2023-2024 PATIENT ENGAGEMENT HIGHLIGHTS

Patient engagement and collaboration have been essential to the success of Alberta Health Services (AHS), the Strategic Clinical Networks (SCNs) and the Provincial Programs. Patients, families and caregivers with lived experience have been active in each network, and their voices and contributions inform health care decisions, actions and priorities and improve safety, quality of care, outcomes, and patient, family and provider experiences.

They are real people, with real experiences, having real impact.



Image: Designed by Freepik

Patients, families and caregivers supported the SCNs and Provincial Programs in a variety of ways:

Patient and Family Advisors

Worked with networks or programs to co-lead, co-design, and collaborate as integral team members on priority initiatives. Some advisors supported several networks or activities, with others opting to support a particular area of interest.

Learn more

Advisory Council, Wisdom Council, Committee or Working Group Members

Participated in direction setting, prioritization, planning, implementation, and knowledge mobilization in various ways that support AHS, SCN and Program quality and outcome improvement, health services research and innovation.

Learn more

Patient and Community
Engagement Researchers

Conducted research or quality improvement studies that support work in priority areas.

Learn more

This document highlights a few examples of the many contributions patients, families and caregivers made over the past fiscal year and describes the impact of this work. It also shares the voices of the patients who have worked alongside SCNs and Provincial Programs as valued partners and provides a glimpse into their experiences as advisors, committee members and research partners.

Patient and Family Advisors

I believe that being a Patient Advisor is as important as being a patient. As a member of Core and other committees, I feel privileged to be able to respond and provide valuable perspectives on the development of research and care improvements.



Winnie Pearson, Patient Advisor (Medicine SCN)

Being a patient and family advisor has been an incredible privilege and opportunity to share my lived experience and be a voice at the table to influence the decisions made in our children's healthcare journey. The collaboration with healthcare providers and researchers has been a true testament to the power of having all the stakeholder voices heard.

Tapuwa Chinhengo, Patient Advisor (Maternal Newborn Child & Youth SCN)



Being part of the DH SCN has not only empowered me to advocate for patient-centered approaches but has also strengthened my belief in the transformative power of collaborative healthcare efforts.

Sophia Khan, Patient Advisor (Digestive Health SCN)



Tapping into the value of the patient's voice: PEPP-TALKS

Embedded within the Medicine SCN is a Patient and Family Advisory Council (PFAC), which provides a platform for meaningful patient engagement and participation. Through PFAC, committees and working groups, patient and family members bring their lived experiences to the work of the SCN.

Among many contributions, patients and family members have generated patient-centered and patient-led priorities and initiatives, such as the PEPP-TALKS project (Patients Effectively Partnering with Providers Towards Active Listening, Kinship, and Safety).

The Medicine Strategic Clinical Network embodies a safe environment where we, as patient partners, feel valued and respected for our insights and direction regarding patient centered care.

MSCN's PFAC Co-chairs, on behalf of PFAC Members

PEPP-TALKS is a research project led by Medicine SCN Patient & Family Advisors.

The study aims to understand how to support and improve communication encounters between patients and providers. High-quality patient-provider encounters are the foundation of partnership, preventive healthcare and safer outcomes. Features of high-quality encounters include communication about what matters to the patient (active listening), empathy and mutual trust (kinship), a positive relationship, holistic approach, balance of power, and psychological safety.

This project is being conducted in two phases, which began in 2023:

- In the first phase, the project team will identify factors that contribute to high quality, safe patient and provider encounters.
- Using learnings from Phase 1, the second phase involves designing and testing a userfriendly communication strategy to support high-quality encounters and better outcomes for patients and providers.

I have appreciated the Medicine SCN's support of our patient led and designed research project on patient and provider communication. From our first presentation of our "big idea" to the SCN Core Committee, the leadership and committee members had faith in our skill sets as leaders and trusted our vision. They facilitated our getting academic sponsorship and provided valuable mentorship throughout the process.



