



SCPOR Saskatchewan Centre for
Patient-Oriented Research

2020/21
**Annual
Report**



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SCPOR's people and partners

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Mission Vision & Values



“ VISION

Working together for a healthier Saskatchewan through patient-oriented research.”

“ MISSION

SCPOR will build capacity and collaborations to conduct responsive, equitable, innovative patient-oriented research that continuously improves the care and health of Saskatchewan people.”

Values



Patient-Oriented



Responsive



Builds Capacity



Equitable



Collaborative



Innovative



Continuous Improvement



Oversight Committee

The Oversight Committee (OC) sets the direction for SCPOR. The OC is comprised of partner representatives, Patient Partners and SCPOR executive staff.

Clifford Ballantyne,
Patient Partner

Jenny Basran,
*Senior Medical Information
Officer, Digital Health
Saskatchewan Health Authority*

Mark Borgares,
*Vice President and
Chief Financial Officer
eHealth Saskatchewan*

Heather Dyck,
Patient Partner

Sally Gray,
*Director, Research Office
University of Regina*

Marg Friesen,
*Minister of Health
Métis Nation Saskatchewan*

David Howland,
*Director, Health System
Policy & Innovation
Ministry of Health,
Government of Saskatchewan*

Malcolm King,
*Scientific Director
Saskatchewan Centre for
Patient-Oriented Research*

Leta Kingfisher,
*FSIN Health &
Social Development
Federation of Sovereign
Indigenous Nations*

Jackie Mann,
*Executive Director
Saskatchewan Centre for
Patient-Oriented Research*

Darcy Marciniuk
*Associate Vice President of
Research
University of Saskatchewan*

Patrick Odnokon,
*Chief Executive Officer
Saskatchewan Health
Research Foundation*

Delores Pahtayken,
Patient Partner

Madeline Press,
*Director, Centre for Health
Research, Improvement
& Scholarship
Saskatchewan Polytechnic*

Mark Radomski,
*Vice Dean of Research,
College of Medicine
University of Saskatchewan*

Tracey Sherin
*Chief Executive Officer
Saskatchewan Health Quality
Council*

Candace Skrapek
Patient Partner

Preston Smith,
*Dean of Medicine
University of Saskatchewan*

Tanya Verrall
*Director, Analysis & Research
Partnerships
Saskatchewan Health Quality
Council*

Brandy Winqvist
*Executive Director,
Academics & Learning
Saskatchewan Health
Authority*



Indigenous Health Advisory Council

The Indigenous Health Advisory Council (IHAC), with Patient Partners and representatives from SCPOR and partner organizations, provides guidance on Indigenous initiatives.

Nicole Akan, *Community Research Coordinator,*
File Hills Qu'Appelle Tribal Council

Louise Bird, *Patient Partner*

Tara Campbell, *Executive Director*
Northern Inter-Tribal Health Authority

Terri Hansen-Gardener, *Patient Partner*

Patricia Ironstand, *Executive Director*
Battle River Treaty 6 Health Centre

Gilbert Kewistep, *Knowledge Keeper*

Maggie King, *Patient Partner*

Raymond Laliberte, *Executive Director*
Métis Addictions Council of Saskatchewan Inc.

Judy Pelly, *Knowledge Keeper*

Adel Panahi, *Director of Health*
Métis Nation–Saskatchewan

Ian Thomas, *Manager, First Nations and Métis Services*
Saskatchewan Health Authority



Patient Partner Advisory Committee

The **Patient Partner Advisory Committee (PPAC)** is comprised of Patient Partners dedicated to furthering patient-oriented research in Saskatchewan and guiding SCPOR's priorities.

Clifford Ballantyne,
Patient Partner

Janet Barnes,
Patient Partner

Heather Dyck,
Patient Partner

Diana Ermel,
Patient Partner

Kathy Evans,
Patient Partner

Janet Gunderson,
Patient Partner

Dale Hall,
Patient Partner

Colleen Hamilton,
Patient Partner

Maggie King,
Patient Partner

Margaret Larocque,
Patient Partner

Tyler Moss,
Patient Partner

Janice Osecap,
Patient Partner

Candace Skrapek,
Patient Partner

Lynn Thompson (Muskakekeway),
Patient Partner

Message from the **Executive and Scientific Directors**

2020/21 was a unique year, to say the least! We were able to continue supporting the advancement of patient-oriented research (POR) during a global pandemic. Although this year came with many challenges, the resiliency and innovation of our Patient Partners, staff and other partners and collaborators ensured that we continued to make significant progress.

