

# Being Bold: Toward a National Spinal Cord Injury Care, Health & Wellness Strategy

Discussion Document &  
Consultation Report

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# Executive Summary

Development of a national strategy for spinal cord injury (SCI) health, care, and wellness provides an opportunity to align the activities done across 13 jurisdictions (covering the provinces and territories), multiple domains of practice, and many disciplines together to achieve something together that can't be done apart. A consultation process was initiated to explore how such a strategy could be developed and what considerations need to inform the process.

## Current and Future States of SCI

The SCI community in Canada is an informal system of systems with networks organized by topics, regions, and professional activity. An initiative to more formally organize and resource these networks has been initiated that can serve as a platform for engaging the community around a national strategy. The Rick Hansen SCI Registry and the emerging accreditation standards in SCI care are among other activities that a strategy can build on.

The future of SCI in Canada is being shaped by social, economic, and technological forces that will require new thinking and action in order to address. Opportunities for improved treatments, post-injury employment, and the changing nature of SCI in the population will affect the way care, treatment, and training for health professionals is done. Research priorities, opportunities, and the means of translating evidence into practice are further areas where changes are coming and will require a strategy to address.

## Creating a National Strategy

A national strategy for health, care, and wellness will serve as the means to provide programmatic, research, and policy coherence to a community of organizations that are spread across the country operating largely within provincial contexts. It will provide guidance for setting care standards, research priorities, identification in gaps and opportunities in the system, and support identification of promising tools and practices. A national strategy will align the prevention, care, and the supportive living needs across the lifespan and spectrum of services and provide a unified focus across the different health jurisdictions across Canada, while recognizing the distinctive priorities that exist within each region.

It is recommended that a strategy develop a clear purpose and vision for a better future for those with SCI in Canada. By creating inclusive, purposeful conversations across the spectrum of care (primary prevention, acute care,



rehabilitation, and longer-term community care) with professionals and those with lived experience and building on what is already in place, the strategy can provide that coherence to activate the sector. By recognizing the unique and shared needs within domains of practice (e.g., specialist-needs care treatment, rehabilitation, etc.) and across streams of shared activities across the spectrum of care.

## Plans and Approach

The recommended strategy is a 'build in/build out' approach that involves focusing on areas where there is already interest and focus, mainly across domains of practice where there is established networks, conferences, and activity that connects actors in the community. The strategy includes:

- **Build in/Build out: take stock of the community assets, mapping the structures, actors and relationships within the system, and then explore areas of need.**
- **Co-create from the start: Identify and connect with leaders in the SCI community and co-develop terms of reference to guide the strategy development process.**
- **Leverage existing resources: Determine what resources are available to scope the plan and identify opportunities within current planned activities (e.g., conferences, meetings, events) to consult and engage the community in the strategy development process.**
- **Identify roles: Set up a working group with expectations, roles, and create a plan for communicating with and being accountable to the community, who will ultimately own and enact the strategy.**
- **Visualize and communicate progress: By establishing indicators of success and reporting on the activities and progress, the strategy development process can engage the community and ensure that feedback is generated and used to inform the strategy.**
- **Provide keystone support: National organizations like the RHI can provide keystone support by aligning activities of provincial and regional partners and providing leadership to connect these activities to a national strategy.**
- **The window of opportunity to make a measurable difference in SCI health, care, and wellness has opened. By connecting Canada's SCI system together through building a shared vision and commitment to action, a national strategy provides the chance to move the country closer to have a well-lived life for every person affected by SCI.**



*Freedom lies in being bold – Robert Frost*

# strat·e·gy

*/stradj/*

*noun*

**1. a plan of action or policy designed to achieve a major or overall aim.**

Bringing people together.

Aligning interests.

Creating a vision.

Achieving focus.

Directing action.

Generating value.

***This is what a strategy brings.***

**B**oldness is about taking risks, confidence, and being courageous. It reflects a decisiveness and direction that can serve as the wellspring of leadership and inspire others to follow. The term ‘bold’ was heard throughout the consultation process that informed this report. What boldness means for the development of a national strategy for spinal cord injury health, care, and wellness in Canada is what we will explore in this document as we chart a path forward.



# Introduction

Spinal cord injury is among the most severe, survivable experiences for a human being affecting the injured and those around them. Advances in research, clinical treatment, rehabilitation science, and improved translation of learning across the spectrum of care has resulted in people with SCI living longer, better, healthier lives. Over 80,000 people in Canada live with paraplegia and tetraplegia with an estimated 4300 new cases occurring each year. It is estimated that \$2.7 billion is spent on healthcare, equipment, life-long care, and related modifications with even more spent when those with non-traumatic and degenerative spinal conditions are included. (Rick Hansen Institute Strategic Plan, 2016)

While progress on SCI care, health, and wellness from the time advocacy pioneer and leader Rick Hansen was injured as a young man to now has been tremendous, advances in technology, communications, and the changing healthcare landscape of SCI in Canada present an opportunity to move things further, faster, to create a better life for Canadians living with SCI.

The time has come to be bold in developing a strategy that will connect the strengths of Canada's research, practice, and care sectors together with a shared vision, moving SCI forward as a community. The strategy is aimed at leveraging the work being done now to create a better future, proving that the whole community is greater than the sum of its parts.

*The time has come to be bold in developing a strategy that will connect the strengths of Canada's research, practice, and care sectors together with a shared vision, moving SCI forward as a community.*

## The Landscape of SCI

A look at the spectrum of activities for SCI in Canada finds some of the top scientists, healthcare leaders, and consumer advocates in the world operating largely within the boundaries of health systems within each province. While there are centres of excellence within some of these provinces and experts distributed across the country, SCI remains a condition with relatively low prevalence, high resource needs, and expertise situated broadly across Canada. This presents a need to align resources – knowledge, people, physical assets – in ways that draw on the strengths within the system to connect Canada's SCI community across the spectrum of care and prepare it for the future.

The present landscape of SCI in Canada finds a vibrant community of engaged researchers, multidisciplinary care practitioners, advocates, and community members with involvement of those with lived experience in these activities



across the spectrum of care. The RHI has played a key role in supporting this community by bringing a national perspective and mandate for funding work across the country, rather than at a regional level (where most SCI organizations operate). This national perspective has helped foster the development of The Rick Hansen SCI Registry (RHSCIR), a pan-Canadian registry of individuals who have sustained a traumatic spinal cord injury. The RHI has also led the development and implementation of a set of national standards and knowledge-mobilization network that seek to implement best-practices within care settings across Canada.

Recently, the RHI and the Ontario Neurotrauma Foundation (ONF) undertook an exploratory look at how existing practice and research networks of practice could be better leveraged and connected across the country. This 'network of networks' or alliance of networks approach could provide a structural means to organize the work done in SCI in Canada through a series of coordinated communities of practice. RHI, as a national organization, is working closely with partners across the country like SCI Canada, the Ontario Neurotrauma Foundation, and collaborators from across the country to explore this idea. The aim of this network has been to align SCI activities and processes nationally; enable equitable and optimal care across the continuum (acute, rehab, community) at the local, provincial, and national levels; facilitate cross-sector collaboration across the country; and ultimately promote the highest level of care and outcomes for persons with SCI. This network further provides a means to engage the entire system in prevention efforts more meaningfully across the lifespan and spectrum of care.

