

SCI Care for Canada: A Framework for Strategy & Action

Prepared for the Praxis Spinal Cord Institute
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Forward

In 2020, the COVID-19 pandemic shifted the world's attention to how we live and work together and the importance of protecting and caring for our health. The response to the pandemic led to limited social movement and isolation, recognition of the risks posed to those with a compromised immune system, disconnection from many of the resources needed to live a full life on a daily basis, and what it means to have to rely on others -- people, services, systems -- to get many simple things done.

For those living with a spinal cord injury, this is their everyday life. They live knowing what it means to require specialized medical care with the knowledge that many are more susceptible to complications associated with contracting something that can affect the immune system.

There is a better way. Just as we have learned more about the importance of having access to care and the many ways in which the systems around us affect our health and wellbeing from recent events, we also recognize how it can be lost. A national strategy for spinal cord injury care across the life course is a way to ensure that thousands of Canadians can live their best life with the support and services that many others take for granted.

It's possible. It is within our reach.

The Case for a National Strategy for Spinal Cord Injury Care in Canada

Spinal cord injury (SCI) affects more than 86,000 Canadians and can result in permanent disability, lifelong health complications, unemployment, poverty, isolation, and mental health challenges. The economic cost exceeds \$2.7 Billion per year. Canadian researchers are at the forefront of advances in spinal cord injury treatment and care, but many of these innovations and best practices are not being translated into treatments and resources that Canadians can readily access. Canada is not realizing the benefits of its investments in research and healthcare and generating the best outcomes for Canadians with spinal cord injuries. A national strategy that links evidence, best practices, and innovations in care across the country will contribute to the quality of life of people living with SCI and help make Canada a leader in SCI care.

Guided by values of collaboration, openness & sharing, partnership, ongoing learning, and commitment to excellence the vision for SCI in Canada is bold, aimed at excellence in research, innovation, performance, and care for all. It is a vision that can be achieved within a decade. It is within reach if we focus our efforts.

The purpose of this document is to provide a framework that not only serves as basis for the strategy, but also provides actionable steps for the SCI community to collaboratively refine and implement a national strategy for care using a developmental approach.

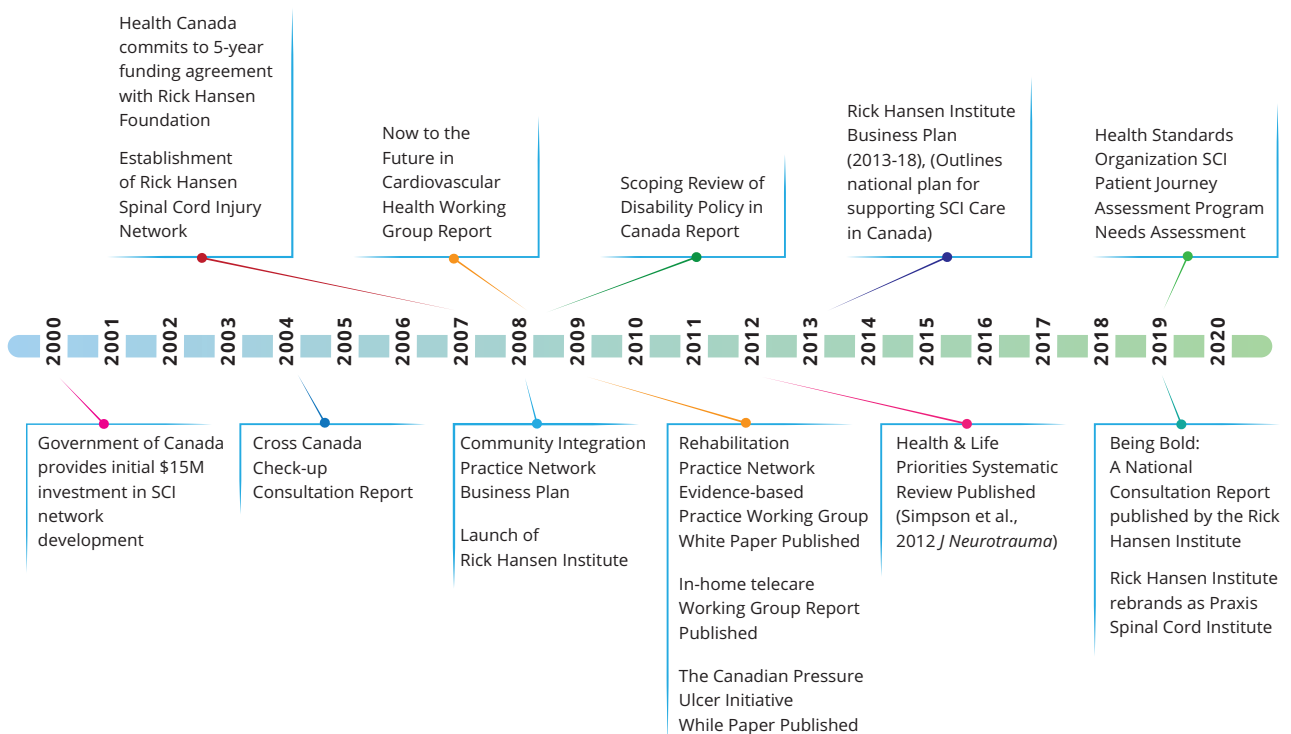
Vision: A timely, human-centred, accessible, equitable, and high-quality system of care driven by evidence and nationally and internationally recognized for its excellence, innovation, and outcomes across the life course.

