sites identified themselves as having *specialized expertise* in educational initiatives. In addition, three sites reported having specialized clinical educators, while others indicated the use and creation of specific educational resources. These include patient manuals, binders, handouts, websites, eLearning modules and local resource centres. Some of the tools were developed or customized in-house and others, by third parties (see Educational Resources).

Peer support services (see Figure 6.0) – identified by at least four sites – are shown to be an important component of effective educational programming to facilitate informed self-management.[5] Most often, these services are coordinated in partnership with SCI Canada who identifies suitable candidates and provides training to ensure the provision of effective peer support.

FIGURE 6.0 PEER SUPPORT

THE UNIQUE ROLE OF THE EDUCATION SPECIALIST

Educational specialists have been hired in three programs to facilitate and enhance patient and/or staff education. These specialists educate staff in the most effective ways to disseminate information, and how to incorporate adult educational or self-management principles, within their programming – an important aspect of their service delivery model.

Typically, adult education principles (such as active learning strategies, structured practice and feedback) are not included in training for healthcare providers, nor for many rehabilitation care providers who equate patient education with information dissemination, rather than skill development about general principals of self-management.

As part of the clinical team, educational specialists are well positioned to enable staff to deliver the most effective methods for structured and unstructured education sessions, to create educational resources, and to conduct activities for all audiences (patients, families, caregivers and staff). Presently, it's uncertain to what extent expertise to facilitate self-management skill development is incorporated in staff training (i.e., if care providers are instructed on the best methods to facilitate barrier identification, action planning, systematic problem solving), and whether these approaches are conducted and/or documented during inpatient rehabilitation.

SELF-MANAGEMENT SKILL DEVELOPMENT AND READINESS TO LEARN

A primary challenge in facilitating self-management, within rehabilitation programs, is that the individual is not ready to learn, or thinks that some issues (such as secondary health complications) may not be relevant to his or her current or future circumstances – especially, if they are dealing with significant medical and or psychological adjustment issues.[6]

Furthermore, general skills associated with informed self-management (e.g., barrier identification, action planning, systematic problem solving) may not seem relevant, whereas specific content (e.g., paralysis, loss of sensation, skin care, bowel and bladder management) may be of great significance.

Recognizing this limitation, two sites have implemented specific self-management programming, based on an approach developed by Kate Lorig,[2] at the Stanford Patient Education Research Centre (http://patienteducation.stanford.edu/programs/). In a workshop series delivered by two trained facilitators (one of which is a peer), each session provides information on relevant topics for managing one's health, including facilitation and practice of techniques. This ensures that individuals are actively engaged in problem solving and action planning, related to personally relevant goals. This program is available for outpatients and, at one site, includes individuals with stroke and multiple sclerosis, in addition to SCI.

Originally targeted for individuals with chronic diseases such as diabetes and arthritis, traditional self-management programs have relevance and value for those with SCI – and may be even more valuable if their content and formats were tailored more specifically to their needs.

Current Canadian Practice Profile

CLINICAL PRACTICE GUIDELINES

Although no SCI-specific CPGs exist regarding the practice of patient education or the most effective methods for facilitating self-management, there is some recognition that education is an important element to manage or better prevent secondary complications. Specific CPG examples from other medical issues include:

1. "Provide individuals with SCI, their families, significant others, and healthcare professionals with specific information on effective strategies for the prevention and treatment of pressure ulcers."[7]

2. "Educational programs for bowel management should be structured and comprehensive, should consider the home setting and available resources, and should be directed at all levels of healthcare providers, patients, and caregivers. The content and timing of such programs will depend on medical stability, readiness to learn, safety, and related factors. An educational program for bowel management after SCI should include…" [various content areas][8]

EDUCATIONAL RESOURCES

1. 5/13 sites report using specific resources which include:
   - SCI Canada's *Life After a Spinal Cord Injury*
   - Canadian Spinal Research Organization's *After and Beyond Manual* and *After and Beyond Manual Journal*
   - Paralyzed Veterans of America's *Yes You Can*
   - Spinal Cord Injury Rehabilitation Evidence (SCIRE) website (www.scireproject.com).

2. Online resources:
   - SCI-U eLearning modules of the University Health Network, Toronto (www.sci-u.ca)
   - Education resources at the Institute for Rehabilitation Research and Development, Ottawa (www.irrd.ca/education/).

Assessments

Standardized or routine use of assessment tools that focus on educational delivery, and their effectiveness for individuals, are infrequent in rehabilitation settings. The Needs Assessment Checklist,[9] a system which indicates the degree to which patients feel they have achieved the knowledge and skills needed, in nine core areas, is conducted at only 16.7% (2/12) of sites. Respondents noted no other assessments. In general, patient-reported outcomes - such as measures of self-efficacy (e.g., Moorong Self-Efficacy Scale[10]), or those that would assess the effectiveness of the education delivered - would be very useful to inform the education process and to determine the desired effect of facilitating informed self-management.

Leaders in Patient Education and Informed Self-Management

1. Tony Burns, MD (Physiatry), Toronto: Led the development and implementation of Spinal Cord Essentials, a comprehensive and integrated approach to patient education that ensures patients are active participants.

2. Mary Mark, RN MHS (Clinical Education), Edmonton: Developing innovative ways to ensure adult education methods are used effectively by staff through her position as a clinical educator.

3. Sandra Mills, MEd (Clinical Education), Toronto: Patient and family educator with a focus on resource creation as well as staff education, thereby enabling more effective point-of-care education.

4. SCI Knowledge Mobilization Network (SCI KMN) team of Transformational Specialists (Cyndie Koning, PhD (Rehabilitation Science), Edmonton; Anna Kras-Dupuis, RN, London; Marie Thérèse Laramée, MSc, Montréal; Valérie Lemay, erg. MSc, Québec City; Suzanne Nicol, RN, Calgary; Raj Parmar, RN, Calgary; Carol Scovil, PhD (Mechanical Engineering), Toronto): Developed, standardized and are implementing best practices in patient education related to pressure ulcer prevention and management; and employing patient-reported outcomes related to the perceived effectiveness of education delivery, as a way to inform quality improvement.

5. John Shepherd, MBA (Health Promotion & Knowledge Translation), Toronto: Creating self-management tools, such as the interactive eLearning series SCI-U, and a toolkit resource to facilitate interactions with primary care providers.

6. Dalton Wolfe, PhD (Neuroscience), London: Evaluating the utility and effectiveness of self-management tools in real-world settings, focused on innovative technologies.

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- Wolfe DL, Potter PJ, Sequeira KAJ. Overcoming Challenges: The role of rehabilitation in educating individuals with SCI to reduce secondary conditions. *Top Spinal Cord Inj Rehabil.* 2004;10(1):41-50.

SPOTLIGHT BEST PRACTICE ORGANIZATION

BRAIN AND SPINAL CORD REHAB PROGRAM –

Toronto Rehabilitation Institute (TRI), University Health Network, Toronto

Lyndhurst Spinal Cord Centre is a leader in education practice with a comprehensive, integrated program to support informed self-management. Foremost is the presence of a dedicated Patient and Family Educator position to develop education resources and provide staff training, thereby ensuring that point of care education, embedded with adult learning principles, is delivered effectively. Additionally, there is a well-equipped Resource Centre (see Figure 7.0) which provides a variety of resources and information in multiple formats, as well as educational workshops and peer support.

KEY COMPONENTS OF STRUCTURED EDUCATION PROGRAMMING INCLUDE:

1. SPINAL CORD ESSENTIALS EDUCATIONAL BINDER – to guide and formalize point-of-care education, and provide individuals with post-rehabilitation resources.

2. GETTING STARTED PATIENT AND FAMILY EDUCATION SERIES – half-hour, inpatient group education sessions on 12 set topics, presented twice weekly. These sessions use a Problem Based Learning (PBL) and Dialogue Education approach.

3. SPINAL CORD CONNECTIONS (SCC) RESOURCE CENTRE – a partnership between Toronto Rehab and SCI Canada (formerly Canadian Paraplegic Association), the Centre provides resources and education for inpatients, outpatients and other community members, in a variety of ways. Monthly educational workshops cover a wide range of topics of interest to individuals with SCI.

4. SPINAL CORD CONNECTIONS WEBSITE – a wide range of SCI information and resources and a connection to the SCI community. (www.sci-u.ca)

5. SCI-U – online e-learning modules on SCI-related issues. Topics include bowel, bladder, skin care, nutrition, using a manual wheelchair, sexuality, parenting, physical activity and pain management. (www.sci-u.ca)

6. THERAPEUTIC RECREATION COTTAGE PROGRAM – encourages independence and provides an opportunity for individuals with SCI to participate in new experiences, in an outdoor setting. 'Challenge by Choice' enables people to test their limits in a safe environment.

7. SCI CANADA – Provides monthly Peer Connections and Regional Service Coordinator information sessions. Group information sessions, co-led by peers, for community members (including inpatients and outpatients), at Toronto Rehab. Information is shared through presentations, discussions and demonstrations.

FIGURE 7.0 RESOURCE CENTRE AT LYNDHURST CENTRE, TORONTO

Roadmap: What's Needed on Key Clinical Issues

The relationship between "informed self-management" and "patient education" is not well understood. Significant effort is required to establish and integrate effective self-management programming, within inpatient and outpatient SCI rehabilitation practice. Ultimately, this would be most effectively driven within a policy framework that is consistent with the chronic disease model,[1] with embedded reimbursement structures that encourage patient-provider interactions, focusing on prevention, wellness and patient empowerment. There is a general and increasing appreciation of the importance of self-management in chronic diseases, such as diabetes or arthritis. However, there needs to be an enhanced awareness that self-management applies to SCI, and that existing tools and methods need to be tailored to best meet individual needs. There are four key clinical priorities, consistent with enhancing rehabilitation practice through integration of self-management programming:

1. INCORPORATE AN EDUCATIONAL SPECIALIST AS PART OF THE REHABILITATION TEAM

- As initiated by other sites in Canada, this specialist should have knowledge of, and responsibility for, facilitating self-management, to ensure the incorporation of adult education principles, to embed self-management processes within educational practice (e.g., problem-solving, systematic barrier and facilitator identification, goal-setting and action planning); and to lead educational resource creation.

2. COORDINATE AND SHARE EXPERTISE AND RESOURCES AMONG CANADIAN REHABILITATION PROGRAMS

- Eliminate duplication of educational/self-management resource creation and best practice application. The SCI KMN serves as a model for the benefits of shared and coordinated expertise and resources, to identify key practice elements and align evaluation processes, relative to educational practice and resource development.
- Tailor self-management programs and tools, originally designed for various chronic diseases, to better meet the needs of individuals with SCI.
- Align nationally and link with strategic partners across the care continuum, driven by rehabilitation providers.
- Collaborate with national sponsors, in partnership with provincial affiliates, to establish educational networks with consolidated infra-structure and shared key resources (e.g., creation of a battery of self-management tools).

3. TRAIN CURRENT AND FUTURE REHABILITATION PROVIDERS ABOUT ADULT EDUCATION PRINCIPLES AND SELF-MANAGEMENT PROCESSES

- Include self-management concepts, within professional school and continuing medical education curriculum.
- Advocate for unmet needs to appropriate administrators, curriculum developers, policy makers, etc.

4. ROUTINELY COLLECT AND NATIONALLY REVIEW THE EFFECTIVENESS OF SELF-MANAGEMENT AND EDUCATION PROGRAMS

- Routinely document rehabilitation educational practice and its perceived effectiveness (refer to Table 1.0 for some best practice indicators and outcome measurement tools). Initial efforts from the SCI KMN can inform comprehensive, pan-Canadian implementation of SCI-specific outcome assessments during rehabilitation.

TABLE 1.0 MEASUREMENT OF EDUCATIONAL PRACTICE – BEST PRACTICE INDICATORS

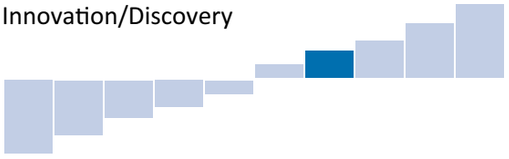
BEST PRACTICE INDICATOR	HOW MEASURED?	HOW MEASURED? WHO MEASURES IT? WHERE?	WHEN IS IT IDEALLY MEASURED?
Routine educational needs assessment: patient priorities, learning readiness, learning styles, barriers, facilitators	Needs Assessment Checklist[9] or interview/ customized assessment	Designated care provider(s) within the rehab team – Educational Specialist	During inpatient rehab stay (near admission with review)
Patient-reported outcomes assessing effectiveness of education delivered	Customized assessment (scale being developed by SCI KMN incorporates Likert scale questions (e.g., Education provided was effective in assisting me self-manage my health)	Patient facilitated by designated care provider(s), within the rehab team	Near inpatient discharge and 3-6 months post-discharge
Patient is confident about ability to self-manage health	Moorong Self-Efficacy Scale[10]	Patient facilitated by designated care provider(s) within the rehab team	Near inpatient discharge and 3-6 months post-discharge
The organization implements documented protocols and procedures for provision of educational practice that facilitates self-management	Checklist from assessor	Organizational level linked with Accreditation Canada (AC)	Based on Accreditation Canada

REPORT CARD: Informed Self-Management

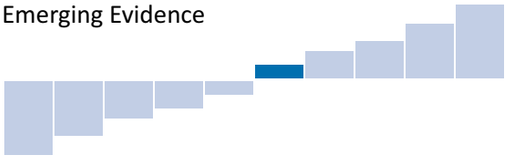
Extreme left below median: ***insufficient***
Extreme right above median: ***optimal***

KNOWLEDGE GENERATION

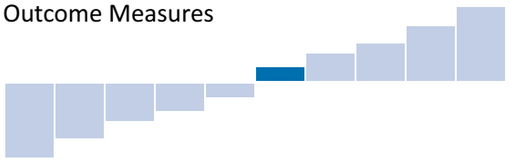
Innovation/Discovery



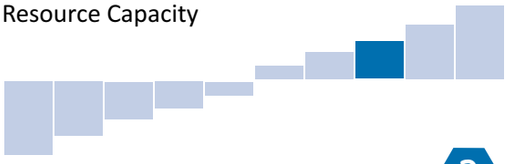
Emerging Evidence



Outcome Measures



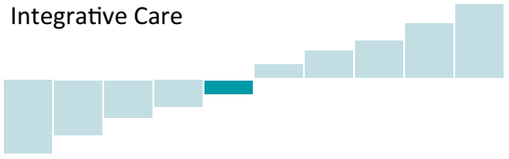
Resource Capacity



2020 PRIORITY 3

CLINICAL APPLICATION

Integrative Care



Effective Practice
(Evidence and Outcomes)

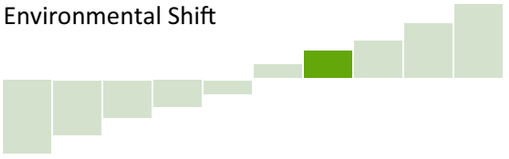
Equity Practice

Capacity

2020 PRIORITY 1

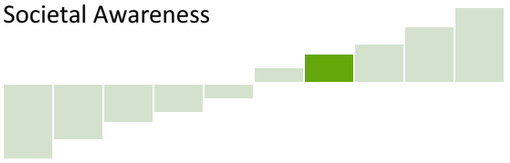
POLICY CHANGE

Environmental Shift

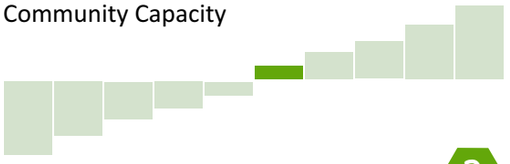


Change Agents

Societal Awareness



Community Capacity



2020 PRIORITY 2

TAKE HOME MESSAGE:

Effective educational practices that incorporate self-management principles are needed to enhance inpatient and outpatient rehabilitation service delivery. Universal inclusion of educational specialists, within the rehabilitation team, can enable the development and mentoring of service providers, with linkage and coordination of services acting as primary drivers for changes in service delivery. Elimination of redundancy in education services, across sites, may enable resource reallocation to address self-management priorities.

RESOURCES

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Physical Activity

DL Wolfe, PhD; K Arbour-Nicitopoulos, PhD; C Craven, MD; K Martin Ginis, PhD; and the E-Scan Investigative Team

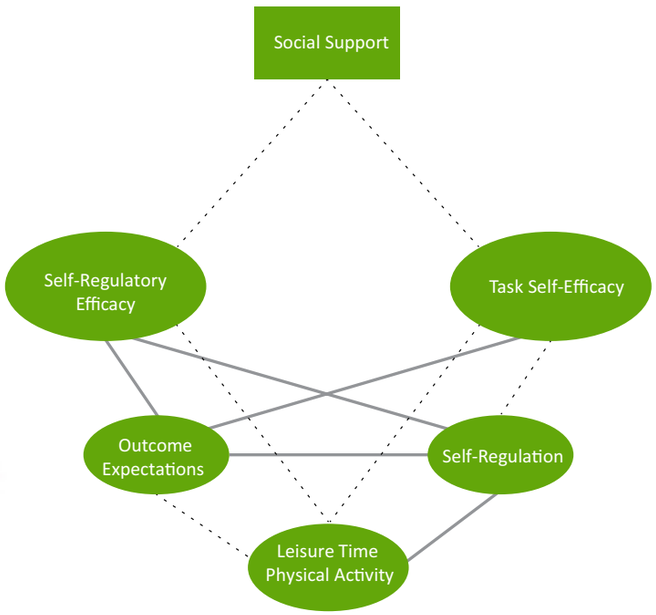
Physical activity, as defined by the World Health Organization, is any bodily movement produced by skeletal muscles that requires energy expenditure. Physical activity may be initiated by voluntary contraction of muscles or involuntary action of muscles, through technologies, including: orthotics, functional electrical stimulation (FES), robotic-controlled devices or aids that compensate for weak or paralyzed muscles. Routine participation in physical activity can enhance or maintain physical fitness, improve health, and enhance wellbeing. Although these health-related objectives may not be the individual's primary goal for getting active, physical activity enhances respiratory, cardiovascular and bone health, and prevents or reduces secondary health conditions including depression, pain and spasticity.[1,2] Physical activity at the recommended frequency, intensity and duration is crucial to health and wellbeing among individuals with spinal cord injury (SCI).

Rehabilitation providers enable physical activity among individuals with SCI in two ways: (1) direct provision of adapted physical activity programs (see Figure 1.0 *Seated Aerobics*), and health-promotional activities that encourage participation and remove barriers to participation. These activities are typically conducted during inpatient rehabilitation or outpatient programs that target individuals living in the community. In general, the primary focus of Canadian SCI rehab programs has been provision of adapted physical activity programs. To date, limited time, attention and resources are dedicated to health promotion activities, despite their increased potential for sustaining physical activity over an individual's lifetime.

FIGURE 1.0 SEATED AEROBICS.

Within a health promotion context, leisure-time physical activities are those one chooses to do in one's free time, including sports, structured fitness activities and unstructured activities (e.g., wheeling around a park) and excludes activities associated with therapy, work or daily living. Figure 2.0 illustrates the relationships between key determinants of leisure-time physical activity participation, including outcome expectations (expected benefits), and self-regulation efficacy (confidence to adopt strategies, goals and plans.[3] These concepts originate from social cognitive theory[4] and are key drivers of self-regulation of leisure-time physical activity.

FIGURE 2.0 KEY DETERMINANTS OF LEISURE-TIME PHYSICAL ACTIVITY.
(THICKER LINES REFLECT CONSTRUCTS THAT HAVE BEEN SHOWN TO HAVE STATISTICALLY SIGNIFICANT CORRELATIONS) REPRODUCED WITH PERMISSION FROM MARTIN GINIS ET AL.[3]

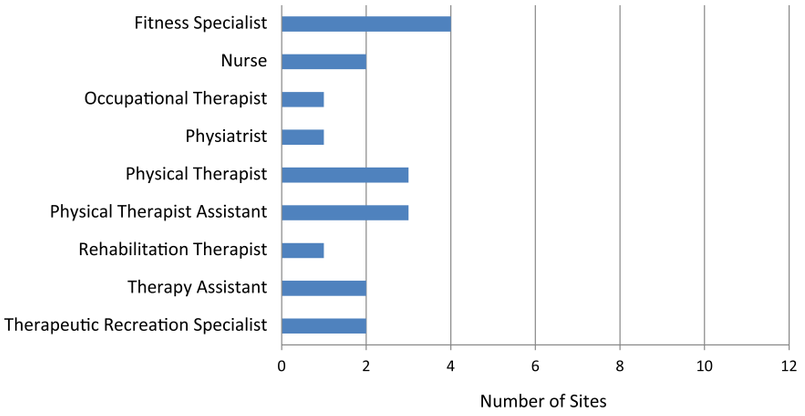


Current Practice: Physical Activity Programming for Individuals with SCI

The majority of E-Scan participating sites (i.e., 83.3%—10/12) report having a fitness centre (See Figure 3.0) that offers specialized or adapted fitness services. These fitness services primarily serve those living in the community, as 75% (9/12) provide fitness services to outpatients; whereas fewer - 58.3% (7/12) - offer similar services to SCI inpatients. One-third - 33% (4/12) - of the adapted fitness programs are provided offsite and external to the organization.

The best model for physical activity service delivery is through interdisciplinary care. However, this model is not used in current SCI fitness facilities. Of the 10 sites with facilities, nine different provider types are reported, often with a single provider group providing service in isolation. The most prevalent physical activity-related provider types are "fitness specialists" (4/10), physiotherapists (3/10) and physiotherapy assistants (3/10). Nurses, therapeutic recreation specialists and therapy assistants are each reported as providing service in two centres; and one centre reports service delivery from occupational therapists (OTs), physiatrists or rehabilitation therapists (Figure 3.0). Fitness specialists included kinesiologists, YMCA fitness instructors and a wellness exercise therapist.

FIGURE 3.0 HISTOGRAM SHOWING THE NUMBER AND VARIETY OF FITNESS PROVIDER TYPES ACROSS FITNESS CENTRES.