Spinal cord injuries present unique challenges for the health system as it is a highly intensive, specialty area of care that exists within a relatively low prevalence condition. It requires diverse, distinctive specialist skills within each of the acute, rehabilitation, and community care contexts bringing together professionals and caregivers from many different disciplines. This specialized group has formed a natural community of interest that serves as a foundation to build on: a national strategy will allow this community to come together in ways that bridge the differences between provinces, disciplines, and practice areas.

The SCI community in Canada is organized largely as a system of systems or network of networks. Organizations such as SCI Canada and RHI are among the few organizations with an SCI-focused national mandate.

*Spinal cord injuries present unique challenges for the health system as it is a highly intensive, specialty area of care that exists within a relatively low prevalence condition.*



The Ontario Neurotrauma Foundation, MEMO Quebec, WorkSafe BC, and attendees to a recent Atlantic Canada Spinal Cord Injury Summit represent examples of formal and informal networks and organizations that are advancing knowledge and practice excellence across Canada.

## Stakeholders

An effective national strategy must consider the needs and perspectives of current and future stakeholders, especially persons with lived SCI experiences (PLE).

### SCI System Partners



### Future Partners

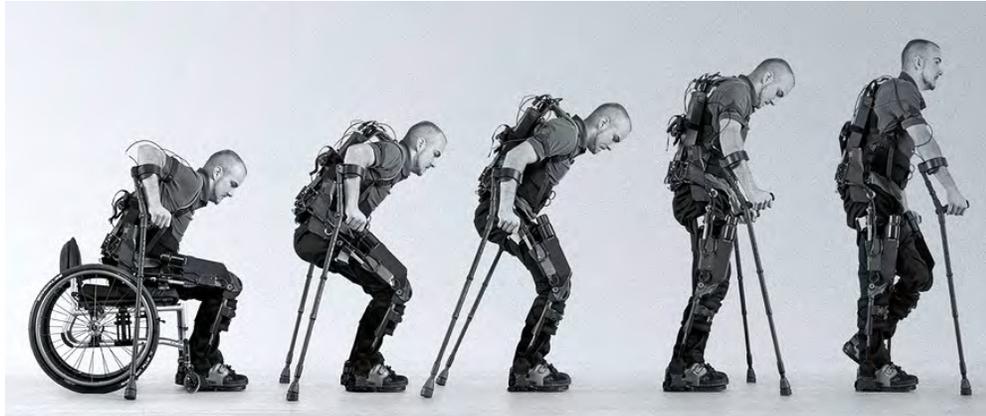


### Target Stakeholders for Funding & Supportive Policy



# The Future of SCI in Canada

*"This river I step in is not the river I stand in"* – Heraclitus



A strategy recognizes that the efforts undertaken today will interact within an environment and context that won't come to pass until tomorrow. Understanding where things are going is as important as assessing where we've been. Heraclitus, in the quote above, spoke on the inevitability of change and it is through contemplation of what changes are needed for the future that a national strategy can support the SCI community. By developing a coordinated, national strategy those working across the country will be better positioned to anticipate change and lead it rather than reacting to it.

A look at the trends and drivers that influence SCI activity in Canada today suggests that the future will require strategic considerations to adapt the system for tomorrow's needs. The most notable of these is captured in the shifting nature of SCI in Canada, with non-traumatic injuries making up the largest proportion of the population (Noonan, Flingas, Farry et al., 2012).

This trend is expected to continue as demographic shifts accompany greater health and safety protections and policies along with sustained preventive efforts for traumatic injury. The rise in numbers of older adults will shift some preventive efforts to falls prevention and supporting those with physical or cognitive impairments (Hughes, Salmon, Galvin, Casey, & Clifford, 2019; Lord & Close, 2018; Meyer, Hill, Hill, & Dow, 2019).

New technologies are enabling people who are not able to walk after a SCI are now able to move and even walk again with assists.

***A look at the trends and drivers that influence SCI activity in Canada today suggests that the future will require strategic considerations to adapt the system for tomorrow's needs.***



Complementing the evolution of these technologies is the steady scientific progress toward improved treatment and rehabilitation for SCI (Badhiwala, Wilson, Kwon, Casha, & Fehlings, 2018; Moritz, 2018). Improvements in the quantity, quality, and strength of communications and translational research activities from bench to bedside has improved the prospects of having more people live a life without paralysis due to spinal cord injury due to better integration of knowledge into practice.

A national strategy will have the benefit of providing greater dialogue about the benefits and costs associated with new innovations and provide guidance to decision-makers about how to fund such innovation development and adoption of certain products (MacNeil et al., 2019). By including patients and those with lived experience among those making decisions and setting priorities, this strategy will align with current trends toward collaborative priority setting (Holroyd-Leduc et al., 2016).

The roles and responsibilities of those working in SCI will evolve as greater numbers of those with SCI will come from non-traumatic and degenerative, chronic, or later-life injuries (e.g., falls) rather than early-life traumatic injuries. New emphasis on adaptive life, quality of life care, and the need to invest in the training and support of those seeking to help those in later life live as comfortably as possible, whether in the community or in institutional care. This shift will require new investments, changes to health human resourcing, and greater attention to the issues associated with 'aging in place' (Goodridge et al., 2015; Jørgensen, Iwarsson, & Lexell, 2017).

For those living and working with SCI, changes in workforce needs and conditions alongside shifts in policy, job demands, and workplace design are creating new opportunities for those with physical function limitations (Anderson, Dumont, Azzaria, Le Bourdais, & Noreau, 2007; Jetha, Bowring, Furrie, Smith, & Breslin, 2019; Jetha et al., 2018). The shifting nature of job roles and functions from work that emphasized physical labour and location-based activities to digital/knowledge work and location independence is a major factor along with the increased role of automation in many jobs (Lamb, 2016).

Advances in technology to support some with SCI move with robotic and computer-supported assists is offering hope for many who once perceived themselves as exclusively wheelchair-bound (Baldassin, Shimizu, & Fachin-Martins, 2018; Cheung, Ng, Yu, Kwan, & Cheing, 2017; Mekki, Delgado, Fry, Putrino, & Huang, 2018). Assistive technologies are enabling those with SCI to do more, go new places, and function more fully in a wider variety of environments than ever.

***Advances in technology to support some with SCI move with robotic and computer-supported assists is offering hope for many who once perceived themselves as exclusively wheelchair-bound***



As the population ages and healthcare costs rise with that population, greater financial and human resource pressure will be placed on health systems. Investments in innovation within the health system will no longer be advised, but required to sustain the system (Advisory Panel on Healthcare Innovation, 2015). Spinal Cord Injury care and research can play a leading role in demonstrating ways to engage multiple sectors of the system together to innovate effectively to meet the needs of those with SCI and their families. Innovation will need to consider not only the patient and care, but the systems of care in which that takes place. Major changes to the way healthcare and research is funded and organized are expected in the next 20 years, putting pressure on those in the system to respond and lead as governments seek to improve access to care, reduce waiting times, manage rising costs, and improve quality and coordination of care (Bielska et al., 2018; Micieli, 2014).

By connecting and coordinating resources across the country, a national SCI care, health, and wellness strategy would enable the sector to better anticipate and get ahead of these changes. It would also provide a way for the SCI community to inform and contribute to the advocacy and preventive work with falls prevention, community care resourcing (such as work on transportation and housing), support the future scientific work needed to ensure that the research, clinical, rehabilitation, and care needs of those with SCI are considered.