In 10 years, Canada will lead the world in SCI care.

SCI Care in Canada

A historical look at the investment in national efforts to coordinate and advance SCI care in Canada over the past twenty years shows an evolution from an initial investment of \$15M made to support the development of a multi-sector, multi-disciplinary, network of SCI researchers, practitioners and organizations representing those with lived experience. Since then, a series of reports, business plans, and networks have laid the foundation for a national strategy to address SCI care in Canada.

National Efforts to Coordinate and Advance SCI Care in Canada: 2000-2020



A review of this body of work finds consistent patterns of interest and opportunity within the SCI community on matters of priority and focus. A partial list of these national reports and consultation documents is located in Appendix 1. Recent consultations, support these earlier findings

¹ Taking an Integrated, People-Centred Approach to Standardizing and Optimizing Care for Individuals with Spinal Cord Injury: A Praxis/HSO Collaborative. Needs Assessment Report, January 2020.

² Being Bold: Toward a National Spinal Cord Injury Health, Care and Wellness Strategy. Rick Hansen Institute / Cense Ltd. April 2019.

and reveal a common understanding of issues facing the SCI community in Canada, and a shared commitment to improving the systems that support people with lived experience. Across the SCI community, individuals and organizations report that:

- **Care is not yet standardized, and timely access to care appears to be an issue regardless of where you live**
- **The continuum of care is fragmented, creating barriers to navigation for persons impacted by SCI**
- **The involvement of persons with lived experience of SCI is inconsistent across systems**

There is also a shared understanding of the benefits of building a strategy based on existing strengths and common goals, standards and metrics.

Evidence & Progress to Date

The documents highlighted in the timeline on page 3 illustrate some of the evidence and recommendations that have helped shape this framework for a national strategy. From this body of evidence three key areas of focus and need have emerged as areas to consider shaping a strategy around: 1) access to equitable and optimal care, 2) translation of ideas into impact, and 3) supporting those with SCI to live their best life in the community. These recommendations have roots in many sources including the national Cross-Canada Checkup consultations with the SCI community in 2004 and more recent consultations by Health Standards Organization and Praxis Spinal Cord Institute (2019-20). A series of white papers developed on issues of cardiovascular health, disability policy, evidence-based practice, in-home telecare, pressure ulcers, rehabilitation and others that were developed in 2008-9 as part of activities undertaken by different SCI practice and research networks provide further evidence to support these areas of focus. The framework is further supported by the 2012 systematic review undertaken by Canadian researchers (Simpson et. al.) on the health and life priorities of individuals with spinal cord injury.

Developing this report

Praxis Spinal Cord Institute with support from Western Economic Diversification Canada conducted an exploratory study examining the feasibility and readiness of the SCI community by creating a national care strategy. The aim of such a strategy was to better align and coordinate resources for care, which spans prevention, research, clinical support, and community living. That process resulted in the 2019 report *Being Bold: Toward a National Spinal Cord Injury Care, Health & Wellness Strategy*. The title of the report was gleaned from comments made by participants in the consultation process who asked that whatever the SCI community did, it was time to take bold action.

