



[ RICK HANSEN INSTITUTE CARE PROGRAM ]

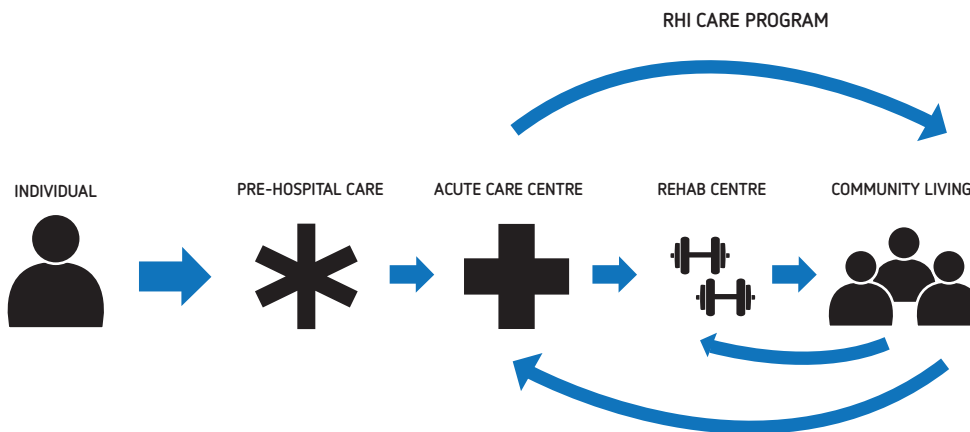
# PROVIDING EQUITABLE AND OPTIMAL CARE FOR CANADIANS WITH SCI

*This document is a roadmap that describes the Rick Hansen Institute’s (RHI) Care Program, its objectives and activities. It was developed based on recommendations provided by the RHI Care Program Advisory Committee.*



## CONTINUUM OF CARE FOR SCI

The continuum of care encompasses the pre-hospital, through acute, rehabilitation and into the community. RHI’s Care Program will span all four phases.



## CURRENT STATUS OF SCI CARE

The provision of spinal cord injury (SCI) care across the country is not standardized and there is tremendous variability in the care provided. There is a critical need to ensure best practices are implemented nationally to reduce this variability. This will improve care delivery and result in improved patient outcomes and ultimately in cost savings for the health care system. As advances are made in cure(s) for SCI, it will also facilitate the investigation and implementation of these treatment advances if SCI care is similar across SCI Centres in Canada.



**RHI'S VISION**

A world without paralysis after spinal cord injury.



**RHI'S MISSION**

To lead collaboration across the global SCI community, by providing resources, infrastructure and knowledge; and to identify, develop, validate and accelerate the translation of evidence and best practices to reduce the incidence and severity of paralysis after SCI, improve health care outcomes, reduce long-term costs, and improve the quality of life for those living with SCI.