*Spinal Cord Injury care and research can play a leading role in demonstrating ways to engage multiple sectors of the system together to innovate effectively to meet the needs of those with SCI*



# Building a National Strategy

*“Effort and courage are not enough without purpose and direction”*

- John F. Kennedy



A national strategy for care, health, and wellness will serve as the means to provide programmatic, research, and policy coherence to a community of organizations that are spread across the country operating largely within provincial contexts. The strategy will align the prevention, care, and the supportive living needs across the lifespan and spectrum of services. By initiating a process of strategy development, the RHI is positioned to use its position as a national organization that works across contexts to convene stakeholders in a manner that can build a focus the entire SCI community can organize around.

A national strategy for care, health, and wellness offers a means to:

1. **Provide direction to activate the passion, commitment, and energy in the community.**
2. **Align activities across sectors and the country toward national targets and goals.**
3. **Set national standards for care that can be measured, benchmarked, and advanced across all provinces and settings.**
4. **Address the known gaps and opportunities within the system to move forward on common issues and to prepare the system for emerging threats and challenges.**



5. Leverage the connections created through the network of networks by creating focal points for action and the means to translate social capital into value for the SCI community.
6. Create a mechanism to identify and clarify research priorities, aligning the interests of the SCI community with existing funding sources to complement and leverage resources, eliminating or mitigating unnecessary competition.
7. Establish a platform for advocacy work that connects the common issues shared across the country with a shared voice.
8. Enhance system capacity for knowledge transfer, exchange, and mobilization connecting research, practice, and policy within and across the system.
9. Influence the identification and development of promising tools, technologies, and activities in a manner that allows for more targeted support to bring them to market and practice. The strategy can guide technology assessment, research synthesis, and economic analyses that are too costly and resource intensive to do on a province-by-province level.
10. Build a 'critical mass' of perspectives and actors focused on SCI issues that can be mobilized quickly and efficiently due to a shared focus and planning process created through the strategy.

*While the strategy must be bold, it also needs to be feasible, situating itself between a conservative reality and unachievable optimism.*

To bring these benefits into existence a consultation was conducted with a sample of SCI experts from different regions and sectors including two workshops with RHI staff as an initial step toward shaping the path toward a national strategy. The intent of these workshops and consultations was to determine the areas of need for a strategy and the key factors that will ensure it meets those needs.

The recommended approach for developing the strategy involves the following considerations:

## Proceed with Purpose

A strategy is about finding and framing a vision and articulating the priorities that define the steps needed to achieve it. The sector wants a bold vision and will rally behind a process that will help the community articulate and achieve



that vision. A national strategy cannot be “all things to all people” and achieve success. Clear priorities for research, care, and engagement will mobilize interest. Without a purpose and plan, there is little appetite for engaging in the necessary work of strategy building. The term ‘bold’ was mentioned in consultations with experts and the RHI; it came up multiple times as a reference for what stakeholders believe this strategy should be. This strategy plan reflects that sentiment.

## Expand the conversation

There is a need to draw on expertise and partners in a manner that is inclusive and diverse. The sector has a strong, passionate, committed core of leaders in research, care, and advocacy that has shaped the Canadian SCI landscape. There is a recognition among these leaders that more and different voices need to be part of the conversation. Going beyond the core disciplines, regional centres, and typical roles and ensuring that the voices of those with lived experience are included is essential for a national strategy to develop into something that represents the needs of the entire SCI community and focuses on the future. This conversation may also include allied areas on specific aspects of the strategy such as those that affect community care, building on work of such multi-sector initiatives as the Federal Accessibility Legislation Alliance (<https://www.include-me.ca/>), whose members could provide support for aspects of a strategy.

*There is a need to draw on expertise and partners in a manner that is inclusive and diverse.*

## Build on what’s already in place

The SCI community has valuable assets (such as The Rick Hansen SCI Registry) that require continued investment and updating. The strategy must consider the need to strengthen and develop existing assets alongside necessary expansion of programs and focus. Improving data management and related infrastructure is one of the examples of something that could greatly enhance the system capacity. The SCI community has numerous budding and established networks that remain active and useful, but largely disconnected from one another. A national strategy, building on the early work done by RHI and partners to look at an alliance of networks, could leverage the existing relationship capital that is in place.



## Activate the sector/achieve results

There is interest in seeing a national strategy with the caveat that it must lead to action. While the strategy must be bold, it also needs to be feasible, situating itself between a conservative reality and unachievable optimism. Evaluating what is done and generated, sharing what is learned, and encouraging active engagement with the SCI community is a way to deliver commitments, show impact, and sustain interest in and commitment to a national vision. There is a risk that a failure to deliver results will prompt partners to disengage and hamper future initiatives. Co-designing the strategy with partners and the community ensures that the strategy is grounded in the needs of the entire sector.

*The RHI is ideally positioned to play a leadership role in the development of a national strategy.*

## Cross the spectrum

The roots of much of Canada's SCI care community infrastructure started in acute care, has since expanded to include emphasis on rehabilitation, and now needs to bring in more of the community perspective—the place where many with SCI live their lives. A successful strategy will seek to build on the historical roots in providing research, clinical excellence, and treatment for acute-care and early-stage rehabilitation of SCI, while resourcing better support for later-stage rehabilitation and community care support. This includes recognizing the growing incidence of non-traumatic and degenerative causes of SCI and the different resourcing needs and circumstances associated with it. A national strategy would provide the means to align the needs and priorities in a manner that can allow the sector to do more than it does now.

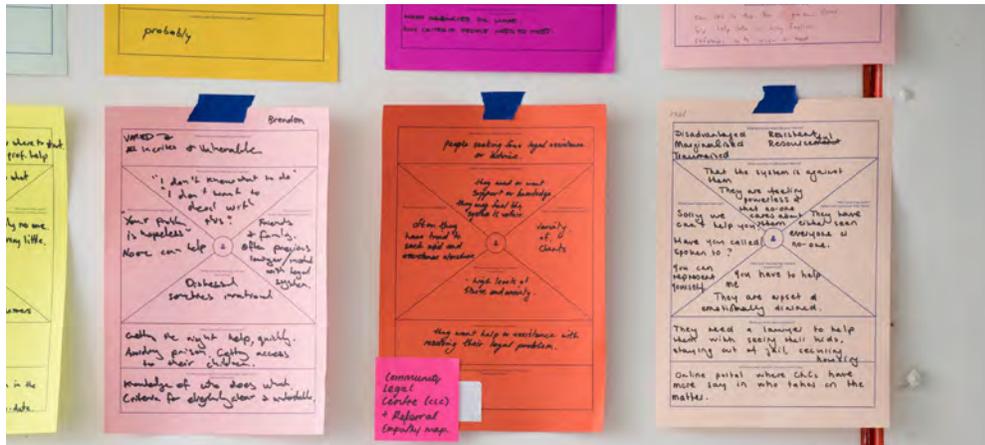
## Know your role

The RHI is ideally positioned to play a leadership role in the development of a national strategy. To best fulfill this role, RHI needs to provide clarity about its role in the national SCI community overall. Many of those consulted spoke highly of the RHI's past, but expressed confusion, some frustration, and uncertainty about where the organization is committed to going in the future. Some perceive that the RHI has focused on doing many small things than taking larger, substantive steps in a one direction. This wide focus contributes to confusion within the sector, promotes distrust, and leads to disengagement with partners. The RHI can lead by clearly articulating its role in the strategy and in its work across Canada. This articulation will also enable better identification of other organizations and individuals who can play specific roles in the strategy development process as well. The strategy needs to be owned and enacted by the community.