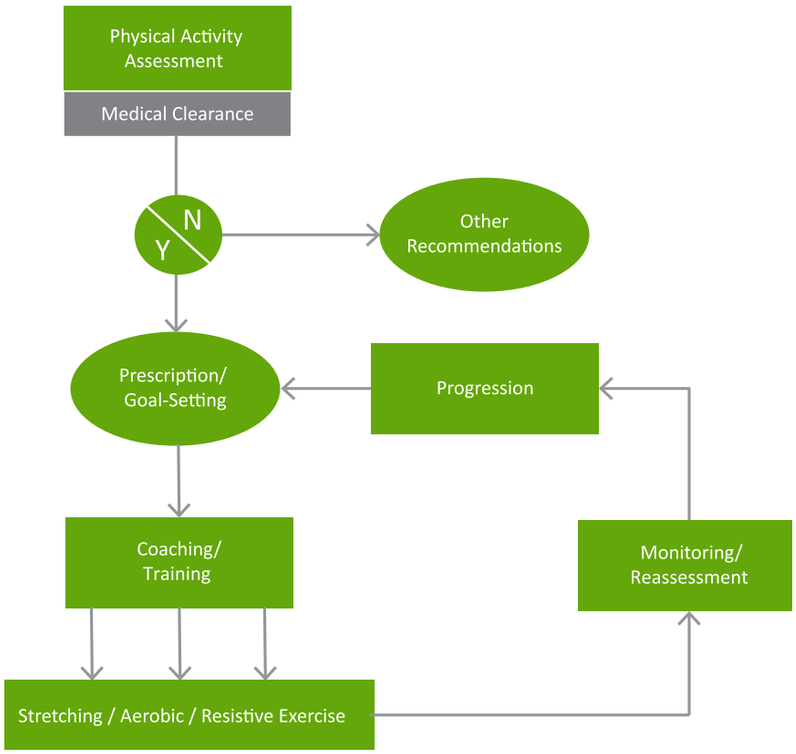
A model illustrating the spectrum of physical activity services currently offered by rehabilitation and fitness professionals, in Canada, is shown in Figure 4.0. Traditionally, exercise or physical activity prescription is developed by considering the individual's history and a formal exercise assessment. The physical activity prescription is then based on the F.I.T. principle, which specifies the frequency (how often), intensity (how much and how hard), and time (how long) one should spend doing a particular physical activity. The type or choice of exercise modality is then matched to consumer abilities, preference, fiscal resources and fitness goals. Monitoring/reassessment is conducted to inform exercise progression, facilitate goal modification and to identify and/or resolve adverse effects.

Health promotion programming focused on enhancing and maintaining physical activity participation (lifestyle modification) follows a similar pattern, although may involve additional activities. Figure 4.0 includes some activities that are consistent with this paradigm. The focus of assessment, within a health promotion context, typically involves identification of preferences, barriers and resources in order to set realistic goals, and to develop an action plan. Counselling can assist with action plan development, building of self-efficacy to facilitate self-regulation of physical activity behaviours, or "coping planning" to overcome barriers. Self-monitoring is essential to ensure continued participation and appropriate modification of goals and action plans, over time.

The role of physical activity in preventing secondary complications and maintaining health and wellness, in individuals with SCI, is well established, and acknowledged by a majority of rehab service providers. As a result, several fitness centres at, or affiliated with, local SCI rehabilitation sites have developed over the last 10–20 years to address SCI client needs. However, current Canadian models of physical activity service delivery are biased toward outpatients with SCI, and typically offered by a single healthcare provider. This pattern of service delivery appears historical, having been derived from a lack of designated funding, rather than from optimal models of service delivery.

Despite the widespread acknowledgement of "exercise is medicine", the majority of programs are run on a fee-for-service basis, with the goal of making them revenue neutral. Several of the fitness centres were developed with the goal of enabling individuals to transition into community-based services, but care providers note that this remains a challenge for a variety of reasons (including environmental barriers), as rural or remote communities are not generally well served by community-based, physical activity organizations.

FIGURE 4.0 PRIMARY SERVICE COMPONENTS FOR THE DIRECT PROVISION OF PHYSICAL ACTIVITY PROGRAMMING, AND HEALTH PROMOTION EFFORTS AIMED AT INCREASING SELF-DIRECTED PHYSICAL ACTIVITY.

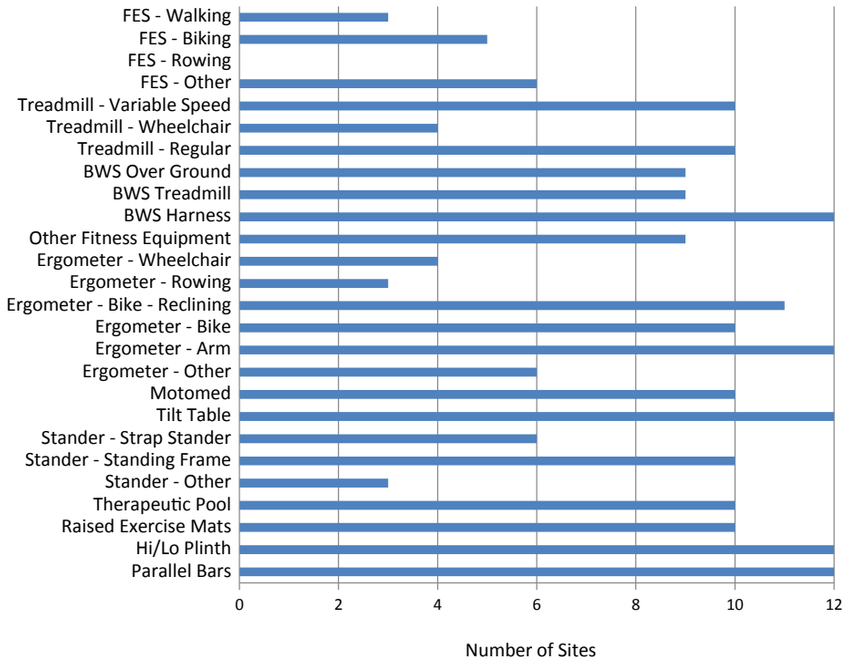


Further, the reimbursement models and historical scope of practice for traditional rehabilitation have not been consistent with establishment of physical activity services that focus on increasing participation. In particular, the immediate medical needs of the individuals and traditional physical therapies, focusing on neurological recovery and mobility, often take precedence.

The relationships between "therapy" and "exercise as therapy" are certainly not well understood, nor do we have a thorough understanding of how "exercise as therapy" might enhance therapeutic outcomes. In practice, current health service and reimbursement frameworks further compound these inter-relationships. The result is that proportionally little time is allocated to structured health-promotional programs or interventions that may result in adoption of an active lifestyle, after discharge from inpatient rehabilitation. In addition, while the majority of specialized SCI rehabilitation programs offer fitness-related services to individuals, there is significant variance in how these are conducted. Current Canadian SCI Physical Activity Practice Profile summarizes the status of current practice across Canada. Of note, there is inconsistent usage of either standardized protocols or outcome measurement tools across sites.

Figure 5.0 shows the variety of fitness-related equipment in use and the relative availability of each piece of equipment, across participating E-Scan sites. E-Scan respondents indicated that the sites are generally well equipped, with a variety of equipment to meet a range of fitness needs (e.g., arm and bicycle ergometry, variable-speed treadmills, standing frames, Motomed, FES-cycling ergometers) However, it is unclear if this equipment is available for fitness-related activities or limited to therapy service provision, as several programs noted availability limitations (mainly for outpatients).

FIGURE 5.0 DISTRIBUTION OF EQUIPMENT USED FOR PHYSICAL ACTIVITY PROGRAMMING IN CANADIAN SCI REHABILITATION CENTRES.



Regardless, when these results are coupled with the findings on the availability of fitness centres and provider types, it is apparent that while most sites are capable of delivering physical activity services, (in terms of space and equipment), staffing may not reflect inter-professional care – perhaps due to inadequate resources or other priorities. Of note, no site identifies kinesiologists as service providers who deliver physical activity programming – although it may have been that the "fitness specialists" identified are kinesiologists. This suggests that kinesiology, although representing a discipline specializing in human movement and fitness expertise, has yet to be routinely included in the rehabilitation team.

There is a general indication across Canadian SCI rehabilitation programs that service delivery related to physical activity is not always adequate, with only 66.7% (8/12) of sites reporting adequate wait times, and 58.3% (7/12) reporting adequate service, overall. In addition, few sites reported using evidence-based resources to guide their service delivery. For example, only 16.7% (2/12) of centres employ a clinical practice guideline (CPG), and only 8.3% (1/12) report following a care standard, with respect to fitness-related services. However, 25% (3/12) noted they do follow a defined protocol (although this was unspecified).

As evident from the E-Scan data, the majority of physical activity services, provided through SCI rehabilitation sites, relate to direct fitness programming, rather than health promotional approaches that focus on facilitating self-directed participation in physical activity. Although most sites provide physical activity services within a fitness centre, only one site reports research expertise in health promotional approaches, aimed at facilitating individuals to self-direct their physical activity. Upon validation, this expertise was determined to reflect participation in research studies associated with SCI Action Canada (described more fully below), and is not an onsite service program. Furthermore, the rehabilitation sites, located in the same cities as the most well – recognized community-based fitness centres (described below), did not acknowledge or recognize their local expertise.

These findings may result from the following dilemmas:

1. Community-based resources likely have insufficient links to the rehabilitation centres. It is generally acknowledged that linkages between rehabilitation professionals and community-based physical activity and sport organizations (e.g., Canadian Wheelchair Sports Association, Active Living Alliance) may be an important part of this picture, although there is a wide discrepancy, across communities, in terms of their effectiveness.

2. Rehabilitation centres often focus their efforts on providing services to inpatients rather than outpatients and these services are most often characterized as delivery of "therapy" and not "physical activity."

3. Health promotional efforts, in the context of physical activity to augment health, wellness or prevention of secondary complications, are often not perceived as a primary goal of inpatient rehabilitation.

4. Approaches designed to facilitate the self-regulation of physical activity are often limited to information only or informal efforts, by individual rehabilitation professionals, not easily captured as explicit components of practice.

Three physical activity programs, initiated at Canadian universities, have the potential to inform and enable more cohesive service provision, across the continuum of care, including linkages between rehabilitation and community providers:

- **Steadward Centre** at the University of Alberta is a fully-functioning fitness centre that provides services to help individuals with disabilities engage in physical activity.

- Researchers at the Department of Kinesiology at McMaster University, have developed numerous initiatives. Dr. Audrey Hicks established the *MacWheelers*, a fitness program for individuals with SCI which operates in the **WB Family Foundation Centre for Spinal Cord Research and Rehabilitation**. In addition, McMaster Kinesiology is also the head quarters for SCI Action Canada, led by Dr. Kathleen Martin Ginis. This organization represents an alliance of nearly 40 researchers and community organizations, working together to develop and mobilize strategies to inform, teach and enable individuals living with SCI to initiate and maintain a physically-active lifestyle.

- **Kingston Revved Up** is a fitness program for individuals with SCI and other disabilities, that was established by Dr. Amy Latimer-Cheung in the School of Kinesiology and Health Studies at Queen's University, Kingston and operates out of both Queen's University and St. Mary's of the Lake Hospital.

Current Canadian SCI Physical Activity Practice Profile

CLINICAL PRACTICE GUIDELINES

1. SCI Action Canada. *Physical Activity Guidelines for Adults with Spinal Cord Injury*. McMaster University, Hamilton, ON; 2011. www.sciactioncanada/guidelines. Accessed May 30, 2012.

2. Figoni SF. Spinal cord disabilities: paraplegia and tetraplegia. In: Durstine JL, Moore GE, Painter PL, Roberts SO, eds. *American College of Sports Medicine (ACSM)'s Exercise Management for Persons with Chronic Diseases and Disabilities*. 3rd ed. Champaign, IL: Human Kinetics; 2009:298-303.

CARE PATHWAYS OR LOCAL PROTOCOLS

1. Half of sites (6/12) report having a treatment protocol. However, only two sites report having a published CPG (ACSM and SCI Action Canada).

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Assessments

Standardized or routine use of assessment tools that focus on physical activity participation, or other aspects of fitness, are infrequently used in rehabilitation settings. The Physical Activity Recall Assessment for People with Spinal Cord Injury (PARA-SCI), or the related short form (Leisure Time Physical Activity Questionnaire for People with SCI (LTPAQ-SCI)), are measures that allow providers to quantify the number of minutes an individual engages in light, medium and heavy leisure time physical activity. These measures are routinely used in 2/12 (16.7%) of sites for research purposes. Similarly, the Borg Rating of Perceived Exertion, a measure to quantify exertion, is employed at 1/12 (8.3%) of E-Scan sites, for both research and clinical purposes.

Most often, physical activity participation patterns are reported as being assessed as part of a leisure and recreation assessment. This is noted by 4/12 (33.3%) of sites, although it is uncertain whether these sites used standardized or customized assessment tools.

Leaders in Physical Activity and SCI Across the Clinical/Academic/Community Interface

1. Kelly Arbour-Nicitopoulos, PhD (Exercise Psychology), Toronto: Applying theory to the understanding and promotion of multiple health behaviour change; translating research into practice.

2. Chris Bourne, MA, Ottawa: An athlete, advocate and leader through organizations such as the Active Living Alliance for Canadians with a Disability, Water Ski and Wakeboard Canada and the Canadian Paralympic Committee (CPC). Leads the *Changing Minds, Changing Lives* program in Ontario and Adapted Water Sports committee.

3. Cathy Craven, MD (Physiatry), Toronto: Understanding how whole body vibration may impact secondary health conditions associated with SCI.

4. David Ditor, PhD (Exercise Physiology), St. Catharines: Effects of exercise as a means to attenuate the secondary health complications that accompany SCI.

5. Laura Domenicucci, BSc (Kinesiology), Ottawa: Paralympic Development Coordinator for the Canadian Paralympic Committee. Educating and supporting healthcare professionals in using sport, within the rehabilitation process as part of managing the *Changing Minds, Changing Lives* program.

6. Donna Goodwin, PhD (Adapted Physical Activity), Edmonton: Bridging the gap between rehabilitation and wellness through community- based physical activity; capturing the experiences of individuals with disabilities in physical activity settings.

7. Audrey Hicks , PhD (Exercise Physiology), Hamilton: Director of MacWheelers exercise program and characterizing physiological benefits of physical activity, for individuals with SCI.

8. Amy Latimer-Cheung, PhD (Exercise Psychology), Kingston: Identifying the factors that motivate individuals with disabilities to adopt healthy behaviours, and testing and implementing motivational interventions to encourage individuals to make healthy lifestyle choices.

9. Desiree Maltais, PhD (Medical Science), Québec: Understanding the links between physical activity (strength, locomotor performance, function) and quality of life, and social integration of individuals with disabilities, with a focus on impairments acquired during early childhood.

10. Kathleen Martin Ginis, PhD (Exercise Psychology), Hamilton: Director of SCI Action Canada. Understanding psychosocial influences and consequences of physical activity participation among individuals with SCI; developing and implementing strategies to enhance physical activity participation in the SCI Community.

11. Sonja McVeigh, MD (Physiatry), Halifax: Assessing the impact of sports participation on quality of life after SCI.

12. Rich Vanderwal, BA (Recreation and Leisure Studies), Toronto: Actively promoting recreation for individuals with physical disabilities; developing and implementing adapted sport programs through such organizations as Canadian Association for Disabled Skiing – Ontario, and the Ontario Wheelchair Sports Association.

13. Dalton Wolfe, PhD (Neuroscience), London: Ensuring effective knowledge mobilization to realize the benefits of physical activity for individuals with disabilities.

SPOTLIGHT BEST PRACTICE ORGANIZATION

DEPARTMENT OF KINESIOLOGY – McMaster University, Hamilton

A group of McMaster researchers, led by Drs. Kathleen Martin Ginis and Audrey Hicks, have directed a series of physical activity-related initiatives. Together, they have conducted randomized, controlled trials of exercise interventions, developed physical activity guidelines for individuals with SCI, and advocated for SCI-specific physical activity resources. In addition, Dr. Martin Ginis led the largest-ever epidemiological study of physical activity and health in individuals with SCI (SHAPE-SCI), and established SCI Action Canada, an alliance of community-based organizations and university-based researchers working together to advance physical activity participation among Canadians living with SCI.

Dr. Hicks established the *MacWheelers*, a community-based fitness program for individuals with SCI which has set the standard for fitness programming for individuals with SCI.

Scientists within the Department of Kinesiology, McMaster University, have been instrumental in building the knowledge base about physical activity and SCI, and then moving this knowledge into action through direct physical activity programming.

OTHER NOTABLE ACHIEVEMENTS OF THIS GROUP INCLUDE:

1. CREATION OF *MACWHEELERS*, an exercise rehabilitation program for adults with SCI.

2. DEVELOPMENT OF THE PARA SCI - a standardized tool to assess physical activity participation.

3. ESTABLISHMENT OF LEISURE-TIME PHYSICAL ACTIVITY PARTICIPATION RATES and their relationship to various measures of health status and social cognitive predictors.

4. INITIATION OF *GET IN MOTION*, the first-ever physical activity-related telephone counselling service available for Canadians living with SCI - www.sciactioncanada.ca/get-in-motion.cfm.

5. DEVELOPMENT OF THE FIRST PHYSICAL ACTIVITY GUIDELINES FOR ADULTS WITH SCI (WORLDWIDE) - www.sciactioncanada.ca/guidelines.

STUDENT VOLUNTEERS WORK WITH INDIVIDUALS WITH SCI, FROM THE LOCAL COMMUNITY, IN THE MACWHEELERS EXERCISE PROGRAM.

Key Clinical Issues: What's Needed

Canada has several of the world's most respected scientists in the area of physical activity programming for individuals with SCI. Their work is derived from the experiences of frontline service providers (e.g., Steadward Centre at the University of Alberta and *MacWheelers* at the McMaster University's Centre for Health Promotion and Rehabilitation), but predominately focuses on enabling participation among individual's living in the community. We need to understand first, how the lessons learned from these initiatives can be applied to inpatient rehabilitation programming and second, how rehabilitation professionals might facilitate their patients' participation in these, and other community- based physical activity and sports organizations.

THREE SPECIFIC ISSUES WHICH RELATE TO THIS NEED INCLUDE:

1. What is the relationship between clinical rehabilitation therapy and physical activity (especially during inpatient rehabilitation)?

- How can physical activity become a priority in specialized rehabilitation centres for individuals with SCI, considering that therapy is reimbursed, while exercise is not?

2. What is the optimal model of care with respect to physical activity?

- How can exercise professionals (e.g., kinesiologists) be incorporated into the rehabilitation team?

3. How can individuals get the skills, strategies or resources necessary to overcome barriers to physical activity participation (e.g., lifestyle modification, fitness or sports participation)?

- What are the most effective messengers and methods and when should they be introduced?

Underlying these questions is a divide between academic focus and clinical rehabilitation practice. For example, much academic research has demonstrated the benefits of physical activity, and there is emerging work on the best methods for encouraging participation in physical activity, from a health-promotion perspective. However, this work has predominantly focused on individuals with chronic SCI, living in the community. Conversely, very few studies have been done on individuals with acute and sub-acute SCI, within an inpatient or day hospital setting.

There are untapped opportunities to increase our understanding of how individuals with SCI, undergoing inpatient rehabilitation, might benefit from physical activity programming. Some evidence suggests that individuals with acute or sub-acute SCI, undergoing more intensive fitness programming, as part of their rehabilitation program, have better rehabilitation outcomes.[5,6]

In addition, health promotional approaches that focus on encouraging participation in active lifestyles applied during, rather than after, inpatient rehabilitation (e.g., Martin Ginis et al.[3]) may be effective in facilitating long-term participation. Inpatient rehabilitation represents an important setting in which a foundation for long-term physical activity participation may be initiated.

Roadmap: SCI Rehabilitation and Physical Activity

INITIATIVES SUCH AS *SCI ACTION CANADA* REPRESENT A LOGICAL MEANS TO ENHANCE SCI REHABILITATION PROGRAMMING, AND ENABLE A HEALTHIER LIFESTYLE FOR INDIVIDUALS WITH SCI.

A specific strategy that would be especially useful would be to better link inpatient rehabilitation programs with SCI Action Canada. This could be done through linkages with networks such as the *SCI Knowledge Mobilization Network* or other Rick Hansen Institute initiatives (Rick Hansen SCI Registry, E-Scan) and would further enable the following objectives:

- Develop optimal physical activity assessment and services, within an inpatient SCI rehabilitation context
- Increase the linkages between SCI rehabilitation and community service providers
- Train rehabilitation providers on how to be effective "agents of change" with individuals (e.g., incorporate a health-promotional perspective, within their practice)
- Ensure clinical relevance and applicability for future research questions.

REASONS WHY THIS IS IMPORTANT:

- Specialized rehabilitation care providers represent important "credible messengers" in disseminating the importance of physical activity to individuals
- Appropriately trained rehabilitation professionals are uniquely positioned to provide "how to" information that is evidence-based, to link individuals to community service providers, and to provide strategies on how to overcome barriers to physical activity participation
- Improved rehabilitation outcomes may result from increased fitness levels achieved during inpatient rehabilitation.

Other mechanisms for enabling these changes could include curriculum development, and subsequent advocacy to professional and health-science academic programs, throughout Canada. Several members of SCI Action Canada have developed courses to foster health-promotional behaviours among health professionals - and to use SCI rehabilitation as a content area to provide these materials, within a clinical context. Sharing these course materials, across an expanded physical activity-related network that links SCI rehabilitation programs with SCI Action Canada, would enable capacity building among students embarking on a career in healthcare.

Another key strategy for change is the identification of practice indicators that would signify success in meeting these goals. Table 1.0 summarizes some suggested practice indicators, the most important of which is a measure that assesses the number of individuals with SCI, living in the community, who meet a minimum standard of adherence to the Canadian Physical Activity Guidelines for Adults with SCI.