To address pandemic restrictions, our Patient Partners spearheaded the immediate transition of SPOR modules to an online format which ensured that the modules remained accessible to all research teams and, in fact, made the modules more accessible than ever before. Building Research Relationships with Indigenous Communities (BRRIC) Module, Realizing Indigenous Rights and Responsibilities in Research (RIRRR) Module and the Saskatchewan Health Research Showcase also pivoted online, each in a unique and accessible virtual format.

Saskatchewan Health Research Showcase was an enormous success, with attendees including participants from not only other provinces, but also from other countries! With over 40 presentations and 100 ePoster presentations, the health research taking place here in Saskatchewan was highlighted and celebrated throughout the three-day conference.

The successful engagement of 70 traineeships this past fiscal year represented a key accomplishment as we reached the peak phase of these trainees. You will note many of their accomplishments throughout this report.

Once again, Saskatchewan is proud to lead Indigenous initiatives as the only SPOR SUPPORT unit with a dedicated Indigenous Research Expertise and Engagement Platform. In addition to providing training opportunities, the IREE team provided valuable support to Indigenous and non-Indigenous projects and provided cultural guidance in many ways with the support of two Knowledge Keepers and the Indigenous Health Advisory Council.

COVID related challenges were brought to light when Patient Partners raised through SCPOR's governance structure the observation that Patient Partners had been left out of COVID-19 research opportunities, prompting SCPOR and our partners to take action in a variety of ways. Shifting priorities caused by the pandemic led to the COVID-19 Evidence Response Team created by the Saskatchewan Health Authority, which provided 115 evidence reviews to stakeholders and developed the COVID-19 Pathway as a system framework for managing COVID-19 patients.



As we move into the final year of the first SCPOR grant, we will focus on completing work within the first grant while preparing to move onto the next phase.

We are grateful for the ongoing collaborations and support we have received from our partners, as well as the researchers, staff and Patient Partners who work so diligently to ensure the success and advancement of patient-oriented research in our province. We look forward to another successful year working alongside the Saskatchewan health research community!

Jackie Mann,
Executive Director

Malcolm King,
Scientific Director

Patient Engagement

Patient Partners play an essential role at SCPOR. With representation on the Oversight Committee, Indigenous Health Advisory Council and, of course, the Patient Partner Advisory Committee, they provide input into the important decisions made every day at SCPOR. Some of the year's highlights follow.

When the **COVID-19 Pandemic** emerged, Patient Partners initiated dialogue after observing that Patient Partners were being left out of COVID-19 research opportunities, prompting SCPOR and our partners to address the issue.

SPOR Training Modules moved online, thanks in large part to the work of three Patient Partners who were instrumental in developing online versions of the modules. The move to a virtual platform enabled a wider audience to access the courses.

Evaluating the Patient Family Advisor Experience in Patient-Oriented Research was published in *healthcare quarterly* and co-presented at Canadian Association of Health Services and Policy Research (CAHSPP) trainee pre-workshop event.

Best Practices for Virtual Patient Engagement, an infographic highlighting ways to engage patients virtually during the COVID-19 pandemic, was developed by Patient Partners and SCPOR staff. The infographic was translated to French enabling access to a wider audience.

James Lind Alliance (JLA) priority setting project was completed in January 2021, with a list of the top 10 questions on obstructive sleep apnea identified, which Saskatchewan Respiratory Research Centre plans to publish and disseminate. The learnings from the JLA process has been shared with the SCPOR team and will be incorporated into coaching and the support provided to POR projects in the area of patient-identified priorities.

SHA Health Networks Evaluation

SCPOR provided coaching on how to set up a Patient Partner Advisory Council and determine best practices for working with Patient Partners/ Patient Family Partners.