Sherry Vera, PEPP-TALKS Project Co-Lead & MSCN Patient & Family Advisor

Co-designing patient resources, pathways and more

The Primary Healthcare Integration Network (PHCIN) continues to interface and co-design with patient partners on priority initiatives such as the Alberta Surgical Initiative, provincial and patient pathways, and transitions in care (H2H2H). Once again, the Primary Health Care Virtual Patient Engagement Network (VPEN) recapped its patient and family advisor contributions in a year-end report. Some highlights from the past fiscal year:

40

24%

27

107

engagement consultations/requests for advisor support

increase in the number of requests for support over 2022/2023

engagement opportunities shared with VPEN advisors

VPEN participants (75 advisors + 32 general members)

Some examples of the diverse range of projects where patient and family advisors have had an impact co-designing new resources and solutions are listed below. To learn more, see the 2023/24 Annual Report - VPEN.

My Next Steps

Co-designed by the Patient Transitions Resources team, this guide aims to help adult patients and their support person(s) be active participants in their transition from hospital to home. The guide was tested at two hospital units in 2023 with feedback from staff and patients informing workflow improvements and redesign of the document from 9 to 3 pages. A communications campaign launched in spring 2024 encourages use of My Next Steps at hospitals across Alberta. Advisors continue to be passionately involved in supporting its implementation.

'My Next Steps' is now being implemented in hospitals around the province. I'm pleased and impressed that Alberta Health Services entrusted our team of patients to design the 'My Next Steps' Project.

John Hanlon, Patient Advisor, Primary Health Care Integration Network

Alberta Surgical Initiative (ASI) Patient & Family Advisory Council (PFAC)

The PFAC now has 10 members and is co-chaired by Joel Bermack, patient advisor. As members of provincial and zonal co-design teams, advisors participated virtually and in-person to draft referral, clinical and patient pathways and develop a plan to deliver non-urgent advice across Alberta. Advisors also participated in validating content for a resource called the Universal Surgical Guide.

Provincial Pathways Unit (PPU)

The PPU has established a standard for having at least two patient and family advisors participate in every pathway co-design project, with a goal to achieve both rural and urban representation. In 2023, The PPU and several advisors developed and launched five patient pathways on MyHealthAlberta using a co-design approach.

Prehabilitation

A team of three patient partners reviewed and recommended improvements to patient-facing resources including the Prehab4Me web page/app and webinars on various Prehab topics. One patient partner served as a member of the Prehab steering committee and the Education working group.



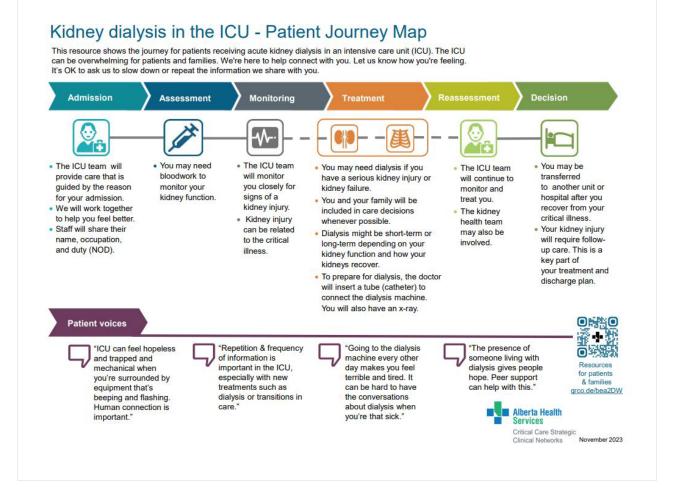
The Primary Care Networks Strategic Forum welcomed the participation of five patient partners who shared their powerful patient perspectives to close the Forum. In this photo, Forum Emcee Dr. Ernst Greyvenstein (left) thanks patient partners (left to right): John Hanlon from Edmonton, Nancy Verdin from Red Deer, Kelly Elhatton from Lethbridge, Jamie Hodge from Calgary, and Karen Moffat from Cochrane. (Photo credit: Joanne Ganton)

Co-designing critical care resources for patients and families in the ICU, including a Patient Journey Map for acute kidney dialysis

Patient and Family advisors are integral to the work of the Critical Care SCN. Over the past year, advisors have actively contributed to the development of a <u>Patient and Family Dialysis Journey Map</u>.

