

 $\textbf{CON} necting \ and \ \textbf{C}oordinating \ an \ \textbf{E} nhanced$ Network for TRansitions In Care: A New Model for Spinal Cord Injury in Alberta

# Annual Report (November 2022 - October 2023)



# **Executive Summary**

As we review the accomplishments and milestones for the past year, it is evident that our unwavering dedication and sacrifices have once more advanced us closer to realizing the goal of the project, particularly plans to create and implement a standardized, evidence-based, provincial transitions in care (TiC) model, often referred to as the CONCENTRIC model.

The groundwork laid down by the Concept Design working group in the previous year was expanded upon by five additional working groups tasked with different assignments. The groups completed their assigned tasks and generated logic models that are currently being integrated to form the CONCENTRIC model.

As a crucial part of the project, collaborative work with our Indigenous partner during the year resulted in charting a new direction for the Indigenous strategy plans for the project.

Within the year, as requested by our collaborators and partners, the mapping of the transitions journey starting from the two main specialized rehabilitation centers in the province was completed to provide clarity and a visual rendition of the current process.

As a long-needed tool, the "My Experience Survey" tool codesigned with and for Persons with SCI to empower them in evaluating their care and guide discussions with their care providers was finally created and launched. Engagement to also create appropriate evaluation tools for support persons and care providers has started as well.

Efforts to improve knowledge of SCI and SCI care continued with the hosting of the 2nd Annual SCI Education Day 2023. Information to evaluate the relevance of the event and the previous one and the practical utility of knowledge gained from them are currently being collected through a post-event follow-up survey sent out recently.

Building on this year's feats, the coming year will be a pivotal year for the project as it concludes synthesis work, pre-implementation evaluations and moves into translating plans into action, that is, it's implementation phase.

With the continued participation and contribution of everyone, we are hopeful that the coming year will be marked with outcomes that move us closer to realizing our collective vision of achieving excellent TiC for persons with SCI in Alberta and beyond.

Thanks for all your invaluable contributions.

The Concentric Team



**CON**necting and **C**oordinating an **E**nhanced **N**etwork for **TR**ansitions **In C**are:

A New Model for Spinal Cord Injury in Alberta

This report provides an update on activities, accomplishments and challenges encountered between November 2022 and October 2023 and reveals plans for the coming year ending October 2024.





Canadian Institutes of Health Research

Instituts de recherche en santé du Canada













- University of Alberta, Faculty of Medicine & Dentistry
- University of Calgary, Department of Clinical Neurosciences
  - University of Calgary, W2!C







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# ♦ Abbreviations

**ASCIP** – Academy of Spinal Cord Injury Professionals

AFNIGC - Alberta First Nations Information Governance Centre

**CCDI**– Canadian Congress on Disability Inclusion

CIHR - Canadian Institutes of Health Research

EAC - External Advisory Committee

FMC - Foothills Medical Centre, Calgary

**GRH** – Glenrose Rehabilitation Hospital, Edmonton

IPHCPR - Indigenous Primary Health Care and Policy Research

SCI - Spinal Cord Injury

TiC - Transitions in Care

WG - Working Group

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# **Vision**

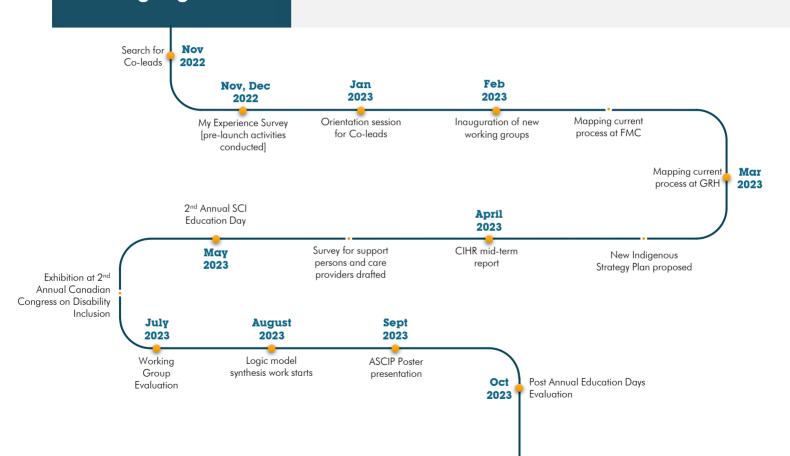
Excellent transitions in care for persons with spinal cord injury

