

# ANNUAL REPORT

Oct 2023 - Nov **2024** 

CONnecting and Coordinating an Enhanced **N**etwork for **TR**ansitions In **C**are [CONCENTRIC]: A New Model for Spinal Cord Injury in Alberta

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Neurosciences, Rehabilitation & Vision Strategic Clinical Network™

# Meet our team Steering Committee



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### Welcome To 2025

# **Executive Summary**



### **Achievements & Outcomes**

A testament to the invaluable contributions of all our partners.

### Working together to improve transitions in care

A big thanks to our sponsors, partners and collaborators who have played an integral role in the success of the project till date. Your contributions have been instrumental in driving progress across key aspects of the project, including CONCENTRIC model development, evaluation initiatives, engagement with Indigenous partners, and knowledge transfer efforts.

This past year, we were able to work together to co-develop and prioritize recommendations for inclusion in the CONCENTRIC model and start implementation planning geared towards achieving desired improvements in transitions in care for persons with spinal cord injury (PwSCI).

For this reporting year, among several achievements, we were able to complete the synthesis of logic models generated by different working groups inaugurated in the previous reporting year, develop and pilot test the caregiver (family & support persons) and care provider surveys, and rollout the My Experience Survey for PwSCI. Through collaboration with our Indigenous partner, we were able to engage Indigenous partners in Treaty 6 Area via a sharing circle event on SCI care experiences of Indigenous PwSCI and also secure a grant to support our Indigenous Strategy work.

In contributing to SCI knowledge, we successfully hosted the 3<sup>rd</sup> Annual SCI Education Day, published a manuscript on SCI care evaluation in a special issue, submitted two manuscripts for peer review and delivered oral presentations at an International conference in Belgium where we were also able to lead a workshop on building a person-centred model of spinal cord injury healthcare.

For the coming year, we hope we can complete all pre-implementation evaluations and start the implementation of all recommendations that constitute the CONCENTRIC model.

We thank you all once again for another progressive and successful year and look forward to another great year together.

The Concentric Team

# **Navigating Our Journey So Far**

### **CONCENTRIC**

A Canadian Institute of Health Research (CIHR) Project based on a community-based participatory research approach and focused on persons with spinal cord injury (PwSCI)



CIHR Grant awarded and project kickoff event held

### 2020

Stage 1 Working Groups (WG) created and members recruited

Stage 1 interviews begin

### 2021

Completion of Stage 1 interviews and preliminary analysis

Co-development of solutions to identified transitions in care (TiC) gaps begin

### 2022

First SCI Education Day held Stage 2 WGs created and members recruited



### 2023

Pre-implementation evaluation surveys drafted

Final recommendations generated and logic models created

Evaluation of significance of past SCI Annual Education Days conducted

### Project Recap (Nov 2023 - Oct 2024)

# Navigating Our Journey So Far



### **November**

- Consultation sessions with Calgary and Edmonton Zone Partners on My Experience Survey for PwSCI
- Consideration of alignment of HSO recommendations with CONCENTRIC's proposed care plan

### **December**

- IPHCPR Grant submission
- Co-development of family/caregiver/support persons experience survey begins
- Presentation of My Experience Survey to PwSCI in GRH & FMC at event organized by SCI-AB



### **January**

- Family/Caregiver/Support Persons Survey drafted and sent out for feedback
- General Meeting with Partners

### **April**

- Meeting with partners to discuss synthesized logic model
- Search for Change Champions begin

### June

- Care Provider experience survey co-developed and launched for pilot testing
- Meeting to review multidisciplinary care plan and align it with HSO recommendations

### July

 Prioritization of recommendations included in synthesized logic model

### July

- Consideration of workload or resource requirement of CONCENTRIC model for pilot sites
- Expert SCI Panel to review validation/reliability results of My Experience Survey
- Sharing circle session held with Indigenous partners to share on TiC experiences of PwSCI

### September

 CONCENTRIC's project deadline extended till March 2026

### October

- Inpatient Rehab peer support approach discussed with partners [SCI-AB, FMC & GRH]
- Expert SCI Panel to review validation/reliability results of My Experience Survey
- CONCENTRIC Model implementation guide drafted

# **Working Group Participation**

# Collaborating, brainstorming, and co-creating solutions, recommendations and strategies with SCI Partners

Since inception till date, a total of 13 working groups/committees have been established. For this reporting year, the main tasks have been to synthesize logic models created by 5 different working groups focused on different aspects of the CONCENTRIC model, create & test surveys for pre and post-implementation evaluation of the model, and consult relevant partners in preparation for implementation. Key working groups active during this report year include;