Patient and Family Advisors involved in the Dialyzing Wisely project identified that the ICU experience can be overwhelming. In collaboration with the Dialyzing Wisely project team, Patient and Family Advisors co-developed a Patient Journey Map as a resource for patients and families in experiencing acute kidney dialysis as part of their care in the ICU.

The Patient Journey Map outlines the patient flow and experience during a typical encounter with kidney dialysis in the ICU. This resource allows patients and their families to better understand common steps in their dialysis encounter and what they can expect next. It is written using plain language and includes the words of patients with lived experience.



Co-design, consultation and collaboration to support improvements in emergency medical care

In 2023/24, the Emergency SCN, through an expression of interest, recruited four new Patient and Family Advisors, bringing its advisory group to nine. This group supported many key initiatives for the SCN, ranging from quality improvement to provincial taskforces, research proposals, patient journey maps, evaluations and clinical and patient-facing communication tools. Some highlights:

- Advisors served on a Patient Advisory Council looking at opportunities to use artificial intelligence to expand data-enabled health research and improve service delivery (in collaboration with Population & Public Health)
- Advisors participated on a Provincial Patient Movement Taskforce that co-designed several communication tools for patients, clinicians & volunteers including:
 - a four-part video series for patients explaining the ED patient journey in a step-by-step manner
 - a scripted messaging tool for healthcare providers building off the Collaborative Care
 Model
 - o revisions to the ED Patient Journey Map
 - o patient, family, and provider survey and interview tools
 - evaluation framework reviews for Allied Health & Pharmacy in EDs and EMS Offload Initiatives
 - o a Physician Clinical Metrics Reporting Dashboard
- Several advisors reviewed and provided feedback on an expression of interest for a machinelearning-based research project (PRIHS 8) and study protocol for a pilot project on harassment and violence in Alberta EDs

As a PFA with an equal voice at the table, I worked with the ESCN team to develop a tool to personalize communication between frontline providers and patients.... [This tool] aims to help providers communicate more clearly with patients and families in the busy emergency department environment. Together, we continue to work on this project and expect to roll it out by year end.

Gloria Wilkinson, Patient and Family Advisor, Emergency SCN

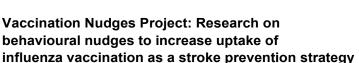
Patient insights, input and efforts are integral to program success, quality improvements and patient-centred care

Patient and family advisors with the Cardiovascular Health & Stroke (CvHS) SCN continue to play a critical role in efforts to enhance cardiovascular health in Alberta. We are grateful for the dedication and insights brought forth by our Patient and Family Advisors. Their voices guide our efforts towards continuous improvement and patient-centered excellence and their partnership is vital in fostering a patient-centered approach to healthcare.

Over the past year, advisors have significantly contributed to several major initiatives, including:

Enhanced Lipid Reporting (ELR)

- Advisors helped creating patient education videos for MyHealth.Alberta, including one answering key questions about statins
- Advisors are actively involved in conducting patient interviews for the ELR quality improvement work, ensuring that strategies are grounded in, and informed by, real patient experiences. To date, they have co-designed an interview script and have begun conducting patient interviews. As data is gathered, they will also be conducting the qualitative analysis and reporting results.