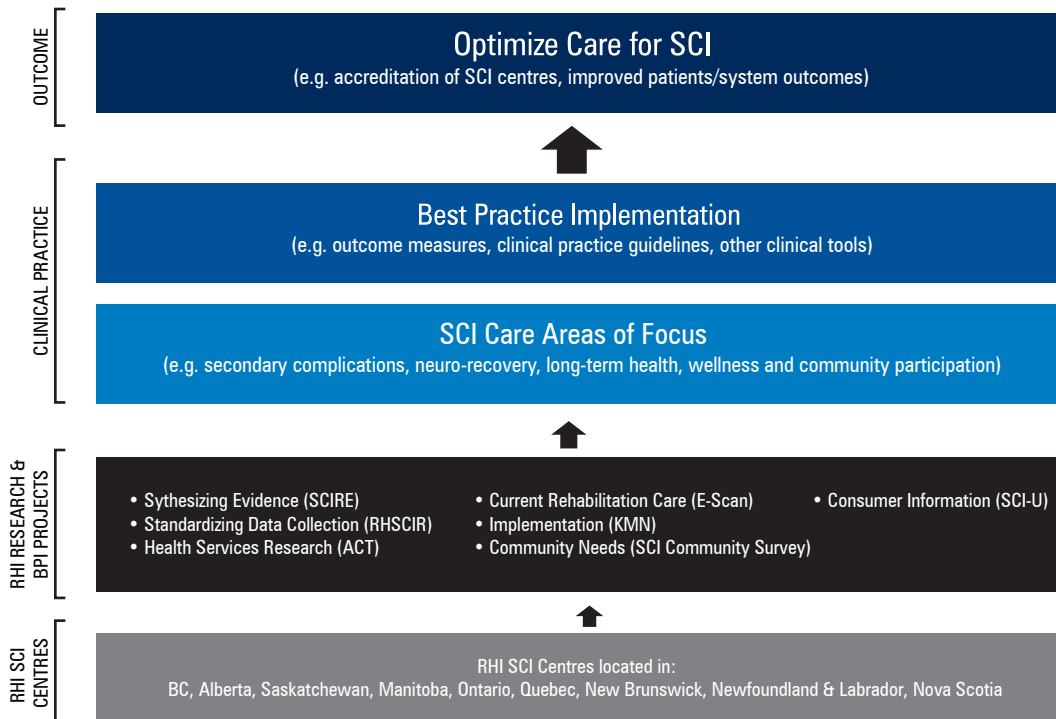


## THE CARE PROGRAM AT RHI

The Care Program at RHI aims to identify and fill gaps in knowledge regarding the clinical management of SCI as well as to promote best practices in SCI care delivery based on existing evidence for Canadians who are newly injured or those living with an existing SCI. The Program’s Advisory Committee was created to provide ongoing advice in care-related activities and recommendations on future activities supported by RHI. The current membership includes a comprehensive group of SCI researchers, clinicians, administrators and national partners (see sidebar for committee members).

While improved care will benefit the individuals with SCI directly, the Care Program is also tightly linked to the Cure Program in that optimized and standardized care is a necessary precursor to the multi-site clinical research and trials to be undertaken in search of SCI cure(s). Our ability to better understand, measure and standardize the clinical environment will enable us to administer emerging treatments and measure the effects in clinical studies. Treatments to minimize paralysis will need to be provided hours following injury and evaluated in multi-centre clinical trials. This will require a detailed understanding of the current health care system and the changes needed to provide treatments ‘out in the field’ hours following the injury.

Below is a diagram highlighting how the RHI sponsored projects and other on-going SCI initiatives can form the basis of the SCI Care Program. A complete description of RHI research and Best Practice Implementation (BPI) projects mentioned in this diagram is provided in Appendix A.



## ✓ OBJECTIVES OF THE RHI CARE PROGRAM

To achieve evidence-informed equitable and optimal care for Canadians sustaining a SCI in Canada as well as to fill important gaps in knowledge that will advance SCI care and facilitate future SCI cure(s).

### Areas of Focus

RHI will focus its support on the following areas, guided by a national panel of SCI experts in addition to project leaders who are currently working on RHI-funded projects that align with the Care Program.

- **Secondary complications** – with a focus on pressure ulcers, urinary tract infections, respiratory infections and neuropathic pain.
- **Neuro-recovery** – with a focus on activities supporting the improvement of neurological outcomes which includes: pre-hospital triage, acute care management and rehabilitation to maximize recovery.
- **Long term health, wellness and community participation** – with a focus on creating the optimal ‘environmental’ conditions to support long-term health, wellness and participation.
- **Accreditation Canada Implementation Strategy** – with a focus on accreditation of 50% of RHI SCI Centres under the new “SCI Acute Care and Rehabilitation Standards”.

## 🔍 RHI'S ROLE IN SUPPORTING CARE-RELATED RESEARCH AND BEST PRACTICE IMPLEMENTATION

To support the above areas of focus, RHI will carry out the following activities:

- Identify gaps in knowledge and the requirements to fill them.
- Leverage existing initiatives in other health conditions (e.g. general trauma) where appropriate.
- Leverage existing RHI projects (e.g. KMN) and ensure ethical approval is in place to be able to link de-identified data across projects.
- Integrate projects where possible to support feasibility and resource requirements.
- Prioritize areas for implementation where there is enough existing evidence to implement and no further studies are needed to maximize impact over the funding period.
- Make a shift from a research to a quality of care model for many RHI projects (e.g. RHSCIR), as this is needed to monitor changes in practice and outcomes.
- Include indicators to measure success (indicators – outcomes – impact) in all areas of focus.
- Partner with SCI organizations such as SCI Canada to facilitate patient engagement in research, lobbying for policy change and best practice implementation.

## LOOKING AHEAD RHI'S PROJECTED TIMELINE OVER THE NEXT 25 YEARS

2013

Renewed funding from the Government of Canada and the Rick Hansen Foundation

2014

RHI international SCI cure strategy

2018

International collaboration on two promising neurorestorative novel therapies  
*Facilitated by: 50% of newly-injured Canadians receive standardized care*

2023

International collaboration on five promising neurorestorative novel therapies  
*Facilitated by: 75% of newly-injured Canadians receive standardized care*

2038

All Canadians have access to SCI-specific novel therapies  
*Facilitated by: All newly-injured Canadians receive standardized care*



## STRATEGIC PARTNERSHIPS

RHI recognizes that the development of a comprehensive Care Program that provides evidence-informed equitable care to Canadians sustaining a SCI and facilitate the development of cure(s) must involve collaborations across nations, disciplines and organizations. RHI will continue to nurture existing and develop new relationships with the following entities towards building collaborative partnerships:

- National and international SCI-related foundations
- Consumer groups (national and provincial)
- Other national or regional SCI research institutions and networks
- Canadian and international universities and hospitals
- Accreditation organizations
- Professional and work safety organizations
- Corporations
- Non-SCI entities that have synergy with RHI's objectives



## MOVING FORWARD

Currently, RHI supports many projects relating to the care of persons with SCI. RHI will continue to support several ongoing projects such as RHSCIR as well as solicit new proposals from existing projects (e.g. KMN and SCIRE). New projects for support will be identified through open and/or targeted Request for Proposals (RFP). RFPs will be evaluated through external peer-review as per RHI's review policies.