### **Indigenous Strategy WG**

Team continues to engage with different Indigenous partners to determine the best approach to achieve the project's objective for improving TiC for Indigenous PwSCI



### **Education Committee**

Reconvened on January 29 2024 to start planning for the 3<sup>rd</sup> SCI Annual Education Day 2024 set to hold in April



### **Evaluation WG**

The tasks the team focused on mostly during this report year included

- Evaluating past Education Days
- Engaging with partners to test newly created survey tools and improve response rates



### **Tool Development WG**

Team successfully

- Conducted validity and reliability testing for survey for PwSCI
- Created survey for Caregivers (family & support persons) and Care Providers' care experience

Throughout the year, the Steering Committee continued relevant behind-the-scene tasks, including engaging partners across our pilot sites and identifying Change Champions that would facilitate the successful implementation of the CONCENTRIC Model.

# Indigenous Strategy

A key objective was obtaining firsthand account of the TiC experience of PwSCI. To create awareness of these experiences and discuss them, our Indigenous partner (AFNIGC) provided guidance to create a culturally appropriate path to allow Indigenous PwSCI to share and discuss their care experience.



### Actions taken so far

- Engaging with AHS' Indigenous Wellness Core and submitting proposal for support to the Indigenous Health Core Committee (Dec. 2023)
- Applying for IPHCPR grant to understand and improve the TiC experience of Indigenous PwSCI in the Treaty 6 Area (December 2023)
- Reaching out with our Indigenous partner (AFNIGC) to Indigenous Elders (April 2024) to identify and invite Indigenous PwSCI to a sharing circle session
- Meeting with AFNIGC to discuss logistics for planned sharing circle session (June 2024) and sending out invites to partners (July 2024).
- Conducting a sharing circle session in Wetaskiwin with Indigenous PwSCI and Elders from the Treaty 6 area and other SCI partners (July 25 2024)
- Drafting and providing AFNIGC a copy of outcome from sharing circle and beginning discussions on next steps (August 2024)
- Approval of IPHCPR Network Annual Seed Grant (October 2024)

### **Evaluation WG**

# **Pre and Post-Implementation Evaluation**

What is not defined cannot be measured. What is not measured, cannot be improved. What is not improved, is always degraded

- Antoine-Augustin Cournot

To ensure continuous, evidence-based improvements, the Evaluation WG and its Tool Development sub-group have been collaborating with partners to identify and cocreate relevant evaluation tools and conduct appropriate evaluations.

For this report year, two experience surveys were co-developed in addition to that of the My Experience Survey co-created with and for PwSCI in the previous reporting year (2023)\*.

Efforts to test the validity and reliability of the My Experience Survey for PwSCI continued this year. A poster to create awareness of the survey to potential respondents was created and sent out to our partners in November 2023 and consultations to improve the initial slow response rate were made in the same

month. The latter further led to the presentation of the survey at two pizza/coffee events organized by our community partner (SCI-AB) in GRH and FMC (December 2023). Testing the psychometric properties of the survey started in May 2024 and a SCI Expert Panel discussion was conducted in July 2024 to review, discuss and address key questions related to results from the test.

To evaluate how participants were using or applying knowledge gained at SCI Annual Education Days, the team created a survey in September 2023 and sent it out in November 2023 to evaluate the 2022 and 2023 Education Days. The survey was closed in December 2023 and analysis began in January 2024.

01

Individuals Caring for or Supporting Persons with SCI Experience Survey

First draft was sent out for review in January 2024 and renamed in March of the same year. It was launched for testing in June 2024 and final draft completed in August 2024.

02

SCI Clinical, Health or Community Care Provider Experience Survey

First draft was reviewed, revised and pilot tested in June 2024. After two months of testing, the final version was put together in September 2024.

<sup>\*</sup>Data collected using the 3 co-created experience surveys before implementation of the CONCENTRIC model would be used to set a baseline to evaluate the model after implementation.

# Manuscripts



The project team took advantage of several avenue to contribute to knowledge and create awareness of the project and relevant SCI knowledge. Among other adopted methods such as presentations at partner meetings and hosting of a SCI Education Day was the use of published manuscripts and conference presentations.