TABLE 1.0 BEST PRACTICE INDICATORS

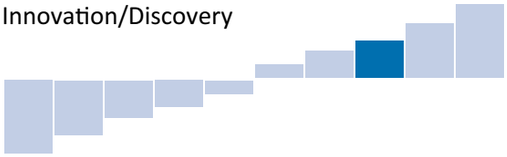
BEST PRACTICE INDICATOR	HOW MEASURED?	HOW MEASURED? WHO MEASURES IT? WHERE?	WHEN IS IT IDEALLY MEASURED?
Routine assessment of patient physical activity preferences, abilities and readiness	Interview / Customized assessment	Designated care provider within the rehab team – therapeutic recreation or kinesiology	During inpatient rehab stay (near admission with follow up close to discharge)
Inclusion of customized physical activity goals incorporated into the inpatient rehab program and discharge summary	Checklist	Designated care provider within the rehab team – therapeutic recreation or kinesiology	During inpatient rehab stay
Routine evaluation of patient adherence to the PA guidelines during routine outpatient follow up	PARA-SCI (or short form LTPAQ-SCI)	Rehab providers during routine follow-up assessments	Six months and one year, post injury
The organization implements documented protocols and procedures to improve physical activity participation	Checklist from assessor	Organizational level linked with Accreditation Canada (AC)	Based on Accreditation Canada

REPORT CARD: Physical Activity

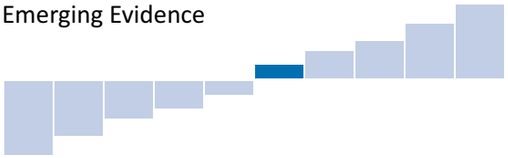
Extreme left below median: ***insufficient***
Extreme right above median: ***optimal***

KNOWLEDGE GENERATION

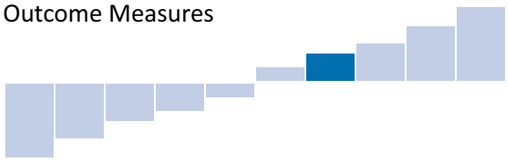
Innovation/Discovery



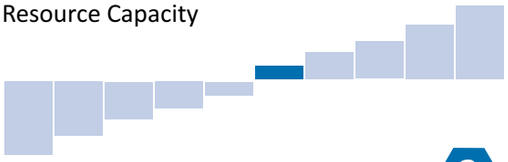
Emerging Evidence



Outcome Measures



Resource Capacity



2020 PRIORITY 2

CLINICAL APPLICATION

Integrative Care

Effective Practice
(Evidence and Outcomes)

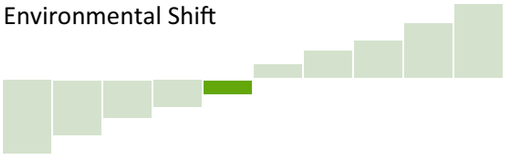
Equity Practice

Capacity

2020 PRIORITY 1

POLICY CHANGE

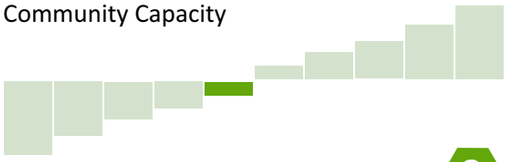
Environmental Shift



Change Agents

Societal Awareness

Community Capacity



2020 PRIORITY 3

TAKE HOME MESSAGE:

Clinical rehabilitation service delivery would be enhanced by improved linkages to academic partners who can provide guidance on evidence-based best practices and community-based organizations that can facilitate ongoing physical activity, post-rehabilitation. Specifically, increased attention to ensure physical activity programming meets recommended guidelines, during rehabilitation, may improve rehabilitation outcomes. In addition, incorporation of a health promotion perspective that focuses on lifestyle modification, and introduces individuals to a variety of sport and exercise opportunities, during rehabilitation, may increase the likelihood of ongoing, habitual physical activity participation, post-discharge.

RESOURCES

1. Wolfe DL, Martin Ginis KA, Latimer AE, et al. Physical activity and SCI. In: Eng JJ, Teasell RW, Miller WC, et al., eds. *Spinal Cord Injury Rehabilitation Evidence*. Version 3.0. Vancouver, BC; 2010. http://www.scireproject.com/rehabilitation-evidence/physical-activity. Accessed June 4, 2012.

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4. Bandura A. Social cognitive theory: an agentic perspective. *Annu Rev Psychol.* 2001;52:1-26.

5. Haisma JA, Post MW, van der Woude LH, et al. Functional independence and health-related functional status following spinal cord injury: a prospective study of the association with physical capacity. *J Rehabil Med*. 2008;40(10):812-8.

6. Tawashy AE, Eng JJ, Krassioukov AV, Miller WC, Sproule S. Aerobic exercise during early rehabilitation for cervical spinal cord injury. *Phys Ther*. 2010;90(3):427-37.

Employment and Vocation

A Jetha, PhD(c); D McCauley, BA; P Athanasopoulos, CA; S Howatt, BA; C Craven, MD; and the E-Scan Investigative Team

Employment is a crucial social and economic determinant to health and quality of life of Canadians with spinal cord injury (SCI), and is recommended as an important rehabilitation outcome.

Key Definitions

Employment is defined as the involvement in paid work for another person, organization or being self-employed in the formal or informal economy.[1] *Vocation* is an occupation in which a person is qualified or trained and finds interesting. *Unemployment* refers to not being employed but available, capable and searching for work or wanting to work. *Underemployment* is characterized as inadequate employment situations that may include involuntary part-time work, an inability to utilize training and skills in one's job, lower job satisfaction, earnings and a reduced likelihood of promotion.[1]

Importance of Employment

Extensive research has highlighted the personal and societal benefits of participating in paid work, following SCI. In particular, employment is a means to economic and residential independence - providing individuals with the opportunity to generate income, access health insurance, interact with others, foster structure and routine for their daily activities, and build self-identity.[2,3] Specific to individuals with SCI, involvement in employment is related to improved community independence, fewer secondary health complications, and greater self-confidence.[4,5] In addition, involvement in paid work can reduce high, indirect costs of SCI, which (in Canada) have been estimated at $1,154,669, over the lifetime of an individual with SCI. Indirect costs include those associated with premature mortality, high morbidity, productivity losses and both short- and long-term disability.[6]

SCI and Employment

Working-aged Canadians with SCI are more likely to be unemployed and underemployed, when compared to their counterparts without SCI. The most recent large-scale survey of Canadians with SCI found that close to 36% were employed, compared to 70% of their able-bodied peers.[7] Additional research finds that employment status ranges from 12% to 74%, based on the characteristics of the SCI sample being studied (e.g., neurological level of injury age at onset, definition of employment or geographical location of study participants).[8] Those who return to work following an injury are less likely to go back to their pre-injury job, and more likely to be underemployed. A majority take on less physically-demanding jobs, work part-time hours, have fewer opportunities to receive a promotion, earn lower salaries and report less career satisfaction.[8]

The employment picture for individuals with SCI is not completely bleak. Despite the low rates of employment and experiences of under-employment, **individuals with SCI report high optimism and motivation regarding returning to work, following their injury.[8] With appropriate support, they can pursue careers that are satisfying, engaging and meet their career aspirations.**

Factors Associated with Employment Among Individuals with SCI

Current research has focused on identifying the factors that predict employment status and return to work. Employment following SCI was found to be related to personal, health, environmental and policy-level factors (Table 1.0). Surprisingly, few studies to date have examined how these factors interact to influence involvement in paid work.

TABLE 1.0 SUMMARY OF FACTORS RELATED TO EMPLOYMENT.

FACTOR	DESCRIPTION
Personal	Age, educational attainment, pre-injury job experience, perceived control, gender and ethnicity.
Health	Injury severity, secondary health complications, injury duration, cause of injury.
Environment	Perceptions of others, access to the physical work environment, transportation and work conditions.
Policy	Access to social assistance and health benefits, and enforcement of employment equity legislation.

PERSONAL FACTORS

Being younger at the time of injury, having attained more education and pre-injury work experience and greater perceptions of control are associated with being employed.[5,9,10] In addition, older adults may exit the workforce at a younger age. Longitudinal research highlights a sharp decline in participation in paid work at 40 years of age, for individuals with SCI, compared to those without any disability, who tend to leave their jobs around 50 to 60 years of age.[8,11] Gender and race have been studied extensively in Americans with SCI. These studies report that being male and Caucasian are related to a greater likelihood of post-injury employment and greater wages.[9,11] Research is required to examine demographic trends of this nature in Canadian samples.

HEALTH FACTORS

Injury severity or neurological impairment plays a significant role in employment participation. Research has found that neurological level of injury (NLI) (e.g., paraplegia), lower pain and fatigue, and fewer secondary health conditions are associated with functional independence, fewer activity limitations and improved employment outcomes, compared to those with a more severe injury.[8,9,11] Having an injury for a longer period is also related to an increased likelihood of being employed. However, this trend plateaus after the first decade and those who remain unemployed, 10 to 12 years post-injury, are more likely to remain out of the workforce.[10,11]

WORK ENVIRONMENT AND POLICY

Aspects of the work environment, including the attitudes of others, physical access to the workplace, transportation and work conditions, may pose the most significant barriers to employment participation, when controlling for health and personal factors.

Negative attitudes and misconceptions towards employees with SCI in the form of prejudice (e.g., a negative overgeneralized image) or discrimination (e.g., negative behaviours or treatment), reduce opportunities to enter the workforce. In addition, discrimination may also lower an individual's perceptions regarding their ability to work.[1]

Aspects of the physical environment such as transportation (e.g., commuting to and from work - See Figure 1.0), access to and within workplaces (e.g., presence of ramps, curb cuts on sidewalks and elevators), accessible workspaces (e.g., wheelchair accessible desks and adapted computers) and adequate toilet facilities produce significant challenges to working,[12] and are rated as one the most critical barriers to employment.

Work conditions, including acts (e.g., sitting for long periods, lifting and reaching) and tasks (e.g., filing and typing for long periods or moving boxes and transporting goods) required for work, as well as the schedule and pace of work, can also dictate employment experiences. Research has found that individuals living with SCI tend to work in less labor-intensive job sectors, like business and administration or sales and service sectors, suggesting that work conditions play an important role in post-injury work choices.[11] More research on the role of work conditions and the influence of workplace accommodations (e.g., flexible schedules, part-time work with full benefits and work-at-home arrangements), on employment participation of individuals with SCI is required.

The policy environment may also significantly influence employment. A major barrier to employment, cited in research, is access to social assistance and health benefits. Among those not covered by private disability insurance or worker's compensation, there exists a dependence on disability supports and health benefits (e.g., prescription drug coverage, rehabilitation services, assistive devices and medical supplies), which are free to individuals with SCI on social assistance. In the absence of social assistance, health benefits may be extremely costly and cannot be sustained by those who are working part-time or in jobs that pay lower wages. Thus, the current structure of social assistance often creates a disincentive to returning to work or working long term.[1,13]

In addition, there are gaps in legislation that support the employment participation of individuals with SCI. Employment equity laws, which promote the hiring of individuals with disabilities, improve accessibility in the workplace and reduce discrimination, contain few enforcement mechanisms and are applied to only a small proportion of Canadian businesses.[1,13]

Outcome Measures in Employment Research

A majority of research has tended to assess employment dichotomously (i.e., employed and not employed), neglecting to capture the variability of employment experiences, including the range of tasks required for work, changes made to work because of health (e.g., reduced work

hours, changing jobs or leaving the labour force), productivity losses (e.g., absenteeism and job disruptions) and work-life balance. Future SCI and employment research can look toward measures used in studies on other musculoskeletal conditions, like arthritis, to fill this gap. Research on arthritis and employment has identified several valid and reliable work productivity measures that describe the impact of a chronic disabling condition, on one's ability to participate in employment.[14] For example, difficulties with work acts and tasks can be assessed using the Work Activities Limitations Scale (WALS). WALS is a 12-item measure, gauging problems with lower mobility (e.g., getting around the workplace or sitting for long periods), upper mobility (e.g., reaching or grasping), and the pace and schedule of work. Items are responded to on a four-point scale (0 = no difficulty, 3 = unable to do), and are totaled to produce a score ranging from 0 to 36. By expanding on the measurement of employment and adapting measures designed for other musculoskeletal conditions, researchers can gain a greater understanding of the experience of working with SCI, and help to identify challenges to participating in work.[15]

FIGURE 1.0 HAVING A WAY TO GET TO AND FROM WORK IS A KEY DETERMINANT OF EMPLOYMENT.

Summary of Current Practice

Figure 2.0 depicts a schematic overview of service delivery related to vocation after SCI. As indicated, the existence of, and access to, employment and vocational resources can significantly impact the nature and prospects of vocational goals and outcomes for an individual with SCI. Although most sites report availability of vocational counselling for their patients (Figure 3.0), the number of sites that employ a designated vocational counsellor is very low (Figure 4.0).

FIGURE 2.0 OVERVIEW OF EMPLOYMENT AND VOCATIONAL SERVICE DELIVERY.

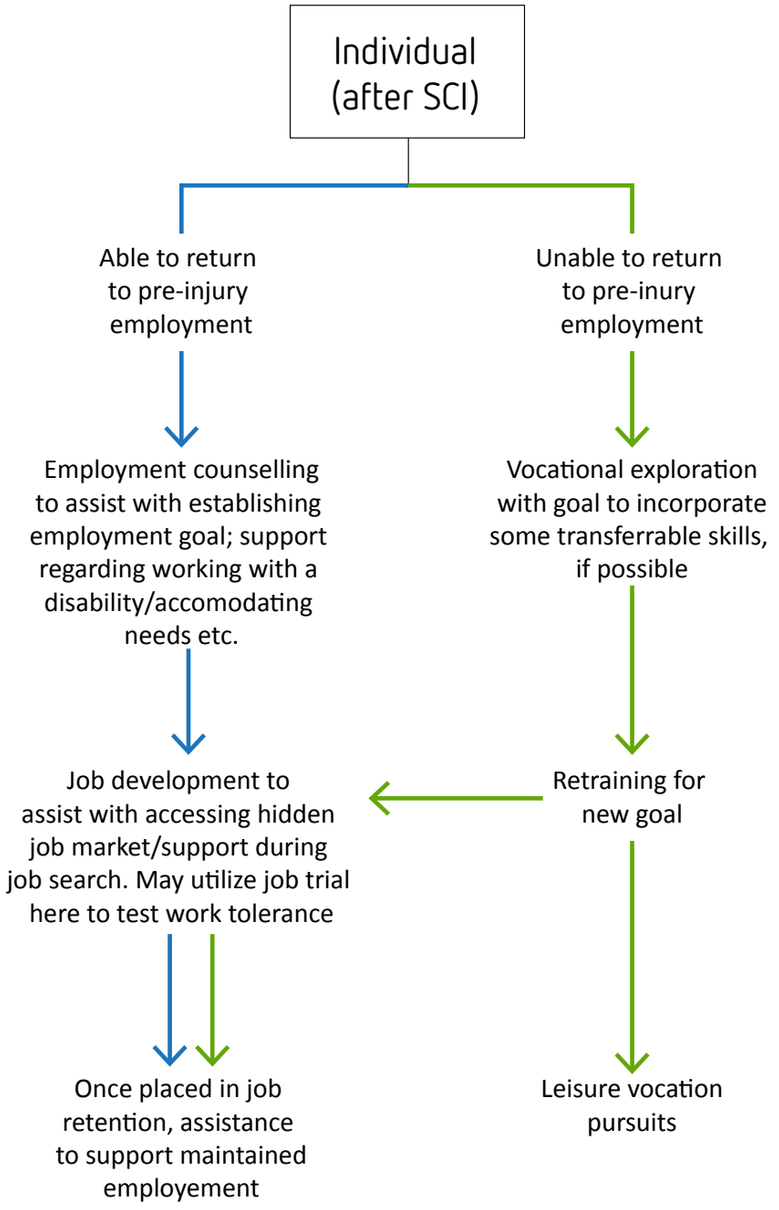


FIGURE 3.0 AVAILABILITY OF VOCATIONAL COUNSELLING ACROSS 12 SCI REHABILITATION SITES.

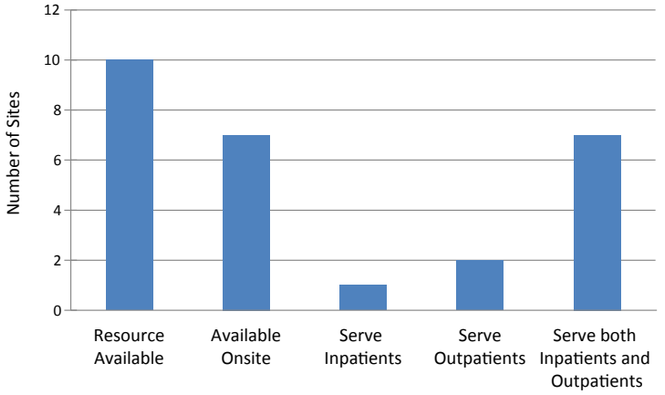
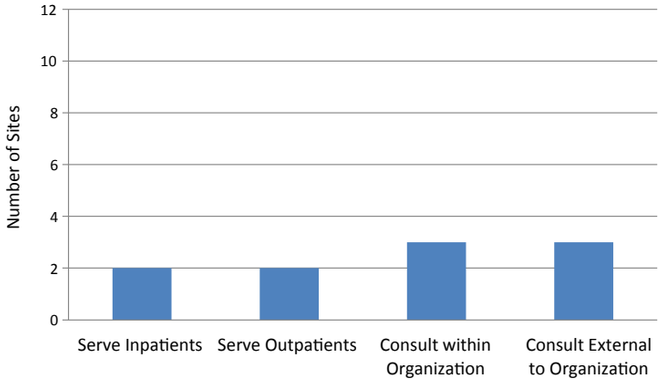


FIGURE 4.0 NUMBER OF SITES EMPLOYING A VOCATIONAL REHABILITATION COUNSELLOR.



Vocational Rehabilitation

Vocational rehabilitation (VR) is a multi-level process which can include medical, psychological, social and occupational activities that aim to restore work capacity, and facilitate return to work, following an injury.[16] Currently, no best practices have been established in VR, specifically for individuals with SCI. However, literature suggests that VR should be individualized and integrate all clinicians, within the circle of care.[17] In addition, VR may be most successful within the first six months post-discharge, where greatest adaptations to living with SCI can be made.[4]

Several approaches to VR (e.g., program-based, supported employment and case-coordinated) have been highlighted in traumatic brain injury literature, and show promise for individuals with SCI.[18] Program-based VR involves intensive individualized work skills rehabilitation, within a structured program environment, and assisted job placement with transitional services. Supported employment VR includes immediate job placement with work site job coaching.[17] Case-coordinated VR is part of the larger rehabilitation program and provides vocational counselling, pre-employment training, assisted job placement and on the job support.[18]

Despite their differences in delivery, the VR programs (described above) share several commonalities. Primarily, clients work with VR counsellors to set up individualized goals and objectives for employment. During the goal-setting process, the needs of the client are established. Approaches to VR also involve providing opportunities for educational upgrading and job retraining, and connecting clients with employers, based on their work goals and skill set.[4] All approaches involve a counselling component, which can address a number of issues related to working with a SCI, including problem-solving skills, independence, practical employment skills and workplace self-management. Lastly, VR counsellors can help to minimize other barriers to employment like transportation, clothing and shelter.

Outcome Assessment in Clinical Practice

Few outcome measures currently exist to assess progress in SCI vocational rehabilitation. Past practice has mainly focused on assessing employment status, satisfaction with employment, aspirations, and efforts to meet vocational goals.[19] In addition, measures are not typically validated and have relied largely on self-assessment (Table 2.0). These measures help VR counsellors to identify ways to customize a program, but may neglect aspects of employment which an individual with SCI finds challenging.

VR practice can also draw upon the Canadian Occupational Performance Measure (COPM).[20] COPM is a client-centered outcome measure (administered through a semi-structured interview) that enables occupational therapists to identify their clients' perceived performance in self care, leisure and productivity. The COPM can be used to determine how a VR program should be developed, based on the individual's perceptions of participation in employment over time.[20]

More recently, the International Classification of Functioning, Disability and Health (ICF) has been accessed to inform VR assessment, intervention and evaluation. The ICF Core Set for VR was designed for practice-based tools, and built on the domains of the ICF classification system (e.g., body function and structure, activity limitations and participation).[16,21] Tools that have been developed for SCI VR practice include:

1) Assessment sheet: Provides an overview of a client's functioning state, with input from the client and the health professional.

2) Categorical profile: Identifies intervention targets and assesses the level of difficulty in each ICF Core Set domain, before and after a VR intervention.

3) Intervention table: Facilitates the coordination of interventions, roles and resources, within an interdisciplinary team.

4) Evaluation tool: Allows for the assessment and re-examination of a VR program.[16,22]

The ICF Core Set is a promising tool for the measurement of VR outcomes. However, more work is needed to examine its efficacy in practice.

TABLE 2.0 OUTCOME MEASUREMENTS USED IN THE ASSESSMENT OF VOCATION.

TOOL/TECHNIQUE/EXERCISE	TYPE OF ASSESSMENT								
	Interest	Hard Skill	Soft Skill	Transferrable Skills	Aptitude	Employability/ Job Readiness	Validated Test	Observational	Self-assessment
Prove-it	X	X	X			X	X		
Mavis Beacon		X							
Barriers to Employment Self-Assessment						X			X
Transferrable Skills Scale		X	X	X					X
Job Survival and Success Scale			X			X			X
CHOICES	X			X					X
Self-Directed Survey	X								X
General Aptitude Test Battery					X		X		
Wide Range Achievement Test		X					X		
Job Success Seminars		X	X			X		X	
Negotiating Behaviour Change – Motivational Interviewing						X		X	
Unpaid Work Experience			X			X		X	
Assistive Technology Assessment		X				X			
One-to-One Counselling	X			X		X		X	

SPOTLIGHT BEST PRACTICE ORGANIZATION

EMPLOYMENT SERVICES TEAM – Canadian Paraplegic Association Ontario (CPA Ontario)

CPA Ontario was founded in 1945, with the mission to assist individuals with SCI and other physical disabilities to achieve independence, self-reliance and full community participation. Their Employment Services Team, which includes employment counsellors, job developers and an employment information coordinator, serves the Toronto region from the Employment Resource Centre (ERC), and is located in the same building as the Brain and Spinal Cord Rehab Program in the Toronto Rehabilitation Institute - University Health Network, Lyndhurst Centre. The ERC is accessible to all clients and provides computers with adaptive technologies (such as adjustable keyboards, screen reading software, and a head and track ball mouse).

Each year the Employment Services Team serves approximately 325 clients - 33% of which have an SCI. The Employment Services Team provides a full service, client-centred program, customized to meet the needs of the individual. Clients can also drop-in to the ERC to receive support from staff or peers, with an SCI, who are employed. With the team's help, over 70 individuals with disabilities are successfully placed each year.

Early in the vocational rehabilitation process, employment counsellors work with clients to identify goals and make career assessments. Clients are informed of work and educational opportunities, and provided with guidance on how to search for a job, develop a resume and cover letter, and prepare for an interview. In addition, guidance is given on disclosure of disability to an employer, and how to talk about accommodations required.

The Employment Services Team works with potential employers to understand their environment, work culture and the job skills required for each position in order to to facilitate an ideal job placement for the client. In addition, staff collaborate with CPA Ontario regional services coordinators to address any other barriers to employment such as housing, health issues and equipment needs. Finally, job retention services are offered to the clients and their employers, which include job coaching, accommodation support, training assistance for new work responsibilities, and disability awareness seminars, tailored to employers and co-workers.