# Creating the Strategy

**“Begin, be bold, and venture to be wise.”** — Horace



Developing a national strategy requires a boldness on its own, not just as an outcome but as a process. To support this complex engagement, a set of principles are recommended.

Principles are those things that can be agreed on up front, but also account for adaptive strategy while providing something that can guide evaluation efforts to demonstrate outcomes (Patton, 2018). The planning process should be principles-focused.

*Developing a national strategy requires a boldness on its own, not just as an outcome but as a process.*

## Principles for a National SCI Strategy

- Focus on strengths and leverage the community's present assets and not depend on unsecured resources
- The strategy belongs to the SCI community and must be developed collaboratively with the community
- Maintain commitment to fully engaging those with lived experiences in a meaningful, substantive manner across the spectrum of care.
- All stakeholder voices are important, and steps must be taken to further engage stakeholder groups/communities throughout the strategy development process
- Clear leadership and decision-making roles are required to effectively implement the strategy
- The strategy will set national goals and priorities that can be supported by regional/provincial action. These goals must complement and align with provincial and regional priorities and capacities.

## Mapping the landscape

Building a map of the SCI Community, the actors (individuals and organizations) within it, the roles and functions performed, and the locations of practice is a key step towards engaging people across the system in the process of building a strategy. A map of the system according to function and roles can help determine the communities of interest or practice that can be leveraged initially.

Figure 1: The Spectrum of Care for SCI

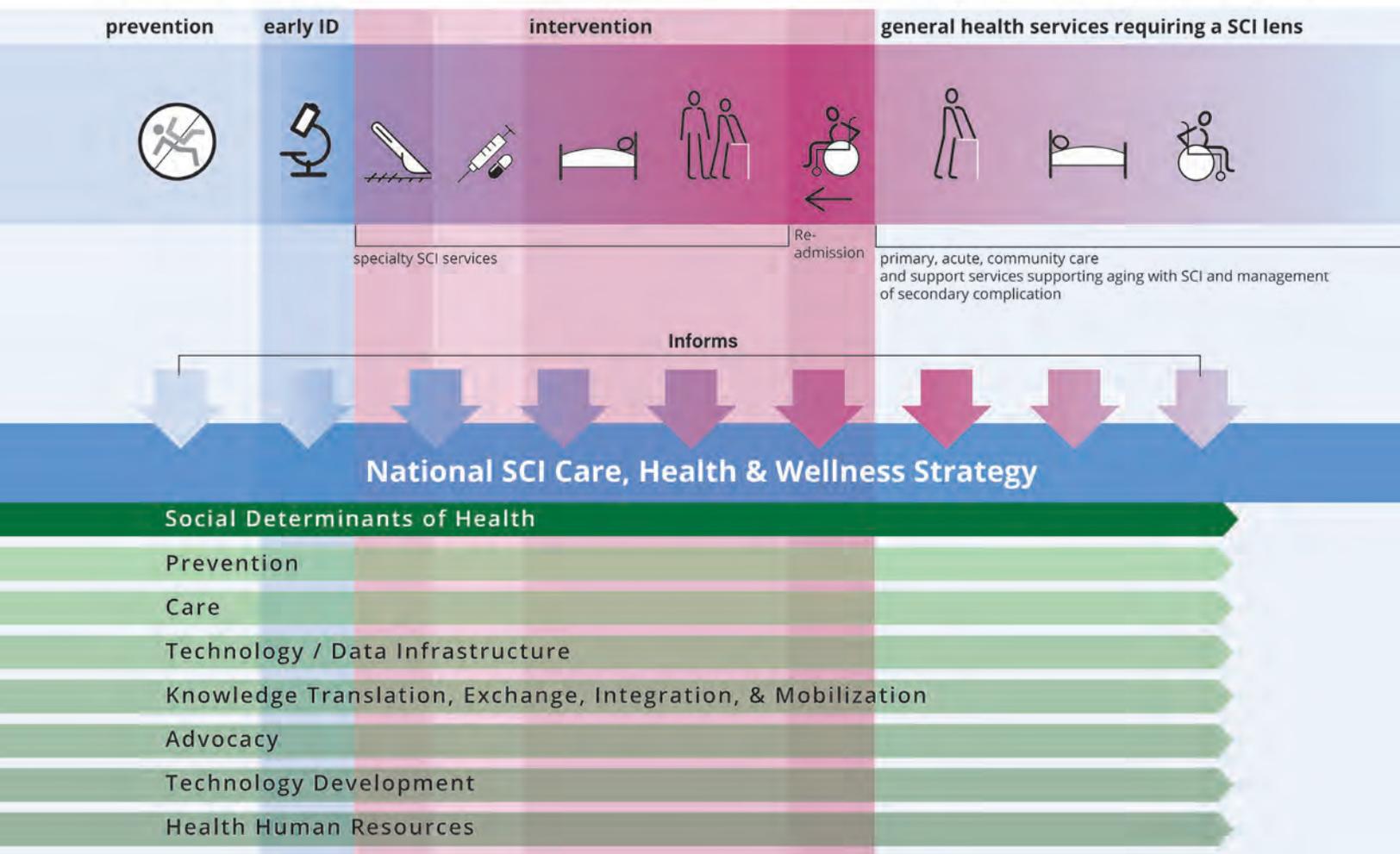


Figure 1 illustrates the spectrum of care from SCI primary prevention efforts through to community-located care. Within this spectrum are bands of activity ('practice domains') that can feed into a national SCI care, health and wellness strategy along with are social determinants of health ( e.g. housing, accessibility, employment, etc.).

Across the domains of practice are activities that are necessary for a national strategy to be successful. These cross-cutting issues require their own specific sub-strategies.

These include:

**Prevention:** Primary, secondary, and tertiary prevention efforts that take place across the lifespan with SCI.

**Care:** The diverse care needs at different stages of SCI and represent that continuity of care for the person across their life.

**Technology/Data Infrastructure:** The core technological supports to gather, process, and utilize data and support development of new tools to aid persons with SCI, researchers, and care staff.

**Health Human Resources:** Ongoing training, skills development, maintenance, and recruitment of qualified health professionals and non-professionals to work within the sector and support those with SCI.

**Knowledge translation, exchange, integration & mobilization:** The skills, structures, and personnel required to generate and identify new knowledge, evidence and skills and communicate across and beyond the sector.

**Advocacy:** Enabling the SCI sector to advocate for its needs and mobilize support for SCI-affected persons, families, and caregivers.

**Technology Development:** The tools, devices, and assists that are a part of the lives of those with SCI from the moment an injury is sustained or realized.

**Research:** The research that provides the core support for diagnostics, treatment, technology development, rehabilitation, community care and life-long support.

*Developing a national strategy requires a boldness on its own, not just as an outcome but as a process.*

Together, this approach of developing strategy from domains of practice and streams of shared activity forms the foundation for a 'build in/build out' approach to creating the strategy.