- With only 42% of adults in Alberta receiving influenza vaccinations over the past decade, strategies to increase uptake are critical for both influenza and stroke prevention. Behavioral nudges, drawing from behavioral economics, have proven effective in this realm.
- This study builds on evidence from randomized controlled trials (RCTs) in Europe, which have shown that behavioural nudges can boost influenza uptake by over 6%.
- Cindy Yagos, a Patient and Family Advisor with the CvHS SCN, is taking a lead role in this
 work, serving as a co-applicant and co-leading a working group that is developing targeted
 behavioral messages aimed at increasing influenza vaccine uptake in Alberta. Drawing on her
 lived experience and expertise, Cindy has been actively involved in developing qualitative
 focus groups and interview guides and will continue to play an active role in data analysis and
 all phases of the research process.

Co-designing education materials and contributing to research and quality improvements to support neurorehabilitation, long COVID care and more

Over the past fiscal year, 19 patient and family advisors have played a pivotal role in shaping and enhancing healthcare innovations and major initiatives with the NRV SCN. Their active involvement in identifying high priority gaps in care and co-designing research projects, educational resources, staff training and program evaluations fosters patient-centered care.

Key contributions over the past year include:

Amplified the patient voice

- Reviewing and collaborating on patient educational materials for two initiatives: Pressure Injury Prevention (PIP) and Vision Loss after Stroke. Advisors also shared their lived experience through patient stories to committee members and frontline providers to underscore the value and importance of this work.
- Contributing to the development of a video for clinical staff on spinal cord injury.

Supported clinical research and evidence review

- Serving as co-investigator on a research study on barriers and facilitators to pressure injury prevention. Their contributions informed study design, data collection and analysis.
- As a member of the Executive Sponsor Committee, an advisor assisted in setting the scope, recruiting participants, and advising on an environmental scan on multiple sclerosis care in Alberta.

Planning input

- Active involvement in planning Neurorehabilitation Discovery Day, which focuses on improving access and efficacy to neurorehabilitation for Albertans.
- Contributed to a provincial working group report for AHS Executive Leadership on the management of Spontaneous Intracranial Hypotension (SIH) in Alberta.

Co-designed a Long COVID care pathway and delivery model

 Informing the Provincial Primary Care Pathway for Long COVID Care in Alberta and model redesign for the Interprofessional Outpatient Programs (IPOP) as members of a Provincial Council and Model Working Group.

Working with the NRV SCN as a Patient Adviser has been an eye opening and rewarding experience, and I look forward to continuing in my role.

Nicola Birchall, Patient and Family Advisor, NRV SCN and past Rehabilitation Counsellor

It is so great to work with the team on many issues...[and] be able to provide lived experience with a condition I have managed over the years... it also helps to make it seem more worth it.

Dave Elphinstone, Patient and Family Advisor, NRV SCN



Co-developing patient and family engagement indicators to assess engagement and identify opportunities to improve it

Within a learning health system, 'value-based' or 'quality' indicators can provide a way to objectively assess whether our efforts, processes and actions reflect our values and intended objective. A consistent set of evidence-based indicators can help organizations like AHS identify areas for improvement and assess progress over time or in different areas of its operations.

Over the past two years, SCN patient and family advisors worked with researchers from the University of Calgary (Dr. Maria Santana, Dr. Paul Fairie, and Dr. Tamara McCarron), the Alberta Strategy for Patient-Oriented Research (SPOR) Support Unit Patient Engagement Team (Sadia Ahmed, Sandra Zelinsky), and SCNs to identify a set of indicators that can be used provincially to assess patient engagement and the experience of advisors and staff working together.

Using a modified Delphi consensus process, the team identified 33 evidence-based indicators to evaluate the experience of advisors and staff members. The initial indicator list was reviewed, refined and reduced to 18. The process of co-developing a short list of indicators is described in a joint publication in BMJ Open (2023).