Being Bold was used by Praxis to assess the readiness and interest among members of the SCI community for taking the next step: developing an actionable framework for a national strategy including goals and setting a vision for the next ten years.

In Fall 2019, Cense Ltd, the consultant team who prepared the *Being Bold* report, were recruited to develop this framework in consultation with members of the SCI community across Canada. The aim was to develop a path forward with clear recommendations that the SCI community could take to further refine, develop and implement the suggestions outlined in the framework over the next ten years.

Consultations involved interviews with stakeholders with lived experience, clinical care professionals, researchers, and policy makers. Widely distributed invitations were sent through SCI-related networks and media channels seeking participation in the consultation process, which included a Canada-wide webinar consultation, online survey, and solicitations for feedback through circulation of the 2-page draft document with a feedback form. Emergent data from a national needs assessment developed in partnership with Health Standards Organization were also used to inform the framework document.

The resulting framework, presented here, has received support from community through these consultations. It is intended to serve as a foundation for the community to refine, using a developmental approach, and articulate how to coordinate resources, scale-up best practices and ensure equal levels of care across the country.

Articulating a Strategy

A national strategy provides an opportunity to transform the lives of those living with SCI. Many people with SCI experience unnecessary health and social complications due to a fragmented system of care that is not yet aligned or optimized nationally. By creating a strategy anchored to the best science, translating evidence into practice, focused on the needs of people living with SCI and providing compassionate, comprehensive care across the life course we can build on the strengths of the current system while sparking transformative initiatives that will demonstrate real impact on SCI care outcomes within 10 years.

Delivery of health care and support services for SCI is funded at multiple levels by national, provincial, and regional governments and organizations in a largely fragmented manner. A national strategy would enable greater alignment between these bodies and seek to foster a true system of support that connects across the country and the entire spectrum of care.

A national strategy positions health practice, policy, research, and advocacy activities within a larger community of care that touches the lives of those affected by SCI across the life course and care continuum.

What is envisioned is a strategy that initially focuses on the best work being done at present and can show impact within two years while initiatives are developed and implemented to shape the decade to come. This adaptive, developmental approach ensures that the strategy engages the entire community and directs effort to what is needed most in order to achieve the vision establishing a timely, human-centred, accessible, equitable, and high-quality system of care system driven by evidence and nationally and internationally recognized for its excellence, innovation, and outcomes across the life course.

Framework

This framework provides guidance for planning and action to further develop, refine, and implement the strategy, recognizing that a successful strategy attends to the dynamic conditions of the world it seeks to influence in the future while grounding itself in what is being done today.

Goals

To achieve this vision, a national strategy is required that creates:

- Pathways for lives well-lived for everyone affected by SCI
- A dynamic, interconnected system integrating care across the continuum of prevention, treatment, rehabilitation and community living
- A continuum of care that supports the needs, preferences, and livelihoods of those living with SCI and their caregivers
- A national system of excellence in discovery, learning, and innovation designed to support SCI prevention and care across the lifespan

Principles

Canada's national SCI care strategy will be rooted in the following principles:

- **Human-centred:** Care meets the social, developmental, cultural, and circumstantial needs and preferences of those living with SCI.
- **Learning:** Knowledge is generated, applied, and shared across the SCI community in a timely and accessible manner.
- **Accessibility:** Barriers to compassionate, supportive, timely, and effective care are uncovered, reduced and eliminated.
- **Connection:** Bring together individuals, organizations, and resources working within and beyond the SCI practice community.
- **Strengths-based:** Build on the strengths of the SCI community and amplify areas of excellence and opportunity.

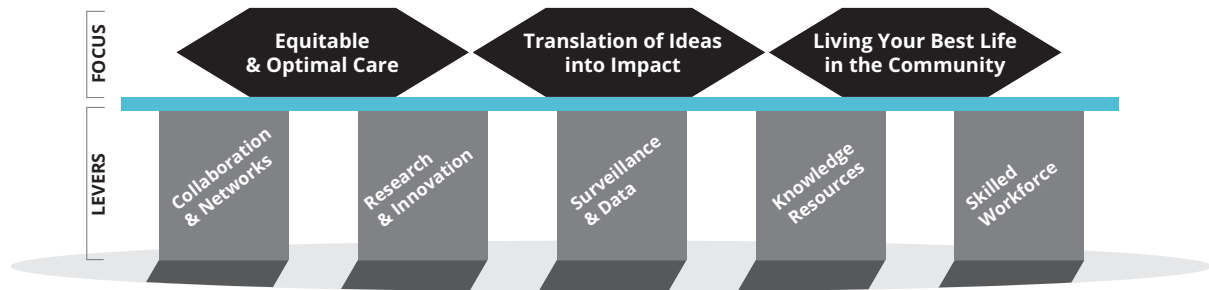
Assumptions

Framework development has been based on the following assumptions:

1. The SCI care community has made great strides in supporting those living with injury and their care providers, produced world-class scientific research, and generated new innovations that serve as a bedrock of the current care system.
2. Many opportunities to translate success in one area of the system have been lost due to fragmentation and 'silos' of practice and research that does not fully reflect the needs and lived experience of those with SCI across the spectrum of care and life course.
3. The approach to funding, organizing, and delivering services across Canada has created gaps that particularly affect areas like SCI care that require specialized resources and knowledge.
4. Many opportunities to make a positive difference and build on the strengths of the community have been lost because there are few means to coordinate and align activities nationally.
5. A Canada-wide approach to the coordination and alignment of resources across the country can address these missed opportunities and fill many of these gaps. A national strategy can provide the means to guide these efforts.
6. A national strategy can enhance understanding of what works for SCI care in what context and accelerate learning from one setting, region or environment to others.
7. Praxis, as a nationally-focused organization with a mission to support translation of discoveries and best practices across the care spectrum, is well-positioned to support the SCI community and convene leaders to refine and implement a Canadian SCI care strategy.
8. The SCI Community is ready to step up and lead developmental implementation of a Canadian care strategy.

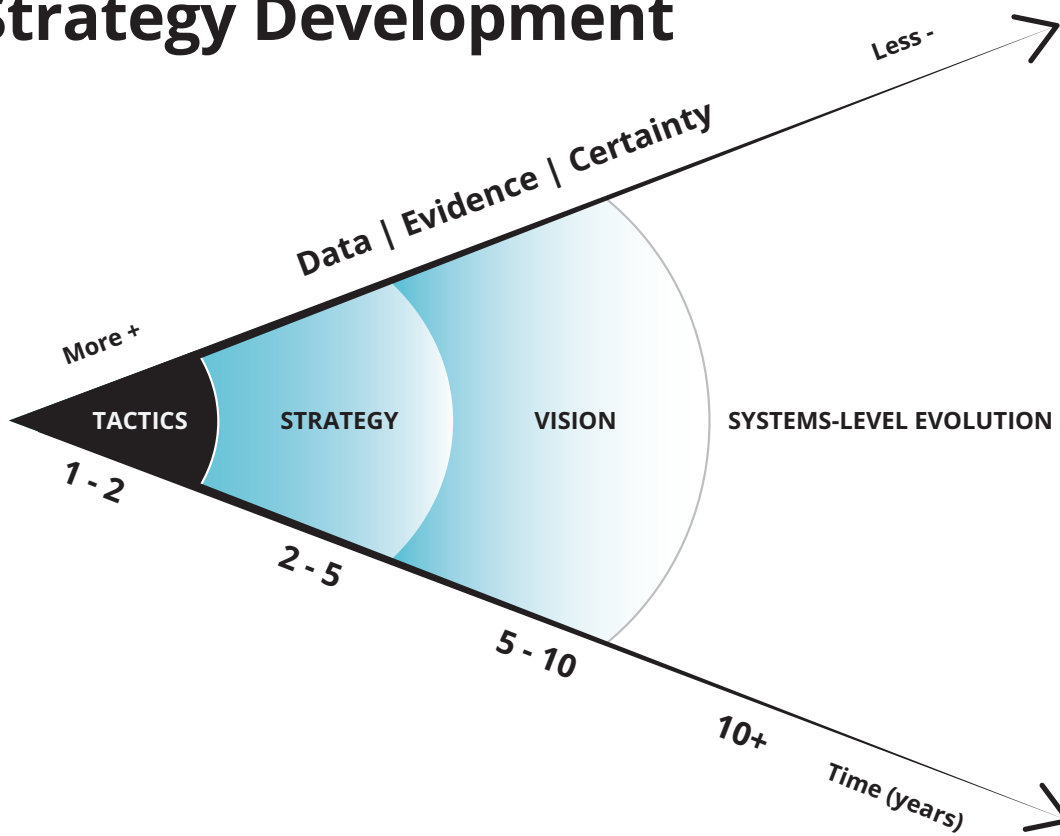
Focus

The framework aligns five pillars of activity (collaboration & networks, research & innovation, surveillance & data, knowledge resources, and a skilled workforce) that support three areas of focus (equitable & optimal care, translation of ideas into impact, and living your best life in the community).