Using this approach, emphasis is placed on developing focal points for a strategy within each topical area along the spectrum and through each of the cross-cutting themes. Those with interest in each area will be able to identify areas of priority, need, and opportunity that can serve as a focus for their work. This process will also help elucidate any regional or geographic issues that might influence the work within a domain of the spectrum. From this focus on the vertical slice of the spectrum across (domains of practice) common themes and issues can be derived to form the basis for more national-level strategic discussions – how to shape a national, unifying strategy. This will include things like assisting in determining the vision for the strategy and key areas of emphasis.



## Tactics for Strategy Development

*The following are some general tactics that can inform the creation of the strategy with recommended steps*

**Build out and in:** This approach to developing strategy emphasizes building depth of perspective within each content area and across the system around the cross-cutting themes. This will allow organization of consultations based on topics, methods, regions, or circumstances in an adaptive manner. It also allows the strategy development process to build on strengths (areas of high activity and depth of expertise) at the beginning to make early progress. This strategy also recognizes the need to gather perspectives from across the spectrum and allows for targeted engagement within those areas of SCI health, care, and wellness that are less developed, represented, or organized within the system. This will ensure both specialist- and non-specialist audiences are engaged in the strategy development process and that the strategy reflects voices from across the SCI spectrum of care.

### **Actions:**

- 1. Map the SCI system in Canada.** Include the key actors (individuals, organizations, networks) that represent the major stakeholder groups. Consider those unknown areas where there is minimal representation or lack of engagement and identify where opportunities exist to engage those areas more fully.
- 2. Take stock of the current state of practice.** Review the key activities being undertaken within the sector across both the domains of practice and streams of activity to assess the SCI community's strengths and areas of need.
- 3. Explore areas of need.** Within those areas where little is known or the information is incomplete or uncertain (e.g., community care, primary prevention), identify those in the system who could help provide the necessary understanding of people, resources, or other institutions that could support the initiative within these domains.

*Building out means engaging those organizations who are allied to SCI on the ends of the spectrum – primary prevention and awareness building on one end and those working within a community care context on the other.*



**Co-create from the start:** Bringing diverse voices to the table, emphasizing the role of those with lived experience, and including perspectives from across the spectrum of care were part of the message delivered through the consultations. While the RHI is well-positioned to facilitate the process of strategy development, the strategy needs to be owned by the community and involving them in the process early and consistently is critical to establishing that ownership stake. Among the first steps to engagement with the community is forming a strategy planning working group that comprises membership of key actors from the SCI community. It is recommended that this working group serve as an action-oriented group, not just an advisory, and should reflect representation from a variety of disciplines and regions, reflect the spectrum of care, and must include those with lived experience. (Some members may fill multiple roles). To keep the group nimble and action-oriented, it is recommended that the size be limited to between 6 and 8 individuals.

*The RHI is in a position to steward the process and seed the initial work on strategy development, however it is incumbent to the success of the process that other partners provide resources as well.*

### **Actions:**

- 1. Identify leaders.** From the system map developed, identify those in the system who represent diversity across the domains of activity and region, competence and leadership qualities, and potential interest to form the Strategy working group.
- 2. Connect with leaders.** Reach out, engage and recruit leaders to form the strategy working group.
- 3. Develop terms of reference.** Develop simple terms of reference for the working group based on this document.

**Leverage existing activities and resources:** A successful strategy development process will build upon the resources available within the community. The RHI is in a position to steward the process and seed the initial work on strategy development, however it is incumbent to the success of the process that other partners contribute as well. These may be in-kind resources or direct, and through leveraging their networks or social and political capital, however there must willingness from stakeholders to invest in this initiative.



Opportunities to convene and meet could be leveraged from existing meetings, conferences, or other planned events where key stakeholders from the SCI community are present. This would enable broad based consultation opportunities with minimal additional cost.

**Actions:**

- 1. Establish resource base.** Determine the capacity of the project through consultation with key partners in Canada. This will include determining what kind of funding, time, and other in-kind resources are available for the project.
- 2. Scope the strategy development process.** Once the resource levels are determined the scope of the consultations can be framed and a plan developed for engaging the community.
- 3. Identify consultation opportunities:** Examine the current calendar of activities within the SCI sector for opportunities to integrate or add-on consultations to support the strategy. This would include identifying key conferences, meetings, or other events that could be leveraged to include an additional meeting or activity to gather information and input into the strategy.

*By seeking those who are both established and emerging leaders, the process is more likely to bring in new perspectives.*

**Identify roles independent of titles:**

To encourage broad participation in the strategy development process, seek out and encourage engagement from a variety of actors and those with leadership interests. This includes current recognized leaders and identification of emerging future leaders. These may not be people with high-ranking positions, leadership ‘titles’, or specific professional roles, rather emphasis is to be placed on those who are passionate, committed, and willing to work to enlist others in supporting the strategy creation process. By seeking those who are both established and emerging leaders, the process is more likely to bring in new perspectives.

**Actions:**

- 1. Set expectations.** Through development of a strategy working group and Terms of Reference, key roles and responsibilities for the group can be developed and discussed once the group has convened. By establishing the group as a working group (not a committee) it sets the expectation that those involved will be asked to invest some energy in the project.



- 2. Identify key roles for the working group.** Identify what activities need to be performed, who is to perform them, what additional resources (e.g., external consultants, affiliated organizations), and what collaboration arrangements are necessary to engage in the consultations.
- 3. Create a reporting structure.** It is recommended that the working group will involve self-management and will require an appropriate accountability mechanism to ensure that progress is made and communicated to the community. A reporting structure that reflects this is critical.

### **Visualize and Communicate Progress:**

To demonstrate activities and progress toward developing the strategy, a concerted effort must be made to communicate with the community throughout the process. Leveraging existing communication channels such as newsletter articles, blog posts, periodic update reports to key SCI committees and organizations (e.g., RHI Care Committee) are means to communicate with stakeholders about the strategy development process. An evaluation strategy for the development process would include documentation of outputs (e.g., meetings, consultations) and outcomes (e.g., strategy products such as timelines, vision statements, plans).

*An evaluation strategy for the development process includes documentation of outputs and outcomes.*

- 1. Establish outcomes.** Once the working group convenes, confirm the desired outputs and outcomes for the project. This will include establishing timelines based on the resources available and expectations of the working group.
- 2. Develop evaluation metrics and methods:** With key processes, outputs, and outcomes determined, an evaluation for the strategy development process can be set up. Recommendations for what this could look like are in Appendix 2.
- 3. Create a communication plan.** Tied to the process of implementation of the strategy is an established communication plan that informs and engages the SCI about the initiative, solicits input and feedback, and reports on progress and emergent products throughout the process.



**Provide keystone support:** Among the roles that RHI is best-suited to play is that of a national supportive partner that serves as a keystone to the strategy development process. The keystone role is one that provides a central cohesive source of support and stability for the process. This role would include initiating the process, convening stakeholders, and guiding the development of a shared initiative. RHI can contribute infrastructure and coordination support to enkindle the networks within the SCI community, connecting people, ideas, and activities together, yet does not have to provide the sole leadership for the strategy to be developed. As part of this keystone role, the RHI would help set the standards, evaluate progress toward goals, and maintain connections within the network, while sectoral actors would be responsible for the specific activities in the strategy themselves. This approach works to facilitate progress and alignment across all jurisdictions in Canada while allowing each of those systems to work with the means and resources unique to each context.