Engagement indicators that made the short list were grouped into seven themes:

- Communication (e.g., having enough information to be able to carry out one's role as an advisor)
- Comfort to contribute (e.g., ability to express views freely)
- Support needed for engagement
- · Impact and influence of engagement initiative
- Diversity of perspectives
- Respectful engagement
- Working together (e.g., extent of engagement project design, execution, disseminating results)

In April 2023, the team used the Public and Patient Engagement Evaluation Tool (PPEET), a validated survey developed by researchers and public and patient engagement practitioners, to survey 157 patient and family advisors and 132 staff with the SCNs and Provincial Programs. The survey was adapted to include some additional questions based on input from key stakeholders.

Outcomes

This work has advanced understanding about patient and family engagement indicators. In addition to the article in BMJ Open, the team co-authored and shared a report summarizing its survey results (Nov 2023). These results provide a baseline from which to monitor, improve and report on patient and family engagement across the networks and Provincial Programs.

Together, the engagement indicators and survey are standardized tools that can be used to assess engagement activities within AHS and to gather feedback and perspectives about the experience of advisors and staff. The plan next is to administer the survey yearly to monitor engagement, use the data to understand areas of strength and gaps in our engagement efforts, and develop strategies for improvement.



Strategic direction that aligns with patient priorities

Patient and family advisors helped guide a refresh of the <u>Cancer SCN's Strategic Plan</u>, released in January 2024. The plan outlines the network's strategic directions, priorities and actions for the next three years (2024-2027) that support its mission to "*Lead transformation to improve care across the cancer continuum in Alberta*." The plan also highlights progress and achievements realized over the past three years.

I am honoured to have been part of the CORE Committee charged with creating the CSCN 2024-2027 Strategic Plan. As a Patient and Family Advisor (PFA), to have the opportunity to help direct the future of Cancer Care in Alberta is a gift. My opinions were actively sought and were valued, and I see my contributions reflected in the work. The collaborative nature of this committee work is quite remarkable. It reflects the deep commitment to involving PFAs and also a belief that cancer care will improve because of it!

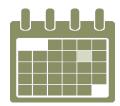


Jane Rogerson, Patient and Family Advisor, Cancer SCN

Support for other provincial collaborations and quality improvement initiatives

Diabetes, Obesity & Nutrition SCN

Patient and family advisors from the Diabetes, Obesity & Nutrition (DON) SCN were integral in co-designing the agenda and providing input for the inaugural **Diabetes Day** (held June 8, 2023) and inaugural **Obesity Day** (held November 6, 2023). These events were organized by the DON SCN Scientific Office and were the first time that these communities have come together provincially.



Several patient and family advisors participated in these events, with one sharing their story of living with type 1 diabetes at the start of Diabetes Day and a patient from the Alberta Obesity Centre sharing their obesity journey at Obesity Day. Patient stories provide a powerful way to orient participants to patients' needs and experiences and keep this information top of mind.

Feedback from both events was positive, with participants indicating that these events were an excellent opportunity to meet and hear from others interested in diabetes and obesity care and research in the province, and to build the relationships and partnerships needed to advance improvements in diabetes and obesity care.

Bone & Joint Health SCN

The BJH SCN has benefited from, and had the privilege of working with, many incredible patient and family advisors. Over the past year, advisors have committed significant time and energy to supporting several key initiatives. Kim Giroux's involvement as advisor, committee member and research partner over the past year, and its impact, are highlighted below:

Adult Rheumatology Learning Health System

This work focuses on developing quality metrics for rheumatoid arthritis, including patient-reported outcomes (PROs) and measures (PROMs) that can be collected using Connect Care. The data, in turn, will be used to monitor and improve the quality of rheumatology services provincially. The project involves extensive collaboration with patients, patient advisors,

clinicians, and AHS and is occurring in the context of a broad, national strategy regarding arthritis quality metrics.



Over the past year, Kim worked closely with the principal investigator and her team to streamline the complex processes of using a Delphi Method to gain insight into patient perspectives on PROMs. She co-led the patient advisory panel and has shard the patient perspective on this work as a presenter at Calgary and Edmonton rheumatology rounds.