Canadians Likely to Influence Practice

1. Institute for Work and Health: Conducts and shares research that protects and improves the health of working individuals. Research produced at the Institute for Work and Health is tailored to policy-makers, workers and workplaces, clinicians, and health and safety professionals. www.iwh.on.ca

2. WORKink: Canada-wide network of organizations and individuals that promote and support meaningful and equitable employment of people with disabilities. www.workink.com

3. Ontario Disability Employment Network: The Employment Services Team also works with potential employers to understand their environment, culture and skills required for each position; and to facilitate an ideal job placement for the client. www.odenetwork.com

4. Arif Jetha, PhD (Candidate), Toronto: Research on the experience of finding and maintaining work among young adults living with SCI, and rheumatic disease, during the transition to adulthood.

Filling the Gaps

As highlighted in this chapter, individuals with SCI face considerable challenges to finding and maintaining paid work. In order to build on current gaps in research and improve practice, several steps can be taken:

RESEARCH AND INNOVATION

First, population-level research should be conducted to gain a greater understanding of employment rates among working-aged Canadians living with SCI, and the complex interaction between personal, health and environmental factors. The SCI Community Survey, currently being administered to Canadians with SCI, will provide an important understanding of the employment rate, various factors related to involvement in work, and reasons for not working.[23]

Secondly, measures of employment outcomes require development. Research is required to move beyond measuring employment status to access measures of work productivity, range of tasks required for work, and changes made to work because of health and work-life balance. Several work productivity measures have been designed for other populations living with musculoskeletal conditions, which can be adapted and applied to research on individuals living with SCI.

Thirdly, vocational rehabilitation practice for Canadians with SCI can be improved. Several approaches have been identified to facilitate the return-to-work process. However, more work is required to understand which approaches are most effective and in which contexts. Furthermore, applying the ICF VR Core Set to practice will be important to acknowledge the multiple domains that can influence employment participation, and to help align with international standards.

ELIMINATION OF BARRIERS

Increased opportunities for vocational and/or skills-based training should be offered for individuals living with SCI. Vocational rehabilitation can provide tools to manage health, while working to overcome environmental barriers to employment. In particular, greater incentives should be provided to access job retraining and educational opportunities, especially for those on disability supports. What is more, employment/training opportunities should be made accessible to all Canadians living with SCI, regardless of geography.

Greater funding should be allocated to community organizations like CPA Ontario, which offers comprehensive vocational counselling to individuals living with SCI. Such organizations are knowledgeable on both their employment needs, and existing government policies; and are important in creating connections between jobseekers and employers. At the policy level, disincentives, including access to health benefits for individuals with SCI regardless of employment status, should be minimized. Accessibility and employment standards require greater enforcement, and ought to be improved to ensure accommodations are made to the physical work environment (e.g., improved transportation and wheelchair accessibility) and work conditions that support employment (e.g., flexible schedules and part-time work with benefits).

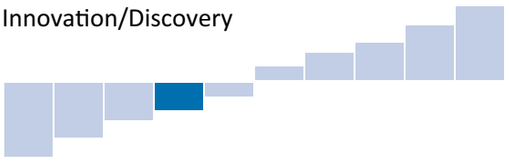
What is more, employers should be provided with information regarding the technical and financial resources available to improve the physical and social environment of their employees with SCI.

REPORT CARD: Employment and Vocation

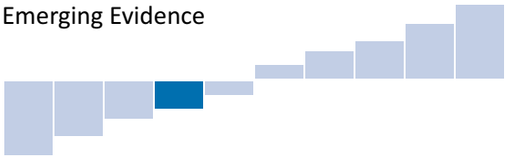
Extreme left below median: ***insufficient***
Extreme right above median: ***optimal***

KNOWLEDGE GENERATION

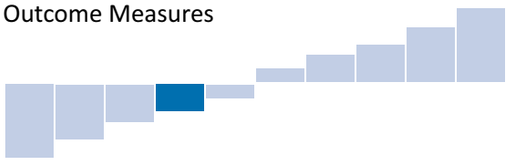
Innovation/Discovery



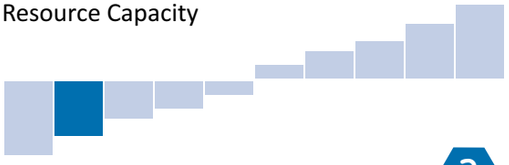
Emerging Evidence



Outcome Measures



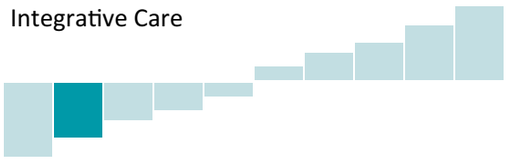
Resource Capacity



2020 PRIORITY **3**

CLINICAL APPLICATION

Integrative Care



Effective Practice
(Evidence and Outcomes)

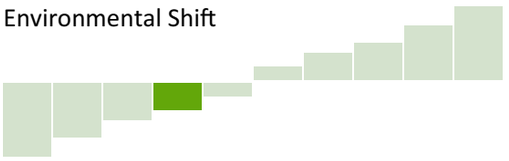
Equity Practice

Capacity

2020 PRIORITY **2**

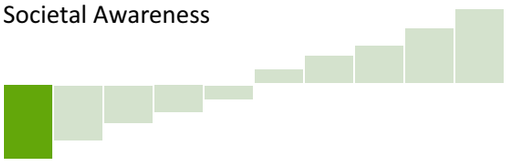
POLICY CHANGE

Environmental Shift

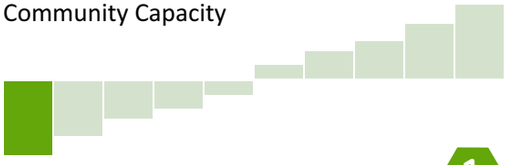


Change Agents

Societal Awareness



Community Capacity



2020 PRIORITY **1**

TAKE HOME MESSAGE:

Employment participation is an important rehabilitation goal, following SCI. A number of personal, health, environmental and policy-level factors play a role in work involvement. Vocational rehabilitation is critical to facilitate return to work, following an injury.

- Policy change is required to remove disincentives to employment
- Vocational rehabilitation best practice needs to be established along with tools to measure progress.

RESOURCES

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Community Participation

VK Noonan, PT, PhD; SL Hitzig, PhD; G Linassi, MB, FRCPC; C Craven, MD; and the E-Scan Investigative Team

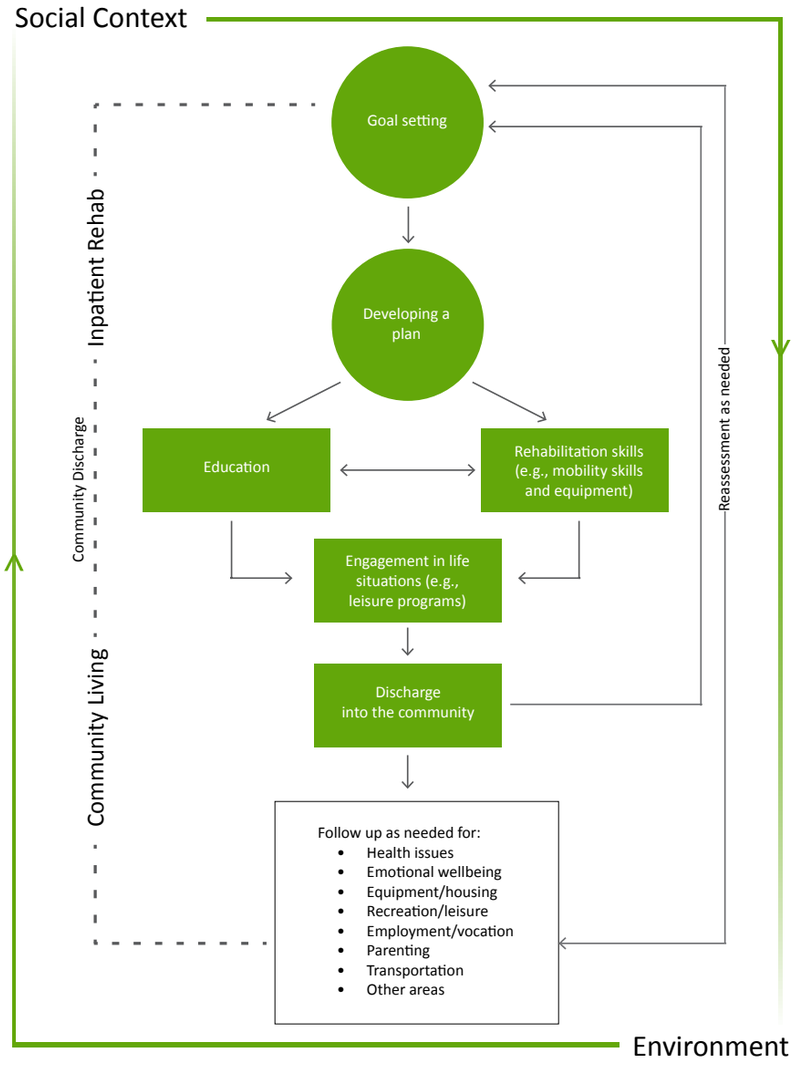
Community participation is a broad construct defined by the World Health Organization (WHO) as *involvement in life situations.*[1] Within the International Classification of Functioning, Disability and Health (ICF),[1] a life situation encompasses several areas, including individuals' ability to move around their home and community, bathe and dress themselves, engage in relationships with others, participate in social activities and civic life, in addition to employment, education, recreation and leisure activities.

The ICF concept under the term *community participation*, has been adapted and defined as a r*eturn to, or participating in, life situations of importance to the individual living with spinal cord injury (SCI).* This definition reflects the focus of transition from inpatient rehabilitation to living and participating in a community setting. Community participation intersects and informs other goals, within the rehabilitation framework (see the Employment/Vocation and the Informed Self-Management chapters, as examples).

The introduction of the ICF, and related research, has highlighted the importance of personal factors and the environment in obtaining optimal community participation - where *environment* relates to external factors such as the role of products/technology, the natural environment, support and relationships, attitudes and social policies, services and systems[1]; and *personal* factors are intrinsic to the individual and include their age, gender, culture, social and religious values.

When developing and implementing rehabilitation goals, it is vital to consider the individual's personal goals and the environment in which he or she lives. The aim of rehabilitation service delivery is to ensure individuals living with SCI are healthy, able and empowered to participate fully in the life situations they deem important (Figure 1.0). This requires customizing goals for individuals during inpatient rehabilitation, and then continuing to support them as they return to the community. Increasingly, there has been a shift away from clinical disciplines providing independent follow-up, towards interprofessional models of care, tailored to meet an individual's goals and needs. Linkages with community resources and service providers are vital to the provision of community participation services. Future service models should include adoption of 'chronic disease models of care', with strong community linkages and a focus on principles of self management[2] (see Informed Self-management chapter).

FIGURE 1.0 THE COMMUNITY PARTICIPATION PROCESS WHICH INVOLVES CUSTOMIZED GOAL SETTING AND INTERPROFESSIONAL IMPLEMENTATION OVER THE TIME COURSE, FROM INPATIENT REHABILITATION TO COMMUNITY LIVING.



Current Practice: Community Participation Following SCI

Preparing individuals for return to the community following SCI requires a comprehensive, multi-disciplinary program that begins during inpatient rehabilitation, and continues as individuals transfer to community living and thereafter. Members of the community participation team may include dietitians, drug and alcohol counsellors, nurses, occupational therapists (OTs), physiatrists, physical therapists (PTs), psychologists, psychiatrists, recreational therapists, social workers, speech language pathologists, therapeutic recreation (TR) therapists, vocational therapists, orthotists and prosthetists, vocational rehabilitation professionals, and experts in other medical specialties including respirology, urology, obstetrics, gynecology and sexual health.

A key member of the community participation team is the TR therapist, who typically provides individuals with SCI with the skills, experience and confidence to participate in the community, in meaningful roles and activities. Currently in Canada, 10 of 12 participating sites report having a TR therapist onsite during inpatient rehabilitation, and the majority of programs provide TR services five days per week. Forty two percent (5/12) report access to TR services, after discharge from inpatient rehabilitation.

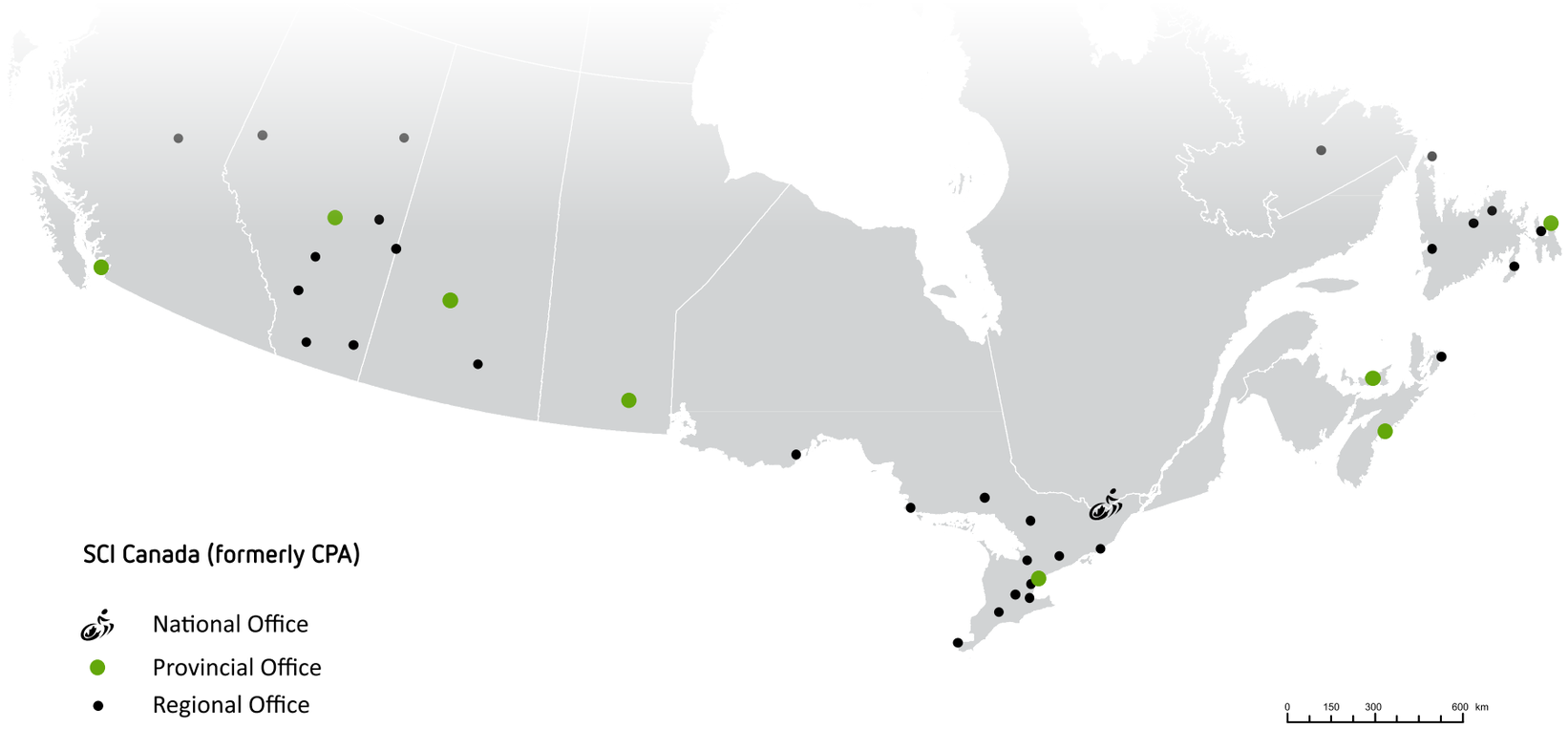
In May 2009, the Canadian Therapeutic Recreation Association and the National Council for Therapeutic Recreation Certification agreed to a partnership in which the NCTRC certification credential – CTRS (Certified Therapeutic Recreation Specialist) – would be the recognized certification credential in Canada. For more information visit: www.canadian-tr.org.

OTHER PROGRAMS AND SERVICES OFFERED IN E-SCAN PARTICIPATING SITES DURING INPATIENT REHABILITATION THAT FACILITATE COMMUNITY PARTICIPATION INCLUDE:

- Wheelchair skills – basic through to advanced (12/12 sites)
- Driver training/ assessment (9/12 sites)
- Access to counselling services (10/12 sites)
- Sexual health/fertility services (12/12 sites)

Canadian rehabilitation sites also have specialized equipment to prepare persons with SCI for life in the community. These include vehicle transfer simulators (8/12 sites) and transitional living units (8/12 centres). There are community support organizations throughout Canada; Spinal Cord Injury Canada has regional and provincial offices across the country with the exception of Québec and New Brunswick, which have independent organizations called Moelle épinière et motricité Québec and Ability New Brunswick, respectively. All E-Scan participating sites report a community liason service with 75% (9/12 sites) having linkages with SCI Canada (formerly Canadian Paraplegic Association) (Figure 2.0). These organizations offer many services including personal counselling, vocational counselling and peer support, and are working towards creating a standardized model for community service provision (www.spinalcordinjurycanada.ca).

FIGURE 2.0 MAP WITH SCI CANADA SITES



Standards are emerging regarding the programs, services and equipment required during inpatient rehabilitation, to facilitate community participation. However, regional disparity prevails with significant variation in the structure, availability and capacity of outpatient services, offered by rehabilitation sites to support community participation.

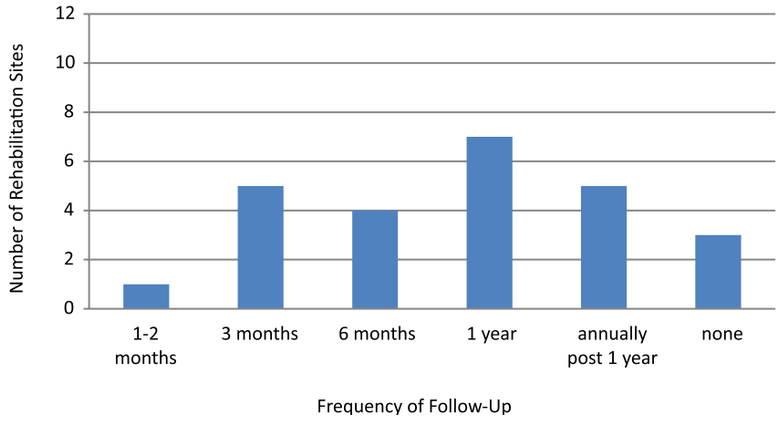
Although all sites report having the equipment and personnel to provide outpatient services, only seven sites (58%) report providing this type of service. Furthermore, the time intervals for follow up, in the first year after discharge and thereafter, vary across provinces and programs (Figure 3.0). From the data gathered in the E-Scan, it is difficult to discern if there are stand alone services to support community participation.

Barriers

Current barriers to providing comprehensive community follow up in SCI rehabilitation centres include a lack of dedicated resources and rehab service providers, and unclear and/or cumbersome referral processes. Current provincial funding models challenge the provision of community participation services. Individuals without third party funding must rely on provincially funded community participation services that are often unique to tertiary sites, and have restricted intake criteria and limited capacity.

There is a need to bridge the transition, from inpatient rehabilitation to community living by providing interprofessional care with coordination and linkage of primary care, community and rehabilitation services, in a manner intended to develop and utilize self-management skills.

FIGURE 3.0 FREQUENCY OF ANY FOLLOW-UP CLINIC ASSESSMENT OFFERED AT PARTICIPATING E-SCAN SITES.



Opportunities

Telecommunication technology has the potential to accelerate community participation service delivery. Currently, all E-Scan sites report video conference capability, 92% (11/12) of sites have telehealth facilities, and 75% (9 /12) report clinical personnel with telehealth expertise. In 75% (9/12) of sites, healthcare professionals are able to consult with one another in the community; and 58% (7/12) of sites report the ability to assess and monitor individuals in distant facilities. There is insufficient data regarding the frequency of telehealth implementation or accessibility of telehealth resources. As the pressures on healthcare spending continue, the length of stay during inpatient rehabilitation will likely decrease further, and novel models of care delivery (which allow for cost savings and expanded patient volumes) will be needed. Current telehealth and future technology advancement offers unique opportunities to reframe current care delivery models, and enhance community participation.

There is also an opportunity to centralize information using an SCI portal, within the Rick Hansen Institute (www.rickhanseninstitute.org). This could provide individuals with SCI with online information using programs such as SCI-U (www.sci-u.ca), and enable completion of standardized outcome assessments, using the Rick Hansen SCI Registry (RHSCIR, www.rickhansenregistry.org), that would be available to clinicians to monitor community participation. A proposed best practice indicator that encompasses these concepts is described later in this chapter.

Outcome Measures Relevant to Community Participation

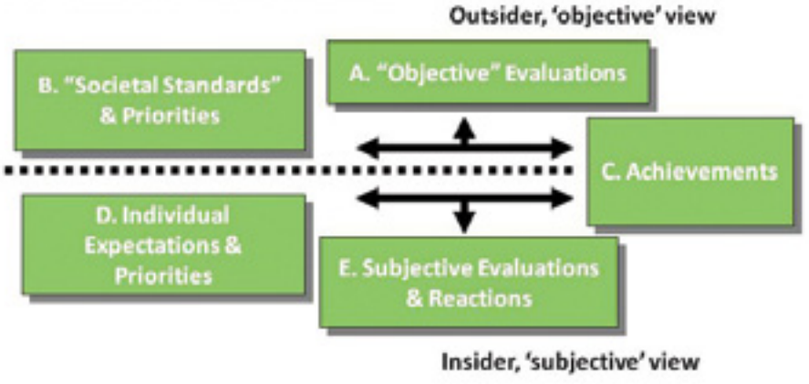
In Canadian rehabilitation centres, there is tremendous variability in the measures used to assess community participation and related concepts, such as environmental factors and quality of life. Below are outcome measures reported in the E-Scan.

Concepts Relevant to Community Participation	Outcome Measure	Reported Use of Measure in the 12 Canadian Sites
Participation	Reintegration to Normal Living Index (RNL)[3]	3/12 (25%)
	Canadian Occupational Performance Measure (COPM)[4]	2/12 (17%)
	Craig Handicap Assessment and Reporting Technique (CHART)[5]	5/12 (42%)
Quality of Life	Life Satisfaction Questionnaire 11 (LiSat-11)[6]	4/12 (36%)
	Satisfaction with Life Scale (SWLS)[7]	3/12 (25%)
Environment	Craig Hospital Inventory of Environmental Factors (CHIEF)[8]	1/12 (8%)

MANY RESOURCES ARE AVAILABLE TO AID CLINICIANS AND RESEARCHERS IN DEVELOPMENT AND EVALUATION OF COMMUNITY PARTICIPATION. THESE INCLUDE:

1. ParQoL (www.parqol.com)
The Canadian-developed Participation and Quality of Life (Par-QoL) Tool-Kit assists clinicians and researchers to identify appropriate outcome measures, to assess the impact of secondary health conditions on participation and quality of life. A detailed description of the three main groups of quality of life, and definitions for the objective and subjective dimensions, is provided on the Par-QoL website. Below is a list of measures commonly used to assess participation, classified according to the boxes covered in Dijkers' model (Figure 4.0).