*The RHI helps set the standards, evaluate progress toward goals, and maintain connections within the network, while sectoral actors would be responsible for the specific activities in the strategy themselves.*

### **Actions:**

- 1. Engage the RHI.** Present, discuss, and enlist support for the strategy development process across the organization from the senior leadership level through to program implementation. As a keystone organization, the RHI will serve as a leader and require support from across the organization to help foster engagement across the sector.
- 2. Align with current activities.** Determine the key areas where RHI's current activities and plans are aligned with the strategy development process. This includes the work on the network of networks and identifying areas where RHI funds projects that could be connected to the strategy development process.
- 3. Clarify roles and activities.** The RHI can use its role as a facilitator and enabler for this project to clarify, define, and better communicate its roles with the SCI community. This process can further support defining where the RHI is best situated in the strategy that emerges from this process.



## From Sectors to A Unified National Strategy

The proposed strategy development process recognizes the work already done within many sectors – disciplines or domains of SCI activity. A national strategy will involve the articulation of plans, actions, and related outcomes that fit within these sectors and cross over to other sectors working on related issues and across the entire system. The strategy development leadership will come from a national perspective (including the working group) and from sector-specific leaders.

SCI Plan Vision		Plan Leadership	Strategy Development Support (e.g. Convening, Communications, progress reporting)
National Priorities and Plan Goal(s)		National	National
National Plan Outcomes			
SECTORAL PLAN	CROSS-SECTORAL PLAN		
Goals	 Goals	Sectoral	Sectoral
Action Plan	 Action Plan		
Outcomes	 Outcomes		



# SCI Strategic Plan Timeline

Suggested timeline (will depend on availability of resources to support the plan).

Timing	Year 1	Year 2	Years 3 – 5/5-10/10-20	Year 20
	Setting the Foundation	Building Commitment / Clarifying focus	Achieving	Desired Future State  Never reached, always aiming for
<b>Key RHI Tasks</b>  With respect to National SCI Strategic Plan	<b>Convene</b> national SCI stakeholders to establish “go forward”, set overall strategy goal(s) and priority(ies)	<b>Build</b> SP outcome measurement framework	<b>Monitor and report</b> progress	To be determined (TBD)
	<b>Find and nurture</b> development of sectoral leadership	<b>Support</b> leaders	same	
	<b>Identify SP</b> national resource infrastructure needs and develop plan to put these in place	<b>Implement</b> resource infrastructure plan	same	
	<b>Determine</b> SP KT strategy	<b>Implement</b> KT strategy	same	
	<b>Establish</b> strategy communication plan	<b>Implement</b> communication plan	same	
	<b>Report</b> on SP progress to SCI stakeholder community	<b>Report</b> to stakeholder community	Report to stakeholder community	
	<b>Establish</b> key goals and outcomes for the strategy	<b>Develop</b> and implement evaluation plan		
<b>Key SCI Community</b>  Tasks (regional and sector-level)	<b>Endorse</b> sectoral leadership and National SP goals and priorities		<b>Monitor</b> and report sectoral progress	(TBD)
	<b>Identify</b> aligned sectoral goals and priorities	<b>Agreement/ feasibility</b> scan on sector-specific outcome measures	Collect and submit outcome data	
	<b>Develop</b> sectoral action plan – roles, responsibilities, accountabilities	<b>Implement</b> sectoral action plan	same	
	<b>Identify</b> SP sectoral resource infrastructure needs and develop plan to put these in place	<b>Implement</b> sectoral resource plan	same	
	<b>Develop</b> inventory of aligned achievements/ work in progress/ planned	<b>Update</b> inventory of achievements	same	
	<b>Develop</b> plan to report progress to national strategy leadership	<b>Implement</b> sectoral progress reporting plan	Report to stakeholder community	
	<b>Report</b> progress to sectoral stakeholders	<b>Implement</b> sectoral stakeholder reporting plan	same	



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## Appendix 1:

### Summary of Findings

A broad consultation of the scholarly literature, program documents from the RHI, and summaries of recent meetings and events held in the sector provided a foundation to begin the project. The information synthesized from this review helped frame questions that were asked of members of the SCI community, including RHI staff, and experts working across the country who had been identified as key informants for this project.

This is the summary of the findings from that consultation that have informed the development of the recommendations for this report.

### Literature & Document Review

The strategy has been developed based on a large body of work that has been initiated or supported by the RHI and its partners. A review and synthesis of the literature was conducted drawing on meeting minutes, strategy documents, evaluations, program outlines and charters. The documents reflected existing efforts to develop strategy within the RHI and sector more broadly, RHI's quality improvement efforts, First Nations-focused programs, key committee notes, and overall strategic planning done to date. The literature review assisted in the development of the question guides, workshop foci, and determine areas for further exploration.

The key findings from the literature indicate the rising incidence of chronic or non-traumatic and degenerative SCI conditions and how this is changing the demands on the healthcare system. Included in this is the role of falls and falls prevention efforts to potentially address some of this rise in incidence of SCI in older adults.

An example to learn from in developing a strategy can be gained from the work of the recent Atlantic Canada Spinal Cord Injury Summit (ACSCIS), which convened leaders within the SCI community to discuss methods of increasing collaboration within the four Atlantic provinces. Stakeholders from disciplines across the spectrum of care, research, advocacy, and policy were convened to discuss and consider strategies that could raise the collaborative activities and related outcomes across the region. The meeting assessed what assets are in place, the needs of stakeholders, and established a set of short- and long-term goals for the SCI community to consider. Part of the report that outlined the recommended actions included an assessment of the present strengths and needs across care, community, and research areas.

The RHI initiated a planning process to inform a strategy to enhance what has been called the Canadian SCI Network Alliance to support research,



the implementation of best practices across the country into care, and the meaningful engagement of persons with lived experience in planning and decision-making. A facilitated working group that comprised representatives from the RHI, Ontario Neurotrauma Foundation, and SCI Canada conducted an environmental scan of the literature and consulted with stakeholders across Canada and abroad to develop the recommendations.

**Among the central findings reported from this initiative include:**

- *Building and strengthening capacity within the SCI community for enhanced knowledge, better practice, and more effective policy development and research. This includes building capacity to translate knowledge from practice and research across contexts, settings, and regions in Canada (and beyond).*
- *There is a real need to engage people with lived experience of SCI, their families, and caregivers in decision-making, planning, and policy.*
- *Attention to the entire spectrum of care and support must be paid including engaging those who work with SCI in the community and beyond the those typically connected to SCI organizations.*
- *Investment in understanding the pathways for both traumatic and non-traumatic SCI populations.*
- *Leveraging existing platforms and systems*
- *Demonstrate value of the work of networks; make activities and outcomes more visible to others.*