The ABCs of Improving Access to Care for People with Inflammatory Arthritis

Kim is listed as a co-applicant on this project's CIHR grant application. This shows patient support and, if the application is successful, sets the stage for continued patient collaboration.

Working with Dr. Barber [Scientific Director, Bone & Joint Health SCN Scientific Office] and her team has been extremely rewarding. My perspectives have been sought out, heard, and incorporated into the research projects, leading to better, more patient focused solutions.

Kim Giroux, Patient Advisor (Bone & Joint Health SCN)

Patient and Community Engagement Researchers (PaCERs)

PaCER Project

What matters most to Albertans from rural, remote, or isolated communities when returning home after being hospitalized

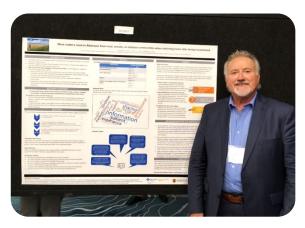
With support from the Primary Health Care Integration Network (PHCIN)

To support the provincial rollout of Home to Hospital to Home (H2H2H) Transitions Guideline, collaborative research by the H2H2H Patient and Community Engagement Research (PaCER) team was conducted in 2022. Their research topic was: What matters most to Albertans from rural, remote, or isolated communities when returning home after being hospitalized. This research was conducted by, with, and for Albertans to better understand patients' experience and needs when transitioning from urban hospitals back to their rural homes, including follow-up care for some cases.

Outcomes

Findings from this study were presented at the Alberta Strategy for Patient-Oriented Research (SPOR) Fall 2023 Collaborative Forum in Edmonton, where the H2H2H Transitions PaCER team was selected as having the best general poster. Congratulations to D'Arcy Duquette, Gary Semeniuk, Jacklynn Trifaux, Joanne Ganton, Kaitlynn Jiang, and Kim Giroux on this accomplishment and their successful completion of the 2022 PaCER program.

The team has continued to present their findings to wider audiences, including at a national conference on Rural and Northern Healthcare in Toronto (May 2023), and at the Canadian Rural Revitalization Foundation Conference in Lethbridge (June 2023). Their poster was also shared by their PaCER instructor at the Citizen Science 4 Health Conference in the Netherlands (October 2023).



Team member Gary Semeniuk showcasing the winning poster at the SPOR 2023 Collaborative Forum.

PaCER Project

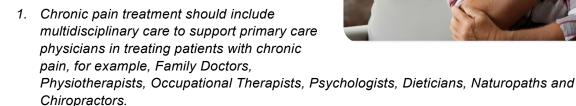
Understanding the chronic pain journey and coping strategies that patients use to manage their chronic pain

With support from the Emergency SCN

Marcia Bruce, Research Manager with the University of Calgary, Department of Medicine, led a qualitative, patient-oriented research study that used a Patient and Community Engagement Research (PaCER) approach. The study was conducted by people with lived experience with chronic pain "ensuring that the patient perspective and needs were considered and addressed throughout the research cycle. Purposeful sampling was used for recruiting individuals living with chronic pain."

Outcomes

Results of this study were published in <u>BMJ Open</u> (July 2023) and revealed that "chronic pain affects all aspects of a person's life and involves a grieving process." Exploring patient experiences of grief and daily coping in management of chronic pain led to six recommendations:



- 2. Doctors should encourage people living with chronic pain to seek support, for example, a person or support group and other mental health supports.
- 3. Care should be focused wholistically to include preventative strategies such as peer mentoring, exercise and mental health support, instead of just reactive solutions such as medication.
- 4. Mental health support for people living with chronic pain should include grief support as patients experience many losses.
- 5. Chronic pain guidelines should be developed for both patients and physicians with information on how to understand and treat chronic pain.
- 6. Doctors should be provided with further training and education on chronic pain, so they are better able to understand and support patients. Ensure that people living with chronic pain are involved with this by sharing their experiences as part of that training.