### **Award**

# Ernest W. Johnson Excellence in Research Writing In-Training Award

The year was marked with an award in February 2024 that recognized one of the project's articles as one of the best papers published in the American Journal of Physical Medicine & Rehabilitation for the year

### **Article**

Novel Application of the World Health Organization Community-Based Rehabilitation Matrix to Understand Services' Contributions to Community Participation for Persons With Traumatic Spinal Cord Injury: A Mixed-Methods Study -Raha et al. 2023

### **Manuscripts**

### **Published**

Kovacs Burns et al. 2024

Measures for persons with spinal cord injury to monitor their transitions in care, health, function, and quality of life experiences and needs: A protocol for co-developing a self-evaluation tool.

 Healthcare 2024, Vol. 12, No. 5, p. 527)

### Submitted for review (August 2024)

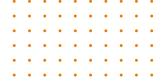
Tan et al.

Validating a Self-Evaluation Tool for Persons with Spinal Cord Injury to Monitor their Transitions in Care, Health, Function, and Quality of Life: Reliability, Validity, and Utility

· Kamran et al.

Experiences of Persons with Spinal Cord Injury, their Family members, and Health Care Providers during Transitions in Care in Alberta: A Qualitative Reflexive Thematic Analysis

### **Presentations**



The project team took advantage of several avenue to contribute to knowledge and create awareness of the project and relevant SCI knowledge. Among other adopted methods such as presentations at partner meetings and hosting of a SCI Education Day was the use of published manuscripts and conference presentations.

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### **Oral presentations**

Presentations at the 63<sup>rd</sup> ISCOS Annual Scientific Meeting in Belgium, Antwerp (September 2024)

Kamran et al. 2024.

Co-designing a model of care for people with SCI in Alberta – A community-based participatory research.

Kovacs Burns et al. 2024.

Persons with spinal cord injury co-designing their self-evaluation tool: Monitoring their experiences with transitions in care & changes in health, function & quality of life.

### **Conference workshops**

Workshop led in conjunction with Praxis Spinal Cord Institute, Health Standards Organization, SCI Ontario, and University of Manitoba at the 63<sup>rd</sup> ISCOS Annual Scientific Meeting in Belgium, Antwerp (September 2024)

- Workshop 10 Building a Person-Centred Model of Spinal Cord Injury Healthcare in Canada
  - Chester Ho (On behalf of CONCENTRIC Team) Development of a Canadian SCI Rehabilitation to Community Model of Care

### Other presentations

The team was also able to present at the Canadian Spinal Cord Injury Meeting and to partners in Grande Prairie in April 2024 and in Germany in June 2024.

# 3<sup>rd</sup> Annual SCI Education Day 2024

- **Topics covered** (selected from a list of 28 topics included in a professional needs assessment survey sent out in November 2021).
  - 1. Bladder Health and SCI
  - 2. Sexual Function after SCI

- 3. Respiratory management
- 4. New developments in SCI research

The Education Committee reconvened in January 2024 to plan the 3<sup>rd</sup> SCI Annual Education Day. After finalizing relevant logistics, registration opened on March 5, 2024. Based on breakdown of registrants, physiotherapists represented the largest group, followed by nurses and occupational therapists, with 111, 100 and 79 participants,

respectively. The Committee ensured that at least one individual with SCI was included as a presenter for each topic at the event which held on the 25<sup>th</sup> of April 2025. An evaluation survey was shared and closed on May 9, 2024. Recording of the sessions and slides used were made available on the project's website and YouTube page (see page 20 for access link).

### • Attendance breakdown - [\*Data collected through poll shared at beginning of event (n=208)]



The post-event evaluation survey showed a general satisfaction with the presentations and participants found having someone with lived experience of SCI present on each of the topics helpful. Participants were divided in terms of how much time to assign to each topics with some requesting to increase the total hours to more than the current 3 hours for the education day.