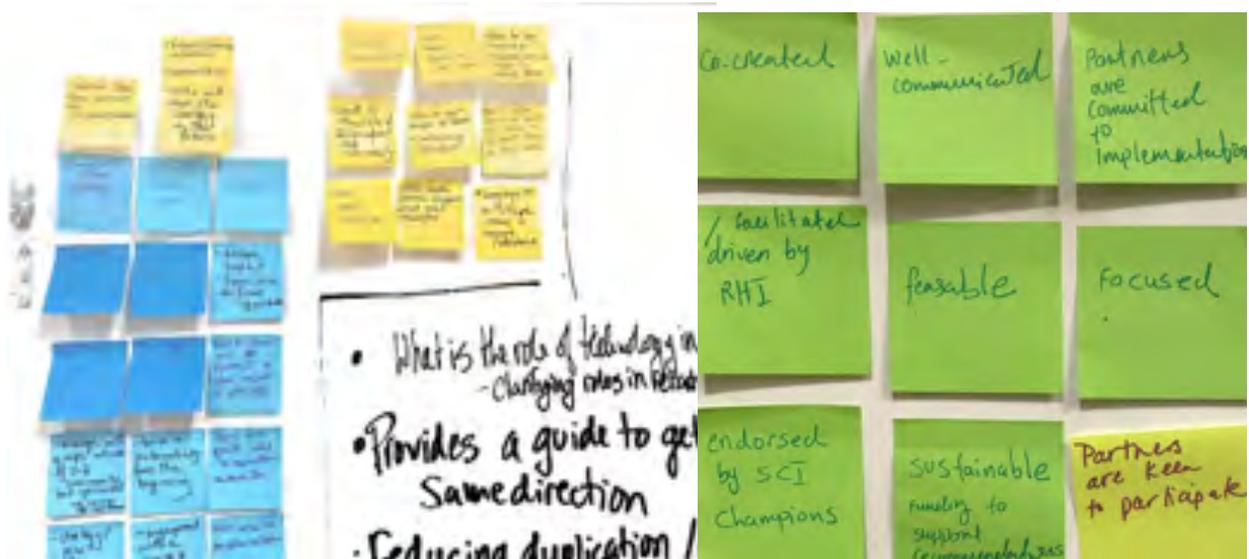
The recommended network strategy planning framework drew on the work of Kaner and colleagues on levels of thinking for collaborative effort, framing a need to articulate each of the five areas in a strategy: 1) Outputs, 2) Activities, 3) Structure(s), 4) Strategy, and 5) Big Picture or why the work is being done in the first place (Kaner, Lind, Toldi, Fisk, & Berger, 2007) .

## Design Workshop

The first design workshop was held January 31, 2019 and involved staff from a variety of areas working within the RHI. The purpose of the workshop was to bring together staff perspectives from across the RHI that reflected work in clinical care, policy, evaluation, informatics, and research as well as lived experience with SCI. The perspectives gained from this initial workshop helped shape the consultations with those outside the RHI and other staff members.



Figure 1: Sample of ideas generated from the workshop



The workshop was meant to reveal different perspectives within the system that RHI works about what a national strategy could look like. It also provided the means to help map out the landscape of health, care, and wellness for those living with SCI and the organizations looking to support them across the lifespan.

About 15 RHI staff from different areas of the organization were involved in the workshop. Participants engaged in a facilitated discussion organized around answering and discussing one statement and three supporting questions:

**Statement: (A National Strategy for Care, Health, and Wellness) will be a success if \_\_\_\_?**

Questions:

*What specific outcomes would you like to see?*

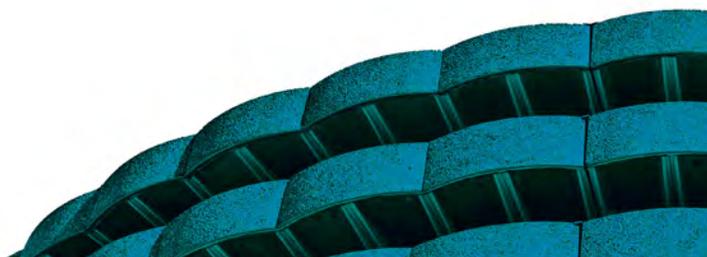
*What activities need to be a part of this strategy?*

*What else do we need to consider?*

Participants organized their responses individually and then as part of one of two groups. A synthesis of the responses found the following themes among the data:

**Strategy success indicators:**

- *Co-created & Inclusive*
- *Endorsed*



- *Feasible*
- *Focused*
- *Supported*
- *Sustainable*

**Specific Outcomes desired:**

- *Measurable, transparent, visible, outcomes*
- *Improved physical function*
- *Linkages with priorities*
- *Improved care access*
- *Reduced incidence & severity of 2o complications*
- *Improved communications*
- *Better organization and distribution of funding*
- *Shared goals, contributions, and buy-in from sector*
- *Data sharing*
- *Monitoring and evaluation across the system*
- *Recognized pathways for care and treatment*
- *Greater efficiency*
- *Improved collaboration*
- *Greater awareness of the various systems, actors, and roles*

**Strategy Activities:**

- *Storytelling*
- *Effective, consistent communications*
- *A brand*
- *Cross-functional teams*
- *Gatherings (events, touchpoints)*
- *Cross-context (regional, national, intl)*
- *Technical capacity, including a data strategy*

**Other factors to consider:**

- *Sustainability*
- *Bring in other disciplines, areas of work, professions, and people*



- *Partners need to see themselves in the strategy*
- *Working RHI out of existence*
- *Full data sharing*
- *Building a shared vision*
- *Leadership*
- *Cultivating and activating 'champions'*
- *Common and clear focus of effort*
- *Be bold*
- *Involve those with SCI lived experience in the process*
- *Integrate data platforms*
- *Going across and beyond the SCI community*
- *Emphasize collaborative effort*

**Cross-cutting themes:**

- *Sustainability*
- *Feasibility*
- *Inclusive, expansive, and participatory (getting beyond the RHI and the usual SCI groups) and stressing need for those with SCI to be a part*
- *Go beyond the RHI and SCI environments*
- *Data and related infrastructure support*
- *Strong communications emphasis*
- *Cultivate cross-cutting awareness and buy-in*

Experts across the country were consulted in short interview-conversations with the consultant team and as part of an invited participation to the RHI Care Committee meeting in March, 2019. Ten experts were contacted and seven participated in the consultation discussions which took place from February through April, 2019. All ten agreed to participate, however not all were able to speak with the consultant team during the consultation period.

Among the key findings from the consultations include the following messages:

- *RHI is well-placed to convene and play a leadership role in the development of a strategy. There is a willingness to support this strategy if the RHI convenes people and plays a role in leading in its development.*
- *There is much energy and interest for co-creating a strategy for the country if it provides focus and results in action.*
- *One of the deciding factors for some is the need for the RHI to be explicit*



*and clear about its role in developing the strategy and in supporting SCI in Canada more broadly. Among the concerns has been that the RHI does not appear to have a clear focus for itself if it is to lead. There is uncertainty about where it is going as an organization.*