Patient & Researcher Connection Site (PRCS)

connects patients with research projects as both participants and Patient Partners on research teams. Evaluations were sent out in April & May 2021; results from the respondents included:

90%

indicated that the tool met their needs

61%



indicated it helped facilitate a connection with a Patient Partner or a POR team

57%

indicated it helped with recruitment of patient participants

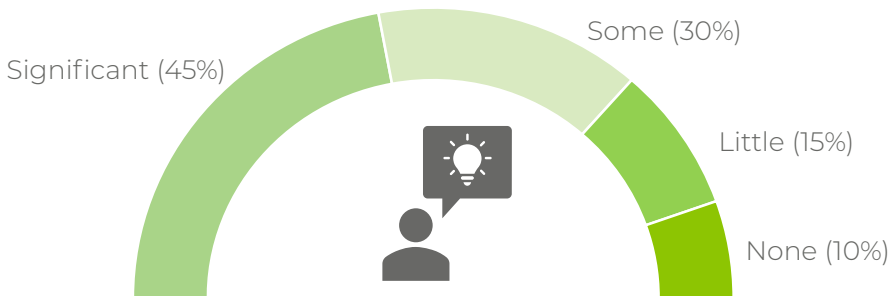


Recommendations for Improvement

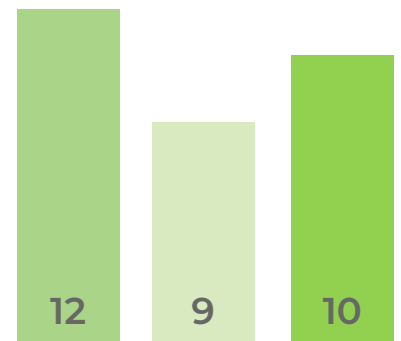
-  Suggestions for email / junk issues
-  Opportunities in monthly newsletter
-  Links to impact stories and events



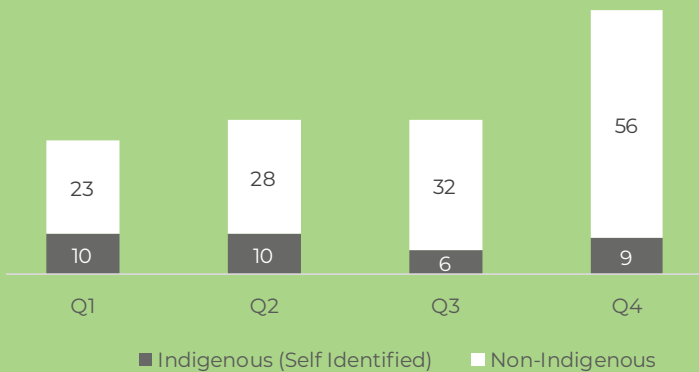
Understanding of SPOR modules (level of understanding of concepts)



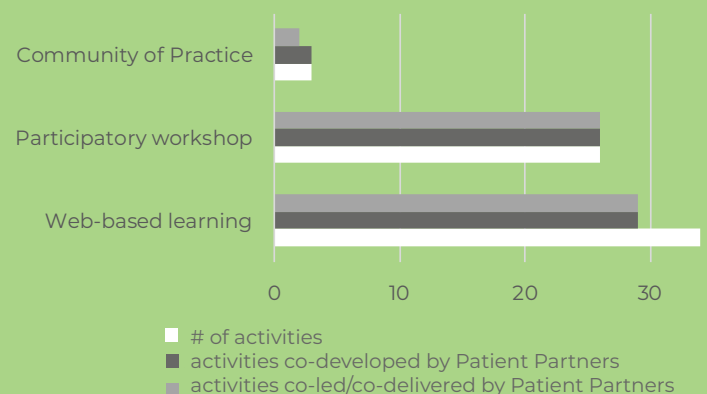
Attendance at SPOR modules



Patients Engaged with SCPOR



Patient Engagement in SCPOR Activities



Methods Platform

Patient-Oriented Research Level of Engagement Tool (PORLET) aims to measure the degree to which projects meet the definition of patient-oriented research as outlined by CIHR. In the past fiscal year, the PORLET team had an article published, conducted reliability analysis to determine the tool's strengths and weaknesses and began development of a companion document for the tool.

To continue **Growing Expertise in POR Methodologies**, the methods team hosted several workshops focused on developing expertise in clinical trials research, qualitative research methods and virtual engagement with Patient Partners in a new pandemic world.

Affiliated Researcher Alliance

3 ARA
events



150 active
members



Building Research Collaborations was achieved through the development of a searchable database highlighting expertise of Affiliated Research Alliance (ARA) members, which would encourage the creation of research teams with complimentary skill sets. The database was accessed over 500 times and allowed SCPOR staff to connect members with other researchers and services such as affiliated labs.