# **Topics for SCI Education Days**

# Topics chosen for the 2022, 2023 & 2024 SCI Education Days

- 1. Autonomic Dysreflexia
- 2. Bladder management
- Expected functional outcomes/prognostication/ISNCSCI
- 4. Mental health issues
- Neuro-modulation, e.g. functional electrical stimulation (FES) cycling, diaphragm pacing, spinal cord stimulators
- 6. Neuro-recovery therapies and research
- Overuse injuries, e.g. shoulder pain/rotator cuff impingement, Limb preservation and posture
- 8. Pain management
- 9. Physical fitness
- 10.Pressure injury prevention and management
- 11.Research update
- 12.Respiratory management and Sleep apnea
- 13.Sexual health

# Other topics included in a professional needs assessment survey

- Aging after SCI
- 2. Bone health, osteoporosis
- 3. Bowel management
- 4. Deep vein thromboembolism (DVT) and PE prevention/management
- Environmental control, Home modification
- 6. Existing clinical practice guidelines
- 7. Heterotopic ossification
- 8. Nutrition, dietary and weight management
- 9. Overview of additional medical complications, e.g. syringomyelia, pneumonia, metabolic complications, thermoregulation, orthostatic hypotension
- Preventive care after SCI including age-appropriate screening and barriers to screening
- 11. Robotics, gait training
- 12. Spasticity
- 13. Transition in care from rehab to home
- 14. Vocational rehabilitation
- 15. Wheelchair seating

### Model of Care

## **Logic Models**

5 working groups created 5 logic models with 38 recommendations that were synthesized into 1 logic model made up of 16 prioritized recommendations organized under 5 thematic areas Partners, through five working groups that included resources, promotion of healing & recovery, individualized care plan & follow-up, regional partnership, and empowerment WG co-developed 5 logic models to consider and integrate into the CONCENTRIC Model.

Actions carried out so far include;



### **SYNTHESIS**

Efforts to synthesize the 5 different logic models co-developed with our partners and to ensure alignment with HSO recommendations began in November 2024.



### CONSULTATION

A meeting was held in April 2024 with co-leads of the WGs that generated the 5 logic models and partners that would be most affected by proposed recommendations for their thoughts on the synthesized logic model.



### **PRIORITIZATION**

Due to variation in impact and feasibility of implementation, partners were consulted in July 2024 for their input in prioritizing a total of 38 recommendations included in the 5 co-developed logic models.



### **GENERATING & SOCIALIZING MODEL**

Based on previous processes, the CONCENTRIC Model was generated and supporting resources such as the implementation guide were developed. Using these resources, the team have been engaging with partners since August 2024 to get them to familiarize with the model and address concerns.



Click or scan QR-Code to see final thematic areas and associated recommendations. Thematic areas and their objectives are shown on the next page

### Model of Care

# **Synthesized Logic Model**

# Final outcome of collaboration, co-creation and prioritization work with partners across Alberta and Canada [Click here to visit Model Webpage]

The process leading to the final list of recommendations for the CONCENTRIC Model began with the Pilgrimages WG (April 2020) who were tasked with overseeing the collection and analysis of semi-structured interviews on TiC experiences from SCI partners including PwSCI. The Concept Design WG (June 2021) used the findings from the analysis to generate

the ideal TiC state which was further developed by five WGs under the Model and Actualization WG (February 2023) into 38 recommendations that were prioritized and resulted in a final list of 16 recommendations (July 2024) organized under the 5 thematic areas shown below and included in the CONCENTRIC Model.

Thematic Area (No. of Recommendations)	Objective
Person-centred Care Planning (4)	Ensure PwSCI and relevant SCI partners are consistently engaged in the development of and have access to an updated person-centred multidisciplinary care plan across the care continuum.
Communication and Collaboration (4)	Ensure PwSCI and relevant SCI partners in the community and hospital settings are connected and able to maintain 2-way communication as needed throughout the care continuum.
Focus on Healing and Recovery (3)	Make healing and recovery key pillars of the rehabilitation process for PwSCI as early as from Inpatient Rehabilitation with recovery viewed as full inclusion in a meaningful life as defined by each individual.
Peer Support and Education (3)	Improve SCI knowledge and self-management skills for PwSCI through peer support, education, and regular relevant knowledge updates.
Resource Accessibility (2)	Streamline ways for PwSCI and partners to identify and access appropriate resources (funding, supports, etc.).

### **Consultations & Collaborations**

### The whole is greater than the sum of the parts

- Aristotle

In keeping with the community-based participatory approach adopted for the project, the team continued engaging with its partners, seeking their valuable input on different aspects of the project including;

### **Experience Surveys:**

- Started discussions with partners on the utility of the My Experience Survey co-created with PwSCI (November 2023).
- Began working with partners to codevelop survey for family, caregivers, and support persons (December 2023) and for care providers (June 2024).

### **Advancing Indigenous Strategy**

- Continued collaboration with AFNIGC throughout the year.
- Consulted the Indigenous and Wellness Core for support to advance its Indigenous Strategy Plans (November– December 2023).