# **Mission**

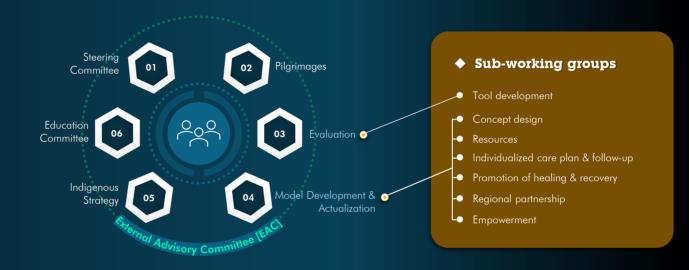
To design, implement and evaluate an improved, evidence-based and standardized provincial model of care with clear transition strategies for persons with spinal cord injury

# Year highlights

# An eventful year made possible by the invaluable contributions and sacrifices of all our partners



# Team (Working Groups)



# ♦ Working Group Status

# Completed

- Pilgrimages 2021
- Concept Design 2022
- Resources, Individualized care plan & follow-up, Promotion of healing & recovery, Regional partnership and Empowerment - 2023

# Ongoing

Steering Committee, Evaluation, Tool development, EAC

## **Paused**

Education Committee – May 2023

# **Project Recap**

**Project objective:** 

To identify the state of transitions in care (TiC) for persons with SCI in Alberta and collaborate with SCI stakeholders to co-design, implement and evaluate an evidence-based SCI TiC model for Alberta

CONnecting and Coordinating an Enhanced Network for TRansitions In Care:

A New Model for Spinal Cord Injury in Alberta

Official Start Date April 2019

Official End Date

Current Stage Stage 2

# **Completion Rate**





Stage 1 - March 2020 - March 2021

Goal: To understand the TiC experience of persons with SCI & other SCI stakeholders

Main activities: Interviews with persons with SCI (22) and

SCI stakeholders (27)

**Preliminary findings:** Themes discovered for successful TiC (MaX ACCESS):

- Managing healing eXpectations
- Access to services appropriate for SCI
- Client-centred care
- Continuity of care
- Education
- Social Support

Stage 2 - June 2021 - present

Goal: To build partnership with SCI stakeholders and co-develop

CONCENTRIC model using Stage 1 findings

Main activities: Working group meetings to brainstorm and generate recommendations for the CONCENTRIC

model and Evaluation of working groups with

completed tasks

# Reports



Concept Design WG Report



2021 Report



SCI Education Day 2022 Report



2022 Report

# Designing a Model of Care



The CONCENTRIC model

# Main purpose

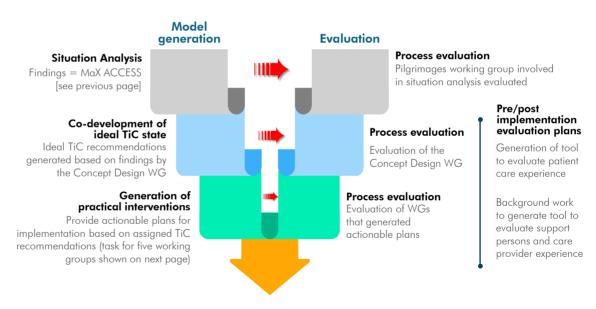
Improve TiC from Inpatient Rehab into the community for Albertans with SCI living in rural or remote areas

# Main activity completed within this report year

Generation of logic models for five identified important aspects of transitions in care (see next page for the working groups assigned this task)



The process of designing a model of care for transitions in care for persons with SCI in Alberta that has been adopted thus far in this project is summarized in the diagram below.





\*TiC = Transitions in Care; \*WG = Working Group

# **New Working Groups**

Following the completion of tasks assigned to the Concept Design WG, a general meeting was called in October 2022 to present the outcome from their work and introduce the new working groups that would build on their work (see the working groups on the right).

Concept Design WG Report

Membership into the new working groups which would continue efforts towards creating a model of care called The CONCENTRIC Model was made open at the general meeting.

To provide opportunity for stakeholders who didn't attend the general meeting to join one or more of the new working groups, a general email was sent out to SCI stakeholders after the meeting in October 2022.

In parallel, the team began to seek for Co-chairs/Facilitators for the working groups in November 2022 and an orientation session was conducted with those that agreed to take up the role in February 2023.



Orientation
session
resource

All the new working groups were inaugurated in February 2023. They completed their assigned tasks in July/August 2023 and were evaluated in August 2023.