During Saskatchewan Health Research Showcase, a networking event was held to connect Patient Partners to researchers. Matching algorithms were developed collaboratively with colleagues from the USask Department of Computer Science that focused on establishing meaningful connections among participants. In a follow up survey, all respondents noted they found the event useful and made at least one new connection, while 70% of respondents claimed to have made two or more new connections.

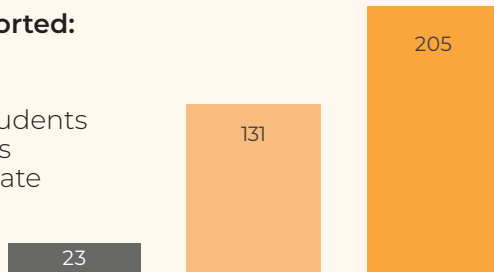


Affiliated Labs

Canadian Hub for Applied and Social Research (CHASR) provided in-kind support services to Saskatchewan POR teams. In clinical trials, CHASR supported a multi-site randomized control trial (RCT) to test the effectiveness of home-based video intervention plus behavioural contact on improving kidney transplant candidates' medication adherence compared to usual care.

CHASR supported:

- Graduate Students
- POR Projects
- Undergraduate Students



Clinical Research Support Unit (CRSU) provided support to 36 unique POR studies, whose findings have been published, presented or have affected local decision making. Examples include understanding complication rates associated with totally implanted venous access devices in the arm versus chest, accuracy of pedicle screw placement with X-ray versus O-arm image guided navigation and further understanding of cervical biopsies, specifically excision correlation and the effect of diagnosis and access to a tertiary centre.

Pedicle screw placement researcher received the Canadian Medical Hall of Fame award!

Advanced Diagnostic Research Lab (ADRL) conducted work that led to meaningful improvement in performing POR, focusing on delivering more personalized treatment and avoiding unnecessary and potentially harmful treatments.

Clinical trials included that of an **early warning system for Saskatchewan patients with Acute Myeloid Leukemia (AML)**. ADRL's experience in rapid mutation profiling techniques was instrumental in developing a real-world clinical trial aimed at improving non-invasive monitoring of treatment responses in patients with AML using blood samples. The trial has provided the health care team with more time to plan and optimize treatment regimens in approximately 40% of AML relapse patients, which is expected to improve cure rates. It is anticipated the early warning system will eventually replace the present standard detection method of a bone marrow biopsy.

Rapid Identification of Acquired and Hereditary BRCA1/2 Mutations in Patients with Ovarian Cancer through analysis of Tumor Tissue DNA in Saskatchewan, a randomized control trial, dramatically reduced wait times for patients and their oncologists and led to significant progress in improving patient access to timely BRCA1/2 testing, with local access decreasing wait times from 2-6 months to under two weeks, resulting in significant cost savings. Ovarian cancer is the second most common, but deadliest of the gynecologic cancers with approximately 20% of ovarian cancers resulting from hereditary or acquired BRCA1/2 mutations.

Clinical Trials Support Unit (CTSU) provided support for 26 real world clinical trials well positioned to change health outcomes and support healthcare decision makers by bringing the latest approaches in patient care to the province, providing patient participants in the trials with state-of-the-art treatments delivered in a rigorous and well-monitored manner, training for participating physicians in leading edge strategies to pass on to colleagues thereby proliferating knowledge throughout the healthcare system and engaging parents in Canadian Childhood Cannabinoid Clinical Trials (C4T) in planning for a new clinical trial.

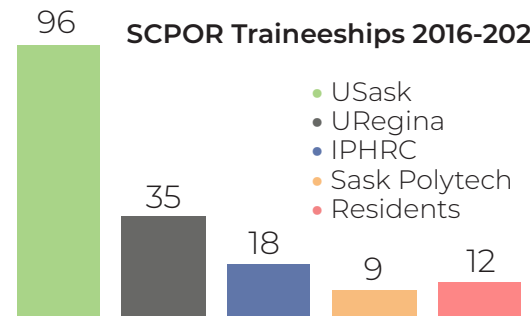
Training & Capacity Development

The Training and Capacity Development (TCD) platform engaged a diverse group of 70 POR trainees with a variety of disciplines, projects and KT products, and awarded several scholarships valued at over \$2M.