The five pillars of activity serve as the system levers for transforming SCI care. The effectiveness of this approach will be demonstrated through an evaluation that considers how a national strategy addresses each of the three areas of focus.

From Ideas to Actions: Strategy Development



A foresight-driven approach to strategy (above) considers what actions (tactics) can be done in the near-term based on current activities, what needs to be developed further (strategy) and a vision that guides everything toward goals and outcomes. This approach builds on what the SCI community is doing now to scaffold further ideas and innovations to develop programs, products, and policies over the coming decade.

The current situation involves drawing on the best evidence from practice, lived experience, and research at present and sets a course to gather data to build the case for what comes next. This is an ongoing process that continues throughout the life of the strategy.

The suggestions for both near- and mid-term strategic activities will need to be confirmed and refined once an official national strategy is finalized by the community. Long-term (more than five years out) activities are emergent and will be designed over the course of the next 10 years.

Near Term

Within the first two years a national SCI Care strategy will focus on:

- Establishing a Pan-Canadian advisory network to guide the strategy and promote healthcare partnerships to realize this vision and sustain the progress throughout the next decade.
- Accelerating the formation of regional networks to connect the best practice and research groups together with people with lived experience.
- Promoting the accelerator programs aimed at technology transfer and commercialization to get the best ideas into the market.
- Investing in the SCI national standards, best practices, and guidelines initiatives to advance excellence.
- Raising the profile of the educational and peer- outreach programming developed for and by those with lived experience.
- Elevating the research on curative and functional therapies to improve and save lives.
- Advancing the national data strategy by optimizing the core infrastructure and processes which will expedite the translation of research to practice.

Mid-Term

Over the next five years the strategy will:

- Establish partnerships with allied organizations on areas of shared interest, particularly home and community care to generate full-spectrum support for SCI across the life course
- Recruit next-generation leaders in SCI care, rehabilitation, research, and policy to create a promising future and sustain the strategy over the next decade.
- Expand and enhance primary care SCI support to broaden access for people in every community in Canada
- Develop commercialization pathways connecting R & D and clinical care research to create value that converts to clinical excellence and innovative products.
- Monitor and evaluate the strategy to ensure it has a real impact on Canadians.
- Further honing a maturing and responsive data strategy as needs and opportunities evolve.

From Framework to Implementation

Getting on With It

In the development of this framework and other recent consultation reports, the term “consultation fatigue” was used by some to reflect the current state of affairs in SCI: there is much agreement on what needs to be done and desire to get doing it, but a growing weariness about more talk. As one participant in the consultation said referring to the need for action on a strategy: “let’s just get on with it”.

Many of those consulted as part of the development of the framework reiterated this point by saying that there has been ‘enough talk about what’s needed’ and that energy needs to be spent putting ideas into action. A look at the consultation reports and research studies that are profiled on page 3 bears this out. By proposing a framework in a condensed form (2-pages) shared electronically by email with consultees, via a survey distributed through SCI-affiliated networks, and as part of a national webinar, the consultant team was able to determine the relative interest in and fit with what has been suggested in previous consultations.

The aim of these consultations on the framework was to create a starting point for the SCI community to work from, building on the evidence gathered to date. They were also meant to recognize and respect what has been said before and not add to the perceived ‘consultation fatigue’ within the community.

What this process revealed was the strategy development requires the following:

1. Endorsement of the model and approach. Ensure that members of the SCI community receive and have opportunity to comment on the framework. Solicit endorsement from leading SCI-serving organizations across the country.
2. SCI Experience. The need to have a strong, visible, empowered presence of those with lived experiences reflected in the content and process of designing and enacting the strategy. This message was voiced by both those with lived experience and care professionals. There was near unanimous agreement that any resulting strategy must be centred on the lives of those with SCI above all.