Synthesis of output from the different working groups [logic models] was presented at a general working group meeting in June 2023 and a modified version is proposed to be presented to the larger SCI stakeholders' audience at a General Meeting in January 2024.

### Working groups with assigned tasks

\*See next page for summary of main focus or anticipated outcomes

#### Resources Working Group

• How to collate, create and maintain an updated list of existing SCI resources



How to support persons with SCI and other SCI stakeholders to access relevant resources

#### Individualized care plan & follow-up Working Group



How to create, maintain and share individualized care plan for persons with SCI in a timely manner

#### Promotion of healing & recovery Working Group



G How to increase access to new and emerging therapies that promote healing/recovery after SCI

## Regional partnership Working Group



 How to connect, improve communication and harmonize practices between inpatient rehab and community teams (Federal, Provincial, Municipal, Private)

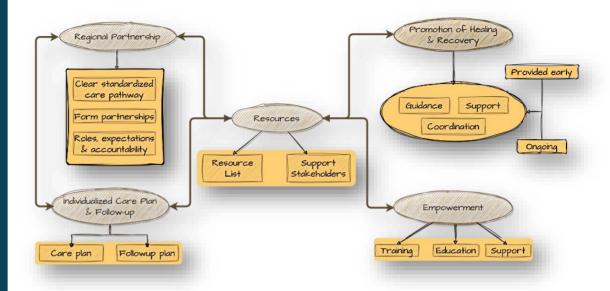
• How to define roles, boundaries and expectations for SCI partners

#### EmpowermentWorking Group



• How to effectively train, educate and support persons with SCI and their care team

Working group summary & considerations



- Resource WG Reached out to the wider public for potential SCI resources and considered best way to host and share the resources.
- Individualized care plan & follow-up WG Drafted a new care plan to synchronize with Connect Care and consulted different care providers to ascertain aspects that should be kept, modified or removed.
- Promotion of healing & recovery WG Identified the need for care providers in the hospital and community setting to have a singular view of rehab that promotes healing and recovery and ensures seamless transition from rehab in hospital to rehab in community.

- Regional partnership WG Requested for draft of pathway that reflects the patient journey process to identify what currently exists and the points where different stakeholders interface with one another. This led to documenting the current patient journey process adopted in the two main specialized rehab centres in Alberta.
- Empowerment WG Broadened assigned recommendations to capture patient rights, expectations and shared responsibility so as to reflect what the rehab journey should encompass.

# Engaged Stakeholders breakdown

Sex breakdown:

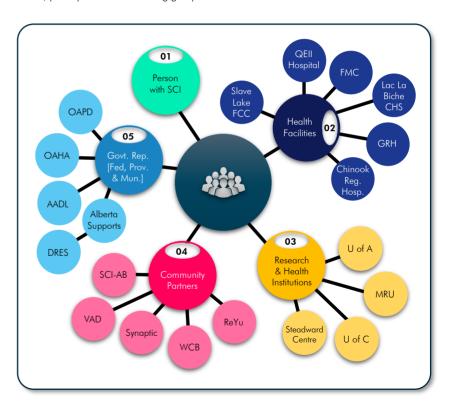


# **Abbreviations**

Chinook Reg. Hosp.	Chinook Regional Hospital
DRES	Disability Related Employment Supports
Fed.	Federal
FMC	Foothills Medical Centre
Govt. Rep.	Government Representative
GRH	Glenrose Rehabilitation Hospital
Lac La Biche CHS	Lac La Biche Community Health Services
MRU	Mount Royal University
Mun.	Municipal
OAPD	Office of Advocate for Persons with Disabilities
OAHA	Office of the Alberta Health Advocates
Prov.	Provincial
QEII Hospital	Queen Elizabeth II Hospital
ReYu	ReYu Paralysis Recovery Centre
SCI-AB	Spinal Cord Injury Alberta
Slave Lake FCC	Slave Lake Family Care Clinic
Synaptic	Synaptic Spinal Cord Injury and Neurological Rehabilitation Centre
U of A	University of Alberta
U of C	University of Calgary
VAD	Voice of Albertans with Disabilities
WCB	Workers' Compensation Board