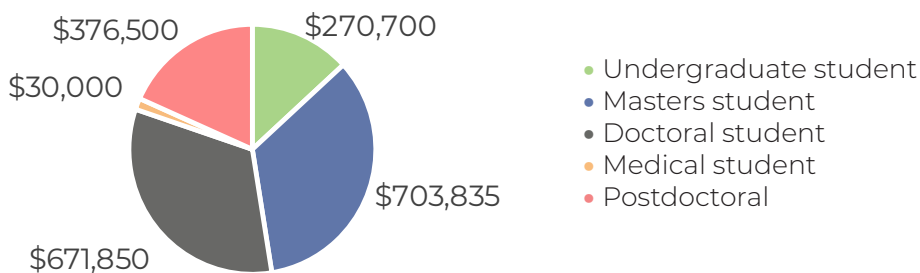
SCPOR Traineeships 2020-2021



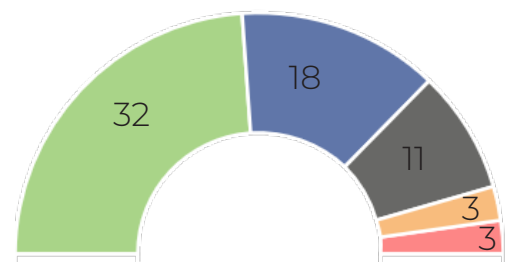
SCPOR Traineeships 2016-2020



Value of Scholarships Awarded by SCPOR



Distribution of Scholarships Awarded by SCPOR



Over the past year, SCPOR moved many of our offerings online as a result of the COVID-19 pandemic. Pivoting from in-person to virtual delivery allowed these workshops to reach a wider audience. The **SPOR Modules**, designed to equip patients, researchers and other stakeholders with the skills necessary to engage meaningfully in a variety of POR roles, moved online in three separate sessions intended to break the content and discussions into manageable virtual sessions for the attendees. SCPOR's **Building Research Relationships with Indigenous Communities** and **Realizing Indigenous Rights and Responsibilities in Research** also pivoted to online delivery, utilizing innovative methods to maintain the personalization found in a classroom setting.

Saskatchewan Health Research Showcase also moved to an online platform. The event, co-hosted with Saskatchewan Health Authority featured three days of exciting Saskatchewan health research and over 100 posters. With 435 attendees, the first virtual Research Showcase was a success.

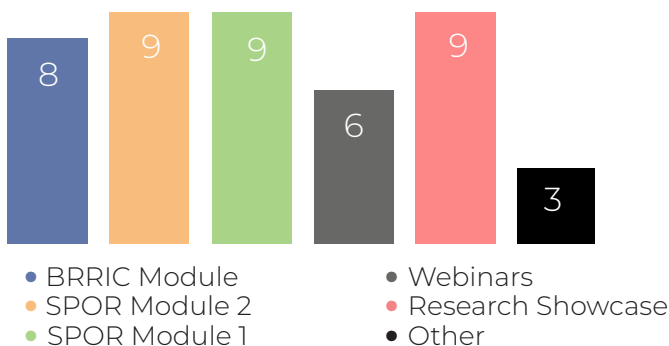
Trainee short film competition winners:

- *Patients first, karate always* - Heather Nelson, SaskPolytech Practical Nursing Program
- *Unifying for Health Equity: Revitalizing the Saskatchewan Health System through Patient Oriented Research* -Lindsey Boechler, Sask Polytech Paramedic Program
- *Knowledge Translation* - Eric Kwabia, Johnson Shoyama School of Public Policy

Trainee Knowledge Translation Products included tools, poster presentations, journal articles, videos, manuscripts, websites, media interviews and oral presentations.

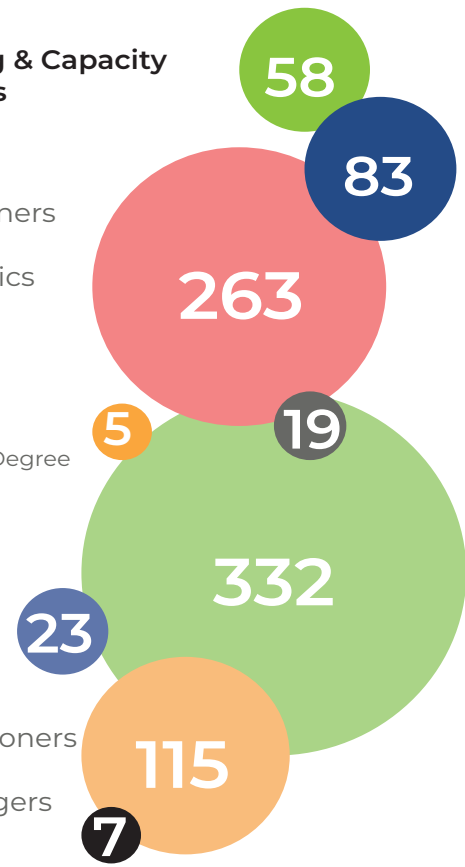
Training & Capacity Development Activities included web-based learning, participatory workshops, lectures or seminars, courses at post-secondary institutions, thesis supervision, mentorship and participation in a community of practice.