3. Engaged and distributed leadership. Action requires that individuals across the SCI community participate in the leadership and stewardship of the strategy process. This cannot be a top-down process and must support the development of a realization of leadership across regions, sectors, and roles.
4. Evidence of action. Activity and progress toward the stated goals must be made visible. The community has voiced clear dissatisfaction with the lack of visible progress and activity resulting from previous consultations. Enacting a monitoring and evaluation plan that provides timely feedback that can be acted on and communicated widely is one way to show this evidence of action.
5. Adaptive and flexible. The framework created provides guidance for how to proceed including ways to consider adaptations to plans over the course of the coming years. A principles-centred perspective drawing on what has been proposed in this framework can help support an adaptive, flexible strategy.
6. Innovative delivery and management. Use of distance technologies, particularly in light of the growing familiarity that many will have with using them after the COVID-19 period of social isolation is one way to remain innovative and build on cost-effective, efficient convening tools. Greater consideration of these approaches reduces the risk and barriers that many living with SCI face without excluding them from active, equitable participation.
7. Momentum. A bias to action is necessary. Funding, while necessary to fully achieve the vision set forth in the framework, cannot be a critical limiting factor to action. A national strategy requires stable, core funding, but also requires contributions from many others to be successful. A developmental, persistent, and staged approach to building momentum will ensure that the strategy achieves some success.
8. Implementation must reflect Canada. The design and implementation of the strategy requires flexibility and attention to the unique needs of those in rural and non-urban communities, our First Nations, seniors, and the many cultural communities within Canada.
9. A life-course approach. Previous plans have emphasized action on areas of current strength and activity (e.g., acute care, rehabilitation) over those that are under-represented such as community care and initiatives that address the social determinants of health. A Canadian SCI care strategy must address a life-course approach.

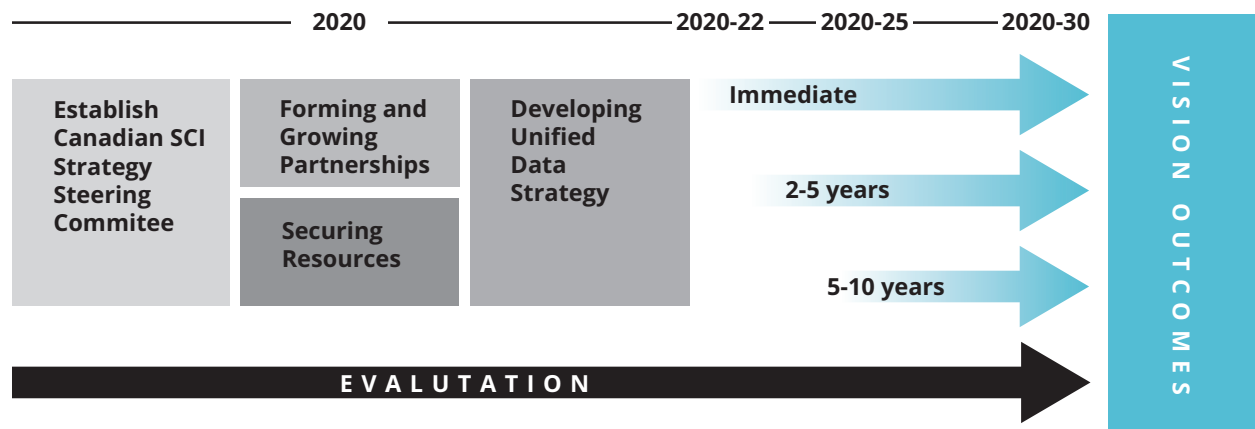
10. Connection. A successful national strategy recognizes that the experience, research, and clinical care related to SCI is part of a constellation of services and activities. For a national SCI strategy to be effective it must connect and align with those activities done through allies addressing areas of mutual benefit and overlap.

The future begins now. This framework provides a focus for initiating alignment with organizations across regions and sectors working within SCI and collaboration with groups presently outside the SCI community within the health system, government, citizen groups, and other stakeholders. Intentions must lead to actions.

Implementation

The recommendations for implementation are grounded in the evidence generated from consultations with the community and reflect the values, principles, and content of the Framework that was developed.