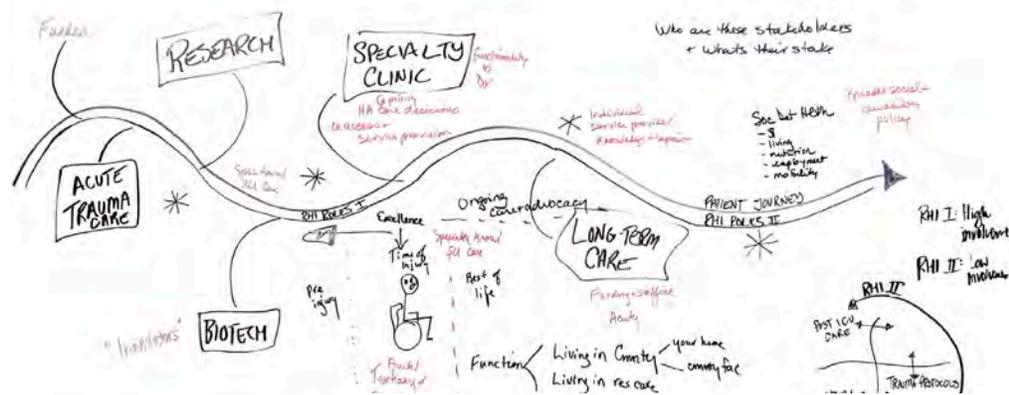
- A repeated and clear message is that the RHI and those working on this strategy must be “bold” and directive with this initiative. Any leadership of this initiative requires that there is an explicit statement of purpose and mandate to engage the sector successfully.*
- A strategy must engage people across the spectrum of care – from primary prevention through to community living. Not enough attention has been paid to those outside of acute care and rehabilitation so far, nor has there been sufficient engagement of those with lived experience in providing direction and contributing to strategic thinking in the country.*
- The strategy development process is starting from a strong base of activities already in place (e.g., The Rick Hansen SCI Registry, RHISCR), but investment in infrastructure needs to be included in any strategy to support and bring these investments up to current standards. Neglecting the infrastructure will hamper any strategy going forward.*
- National standards for care and practice can be a means to focus certain strategic activities if they are built into a strategy. Concern was raised that the current standards are too low and seen as undermining efforts to improve the overall quality of care in the system to where it could be by focusing standards on where people currently are. Standards should be aspirational as well as evidence-based.*
- Non-traumatic SCI is an area that needs attention. SCI work needs to expand beyond its traditional foci and disciplinary roots to bring more attention to the community of care beyond treatment and the issues that face those with non-traumatic and degenerative or chronic conditions. The aging population and changing nature of SCI needs to be addressed in planning for the future.*
- Involvement of others – particularly those with SCI lived experience – is key to a successful strategy. Much of the direction in Canada for SCI research and practice is a legacy of the SCI community’s beginnings in acute care and rehabilitation and don’t fully include other areas to the same extent. Expanding the scope of attention is necessary.*
- Expand the frame of what SCI is and needs, but don’t lose focus. Consider the common interests with others in community care, primary care, and rehab (e.g., MS, ALS, Heart & Stroke), but also don’t lose attention on the unique needs of those with SCI. Alliances with organizations with common interest can be useful for certain areas of the strategy, however the SCI community needs to be at the heart of whatever is produced.*



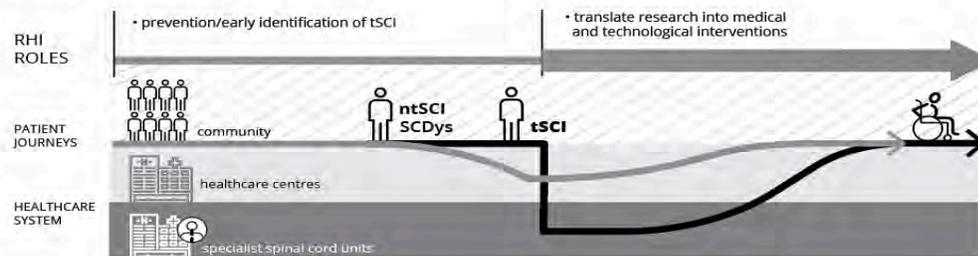
## System Maps

To help understand the entire context in which the strategy is to influence and the pathways that individuals with SCI take through their treatment and care journey, a series of visual maps were produced. The first of these maps were developed after the initial workshop by the consultant team with input from the RHI team, including a member of the RHI living with SCI to provide the lived-experience perspective. These initial rough maps were later transformed into a series of maps that indicated the present state of the system and (possible) future states of the system. This future state was meant to provide a possible vision for where SCI health, care, and wellness could go if supported by a strategy like the one being envisioned by the process under development.

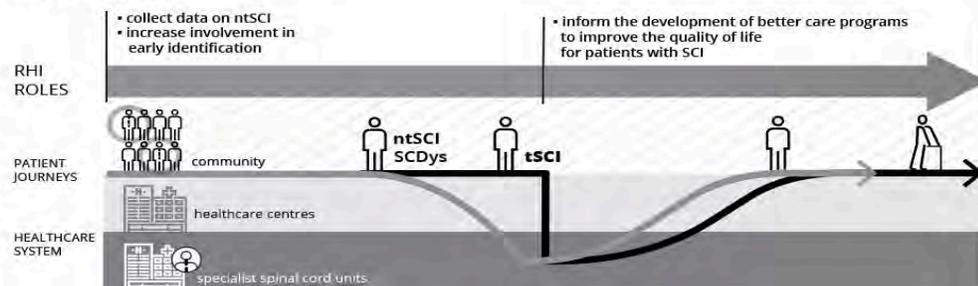
The maps were used to generate discussion about how the strategy could be realized throughout the entire spectrum of care, with examples below.



### Current State



### Future State



## Appendix 2: Sample Evaluation Design

The strategy development process must have an organic quality that emerges from the needs and capacities of the SCI community if implemented as recommended.

It is recommended that the strategy development process involve a means of evaluation that documents progress toward a goal (the strategy itself) as the primary focus. The aim of the evaluation is to demonstrate that progress and accomplishment, not to assess the value of the product itself (the strategy), which is beyond the scope of such an exercise.

*Some suggested questions, methods, and products could include the following:*

Evaluation Question	Method(s) & Activities	Products
What does the current SCI system look like?	System mapping exercise that lays out the key actors relative to each other across the spectrum of care.  This is informed by consultation interviews and suggestions by members of the SCI community	SCI system map across the spectrum of care.  National roster of SCI-related organizations and key stakeholders.
What activities are conducted in support of the strategy development?	Documented meetings, attendance, and roster of those involved in consultations.	List of activities performed in support of the strategy development initiative
What are the key priorities for each practice domain and activity stream?	Consultation interviews (individual and group) with key stakeholders.  Facilitated synthesis meetings with the working group	List of priorities for action across each of the different domains of practice, regions, and activity streams



<p>What is the vision for the SCI community?</p>	<p>Consultation interviews (individual and group) with key stakeholders.</p> <p>Facilitated synthesis meetings with the working group</p> <p>Web survey distributed to the SCI community through partners</p>	<p>Vision statement for a national strategy</p>
<p>What has the strategy consultation process produced?</p>	<p>Review of activities across the consultation from interviews, meeting notes, and communication briefs</p>	<p>The strategy document and list of other products generated in the communication of and support for the strategy</p>
<p>How has the SCI community been informed and engaged in the process?</p>	<p>Creation, distribution, and documentation of key knowledge products throughout the course of the initiative.</p> <p>List of invitations sent from the working group to SCI community members</p> <p>Re-posting and sharing of content generated from the working group across communication channels.</p>	<p>List of artifacts (e.g., blog posts, newsletter articles, reports, presentations etc..)</p>
<p>How did the strategy development process adhere to principles?</p>	<p>Matching the activities with the key principles.</p>	<p>Report outlining the degree to which principles were supportive of the development process.</p>



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