FIGURE 4.0 DIJKERS' CONCEPTUALIZATION OF QUALITY OF LIFE.
ADAPTED WITH PERMISSION FROM DIJKERS.[9]



A prominent feature of the model is the distinction between *objective* and *subjective* dimensions of quality of life. Objective measures take into account the 'societal' or 'outsider' perspective of what constitutes quality of life. Measures, from the objective standpoint, rate quality of life in terms of measurable 'achievements' taken to be representative of good quality of life, such as being married, having a job, being educated, having good health, etc. (Figure 4.0 Boxes A and B versus C).

Conversely, the *subjective* standpoint takes the individual or the 'insider' viewpoint. In other words, it asks respondents to share 'how they feel' about their quality of life. Subjective measures typically ask individuals to rate how satisfied they are with a particular domain in their life, and may even ask them to rank their relative importance to their overall wellbeing (Figure 4.0 Boxes D and E versus C).

The above framework also applies to measures of community participation, and can inform which dimensions various participation measures assess.

EXAMPLES OF *OBJECTIVE* COMMUNITY PARTICIPATION MEASURES INCLUDE:

- Community Integration Measure (CIQ)[10] – Dijkers' Model Boxes B and C
- Craig Handicap and Assessment Reporting Technique (CHART)[5] – Dijkers' Model Boxes B and C.

EXAMPLES OF *SUBJECTIVE* COMMUNITY PARTICIPATION MEASURES INCLUDE:

- Person-Perceived Participation in Daily Activities (PDAQ)[11] – Dijkers' Model Boxes C, D and E
- Reintegration to Normal Living (RNL) Index[3] – Dijkers' Model Boxes C and E
- Assessment of Life Habits (LIFE-H)[12] – Dijkers' Model Boxes C and E
- Impact on Participation and Autonomy (IPA)[13] – Dijkers' Model Boxes C and E
- Adult Needs Assessment Checklist[14] – Dijkers' Model Boxes C, D and E.

2. SCIRE (www.scireproject.com)
The *Spinal Cord Injury Rehabilitation Evidence* (SCIRE) project contains an overview of outcome measures that have established psychometric properties in individuals with SCI. One section coves outcome measures to assess participation and environmental factors. Recently, the SCIRE Outcome Measures Toolkit was produced to facilitate consensus regarding the outcome measures routinely used in clinical practice and research. Recommended participation measures are the *Craig Handicap and Assessment Reporting Technique* (CHART)[5] to assess *objective* aspects of participation, and the *World Health Organization Disability Assessment Schedule II*[15] to assess subjective aspects of participation.

Current Canadian Community Participation Practice Profile: Canadian Experts in Community Participation

1. Luc Noreau, PhD (Community Health), Québec City: Works at Laval University and is leading the development of new and novel measures that can be routinely used to assess community participation.

2. Vanessa Noonan, PhD PT (Health Care & Epidemiology), Vancouver: Expertise in measuring participation using the ICF. She is working with Dr. Noreau on the development of new participation measures, and on understanding the relationship among concepts (e.g., body function and structures, activity, participation, environmental factors, personal factors) in the ICF model.

3. Sander L. Hitzig, PhD (Psychology), Toronto: A scientist at University Health Network - Toronto Rehab's Spinal Cord Rehabilitation Program with expertise on factors that influence community participation, post-SCI.

4. Gary Linassi, MB (Physiatry) FRCPC, Saskatoon: A physiatrist and researcher at the University of Saskatchewan, interested in the transition from inpatient rehabilitation to community following SCI. He is leading a team looking at health care services for, and needs of, individuals with SCI living in the community. The goal of this research is to ensure a continuum of care after transition to the community.

5. Charlene Alton, TR; and Rich VanderWal, TR, Toronto: Recreational therapists at Toronto Rehab's Spinal Cord Injury Program at Lyndhurst Centre, who have developed a program to promote community participation, based on an interdisciplinary model of care, which has recently undergone formal program evaluation.

6. Sonja McVeigh, MD (Physiatry), Halifax and Rhonda Willms, MD (Physiatry), Vancouver: Related clinical expertise likely to influence practice.

BRAIN AND SPINAL CORD REHAB PROGRAM

Toronto Rehabilitation Institute (TRI), University Health Network, Toronto

Toronto Rehab's Spinal Cord Rehabilitation Program (SCRP) offers a number of interprofessional clinical services, aimed at providing individuals with the knowledge and skills to live more active and fulfilling lives, post-injury. Notable programs include the SCRP Cottage Program, a four-day cottage experience where individuals can engage in a number of adapted leisure activities (e.g., handcycling, sailing and swimming); and the Community Reintegration OutPatient (CROP) Service, a therapeutic educational initiative that provides individuals with opportunities to discuss topics relevant to emotional, physical and social wellbeing.

Other notable services, geared to facilitating community participation, include a Toronto Transit Corporation (TTC) orientation (transportation), the CPA Ontario Employment Resource Centre (employment), the Peer Support Program (social), and Lyndhurst Fitness Centre (physical activity). In addition, various online resources promote health and wellbeing, including Spinal Cord Connections ***(www.spinalcordconnections.ca***), and the Spinal Cord Essentials Tool-Kit ***(www.torontorehab.com/Our-Services/Spinal-Cord-Injury-and-Disease/Spinal-Cord-Essentials-Toolkit.aspx)***.

Notable programs include the SCRP Cottage Program, a four-day cottage experience where individuals can engage in a number of adapted leisure activities.

ROADMAP: Where Do We Need to Go?

COMMUNITY PARTICIPATION ENHANCEMENT MUST PROCEED ON THREE LEVELS:

1. Develop and implement routine follow up
Routine standardized follow-up assessments, to address community participation are needed. Routine follow up is, in itself, a best practice indicator to enable optimal participation.

What?
Community participation assessments should include an assessment of participation and environmental factors. Recommended is use of the Person-Perceived Participation in Daily Activities (PDAQ),[11] part of the RHSCIR Community Follow-up Version 2.0, and the Craig Hospital Inventory of Environmental Factors (CHIEF)[8] to minimize time, and to ensure assessment of modifiable aspects of community participation. To further minimize the time requirements, a subset of key indicators could be selected for routine follow-up (e.g., assessment of important roles such as parenting, employment/vocation, etc.).

When?
Community follow up should be started at the first year following discharge and annually, thereafter. Based on literature (as well as on feasibility/sustainability), follow ups may be spaced out at longer intervals after the first two to five years…10 years, 15 years, etc.

How?
Individuals with SCI would complete the measures either on-line or by phone. Information from the measures could be used to identify specific services, based on the individual's needs pertaining to community participation (e.g., follow-up with a TR, physiatrist, vocational counsellor, SCI Canada).

2. Utilize current resources
The Rick Hansen Foundation has developed an easy-to-use online tool called *planat* (formerly known as the *Rick Hansen Global Accessibility Map*) for individuals with disabilities to submit reviews on the accessibility of buildings and public spaces (e.g. parks, trails, etc.) around the world (www.planat.com).

3. Make decisions based on data from Canadians
The SCI Community Survey is a national survey conducted in 2012. Results from this survey will identify priorities for individuals with SCI, and determine how successful the Canadian health and social services system is, at meeting their needs. This information will inform clinical practice, research and policy future directions. Specific examples of areas for further policy development are described in the 'What's Needed' section.

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Conceptualization and Outcome Measures

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Relationship with Concepts Relevant to Community Participation

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What's Needed?

FUTURE CLINICAL DIRECTIONS

- Identify which resources and interventions (e.g., educational and technological programs) are useful to individuals and their social networks, to support community participation following SCI
- Identify which cognitive-emotional factors, such as self-efficacy and coping styles, predict successful community participation following SCI
- Establish mechanisms to transfer content of the community participation assessment (above) to the appropriate provider or group of providers.

FUTURE RESEARCH

- Examine if social and environmental barriers to community participation, following SCI, can be positively affected by changes in policy. For example, evaluate whether making family physician offices accessible (e.g., stairs, door widths) decreases visits to the emergency department
- Examine if factors such as age, income, rural/urban, transportation, ethnicity and culture affect community participation following SCI.

FUTURE POLICY INITIATIVES

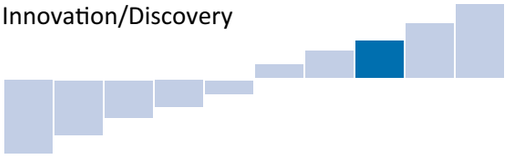
- Promote nationwide legislation that requires accessible transportation across the country
- Include criteria related to the definition of accessible work and recreation environments in Canadian disability policy.

REPORT CARD: Community Participation

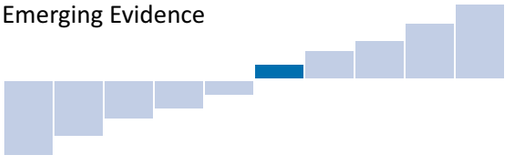
Extreme left below median: ***insufficient***
Extreme right above median: ***optimal***

KNOWLEDGE GENERATION

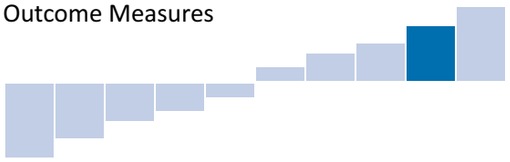
Innovation/Discovery



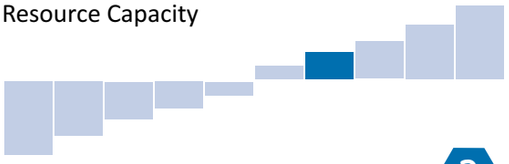
Emerging Evidence



Outcome Measures



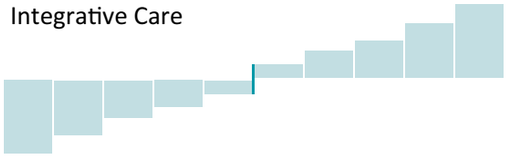
Resource Capacity



2020 PRIORITY 3

CLINICAL APPLICATION

Integrative Care



Effective Practice
(Evidence and Outcomes)

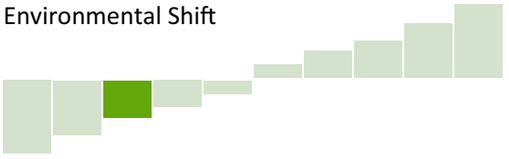
Equity Practice

Capacity

2020 PRIORITY 2

POLICY CHANGE

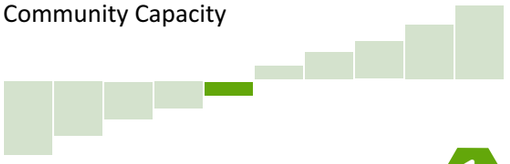
Environmental Shift



Change Agents

Societal Awareness

Community Capacity



2020 PRIORITY 1

TAKE HOME MESSAGE:

Given the societal and environmental barriers that hinder community participation, there is a need to create and implement social policies – such as the Accessibility for Ontarians with Disabilities Act – that support community participation following SCI.

RESOURCES

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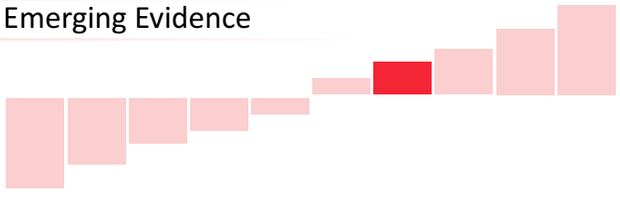
National Report Card and New Perspectives

National Report Card

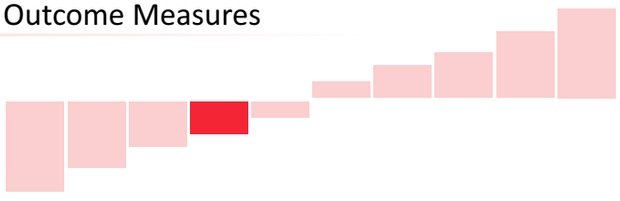
KNOWLEDGE GENERATION

Innovation/Discovery
Novel methods, ideas, and/or practices that lead to advances in the field.

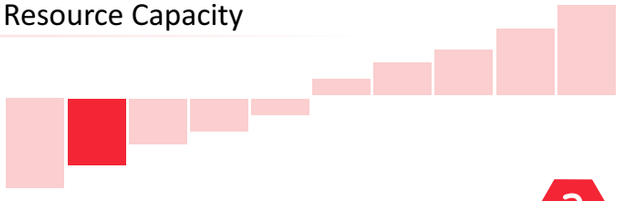
Emerging Evidence
The academic weight and clinical value of findings from ongoing and recently completed research studies.



Outcome Measures
The tools being used to estimate the results of a treatment and evaluate its effectiveness.



Resource Capacity
The extent to which the field has adequate graduate students, and basic and clinical scientists with the appropriate skills to investigate the needs expressed by individuals and service providers.



2020 PRIORITY 3

Integrative Care
The multidisciplinary and synergistic approach to healthcare service delivery.

Effective Practice
The existence of clinical practice guidelines, best practice indicators or other relevant evidence to support practice implementation.

Equity Practice
The equivalence of care provision across the country.

Capacity
The number of specialized staff members and the state of their professional development across the country.

Invest in Science
KNOWLEDGE GENERATION

This component reflects the state of rehabilitation research and research outcomes in Canada. Although many E-Scan providers acknowledge excitement regarding innovations and ongoing discovery, there is national consensus that the current VOLUME and QUALITY of rehabilitation-related outcomes and researchers are insufficient. Among these indicators, development of human capital in the form of studentships and salary support for early and mid-career scientists is viewed as a strategic imperative to secure the field's future.

Enable Best in Practice
CLINICAL APPLICATION

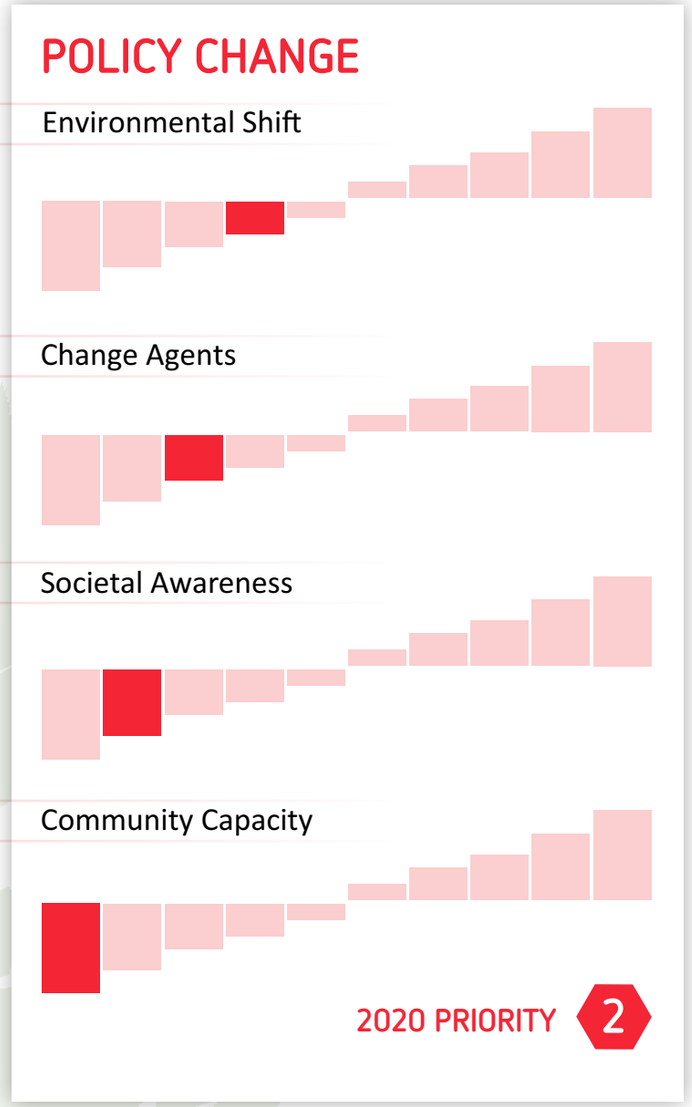
There is insufficient IMPLEMENTATION of published rehabilitation research or practice science data throughout Canada. Despite foci of exemplary care, most sites have poor to mediocre clinical application. National IMPLEMENTATION of current knowledge in best practice

Environmental Shift
Formation of community groups or coalitions with common SCI rehabilitation/health interests.

Change Agents
Leaders, experts or organizations willing to partner to effect policy change.

Societal Awareness
General community awareness of the need for policy change to alter practice and influence the health of individuals with SCI and/or rehabilitation service delivery.

Community Capacity
Capacity of the SCI community and its' stakeholders to collaborate with policy makers during the planning, implementation, and evaluation of policy change.



is viewed as a strategic first step toward eliminating regional disparity in service provision. Interprofessional models of care with appropriate ratios of credentialed clinicians with SCI SPECIALTY training are needed to address the gaps between the complex care needs of individuals with SCI, available services and the lag time between knowledge generation and practice implementation.

Force Policy Change
POLICY CHANGE

This component reflects the state of awareness and readiness to lobby for meaningful changes in health policy. There is uniform national consensus that the MAGNITUDE and EFFECTIVENESS of the national lobby for SCI health policy change is currently insufficient and ineffective.

Strategic investment in a group responsible for facilitating changes in policy is viewed as a PRESSING priority to facilitate changes in practice.

National Report Card

KNOWLEDGE GENERATION
Current research endeavours (innovation) and their outcomes.

CLINICAL APPLICATION
The use of research and best practice findings, and their alignment with current clinical practice.

POLICY CHANGE
The extent to which health policy currently enables or impedes changes to service delivery.

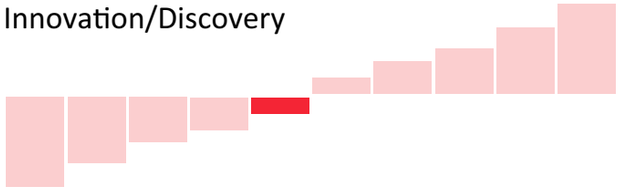
TAKE HOME MESSAGE

Content and participating experts also provide this summary, describing the steps required to revitalize the area of highest priority, between the time of the Atlas publication and 2020.

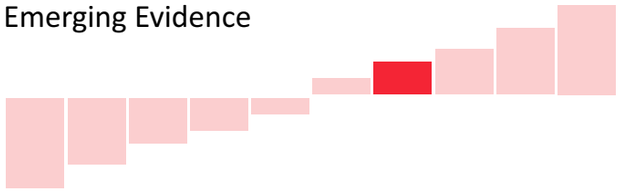
REPORT CARD: National

KNOWLEDGE GENERATION

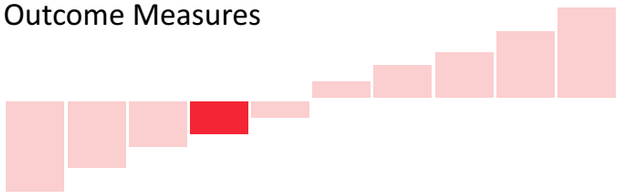
Innovation/Discovery



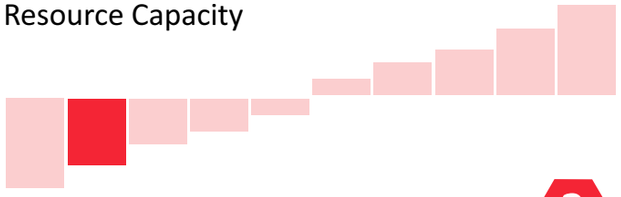
Emerging Evidence



Outcome Measures



Resource Capacity



2020 PRIORITY 3

CLINICAL A

Integrative Care

Effective Practic
(Evidence and O

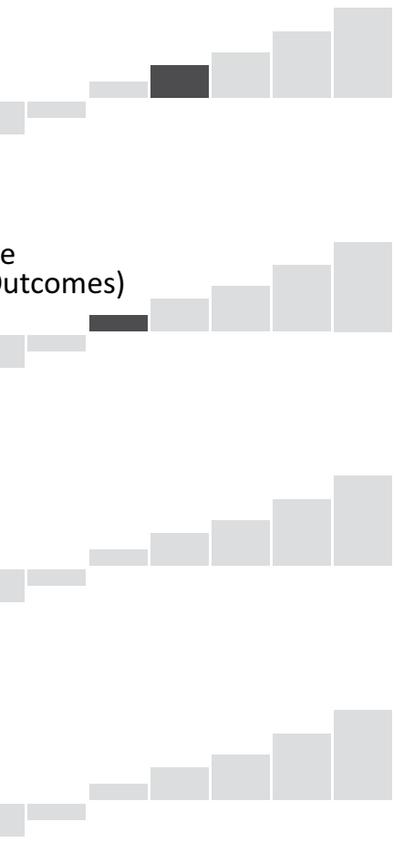
Equity Practice

Capacity

TAKE HOME MESSAGE:

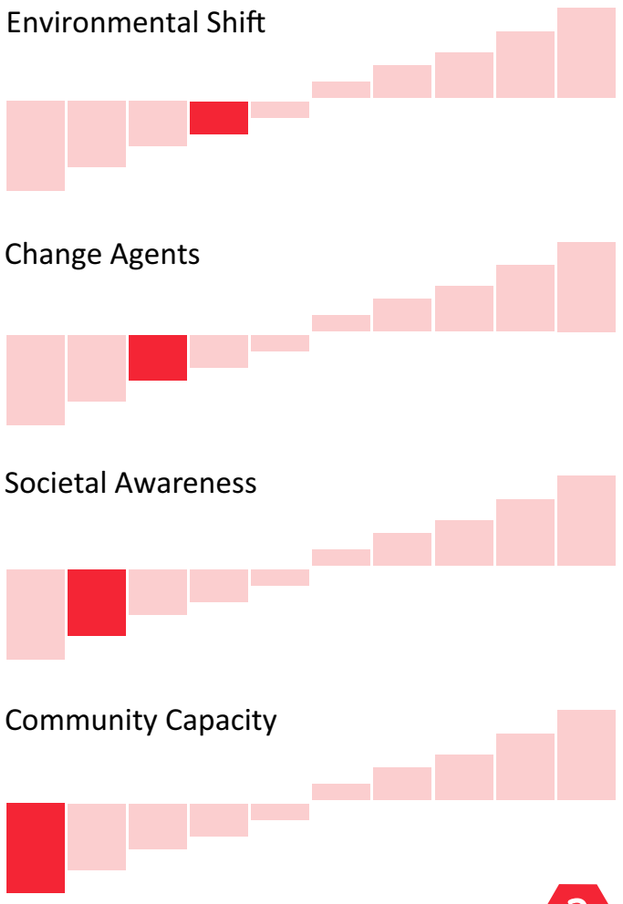
Throughout the E-Scan process, NUMEROUS TARGETS are identified to enhance rehabilitation service delivery, where a culture of best practice adoption and a willingness of SCI rehabilitation service providers to abandon ineffective practice are necessary to realize measurable changes in SCI rehabilitation services by 2020. Administrative, clinical, scientific and political leaders in SCI rehabilitation across the country need to unite around a common vision, and lobby

Extreme left below median: ***insufficient***
Extreme right above median: ***optimal***



2020 PRIORITY 1

POLICY CHANGE



2020 PRIORITY 2

FOUR OPERATIONALLY-DEFINED SUB ELEMENTS

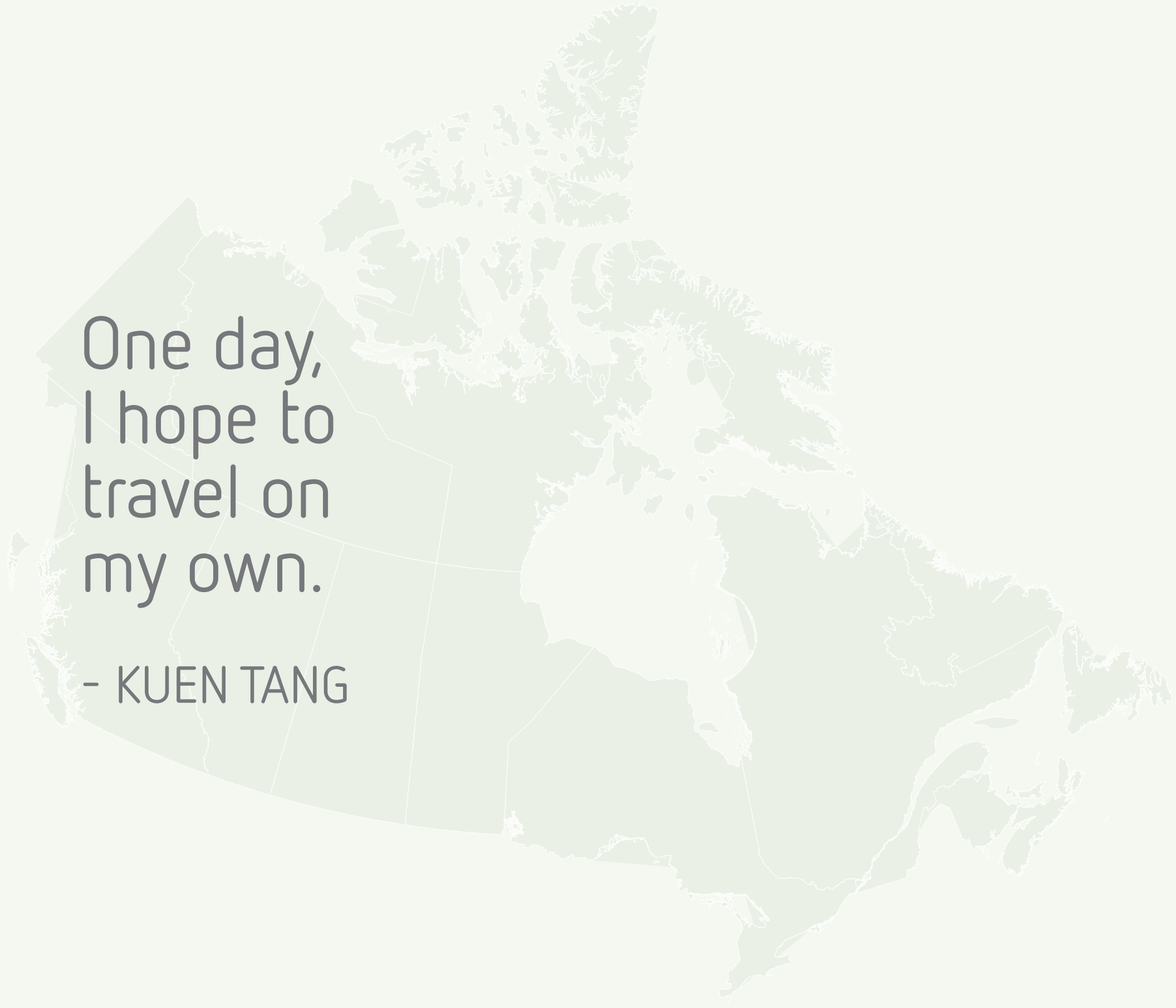
Rated on a scale from insufficient to optimal (-5 to +5) and converted to a visual scale. Definitions for each sub element are provided on the subsequent pages.

PRIORITY RATING

Ranging on a numerical scale from 1 to 3, with 1 indicating the category/domain of highest priority. Priority ratings identify one of the three categories to which prospective efforts and funding must be directed, in order to achieve evolution in rehabilitation service delivery and practice.

Specifically, sights are set on the year 2020, to achieve significant enhancement in best practice. **Thus, the report cards serve as summaries for specific goals, as well as a means by which all rehabilitation goals, included in the Atlas, can be compared.**

for strategic reinvestments in that vision, to ensure the realignment of health system priorities and policies. These are necessary to enable interprofessional care delivery – which supports the philosophical underpinnings and customization of care contained within the rehabilitation framework – and to guarantee the best health, quality of life and economic outcomes for Canadians with SCI over their lifetime.



One day,
I hope to
travel on
my own.

- KUEN TANG

New Perspectives From E-Scan

C Craven, MD; M Verrier, MHSc PT; and the E-Scan Investigative Team

FIGURE 1.0 TOTAL TRAUMATIC AND NON-TRAUMATIC IN-PATIENT SCI ADMISSIONS BY SITE
DATA PROVIDED BY THE NATIONAL REHABILITATION REPORTING SYSTEM (NRS) AT THE CANADIAN INSTITUTE FOR HEALTH INFORMATION (CIHI).
DATA PERTAINS TO INPATIENT REHABILITATION IN FISCAL YEAR 2010

The primary objective of this scoping review is to describe current SCI rehabilitation services, for individuals with subacute and chronic SCI, admitted to tertiary SCI rehabilitation sites, in Canada. Secondary objectives are to identify national trends, gaps (regional and/or process disparity) and priorities in SCI rehabilitation service delivery; and to use these findings to inform future enhancements in that delivery. The following section contains emerging themes, and key national messages, derived from the scoping review process.

SCI CHALLENGES THE SINGLE DISEASE FRAMEWORK FOR HEALTHCARE DELIVERY

The sequelae of SCI are catastrophic for individuals and their families. Individuals with SCI develop complex health states, including chronic multi morbidity, secondary health conditions and disruption of wellbeing. SCI challenges the Canadian healthcare system at all levels - locally, provincially and nationally - to discover new evidence, ensure an informed, integrated continuum of care; and to develop and enact health policies that recognize state-of-the-art rehabilitation practices to improve health, wellbeing and prosperity. The comprehensive nature of approaches required is daunting. The E-Scan has examined the complexities of SCI rehabilitation, provides a description of the state of rehabilitation practice, and maps the actions required to transform practice.

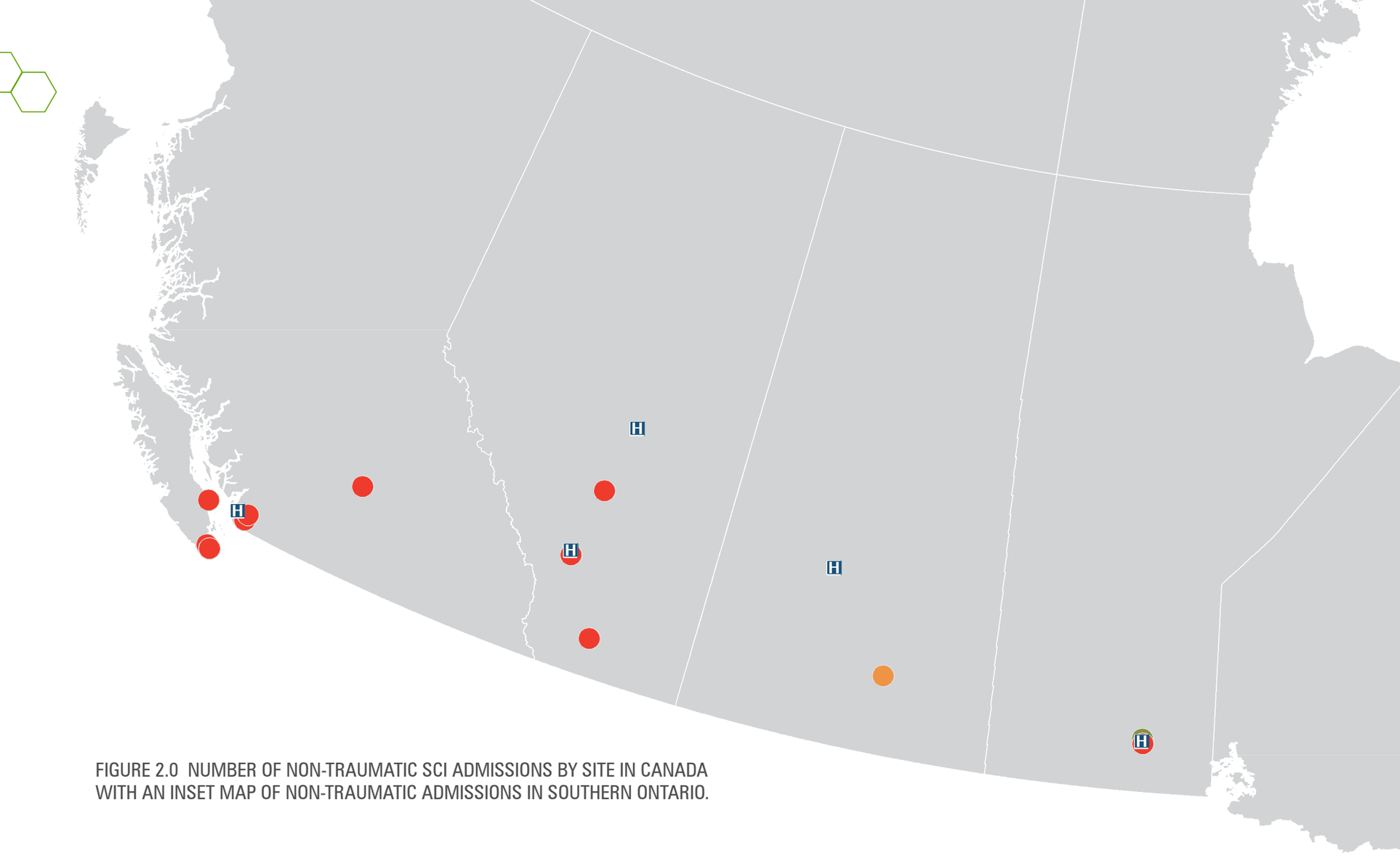
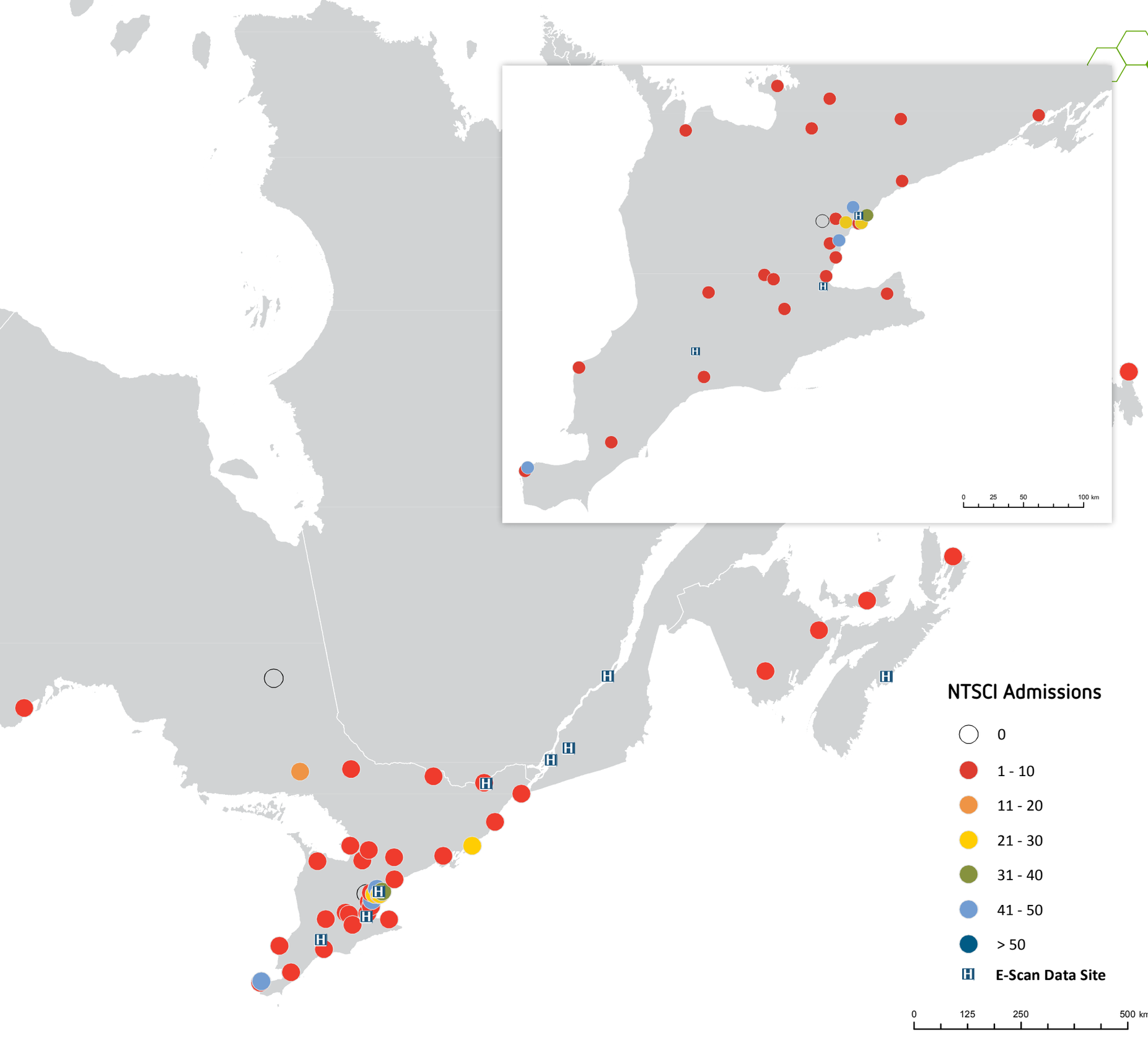


FIGURE 2.0 NUMBER OF NON-TRAUMATIC SCI ADMISSIONS BY SITE IN CANADA WITH AN INSET MAP OF NON-TRAUMATIC ADMISSIONS IN SOUTHERN ONTARIO.

A TSUNAMI OF NON-TRAUMATIC SCI

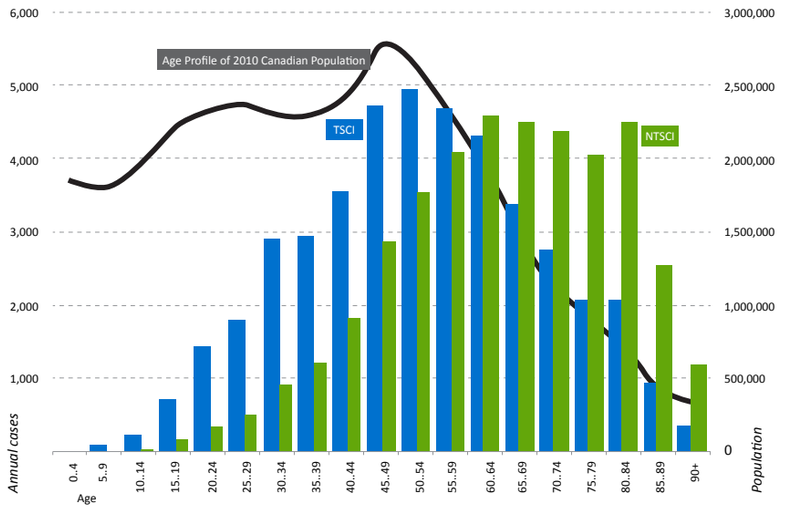
Given the rising incidence of non-traumatic spinal cord injury (NTSCI) and the concurrent aging of baby boomers, rehab service providers anticipate an overwhelming wave of NTSCI incidences, likely to overwhelm current system resources. As shown, individuals with NTSCI now comprise the majority admitted for inpatient SCI rehabilitation, in Canada. As shown in Figure 2.0, many individuals with NTSCI receive rehabilitation outside designated regional SCI rehabilitation centres (E-Scan sites).

The anticipated tsunami is particularly evident if one examines the inset map of southern Ontario where there is a high density of rehab centres, and a large volume of individuals with NTSCI. As discussed, persons with NTSCI tend to be older, have a greater number of concurrent medical conditions and incomplete injuries. As a result, individuals with NTSCI require substantial resources (medical and rehabilitative), and longer periods of time (greater rehab length of stay), to achieve similar outcomes to their traumatic SCI (TSCI) counterparts with similar impairments.


NTSCI Admissions
0
1 - 10
11 - 20
21 - 30
31 - 40
41 - 50
> 50
E-Scan Data Site
0 125 250 500 km
0 25 50 100 km

The consequences of NTSCI are equally catastrophic to those with TSCI. Individuals with NTSCI require a similar, parallel and integrated system of care, with linked resources across the continuum of prehospital, acute, rehabilitation and outpatient service delivery.

FIGURE 3.0. THE AGE PROFILE OF THE 2010 CANADIAN POPULATION, BIMODAL DISTRIBUTION OF TSCI AND NTSCI, AND THE RISING INCIDENCE OF NTSCI. REPRODUCED FROM NOONAN V, FINGAS M, FARRY A, ET AL. INCIDENCE AND PREVALENCE OF SPINAL CORD INJURY IN CANADA: A NATIONAL PERSPECTIVE. *NEUROEPIDEMIOLOGY.* 2012;38 :219-26. © 2012 S. KARGER AG BASEL. REPRINTED WITH PERMISSION.



Surveillance for Non-traumatic SCI (NTSCI)

Individuals with NTSCI now comprise 50% or more of those admitted for inpatient rehabilitation (Figure 3.0). Current SCI surveillance strategies in Canada (RHSCIR, NTR, NRS) have limited ability to identify or track the incidence, prevalence, resource requirements and outcomes of persons with NTSCI prior to admission to rehabilitation. A substantial portion of this challenge is attributable to difficulties with case finding, due to a lack of consensus regarding how to best use current ICD-10 codes, to identify individuals with NTSCI. Resolution of these coding controversies, and addition of NTSCI data fields, service interruptions, and relevant measures of medical co-morbidity to RHSCIR would substantially enhance our understanding of the incidence, prevalence, and rehabilitation resource utilization, as well as future resource requirements, of this population.

A Cross-Continuum System of Care for NTSCI is Needed

For individuals with traumatic SCI, an established system of care recognizes:

- The value of appropriate prehospital care
- Timely referral to a Level I trauma/spine centre
- Early decompression (where appropriate) by a skilled spine surgeon, recognizing the principle of “Time to Spine”
- Early admission to tertiary rehabilitation, to access interprofessional expertise and optimize neurological and functional outcomes, with minimization of the frequency and severity of secondary health complications
- Lifetime surveillance and management of related health conditions, by healthcare professionals, with appropriate expertise.

The strategy, for individuals with NTSCI, must be predicated on the principle of prevention to eliminate current high rates of misdiagnosis, late pickup of disease (once motor symptoms are present), long waiting lists for appropriate medical and surgical intervention, and self-referrals to rehabilitation settings with insufficient expertise to appropriately manage these individuals and their impairments. Rather, care must be customized for the individual’s presenting impairment, the underlying disease or pathology, and their co-morbid medical conditions. **The system of care must be tailored to minimize injury, preserve function, maximize recovery and facilitate community integration.** From National Reporting System (NRS) data, it is evident that a high proportion of individuals with NTSCI, are receiving inpatient rehabilitation, outside of tertiary academic sites, potentially compromising their access to the appropriate timing and intensity of rehabilitation services. The reasons for the observed referral patterns were not self-evident but may relate to having initial surgical/medical intervention outside of a tertiary spine centre, medical co-morbidity, proximity to family or tertiary SCI rehabilitation admission criteria and intake processes. In an ideal model of NTSCI care, there should be opportunities for pre-hab – interprofessional assessment and monitoring of individuals, prior to or at the time of initial onset of motor or autonomic deficits, prior to surgical intervention.

A Lifetime of Care

During the conduct of the E-scan, rehabilitation service providers repeatedly spoke about the importance of long-term follow up of individuals with SCI, over the course of their lifetime. Many described future rehab service models as “hubs of service”, rather than the current one-way streets. Many providers spoke passionately of many individuals’ need to re-access rehabilitation services.

Long-term Follow Up is Intended to:

- Address new rehabilitation goals as they emerge
- Ensure optimization of functional outcome and maintenance of functional abilities, over time
- Monitor neurologic impairment in order to detect late neurological deterioration (syrinx, disc, spondylolisthesis, hardware failure, peripheral neuropathy, etc.)
- Provide primary and secondary prevention of SCI-related secondary health conditions
- Enable access to new therapies and technologies
- Assist with accommodation to aging with a disability, and
- Enable living with multimorbidity after SCI (e.g., paraplegia, syrinx with myelopathy, neuropathic pain, diabetes, hyperlipidemia, elbow tenosynovitis, breast cancer and charcot spine).

Ideally, this care should be provided in a multidisciplinary setting. Current outpatient service models either do not exist or are not adequately funded, nor are the variety of healthcare professionals or services available, to support interprofessional care. Further, the system of care is not designed to incorporate preventive approaches that aim to reduce ongoing morbidity, such as those that facilitate self-management skill development (see below) or promote the adoption of healthy lifestyle practices. Given the high frequency of inappropriate emergency department use, and frequency of physician visits observed in the chronic SCI population, development of interprofessional models to support lifetime care is a key priority that warrants rethinking, and would likely result in substantial system savings.