Implementation strategy



Steps

To successfully move the framework into a strategy will require the following:

1. Establish a National Strategy Development Transition Team.

The establishment of a transition team will guide the ongoing, planned development of the strategy as it moves from tactical focus (near-term) to strategic actions (mid-term) with new projects and initiatives being included each year to achieve the long-term vision.

This dynamic approach ensures the strategy is responsive to changing conditions and emerging innovations without losing focus on the key outcomes of interest.

- This working team should reflect membership that includes those with lived experience, academic health sciences (research), clinical care and rehabilitation, and regional representation across the country including those from English and French-speaking jurisdictions, rural/non-urban communities, and Canada's First Nations.

This transitional team should encompass recognized individuals within the SCI community from national organizations or provincial leadership groups.

These roles are not mutually exclusive of one another.

- As a working team, it is recommended that group membership be limited to between 8 and 12 members and the term of the appointment be one-year. The team size needs to be made manageable to ensure that decisions can be made, actions taken, and visible progress achieved. There is a risk with such processes that inertia can set in and that teams resemble advisory committees unless tangible actions are taken. The transition team will undertake the following over a ten-month period (plus two-month wind-down) once initiated:
- Recruit members for the initial SCI Strategy Steering Committee. The membership structure for this Committee (or resulting arms-length organization, however defined by the transition team) is to have members that reflect the SCI community and include substantial representation of those living with SCI. These members may play multiple roles.
- Develop the Terms of Reference and organizational model for the SCI Strategy Steering Committee that will oversee the enactment of the strategy. This will include determining the roles, membership, and terms of appointment.
- Solicit further feedback and endorsement of the framework, including making necessary modifications to reflect needs and preferences of the community. This may include developing a working group to oversee the document revisions. Feedback can be obtained through consultation and endorsement from leading SCI organizations across the country.
- Develop and implement a communications and engagement process for the framework. This includes identification of key stakeholder groups across the country and in each domain of practice (e.g. research, clinical care, community support, advocacy) as well as population focus (e.g., First Nations, pediatrics, seniors).
- The transitional board is to be recruited and initiated in mid-2020 with a goal of having its mandate completed within 10 months of forming.

2. Secure funding & partnerships. Funding creates a contractual arrangement and focuses individuals on a goal of action. It creates the necessary incentives to act based on the accountability to the funder. Preparation and submission of funding proposals and agreements are intended to secure the necessary resources for moving the framework into a full strategy. Partnerships with the federal and provincial governments, national research funders, SCI-supporting health charities and advocacy organizations, and appropriate commercial product and service organizations can provide a means to support the strategy.

3. Develop and implement an evaluation framework. Making change visible is critical to maintaining interest and commitment to the aims of the strategy within the SCI community. An evaluation framework that supports the development of the strategy and guides implementation is one the ways that progress and activities can be made visible. A Principles-focused and Developmental Evaluation approach will provide the means to support the design and implementation of a national framework. These two complementary and commensurate approaches to evaluation provides a means to gather real-time data and position evaluation within a larger strategic learning process. Data gathered through the evaluation will be used to inform the evolution of the strategy while ensuring it remains responsive and accountable to the community. A strong evaluation will demonstrate how SCI care in Canada is transformed and highlight its outcomes.

A Developmental Evaluation (DE) framework will ensure that there is ongoing documentation of activities and the creation of a feedback mechanism to ensure that what is being done in support of developing the strategy is reflected back to the implementation team so that necessary ongoing modifications can be made. A DE approach is designed to create a system of learning and action -- praxis -- within the project.

4. Form and grow partnerships within SCI and initiate discussions outside of SCI. Initiation of conversations with allied organizations who have similar and complementary missions and focus to explore strategic partnerships, collaborations and areas of shared investment potential. By initiating these conversations early in the process, the transition team signals the interest to funders and partners that the SCI national care strategy is going to be different than traditional strategies and draws in knowledge, resources, and social engagement from across the spectrum of care early.

5. Develop a unified data strategy. Canada has multiple data collection systems and development of a national strategy is dependent on having a more unified approach to data management. Collaboration with national and provincial partners working with SCI data will ensure that a shared vision and delivery can be achieved.

Appendix 1: Selected Reports & Bibliography (2000-2020)

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