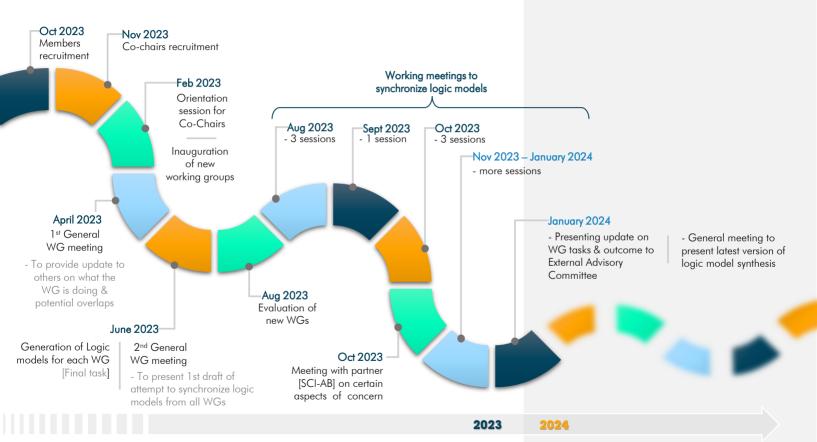
Different SCI stakeholders were engaged in five different workings groups to brainstorm and co-develop solutions or interventions that improves transitions in care for persons with SCI.

A total of 53 stakeholders across five main stakeholder groups, as shown in the diagram below, participated in the working groups.



# **Activity timeline summary**

The diagram below summarizes the journey from recruiting members into five new working groups to the current state of working to synthesize the logic models they generated based on the tasks they were assigned.



# **Indigenous Strategy**

Actions taken this report year can be summarized as

- Having a working contract with our Indigenous partner [AFNIGC]
- Co-developing a suitable strategy for engaging Indigenous stakeholders
- Seeking additional funding to successfully implement co-developed Indiaenous strategy

A key challenge encountered had to do with funding. There was a disparity between the amount set out in the grant for the Indigenous plans and the actual cost for the co-developed Indigenous strategy.

To address the funding disparity, two steps were taken;

- 1 Indigenous strategy plans were adjusted to reflect funding realities
- 2 Application for additional funding was submitted to IPHCPR.

An additional issue that had to be considered in November 2023 had to do with determining the appropriate custodian of data collected with the My Experience Survey from Indigenous persons with SCI.

# **Proposed Indigenous Strategy Plan**

After several iterations, the most recent plan is to hold a sharing circle with Indigenous stakeholders from the Treaty 6 territory.

The event will take place within the Central Treaty 6 area and is hoped to help generate culturally appropriate interventions for improving transitions in care for Indigenous persons with SCI.

# Timalina

Follow-up on co-designed contract with Indigenous Nov 2022 Partner [AFNIGC] and proposed case study plans Meeting with Indigenous partner to review budget Dec 2022 for case study plans Applying for a new grant to obtain additional Jan 2023 funding considered Steering Committee meets with Indigenous Partner Feb 2023 [funding challenges and evaluation tool for non-Indigenous persons discussed] EAC member consulted [Richard Peter] on Indigenous Strategy plans Meeting held to consider SCI incidence map, March 2023 choose a suitable Indigenous territory, and chart new way forward Application to IPHCPR Network grant for April 2023 additional funding starts May 2023 One-pager generated and sent out to Indigenous partner for discussions with Indigenous stakeholders June - Nov 2023

Reaching out to relevant Treaty 6 stakeholders

Reviewing and finalizing grant application to IPHCPR Network

\*AFNIGC - Alberta First Nations Information Governance Centre

\*EAC - External Advisory Committee

\*IPHCPR Network - Indigenous Primary Health Care and Policy Research Network

# Events & Knowledge Transfer Activities

# **Manuscripts**

#### **Published**

Raha et al. 2023 - "A 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." *American Journal of Physical Medicine & Rehabilitation* 

#### Ongoing

- •Developing and validating a patient experience tool [2 papers];
- Exploring the health pilgrimages of persons with SCI;
- Reflexive thematic analysis of TiC experience of SCI stakeholders in Alberta

#### **Events**

## CIHR Mid-term Report

Concentric project team joined some other CIHR grant awardees at a virtual meeting to present a midterm update in April 2023 as part of CIHR's Sharing Practical Advances in Research Knowledge (SPARK).



# 2<sup>nd</sup> Annual SCI Education Day

Designed mostly for nurses and allied health, the Concentric project held its 2<sup>nd</sup> Education Day on the 15<sup>th</sup> of May 2023.

Further details can be found on next page.



## Exhibition at 2<sup>nd</sup> Annual CCDI

To spread the word on the Concentric project and as part of public engagement activities, the project took advantage of the CCDI exhibition to showcase the project's work to a wider audience in May 2023.