Resolve the Disconnect between Evolving Evidence Regarding Rehabilitation Efficacy and Current Service Models

Emerging and established evidence shows that the volume and intensity of rehabilitation services dramatically influences functional outcomes – specifically, the ability of individuals with AIS C and D impairment to return to walking, within their homes and communities, and the ability of functional electrical stimulation therapy to augment hand function in those with tetraplegia. Ironically, this evidence comes at a time of unprecedented system pressures to reduce rehab onset days and rehabilitation lengths of stay. As individuals with SCI are being discharged earlier from inpatient rehabilitation settings, structures and services to support optimization of rehabilitation outcomes, and access to the right type and intensity of rehabilitation service, in an outpatient or community setting, is imperative. Current administrative structures and processes appear overly focused on the flow of individuals (from acute care to inpatient rehabilitation), with little thought or attention on the impact of early system efficiency, or the back half of the continuum of care - inpatient rehabilitation through transition to community living.

Provincial Delisting of Rehabilitation Services Overwhelming Tertiary Outpatient SCI Services

Substantial portions of individuals with SCI attribute the etiology of their injury to a motor vehicle or work-related accident. They have, therefore, sufficient accident or work-related injury benefits to fund participation in third party physical therapy, occupational therapy, nursing and/or counselling services, from a psychologist or social worker. However, individuals without these benefits, who rely on federal disability support, face long waiting lists for provincially funded services, or are turned away from tertiary outpatient therapy services, with no financially feasible therapy alternative.

For example, an individual with SCI may develop an episode of acute shoulder pain, which makes wheeling difficult about his or her home and community. Their untreated shoulder injury can contribute to poor transfers, and lead to skin breakdown or development of an ischial pressure sore, followed by months of bed rest to enable wound healing. This, in turn, contributes to a first episode of depression due to social isolation, and results in bed rest-induced global deconditioning. A cascade of events and costs that likely would have been prevented with eight to ten weeks of conventional physiotherapy, therefore ensues. Triaged access to provincially funded, community rehabilitation service providers should self-limit the course of these events, and prevent initiation of cascades of secondary health conditions that plague individuals living in the community, who are dependent on tertiary outpatient services.

Inadequate Services to Support Informed Self Management and Emotional Wellbeing

Current staff-to-patient ratios of patient educators, psychologists, psychiatrists, social workers, and recreation therapists for outpatients with SCI, are inadequate. Dramatic increases, in availability of resources to support the biopsychological care of individuals with SCI living in the community, are needed. Programs, which empower the individual through provision of self-management strategies and counselling, are currently low priority – although these services are likely the interventions with the greatest yield, and most likely to reduce the frequency of health service utilization. There is a need for a dramatic paradigm shift in service delivery, acknowledging the value of pre-emptive models of care versus the current reactionary models, where provincially funded services become available once an individual is in crisis.

Include Support Providers as Crucial Members of the Care Team

Individuals with SCI have smaller social networks, with more intense bonds, than those with chronic disease. Family members, neighbours and friends play significant roles in assisting the individual with SCI to remain independent in the community. Services to support these crucial, unpaid members of the care team are absent and particularly problematic, given the inability of the healthcare system to absorb the associated burden of care, in the absence of these support providers. When a member of an individual's care network becomes ill or incapacitated, increased respite care, supportive emotional and logistical resources for care providers, and access to short-term attendant care, are crucial to sustained community living.

Make Employment an Outcome of Critical Importance

With shortened rehabilitation length of stay and erosion of infrastructure to support inpatient rehabilitation, over time, there has been a profound overemphasis on self-care activities, and a de-emphasis on employment as an important outcome. This de-emphasis has profound economic and health consequences for the individual with SCI over his or her lifetime.

In addition, there are substantial systemic and financial disincentives for individuals to return to employment or to complete a work trial, that contribute to career disability and abysmally low employment rates - despite advancing technology and growing acceptance of flextime and flexible work environments.

Policy Barriers to Best Practice Abound

One of the most common and frustrating refrains heard from rehabilitation service providers is their ability to identify the best therapy available, for specific health conditions, and their inability to provide it to individuals with SCI, who receive provincial disability support. It is not the lack of a clinician's knowledge of best available therapies, but rather the lack of funding that routinely precludes provision of best care. Development of a national body (akin to the Ontario SCI Solutions Alliance and its member organizations), to lobby and routinely advocate for changes in health policy - that enable optimization of service delivery, and elimination of the observed regional disparity in access to medication, devices and supplies - is critical to future service enhancement. Conduct of the E-Scan also highlights the inequity and perceived challenges inherent in bringing about policy change for individuals with a relatively rare disease, compared to those individuals with large scale, common diseases (e.g., diabetes, heart disease or cancer). It is extremely difficult to conduct clinical trials - never mind provide the necessary efficacy data from both clinical trials and economic evaluations, demonstrating that the cost-utility of the proposed interventions is favourable - prior to obtaining provincial service enhancements. Mechanisms to enable early adoption of effective therapy among neurologic populations need to be explored with provincial formularies.

Technology Offers Opportunity to Enhance Rehabilitation Service Delivery

Technology is rapidly changing the face of healthcare delivery, and offers an opportunity to advance the field in two ways: through efficient use of informatics to ensure timely and accurate assessment, and communication of outcomes; and to interface with devices, that enhance recovery, and assist or compensate for specific functional impairments. The typical lag time from development of a new therapy to routine practice implementation for drug therapy is about 17 years. The lag time for uptake of novel rehabilitation devices is often longer, due to the barriers associated with regulatory approvals and established funding mechanisms. A focus on bioinformatics, our strengths in biomedical engineering in Canada, and widespread use of mobile devices should enable rapid cycle changes in communication and data transmittal. Practice transformation and early adoption of clinically effective technologies and/or devices will require a national implementation strategy.

Marriage of Accreditation Canada and a Culture of Best Practice Can Advance Service Delivery

Improved standards of care require that frontline clinicians inform accreditation, with consideration given to practice gaps, evidence, impact (outcomes), feasibility and other factors. The work of the SCI Knowledge Mobilization Network (SCI KMN) - a national, networked community of practice consisting of a wide spectrum of stakeholders, at six participating rehabilitation centres across Alberta, Ontario and Québec - incorporates rigorous methods of consensus prioritization, with implementation of science innovations, to ensure buy-in for chosen best practices.

Choices made via the SCI KMN consensus process are, at times, unexpected because of real-life factors considered by frontline staff. For example, while an intervention may have ample high-level evidence, other factors may not resonate with the clinicians and patients that would implicate a best practice (cost benefit ratio, training and equipment for the intervention, etc.). Ongoing, three-way conversations are an urgent priority among funders (health ministries, NGOs, etc.), regulators (Accreditation Canada (AC), and healthcare organizations) and healthcare targets (SCI KMN that represents frontline clinicians, patients, healthcare administrators and others).

As a first step, AC and SCI KMN need to share knowledge immediately. The second step is to produce a briefing note, co-authored by AC and SCI KMN, for funders' consideration. The third step is a tripartite meeting, to map out priorities, for improving health outcomes. The latter would include funding for SCI KMN's expansion to incorporate the nine remaining rehabilitation centres and other pressing initiatives. This is a necessary, relatively inexpensive approach to standardize rehabilitation best practices, across Canada. Recipient stakeholders with a voice to inform accreditation standards, and funders to ensure that support barriers are overcome, can result in national buy-in for high-level, AC-monitored best practices.

SPINAL CORD INJURY
Knowledge Mobilization
Network

ACCREDITATION CANADA
AGRÉMENT CANADA
Driving Quality Health Services
Force motrice de la qualité des services de santé

Careful Attention to Implementation of "Extenders" with Specialty or Advanced Practice Training is Required

Within the current healthcare system, there is a move afoot to introduce physician, nursing, physical and occupational therapy "extenders" to provide a cost-effective means of increasing the volume of individual patients assessed and served in specific settings. For example, in Ontario and Alberta there are now established physician assistant training programs, intended to enhance the volume and complexity of issues of individuals served by a physician, through provision of collaborative care in a setting where delegation is feasible. In other settings, kinesiologists or physiotherapy assistants are used to extend the activities of physical therapists, and seating technicians for occupational therapists. While introduction of extenders is, in general, a rational move, it will be critically important for the SCI community to advocate for use of "extenders" with appropriate knowledge, skills and training to manage complex SCI patients. The importance of this issue should not be underestimated. Strategic partnerships with local colleges and universities are recommended to ensure appropriate training and clinical competence in SCI Care, as the models of care expand over time.

THE STAGE IS SET

The combined perspectives and products from these projects, provide a unique opportunity for the creation of a national blueprint for rehabilitation. This blueprint can assure customized care for individuals with SCI that is consistent with the values and goals imbedded in the rehabilitation framework (predicated upon best practice), national surveillance, and an expanded service perspective that supports the lifetime care of people with SCI (Figure 4.0).

FIGURE 4.0 A MODIFIED MODEL OF PRACTICE SUPERSTRUCTURE HIGHLIGHTING THE INTERRELATIONSHIPS BETWEEN E-SCAN, KMN, AC AND RHSCIR.
ADAPTED CIPP MODEL SHUFFLEBEAM, THEORY INTO PRACTICE 1966;5:121-133

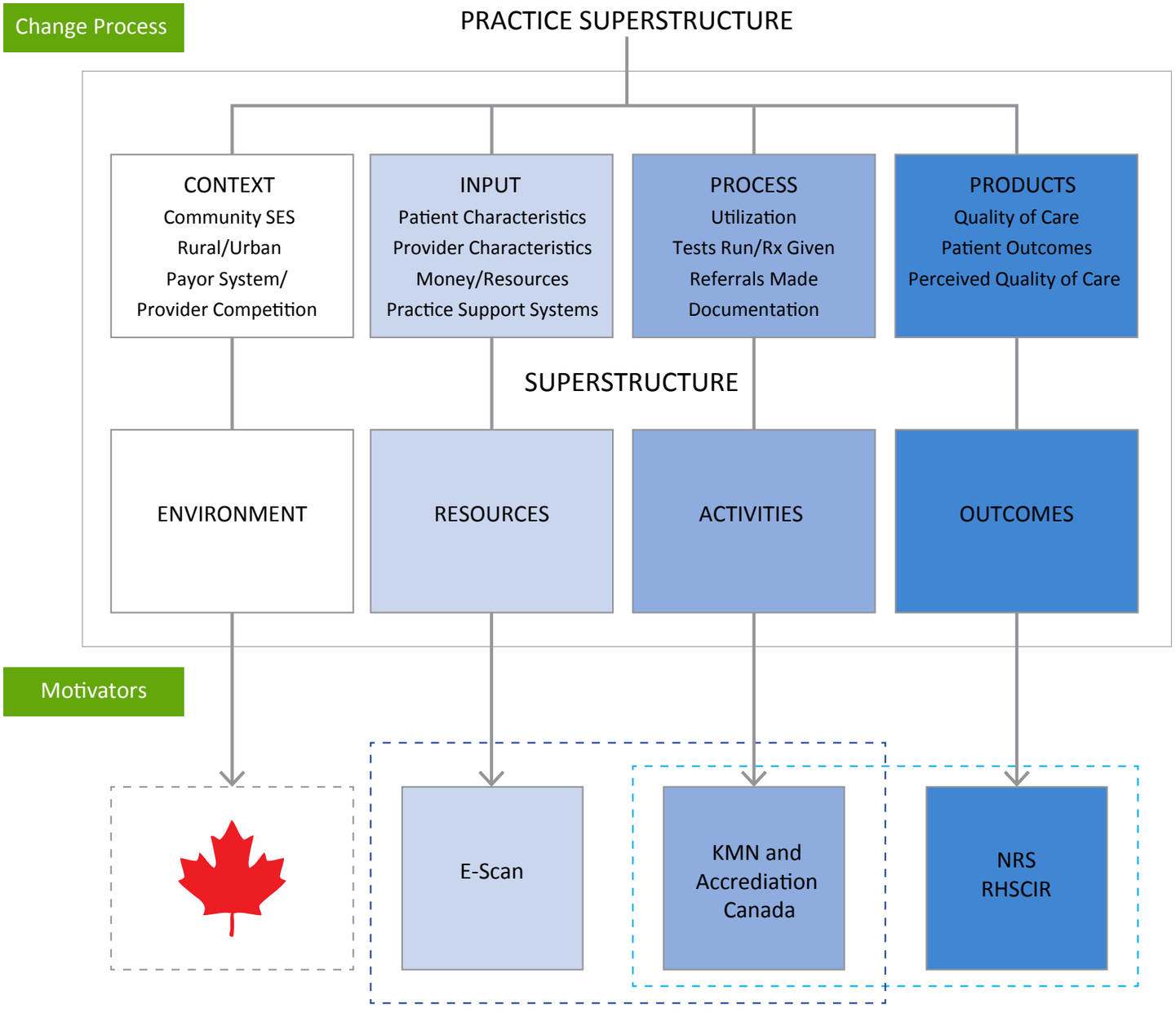
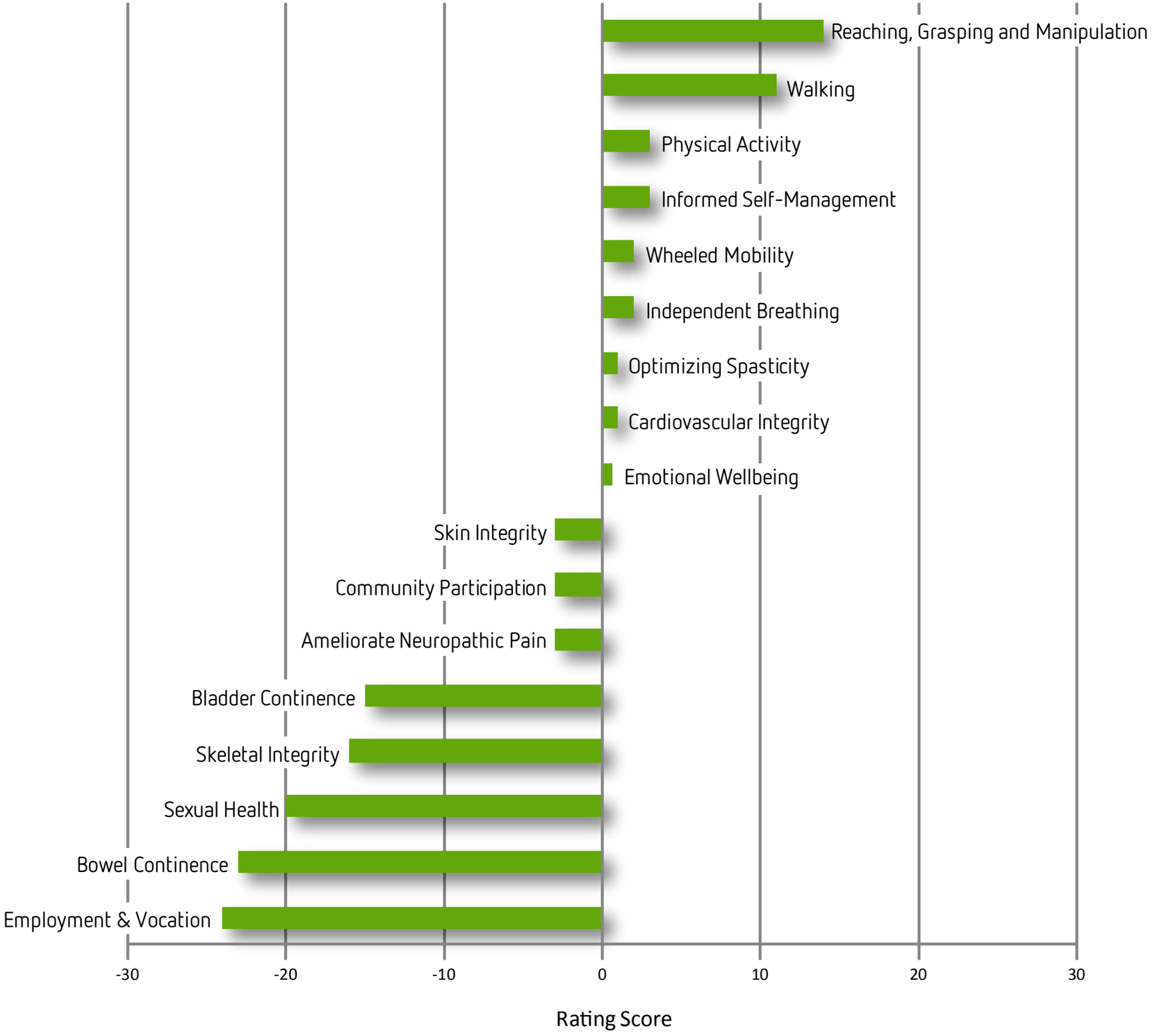


FIGURE 5.0 HISTOGRAM ILLUSTRATING CURRENT CAPACITY IN SCI REHABILITATION ACROSS ALL THREE REPORT CARD DOMAINS, BY REHAB GOAL



Tipping Point – Moving from Outbreak to Epidemic

Through conduct of the E-Scan, “outbreaks” of exemplary practice were pinpointed in spotlight best practice organizations, throughout the country. As rehabilitation professionals, we can convert these outbreaks into an epidemic of excellence. This first, national look at the Canadian SCI rehabilitation landscape is intended to be a tipping point.

A tipping point, described by Malcolm Gladwell is **“…that magic moment when an idea, trend or behaviour crosses a threshold, tips and spreads like wildfire”.**

Exponential change can be created by harnessing the passion, commitment and expertise of rehabilitation professionals in these spotlight best practice organizations, and finding strategies to infiltrate other SCI rehabilitation sites.

Mutual engagement is necessary to:

- INVEST IN SCIENCE
- REWARD BEST PRACTICE
- FORCE POLICY CHANGE.

We trust these key messages will prompt stakeholders to focus their collective efforts on creating services (unencumbered by the challenges and gaps identified) that ensure the best possible rehabilitation outcomes, for individuals with SCI, by 2020.

"From the minute I'd wheeled through the doors
I'd made myself another promise...
to get functional enough so I could go home."

- Rick Hansen

A Message from Rick Hansen

When I embarked on the Man In Motion World Tour (MIMWT) to raise awareness and funds for spinal cord injury (SCI) research, I listened to the stories of countless people living with SCI, across Canada, and around the world. Many had post-injury care experiences similar to mine: I was flown from my small, hometown – away from family and friends – to a major centre for acute care and rehabilitation. When I returned home, there was very little in the way of ongoing support, and I struggled to adapt and manage my own care. I missed the guidance and skill of the rehab professionals, at GF Strong.

It's been twenty-five years since we returned from the MIMWT, and I'm pleased to say that a lot has improved since then – in what we know, and how we are starting to work together to standardize care and improve best practices. But the quality of care still varies, depending on where we live in this country. Some people have access to a wide range of services. Others, particularly in remote or rural areas, aren't as fortunate.

Every single person with SCI needs highly specialized care, tailored to his or her unique needs. Rehab is where the very hard work is done... by patients and collaborative practitioners, in a wide variety of disciplines, dedicated to helping them regain their physical, emotional and social independence...allowing them to return to their families and communities. We owe these professionals a huge debt of gratitude. This E-Scan Atlas is a ground breaking document – the first ever resource of SCI-related rehabilitation services in Canada, and one of many projects funded by SCI organizations in Canada – that contribute to a blueprint for enduring improvements in the quality of life of people with spinal cord injury. By doing this project, we have learned a lot about this landscape and can better see where and how services can be improved, and resources allocated. Most of all, it's a document to be shared by professionals, to improve their knowledge and practice, as they help thousands of people who are newly-injured in Canada, every year.

My heartfelt thanks go out to the over 100 professionals who contributed to this Atlas – the RHSCIR site leads, coordinators, administrators, content experts, photographers and hospital site communication teams. Special thanks go to the E-Scan team, for their vision, guidance and dedication. Each is driven by a passion to ensure that everyone who sustains a spinal cord injury has access to the best rehabilitation treatments and services possible – no matter where they live.

Their work contributes to Canada's reputation as one of the world's leaders in research, care and treatment of spinal cord injury, and I'm excited about what more we will continue to accomplish together.

Regards,

Rick Hansen

Site Lead Profiles

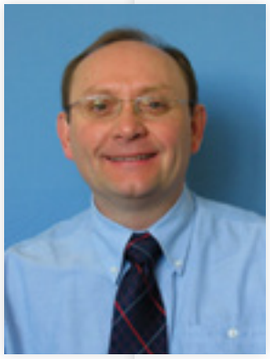
A *physiatrist* is a medical specialist who focuses on the areas of physical medicine and rehabilitation medicine, and provides care to individuals who have lost partial or complete physical function, to restore or maximize functional ability and improve their quality of life. In Canada, the Royal College of Physicians and Surgeons accredits postgraduate education programs for physiatrists.

A *rehabilitation scientist* focuses on the systematic study of promoting, maintaining or restoring human function, mobility, occupation and wellbeing. Using basic and applied methodologies to understand phenomena at the level of the cell, person, family, community or society, a rehabilitation scientist develops and evaluates theories, models, processes and measures interventions and policies to prevent, reverse, or minimize impairments, enable activity and facilitate participation. In Canada, most *rehabilitation scientists* have graduate degrees at the doctoral level.

VANCOUVER, BRITISH COLUMBIA

SPINAL CORD INJURY PROGRAM – GF STRONG REHABILITATION CENTRE, VANCOUVER COASTAL HEALTH

Andrea Townson MD, FRCPC (PM&R) is clinical associate professor and head, University of British Columbia Division of Physical Medicine and Rehabilitation. She is also medical site lead, GF Strong Rehab Centre, and head of the Vancouver Acute Division of PM&R, Vancouver, B.C. Dr. Townson's primary research interests are in the areas of high-lesion tetraplegia, fatigue and education.



SASKATOON, SASKATCHEWAN

SPINAL CORD INJURY PROGRAM – SASKATOON CITY HOSPITAL, SASKATOON HEALTH REGION; AND UNIVERSITY OF SASKATCHEWAN

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WINNIPEG, MANITOBA

SPINAL CORD INJURY PROGRAM – HEALTH SCIENCES CENTRE WINNIPEG, WINNIPEG REGIONAL HEALTH AUTHORITY

Karen Ethans MD, FRCPC (PM&R) is a physiatrist with subspecialty certification in SCI medicine, and an associate professor at the University of Manitoba. She completed her medical degree and specialty training at Dalhousie University, and has been the chief of the SCI Rehabilitation program in Winnipeg since 1999. Dr. Ethans is both a clinician and a researcher, focusing on symptom management and secondary prevention for individuals with SCI. In particular, her main areas of research interest include management of spasticity, pain, and erectile, bladder and cardiovascular dysfunction.

