

# **NEUROSCIENCES, REHABILITATION & VISION**

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## **KEY PARTNERS**

Campus Alberta Neuroscience

Eye Institute of Alberta (Univ. of Alberta)

Faculty of Rehabilitation Sciences (Univ. of

Hotchkiss Brain Institute (Univ. of Calgary)

Neuroscience & Mental Health Institute (Univ. of Alberta)

Spinal Cord Injury Alberta

# Major initiatives and achievements, 2021-2022

This past year, the Neurosciences, Rehabilitation & Vision (NRV) SCN and its Scientific Office advanced collaborative work on several provincial initiatives focused on clarifying patient experiences, advancing data- and evidence-informed performance measurement and decision-making, and promoting equity in access to care for patients and families requiring neurosciences, rehabilitation & vision care.

## Clarifying the Burden of Vision Loss in Stroke

In November 2021, Drs. Fiona Costello, Karim Damji and Kiran Pohar Manhas shared the final report of a two-year research study examining patient and provider perspectives on gaps in care experienced by stroke survivors with visual impairment (VI). The study looked across the care continuum, including acute, tertiary and community care settings and involved two online surveys, each developed and validated from a Phase 1 qualitative study (n=50 interviews) and cognitive interviews (n=12). Participant recruitment extended sites across four Zones and 12 sites, targeting diverse participation including patients, stroke neurology teams, vision care providers, and rehabilitation providers. In total, 46 stroke survivors (43% female, 93.5% had VI post-stroke) and 87 providers (46% male) completed the surveys. Read first publication



Provincial priorities for improvement included professional training, patient and family resources, referral processes, and supporting patients with return to driving. The NRV SCN will now mobilize the community and form provincial working groups to address these priorities. This research was funded by the NRV SCN, CvHS SCN, and the Eye Institute of Alberta. Research funds from the Royal Alexandra Hospital Foundation will enable next steps.

## Understanding Patient and System Impact of Post-COVID Rehabilitation Tools, Pathways & Resources

The NRV SCN continues to inform and advance a provincial approach to timely, standardized, and coordinated rehabilitation for adult patients recovering from COVID-19. Learn more about its approach and progress in developing the Provincial Post COVID-19 Rehabilitation Response Framework (PCRF) in this publication (June 2022).

The Scientific Office is currently leading a new, CIHR-funded study evaluating the implementation of the Provincial PCRF, which recommends care pathways, standardized screening and assessment tools, and patient and provider resources. For patients recovering from COVID-19, the study examines (a) health service utilization and wait times; (b) patient experiences: and (c) provider perceptions and experiences of the Framework and its implementation. This evaluation will inform ongoing provincial implementation of the PCRF, and support persons recovering from COVID-19, particularly those impacted by Long COVID.

The CIHR grant has also enabled related research activities and outputs. For example:

- Three rural zone implementation consultants were hired to support locally appropriate implementation of the PCRF
- AHS Clinical Analytics developed a dashboard to assess provincial health service utilization data in the pre-implementation phase, corresponding to COVID-19 survivors from Waves 3 and 4 of the COVID-19 pandemic.
- The NRV SCN Scientific Office co-designed a patient experience survey to identify priority measures regarding rehabilitation access and navigation for patients recovering from post-COVID conditions. Initial priorities related to patient experience of symptoms, information access, access to services and providers, as well as perceived provider knowledgeability.
- The survey was pilot-tested with AHS' Primary Data Support, who began data collection in March 2022 and sought a stratified, random sample of 300 persons who tested positive during Waves 3 or 4 (50:50 hospitalized:non-hospitalized experience; and 60:40 urban:rural dwelling).

Networks™

Together.

## Advancing a Strategy for Data-Informed Quality Improvement in Spinal Cord Injury (SCI)

In 2020-2022, the Scientific Office sought to co-design a provincial quality improvement strategy for SCI care that mobilizes nationally-independent registry data currently collected for research purposes: the Rick Hanson SCI Registry (RHSCIR).

In 2021, the Scientific Office completed an environmental scan that generated six key learnings to guide QI initiatives that use patient registry data. A patient advisor focus group was held in summer 2021 to discuss priority areas of SCI care and RHSCIR data elements. Since then, a provincial steering committee has led discussions on how RHSCIR data could be used for provincial quality improvement in SCI care.

The committee has identified 3 priority areas: secondary complications; discharge planning; and transitions in care. Learnings to date were shared at the Canadian Association of Health Services and Policy Research (CAHSPR) national conference (May 2021) and a provincial quality improvement strategy report is currently under development.

"I've been a part of [the RHSCIR for QI grant] for almost a year.... I found interesting there are different programs used to collect data. I have worked with SCI individuals for 10 years. During that time, I assisted in collecting data for RHSICR. This data is important and valuable; but let's not let it sit and keep collecting numbers. These findings and other research can help improve best practice and improve the quality of life to those who have a SCI. SCI peers have shared their experiences and the data also shows areas that are so important in the lives of people living with a SCI and those who care for them."

Patient Advisor living with SCI

## Other highlights

Patient Advisory Focus Groups support development of Neurosurgery and Vision Quality Indicators

The NRV SCN Scientific Office ensures patient and family advisor representation on all initiatives, steering committees and working groups. In June 2021, the NRV SCN convened two provincial Steering Committees representing multidisciplinary stakeholders in Neurosurgery and Vision. The Scientific Office provided rigourous, detailed environmental scans to complement their expertise on candidate key quality indicators. The Steering Committees met monthly to co-design a modified e-Delphi process to reach consensus on a core set of key quality indicators in each area.

## Impact on health and care in Alberta

The NRV SCN continues to build relationships with patients, families, research institutes, academics, clinicians and operational partners to leverage available resources and expertise. Together, they actively collaborate to:

- Co-design care transformation through evidence
- Harness innovation to drive care excellence
- Enhance equitable access to quality care for all in Alberta



## Actions and areas of focus

- Understand and improve the patient experience
- Promote a provincial rehabilitation innovation strategy
- Identify quality indicators and performance measures that can support evidenceinformed decision-making
- Develop and implement provincial clinical pathways
- Integrate virtual health into service delivery
- Improve care transitions across the lifespan
- Bridge clinical expertise and knowledge across Alberta

## NEUROSCIENCES, REHABILITATION AND VISION

#### **Grants and Publications**

## **Engagement**

### **Outcomes and Impact**



20

Peer-reviewed

**Publications** 

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3U Vorkshops

Workshops & Presentations



\$1.96M

Research Grants



187

Research Members

Development & launch of an integrated provincial Post-COVID Rehabilitation Response Framework that supports screening, assessment and patient-specific rehabilitation needs.

Ongoing rehabilitation support for patients with Post-COVID syndrome is expected to improve patient outcomes and experience and reduce avoidable ED visits and hospital readmissions.

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