*The Rick Hansen Institute would like to thank the following for their support: Government of Canada through Western Economic Diversification Canada, Health Canada, Rick Hansen Foundation, and the governments of BC, Alberta, Ontario, Manitoba, Saskatchewan, New Brunswick and Yukon Territory.*

*The Rick Hansen Institute is a Canadian-based not-for-profit organization with the goal of creating a world without paralysis after spinal cord injury. It works towards this goal by accelerating research and translating clinical findings into practical solutions to develop new treatments, improve health care outcomes, reduce long-term costs and improve the quality of life for those living with spinal cord injury. [www.rickhanseninstitute.org](http://www.rickhanseninstitute.org).*

## About RHI's Programs

The Rick Hansen Institute's Care Program is one of four key programs under RHI's new strategic direction for 2013-2018. The key program areas are Cure, Care, Consumer Engagement and Commercialization and are supported by six strategies (translational research, best practices implementation, informatics, network development, consumer engagement and supporting the next generation of the "Best & Brightest" researchers). Together, these programs and strategies will help support RHI's vision of a world without paralysis after spinal cord injury.

Learn more about RHI's strategic direction for 2013-2018 at [www.rickhanseninstitute.org/about-us/who-we-are/strategic-direction](http://www.rickhanseninstitute.org/about-us/who-we-are/strategic-direction).

## CARE PROGRAM

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## APPENDIX A

### SYNTHESIZING EVIDENCE — SCIRE

**SPINAL CORD INJURY REHABILITATION EVIDENCE (SCIRE)** is a Canadian-led international collaboration which has facilitated the translation of existing knowledge into SCI rehabilitation best practice. The core foundation of the SCIRE project is based on a synthesis of the research evidence underlying rehabilitation interventions to improve the health of people living with SCI, as well as outcome measures to evaluate these effects.

### STANDARDIZING DATA COLLECTION — RHSCIR

**The Rick Hansen SCI Registry (RHSCIR)** is a pan-Canadian prospective observational registry of individuals sustaining a traumatic spinal cord injury who are treated at one of 31 major Canadian acute care and rehabilitation hospitals. Using a standardized research protocol and data collection forms, RHSCIR tracks the care and outcomes of people with traumatic SCI during their journey from injury through acute care and rehabilitation and into the community. Details about participants' spinal cord injuries including cause of injury and neurological impairment, recovery and success of various treatments are among the types of data recorded.

### HEALTH SERVICES RESEARCH — ACT

**The Access to Care and Timing (ACT)** project is a national, multi-centre research study focused on describing the processes of health care delivery for people with traumatic SCI in Canada. RHI has partnered with the Centre for Operations Excellence at the University of BC Sauder School of Business and has developed a computer simulation model which can be used to 'simulate' changes in patient flow or the implementation of best practices to see the effect on patient and system outcomes.

### CURRENT REHABILITATION CARE — E-SCAN

**The Rehabilitation Environmental Scan (E-Scan)** project is the first ever national scoping review of Canadian spinal cord injury (SCI)-related rehabilitation practice. The purpose of the E-Scan was to describe current SCI rehabilitation service delivery, research capability and capacity (at 12 RHSCIR rehabilitation sites) for rehabilitation goals articulated in the SCI rehabilitation framework. The E-Scan data will support future SCI initiatives, help with implementing best practice and informing the optimal rehabilitation resources, outcomes and future research.

### IMPLEMENTATION — KMN

**The Knowledge Mobilization Network (KMN)** is a community of practice that has evolved out of a national best practices implementation effort. The goal of the network is to adopt and utilize the best available practices in SCI care to improve outcomes in the areas of pressure ulcer and pain management using an evidence-informed implementation methodology.

### COMMUNITY NEEDS — SCI COMMUNITY SURVEY

**The SCI Community Survey** was the largest ever consumer survey of its type undertaken in Canada. Conducted with the participation of people with traumatic and non-traumatic SCI living in the community, the purpose of this nationwide survey examined whether or not the needs of people with SCI are being met by existing health and social service programs. Results from this survey will inform best practices and policies in the community and fill gaps in existing knowledge regarding participation and quality of life following SCI.

### CONSUMER INFORMATION — SCI-U

**SCI-U** was developed to provide a new approach to online patient education in SCI. A series of multimedia courses on topics such as physical activity and nutrition, bladder and bowel management, pain management and sexuality, SCI-U is individualized, problem-based and designed to provide people with SCI with the information needed to live a healthy, active life.