CALGARY, ALBERTA

TERTIARY NEUROLOGICAL REHABILITATION – FOOTHILLS MEDICAL CENTRE, ALBERTA HEALTH SERVICES

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EDMONTON, ALBERTA

SPINAL CORD INJURY PROGRAM – GLENROSE REHABILITATION HOSPITAL, ALBERTA HEALTH SERVICES

John Guthrie MD, FRCPC is the site medical lead for SCI/General Neurology. As an active member of the residency program and a supporter of research endeavours, he is currently involved in the Knowledge Mobilization Network (Pressure Ulcer Prevention). Dr. Guthrie is also on the Accreditation Canada Steering Committee for SCI.

LONDON, ONTARIO

REGIONAL SCI REHABILITATION PROGRAM – PARKWOOD HOSPITAL, ST. JOSEPH'S HEALTHCARE LONDON

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HAMILTON, ONTARIO

SPINAL CORD INJURY REHABILITATION PROGRAM – HAMILTON HEALTH SCIENCES, REGIONAL REHABILITATION CENTRE

Agnes Chmiel MD, FRCPC (PM&R) is the physician lead for the SCI Rehabilitation Program at the Regional Rehabilitation Centre. As physiatry consultant for Hamilton General Hospital, she assesses individuals with acute SCI, and suggests the most appropriate rehabilitation stream. She also follows individuals with SCI in the community and assists with chronic SCI-related health issues. Dr. Chmiel is an assistant clinical professor in McMaster University's Department of Medicine. As curriculum development director and OSCE coordinator, she is an active member of the McMaster University Physical Medicine and Rehabilitation Residency Program Training Committee.

TORONTO, ONTARIO

BRAIN AND SPINAL CORD REHAB PROGRAM – TORONTO REHABILITATION INSTITUTE, UNIVERSITY HEALTH NETWORK

Cathy Craven MD, FRCPC (PM&R) is a physiatrist with a clinician scientist role, at Toronto Rehabilitation Institute. She is an assistant professor in the departments of Medicine and Health Policy Management and Evaluation, at the University of Toronto. Her expertise is in the prevention and treatment of secondary health conditions of SCI, with a focus on sublesional osteoporosis and health service provision. Dr. Craven is the Ontario lead for the SCI-IMPACT team, an inter-provincial working group exploring the economic and quality-of-life impacts of health complications after SCI. She is a Rick Hansen Spinal Cord Injury Registry site lead, and has been the scientific co-chair of the 1st to 5th National SCI Conference.

KINGSTON, ONTARIO

PHYSICAL MEDICINE AND REHABILITATION PROGRAM – ST MARY'S OF THE LAKE HOSPITAL, PROVIDENCE CARE

Karen M. Smith MD, FRCPC DAPMR is a physiatrist with subspecialty certification in SCI medicine. At Queen's University, she is an associate professor in the Faculty of Health Sciences and the interim associate dean, Continuing Professional Development. She completed her medical degree at Queen's University with specialty training at McMaster University, and subspecialty training in paediatrics with Dr. Gabriella Molnar. Dr. Smith was the service director of SCI Rehabilitation at McMaster from 1987-1994, and at Queen's University from 1994 to the present. She is a clinician and an administrator, and participates in collaborative research focusing on neurogenic bowel function, exercise prescription and promotion, primary care access for individuals with disabilities, and knowledge translation to primary-care practitioners.

MONTRÉAL, QUÉBEC

PROGRAMME LÉSIONS MÉDULLAIRES – INSTITUT DE RÉADAPTATION GINGRAS-LINDSAY DE MONTRÉAL; MINISTÈRE DE LA SANTÉ ET DES SERVICES SOCIAUX DU QUÉBEC

Dany Gagnon PhD (Physiotherapy) is an assistant professor at the School of Rehabilitation, Faculty of Medicine, Université de Montréal; and an emerging researcher at the Centre for Interdisciplinary Research in Rehabilitation of Greater Montréal. Using biomechanical approaches, his research focuses predominantly on the upper extremity, seated postural stability and functional-activity assessments in individuals with SCI.

QUÉBEC CITY, QUÉBEC

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OTTAWA, ONTARIO

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MONTRÉAL, QUÉBEC

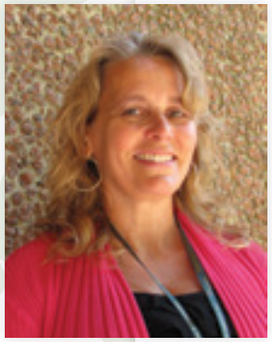
PROGRAMME POUR LES PERSONNES PRÉSENTANT UNE PATHOLOGIE DU SYSTÈME LOCOMOTEUR – CENTRE DE RÉADAPTATION LUCIE-BRUNEAU, AGENCE DE LA SANTÉ ET DES SERVICES SOCIAUX DE MONTRÉAL

Julie Charron PhD is a psychologist on the clinical SCI team. She is actively involved in collecting E-Scan data and is a local investigator for the Access to Care and Timing Project. Future areas of research for the local SCI program include social reintegration after the rehabilitation process.

FREDERICTON, NEW BRUNSWICK

NEW BRUNSWICK PROVINCIAL SCI PROGRAM – STAN CASSIDY CENTRE FOR REHABILITATION, HORIZON HEALTH NETWORK

Colleen O'Connell MD, FRCPC (PM&R) is a staff physiatrist and research chief at the Stan Cassidy Centre for Rehabilitation. She holds faculty appointments at both Dalhousie University's Faculty of Medicine and the University of New Brunswick's Faculty of Graduate Studies. Dr. O'Connell's research and clinical interests focus on spasticity, pain measurement and management, motor neuron disease genetics and epidemiology, and quality-of-life outcomes. In addition, she is active in international health and disaster rehabilitation, and participates in numerous guidelines and training initiatives that address care for individuals with SCI in low-resource settings.



HALIFAX, NOVA SCOTIA

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Christine Short MD, FRCPC (PM&R) is a physiatrist, who specializes in treating individuals with SCI, multiple sclerosis (MS) and other neurologic disorders. Through research, she hopes to maximize her patients' function and solve their most pressing problems. Dr. Short is currently studying medications that help improve walking and function among individuals with MS and SCI, and for preventing and treating SCI pain; and spasticity treatments to enhance mobility. She is currently chief of the Division of PM&R at the QEII Health Sciences Centre, and is an associate professor at Dalhousie University, where she is cross-appointed to the Division of Neurosurgery.

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Maps

All base maps used in the E-Scan Atlas were provided by Lambert Conformal Conic Projection. Source: Geography Division, Statistics Canada, Boundary Files, 2006 Census 92-160-XWE/XWF. The incorporation of data sourced from Statistics Canada within this document shall not be construed as constituting an endorsement by Statistics Canada of this document.

Every effort has been made to ensure the accuracy of contributor names and acknowledgements.

If we have missed you, please email us at studies@rickhanseninstitute.org

Glossary of Acronyms

AASECT	American Association of Sexuality Educators, Counsellors and Therapists
ABD	Abdominal Distension
ABI	Ankle Brachial Pressure Index
aBMD	Aerial Bone Mineral Density
AC	Accreditation Canada
AC - DSCI	Accreditation Canada - Spinal Cord Injury Distinction Status
ACSM	American College of Sports Medicine
AD	Autonomic Dysreflexia
ADG	Amitryptiline - Diphenhydramine - Gabapentin
ADL	Activities of Daily Living
AHA	American Heart Association
AHCPR	Agency for Healthcare Policy and Research
AHRQ	Agency for Healthcare Research and Quality
AIS	American Spinal Injury Association Impairment Scale
APF	Alberta Paraplegic Foundation
ASCRS	American Society of Colon and Rectal Surgeons
BCIT	British Columbia Institute of Technology
BCPA	British Columbia Paraplegic Association (now Spinal Cord Injury BC)
BDI	Beck Depression Inventory
BiPAP	Bilevel Positive Airway Pressure
BMD	Bone Mineral Density
BMedSc	Bachelor of Medical Science
BMR	Bachelor of Medical Rehabilitation
BoNT - A	Botulinum Toxin A
Borg CR10 Scale	Borg Category Ratio 10 Scale
BPG	Best Practice Guideline
BPI	Best Practice Implementation
BPI	Brief Pain Inventory
BSc	Bachelor of Science
BScOT	Bachelor of Science in Occupational Therapy
BTX	Botulinum Toxin
BWAT	Bates Jenson Wound Assessment Tool
BWS	Body Weight Support
BWSTT	Body Weight Supported Treadmill Training
CAGE	Cut down, Annoyed by criticism, Guilty feeling, Eye opener (the acronym was intended to help physicians recall the questions)
CANVent	Canadian Alternatives in Non-Invasive Ventilation
CAREN	Computer Assisted Rehabilitation Environment
CARRE	Centre for Ambulatory Rehabilitation Research and Education
CBT	Cognitive Behavioural Therapy
cc	Cubic Centimetres
CCCSS	Cleveland Clinic Constipation Scoring System
CCI	Cleveland Clinic Incontinence Score
CEBMOQ	Centre d'expertise pour les personnes blessées médullaires de l'Ouest du Québec
CES - D	Centre for Epidemiological Studies Depression Scale
CESD - SF	Centre for Epidemiological Studies Depression Scale - Short Form
CHA - HEJ	Centre Hospitalier Affilié - Hôpital de l'Enfant-Jésus
CHART	Craig Handicap and Assessment Reporting Technique
CHD	Coronary Heart Disease
CHIEF	Craig Hospital Inventory of Environmental Factors
CHPR	Centre for Health Promotion & Rehabilitation
CIHR	Canadian Institutes of Health Research
CILB	Citizens for Independence in Living and Breathing
CIQ	Community Integration Measure
CIRRIS	Centre Interdisciplinaire de Recherche en Réadaptation et Intégration Sociale
CISS	Coping Inventory for Stressful Situations
cm^3	Cubic Centimetres
CME	Continuing Medical Education
CNS	Central Nervous System
CO2	Carbon Dioxide
COPM	Canadian Occupational Performance Measure
CPA	Canadian Paraplegic Association (as of 2012, the National CPA office name has changed to SCI Canada. Affiliated provincial office names vary according to each province.)
CPAO	Canadian Paraplegic Association of Ontario
CPAP	Continuous Positive Airway Pressure
CPC	Canadian Paraplegic Committee
CPD	Canal Pinch Diameter
CPG	Clinical Practice Guideline
CPGS	Chronic Pain Grade Scale
C. Psyc	Clinical Psychologist
CQI	Continuous Quality Improvement
CROP Service	Community Reintegration Out-Patient Service (Toronto Rehabilitation Institute)
CRP	C - Reactive Protein
CSCM	Consortium for Spinal Cord Medicine
CSRO	Canadian Spinal Research Organization
CTRA	Canadian Therapeutic Recreation Association
CTRS	Certified Therapeutic Recreation Specialist
CTx	C - Telopeptide (resorption marker)
CVD	Cardiovascular Disease
CWIS	Cardiff Wound Impact Scale

CWSA	Canadian Wheelchair Sports Association
DAG	Diphenhydramine - Amitriptyline - Gabapentin
DASS	Depression Anxiety Stress Scale
D/C	Discharge Discontinue
DGA	Diphenhydramine - Gabapentin - Amitriptyline
dL	Decilitre
D_LCO	Diffusing Lung Capacity for Carbon Monoxide
DN4	Neuropathic Pain Diagnostic Questionnaire
DREZ	Dorsal Root Entry Zone
DVT	Deep Vein Thrombosis
DXA	Dual-energy X-ray Absorpiometry
ECG	Electrocardiogram
ECT	Electroconvulsive Therapy
EFNS	European Federation of Neurological Societies
EQR	Emotional Quality of the Relationship Scale
ERC	Employment Resource Centre
ES	Electrical Stimulation
EST	Electrical Stimulation Therapy
FES	Functional Electrical Stimulation
FES - CE	Functional Electrical Stimulation - Cycle Ergometry
FEST	Functional Electrical Stimulation Therapy
FEV_1	Forced Expiratory Volume in One Second
FFQ	Food Frequency Questionnaire
FIGS	St. Mark's Fecal Incontinence Grading System
FIM	Functional Independence Measure
FIT Principle	Frequency, Intensity, and Time Principle
fMRI	Functional Magnetic Resonance Imaging
FRCPC	Fellow of the Royal College of Physicians and Surgeons of Canada
FSFI	Female Sexual Function Index
FTE	Full-Time Equivalent
FVC	Forced Vital Capacity
GAD	Gabapentin - Amitriptyline - Diphenhydramine
GAS	Goal Attainment Scaling
GDA	Gabapentin - Diphenhydramine - Amitriptyline
GDS	Geriatric Depression Scale
GFSRC	GF Strong Rehabilitation Centre
GITT	Gastrointestinal Transit Times
GRASSP	Graded and Redefined Assessment of Strength, Sensibility, and Prehension
GRP	Group
GSW	Gun Shot Wound
HADS	Hospital Anxiety and Depression Scale
Hg	Mercury
HPME	Health Policy Management and Evaluation
HRDC	Human Resources Development Canada
HRIC	Health and Research Innovation Centre
HrQoL	Health-Related Quality of Life
HSC	Health Sciences Centre
HSR&D	Health Services Research and Development
Hz	Hertz
iADL	Instrumental Activities of Daily Living
IASP	International Association for the Study of Pain
IBDQ	Inflammatory Bowel Disease Questionnaire
IBME	Institute of Biomedical Engineering
IC	Intermittent Catheterization
ICD	International Classification of Diseases
ICF	International Classification of Functioning, Disability and Health
ICI	Impediments to Community Integration
ICORD	International Collaboration on Repair Discoveries
IIEF	International Index of Erectile Function
ILO	International Labour Organization
IPA	Impact on Participation and Autonomy
IRGLM	Institut de réadaptation Gingras - Lindsay de Montréal
IRDPQ	Institut de réadaptation en déficience physique de Québec
ISAFSCI	International Standards for documentation of Autonomic Functions after Spinal Cord Injury
ISCD	International Society for Clinical Densitometry
ISCoS	International Spinal Cord Society
ISH	International Society of Hypertension
ISNCSCI	International Standards for the Neurological Classification of Spinal Cord Injury
IV	Intravenous
JRH	Jewish Rehabilitation Hospital
KCAASS	Knowledge, Comfort, Approach and Attitude towards Sexuality Scale
Kg	Kilograms
KMN	Knowledge Mobilization Network
kpm	Kiloponds - meters
LANSS	Leeds Assessment of Neuropathic Symptoms and Signs
LC	Lyndhurst Centre (Toronto)
LEMS	Lower Extremity Motor Scores
LIFE - H	Assessment of Life Habits
LiSat - 11	Life Satisfaction Questionnaire - 11
LMN	Lower Motor Neuron
LOS	Length of Stay
LSC	Least Significant Change
LTPAQ - SCI	Leisure Time Physical Activity Questionnaire for People with SCI
MAST	Michigan Alcohol Screening Test
MB	Bachelor of Medicine
MCID	Minimal Clinically Important Difference

MD	Medical Doctor
MEMO - Qc	Moelle épinière et motricité Québec
MEP	Maximal Expiratory Pressure
MetS	Metabolic Syndrome
Mg	Milligrams
MINI	Mini - International Neuropsychiatric Interview
MIP	Maximal Inspiratory Pressure
Ml	Millilitres
Mm	Millimetres
Mmol/L	Millimoles per Litre
MPI	West Haven - Yale Multidimensional Pain Inventory
MPI - SCI	Multidimensional Pain Inventory for Spinal Cord Injury
MPQ	McGill Pain Questionnaire
MRI	Magnetic Resonance Imaging
MPRCQ2	Multidimensional Pain Readiness to Change Questionnaire - Version 2
MS	Multiple Sclerosis
MSc	Master of Science
MScCH	Master of Science in Community Health
MSK	Musculoskeletal
MSW	Master's of Social Work
MVA	Motor Vehicle Accident
NBD	Neurogenic Bowel Dysfunction
NCEP	National Cholesterol Education Program
NCTRC	National Council for Therapeutic Recreation Certification
NeP	Neuropathic Pain
NET Team	Neural Engineering and Therapeutics Team
NGO	Non-government Organization
NHLBI	National Heart, Lung and Blood Institute
NICE	National Institute for Health and Clinical Excellence
NLI	Neurological Level of Injury
Nmol/L	Nanomole per Litre
NPUAP	National Pressure Ulcer Advisory Panel
NRS	National Rehabilitation Reporting System
NSRC	Nova Scotia Rehabilitation Centre
NTR	NeuroTrauma Rehabilitation
OAB	Overactive Bladder
OH	Orthostatic Hypotension
(OH) Vitamin D	Hydroxy Vitamin D
OSCE	Objective Structured Clinical Examination
ONF	Ontario Neurotrauma Foundation
OP	Osteoporosis
ORT	Webster's Opioid Risk Tool
OT	Occupational Therapist
PA	Physical Activity
PAI	Patient Assessment Instrument
PARA - SCI	Physical Activity Recall Assessment for People with Spinal Cord Injury
PAR - QoL	Participation and Quality of Life Toolkit
PBL	Problem Based Learning
PC - PTSD	Primary Care - Post Traumatic Stress Disorder
PDAQ	Person - Perceived Participation in Daily Activities
PEDro	Physiotherapy Evidence Database
PET	Positron Emission Tomography
PhD	Doctor of Philosophy
PHQ - 9	Patient Health Questionnaire - 9
PIADS	Psychosocial Impact of Assistive Devices Scale
PM	Performance Measures
PM&R	Physical Medicine & Rehabilitation
PPI	Present Pain Intensity
pQCT	Peripheral Quantitative Computed Tomography
PQoL Scale	Perceived Quality of Life Scale
PRE	Rating of Perceived Exertion
PSFS	Penn Spasm Frequency and Severity Scale
PSS	Perceived Stress Scale
PT	Physiotherapist
PTA	Physiotherapy Assistant
Pts	Patients
PTSD	Post-Traumatic Stress Disorder
PVA	Paralyzed Veterans of America
QEII	Queen Elizabeth II
QoL	Quality of Life
QST	Quantitative Sensory Testing
RCT	Randomized Clinical Trial
REPAR	Réseau Provincial de Recherche en Adaptation - Réadaptation
RERC	Rehabilitation Engineering Research Center
RESNA	Rehabilitation Engineering and Assistive Technology Society of North America
RHF	Rick Hansen Foundation
RHI	Rick Hansen Institute
RHSCIR	Rick Hansen Spinal Cord Injury Registry
RN	Registered Nurse
RNA	Registered Nursing Assistant
RNAO	Registered Nurses Association of Ontario
RNL	Reintegration to Normal Living Index
ROM	Range of Motion
RPN	Registered Practical Nurse
rPTH	Recombinant Parathyroid Hormone
RSW	Registered Social Worker
RCT	Randomized Clinical Trial
rTMS	Repetitive Transcranial Magnetic Stimulation
SAS	Sexual Activity and Satisfaction Scale
SCATS	Spinal Cord Assessment Tool for Spasticity
SCC	Spinal Cord Connections
SCI	Spinal Cord Injury
SCI Canada	Spinal Cord Injury Canada (formerly Canadian Paraplegic Association)
SCID	Structured Clinical Interview for DSM Disorders
SCI BC	Spinal Cord Injury British Columbia (formerly British Columbia Paraplegic Association)

SCI - FAP	Spinal Cord Injury Functional Ambulation Profile
SCIM	Spinal Cord Independence Measure
SCIRE	Spinal Cord Injury Rehabilitation Evidence
SCI - SCS	Spinal Cord Injury Secondary Conditions Scale
SCI - SET	Spinal Cord Injury Spasticity Evaluation Tool
SCI - U	Spinal Cord Injury University
SCRP	Spinal Cord Rehabilitation Program
SF - 36	Short Form Health Survey (36)
SFSS	Penn Spasm Frequency and Severity Scale
SHRS	Sexual Health Rehabilitation Service
SIAS	Sexual Interest, Activity and Satisfaction Scale
SIS	Sexual Interest and Satisfaction Scale
S - LANSS	Self-report Leeds Assessment of Neuropathic Symptoms and Signs
SLOP	Sublesional Osteoporosis
SOC	Sense of Coherence
SpO2	Saturation of Peripheral Oxygen
SQLP	Subjective Quality of Life Profile
SSR	Sympathetic Skin Responses
STAI	State Trait Anxiety Inventory
STASCIS	Surgical Treatment of Acute Spinal Cord Injury Study
SUAS	Suicide Assessment Scale
SUAS - S	Suicide Assessment Scale - Self Report Version
SWLS	Satisfaction with Life Scale
TAI	Transanal Irrigation
TBCC	Tom Baker Cancer Centre
TBI	Traumatic Brain Injury
TENS	Transcutaneous Electrical Nerve Stimulation
TLC	Therapeutic Lifestyle Changes
TR	Therapeutic Recreation
TRI	Toronto Rehabilitation Institute
TRI - HFT	Toronto Rehabilitation Institute - Hand Function Test
TRI - UHN	Toronto Rehabilitation Institute - University Health Network
TRW	Teach Research and Wellness
TTC	Toronto Transit Corporation
TTT	Tilt-Table Test
UAB	University of Alabama at Birmingham
UBC	University of British Columbia
UHN	University Health Network
UK	United Kingdom
UMN	Upper Motor Neuron
UNB	University of New Brunswick
U of C	University of Calgary
UTI	Urinary Tract Infections
UV	Ultra Violet
UVC	Ultra Violet Light C
UWO	University of Western Ontario
VAS	Visual Analog Scale
vBMD	Volumetric Bone Mineral Density
VO2	Oxygen Consumption
VR	Vocational Rehabilitation
VSRC	Vancouver Sperm Retrieval Clinic
WALS	Work Activities Limitations Scale
W/C	Wheelchair
WheelCon - M	Wheelchair Use Confidence Scale - Manual
WheelCon - P	Wheelchair Use Confidence Scale - Power
WHO	World Health Organization
WhOM	Wheelchair Outcome Measure
WSP	Wheelchair Skills Program
WST	Wheelchair Skills Test
WSTP	Wheelchair Skills Training Program
WUFA	Wheelchair Users Functional Assessment
WUSPI	Wheelchair Users Shoulder Pain Index
YMCA	Young Men's Christian Association

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