### **General Updates and Advisory**

 Organized a General Meeting and an External Advisory Committee meeting to update partners on project progress, and receive their input and guidance on next steps (January 2024).

### **Knowledge Sharing**

 Worked with partners to plan, host and evaluate the 3<sup>rd</sup> Annual SCI Education Day (January-April 2024) which was set up to create opportunity for partners to network, learn and refresh their knowledge on SCI and SCI care.

### **Model Refinement and Alignment**

- Held discussions with partners to highlight existing variation in peer support approach at pilot sites and co-determine best strategy for CONCENTRIC (December 2023).
- Brought partners via the Individualized Care Plan and Follow-Up WG together to consider how to integrate recommendations from the HSO into the proposed care plan for CONCENTRIC (June 2024).
- Consulted WG Co-leads to verify that the 38 recommendations created by their individual WGs were reflected in the synthesized logic model (February 2024).
- Reached out to key front-line partners for feedback on synthesized logic model (April 2024) and replaced the term "stakeholders" with "partners" based on their recommendation.
- Sent out prioritization survey for revised logic model to the broader SCI community (July 2024) and created a final list of 16 recommendations based on the results (November 2024).

### **Model Implementation Planning**

- Worked with partners to identify and establish requirements to engage potential Change Champions to support model implementation (April-November 2024).
- Consulted partners to determine best approach to create digital stories that emphasize significance of recommendations included in the CONCENTRIC Model (September-October 2024).

# **Future Plans**

### Looking ahead...

The CONCENTRIC project is a 3-Stage project that has now entered its third and final stage that focuses on model implementation. The coming year would focus primarily on CONCENTRIC Model implementation, monitoring and evaluation.



# **Project links & resources**

Resource	Visit or click link to access
2022 Education Day Resources	www.tinyurl.com/2022sciday
2023 Education Day Resources	www.tinyurl.com/2023sciday
2024 Education Day Resources	www.tinyurl.com/2024sciday
2021 Annual Project Report	www.tinyurl.com/concentricreport2021
2022 Annual Project Report	www.tinyurl.com/concentricreport2022
2023 Annual Project Report	www.tinyurl.com/concentricreport2023
CONCENTRIC YouTube Channel	www.tinyurl.com/concentricvideo
© CONCENTRIC project Website	www.concentricproject.com
CONCENTRIC Model Webpage	www.concentricproject.com/model-of-care
© CONCENTRIC Model Resources	www.concentricproject.com/model-resources
Measures for Persons with Spinal Cord Injury to Monitor Their Transitions in Care, Health, Function, and Quality of Life Experiences and Needs: A Protocol for Co-Developing a Self-Evaluation Tool	www. tinyurl.com/Kovacsburns2024
Novel Application of the World Health Organization Community-Based Rehabilitation Matrix to Understand Services' Contributions to Community Participation for Persons With Traumatic Spinal Cord Injury: A Mixed-Methods Study	www.tinyurl.com/Srijan2023

# **Acronyms adopted in Report**

Acronym	Full Meaning
AFNIGC	The Alberta First Nations Information Governance Centre
CONCENTRIC	CONnecting and Coordinating an Enhanced Network for TRansitions In Care
DVT	Deep Vein Thrombosis
FES	Functional Electrical Stimulation
FMC	Foothills Medical Centre
GRH	Glenrose Rehabilitation Hospital
нѕо	Health Standards Organization
IPHCPR	Indigenous Primary Health Care and Policy Research
ISCOS	The International Spinal Cord Society
ISNCSCI	International Standards for Neurological Classification of Spinal Cord Injury
MDPI	Multidisciplinary Digital Publishing Institute
PE	Pulmonary Embolism
PwSCI	Person(s) with Spinal Cord Injury
SCI	Spinal Cord Injury
SCI-AB	Spinal Cord Injury Alberta
TiC	Transitions in Care
WG	Working Group

# **More Information About Us**



### Working together to improve transitions in care

Approved in 2019, CONCENTRIC is a Spinal Cord Injury project based on a community-based participatory research approach that aims to develop a Provincial SCI Transitions in Care Model. The project thrives on the engagement and input of multiple SCI stakeholders across the healthcare system and in the community and welcomes every input focused on improving the care experience of persons with SCI in Alberta, Canada.



www.concentricproject.com



www.tinyurl.com/concentricvideo

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