#### ASCIP Conference Presentation

As part of knowledge transfer efforts, the team presented a poster in September 2023 describing the planning, delivery and evaluation of the first SCI Annual Education Day held in 2022.



<sup>\*</sup>ASCIP - Academy of Spinal Cord Injury Professionals

<sup>\*</sup>CCDI - Canadian Congress on Disability Inclusion

<sup>\*</sup>CIHR - Canadian Institutes of Health Research

# 2<sup>nd</sup> Annual SCI Education Day

#### Date held - May 2023

#### **Topics covered**

- Pressure Injury
- Autonomic dysreflexia
- Physical fitness after SCI
- Patient Orientated Discharge Summaries



#### Goal

To provide opportunity for SCI stakeholders to build knowledge relevant to improve care of persons with SCI and develop a community of practice



Speakers for the event included persons with SCI (3), a community partner and five health care providers from within and outside Alberta.



In response to feedback from previous year's education day, the number of topics for the Education Day was limited to four to allow for more time for each topic.



Attendees at the event were provided shareable links to access the recordings for the event and the slides used (if provided by the speaker).



Resources for the event were placed on the project's website to make them accessible to the public.

# Breakdown of Attendees

\*Numbers reflected here are for only the 173 participants that filled the survey posted at the start of the event (First response - 1:05pm, Last response - 1:17pm)







By years of experience with SCI (personal, professional, etc)

By stakeholder group

# **Evaluation**

Tasked with anticipating and preparing appropriate means to evaluate relevant aspects of the project is the Evaluation WG and its sub-working group called the Tool development WG.

\*WG - Working group

- Over the past year, the WGs have engaged SCI stakeholders in focus group discussions, consultation sessions, launched the My Experience Survey tool and made first efforts to validate the tool.
- In addition, the WG designed and conducted evaluation surveys for the past SCI education days and WGs that completed their tasks within the year.
- Find further details below

#### My Experience Survey

Efforts to generate and validate the tool for capturing the TiC experience of persons with SCI continued. The tool was launched in April 2023 and an orientation session with two persons with SCI giving their experience and thoughts on the tool to care providers in Alberta was held in June 2023. To facilitate awareness of and use of the tool, relevant materials were developed and made accessible through our partners.

### **Working Group Evaluation**

Evaluation surveys were prepared and sent out to members of five WGs under the Model Development and Actaulization WG who completed their tasks in July and August 2023. The goal of the evaluations is to use responses to improve and guide subsequent engagements in existing and new working groups.



# Survey for Support Persons and Care Providers

To capture the experience of family, care givers/support persons and care providers, the Evaluation WG re-visited plans to generate an appropriate tool in June 2023 and held the first session out of 3 planned formal deliberation sessions in October 2023.



## Follow-up Survey for Education Days

In the survey sent out in May 2023 to evaluate the 2<sup>nd</sup> Annual SCI Education Day, participants were informed about intention to conduct a follow-up survey later in the year. The survey was designed for the last two SCI Education Days (2022 & 2023) and was sent out in October 2023. The goal of the survey was to explore what participants found useful, what they applied and how they did so.



# **Logic Model Synthesis**

Anticipated in the coming report year is the completion of sessions required to synthesize all logic models generated by the five Model Development & Actualization WGs in the last report year.

The synthesized work is scheduled to be presented to SCI stakeholders in January 2024. Feedback from the meeting would be incorporated into the synthesized model.

#### **Evaluation**

Efforts to meet the target number for validating the My Experience Survey Tool would continue. The first psychometric test for the tool is anticipated to be completed by February 2024.

Additional orientation sessions would be organized for specific stakeholder groups to aid utilization of the tool and its spread.

Preparatory work to develop and validate the surveys for capturing the experience of support persons and care providers would continue.

All pre-implementation evaluations would be conducted in anticipation of the implementation of the CONCENTRIC model later in the year.

# **Implementation**

Site visitations are planned as part of pre-implementation plans for the project.

In the last report year, stakeholders in the four pilot sites for the project were pre-notified about site visitation intentions which would be actualized in the coming year once it becomes conducive to travel.

Once a functional draft of the CONCENTRIC model is ready, it will be shared with frontline workers and key decision-makers at the implementation sites.

Feedback from engagement with key stakeholders would be incorporated into successive iteration(s) of the model before it is finally implemented.









# Thank You

This year's accomplishments were made possible by your unrelenting support, contributions and sacrifices.

Thanks for everything.

We look forward to another successful year ahead.

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