PaCER Project

Childhood mental health histories and interaction with the mental health care system

With support from the Addiction and Mental Health Integration Network

The mental health of young people has become a global health priority with one in seven youth (ages 10-19) experiencing a mental health disorder, accounting for 13% of the global burden of disease in this age group. Despite an increase in young people with reported mental health concerns and emotional distress, helpseeking behaviors among this group are limited by societal (stigma), support (lack of resources), and organizational (navigational) barriers.



Although the emergency department (ED) is often a first point of contact for young people with mental health disorder, it is well-known that the ED is not typically the appropriate setting for low-acuity youth mental health concerns. Risk factors regarding ED usage for mental health concerns have been well documented; however, less is known about the nuanced decision-making that leads young people (and often their parents, guardians, and support people) to come to the hospital versus accessing other supports. Although it is understood that a lack of timely outpatient mental health supports encourages ED usage, it is unclear what other factors mediate access to mental health supports—from the initial disclosure of a mental health concern or any type of emotional distress.

This study explores the health journey of young people and their supports from their initial mental health symptoms and disclosures to their eventual access to the mental health care system. The study is co-led with a PaCER graduate and uses qualitative methods designed, developed, and conducted by a person with lived experience of the child and youth mental health care system in Alberta. Interviews will be conducted with young people, as well as parents and other adult supports, to address three research questions:

- 1. What are the experiences of young people that led them to seek care in the Alberta Health Services mental health care system?
- 2. What, or who, are the natural supports for young people who have experienced emotional or mental distress? What is their role in assisting the young person?
- 3. How did parents or guardians and other natural supports experience the mental health system as it relates to a child/youth?

Outcomes

This work began in 2023-24 and is actively underway. We anticipate that findings from this study will provide a foundation for a larger research program examining preventative measures in child and youth mental health.

PaCERs part of core Research Team

Engaging patient-researchers to understand patients' and providers' experiences of the MSK heatlhcare system in Alberta

With support from the Bone & Joint Health SCN

Two patient researchers, PaCER-trained and both with PhDs, collaborated as core research team members on a qualitative study led by the BJH SCN. The study aimed to explore and describe how patients and providers experience Alberta's musculoskeletal (MSK) health care system, and identify recommendations for improving service delivery.

The patient-researchers were part of a diverse research team that completed interviews with:

- 73 patients from across Alberta, all with conditions of the knee, low back and/or shoulder, and
- 45 healthcare providers, including physiotherapists, physicians, chiropractors, and nurses

The diversity of the team provided opportunities to unpack and understand study participants' experiences from various lens and perspectives, leading to robust discussions and richness of findings. Deep engagement of the patient researchers in the analysis enabled identification of important patient-relevant themes and presentation of these themes in a way that truly reflects the patient experience.



MSK Experience Project Research Team: from left to right: Kyle McCullum, PhD; Romita Choudhury, PhD (patient researcher); Kathy GermAnn, PhD, Jean Miller, PhD (patient researcher, patient advisor, PaCER); Ania Kania-Richmond, PhD (Assistant Scientific Director, BJH SCN). Team members missing from this photo: Paige Campbell (current medical student); Genevieve Jessiman-Perreault.PhD.

Funded by AHS, this research establishes a critical baseline against which initiatives, such as the Rapid Access Clinics (RACs), may be assessed to determine impact on the quality of care and improvement of the patient and provider experience in the MSK space. It is part of the MSK Transformation work led by the Bone & Joint Health SCN.

Outcomes

MSK conditions are some of the most prevalent chronic conditions, impacting a great number of Albertans. Insights and knowledge generated through this research will be shared with key partners, including patients, system designers and decision makers, to support provincial transformation of MSK healthcare services. Services to address MSK conditions span acute care and community sectors, with involvement of family doctors, specialists, and rehabilitation professionals in both the public and private healthcare settings.