SCPOR Online Training & Event Sessions



Participants in Training & Capacity Development Activities

- SUPPORT Unit Staff
- Patients/Patient Partners
- Researchers/Academics
- Trainees -Postdoctoral Fellows
- Trainees -Post Health Professional Degree
- Trainees - Students
- Clinical Scientists
- Health System/ Care Practitioners/ Public Health Practitioners
- Health System Managers



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Knowledge Translation

Knowledge Translation

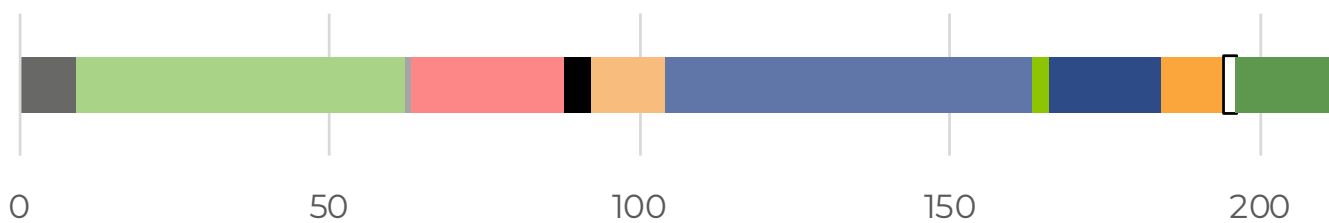
SCPOR-supported projects developed hundreds of KT products in the 2020/21 year. Some of the highlights are as follows:

In response to the COVID-19 pandemic, Dr. Roslyn Compton's Saskatchewan Long Term Care Network developed a video *Not just a Visitor: The essential role of family members in long-term care* as did Dr. Shela Harani's team, which included SCPOR trainee Megan Pearce, to promote, protect and support breastfeeding during the pandemic.

Findings of advancing dementia care in rural and remote Saskatchewan communities was presented by Dr. Juanita Bascu and team at eight major conferences and to the Government of Saskatchewan Seniors' Initiative Community Care Branch. Dementia interventions were published in notable journals and generated nine media products.

Dr. Michelle Pavloff's research on *Supporting Farmers' Mental Health* was showcased in an interview that aired on CBC: the Afternoon Edition, one of many exciting KT initiatives implemented by the team.

KT Products or Events Produced or Supported by SCPOR



- Plain Language Publication
- Peer-Reviewed Journal Articles
- Books/Book Chapters
- Reports/Technical Reports
- Education Material
- Social Media Campaigns
- Conference Presentations
- KT-Related Workshops
- KT-Related meetings
- KT-Related Webinars
- Online KT Tools
- Other

Indigenous Research

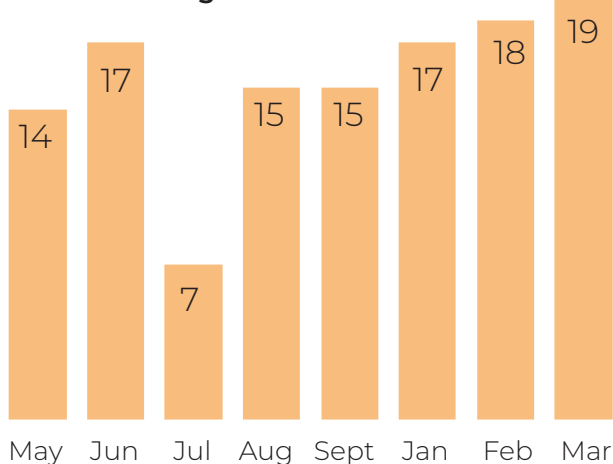


The **Indigenous Research Engagement & Expertise (IREE) Platform** continued to launch new initiatives and provide ongoing support to those engaged in patient-oriented research.

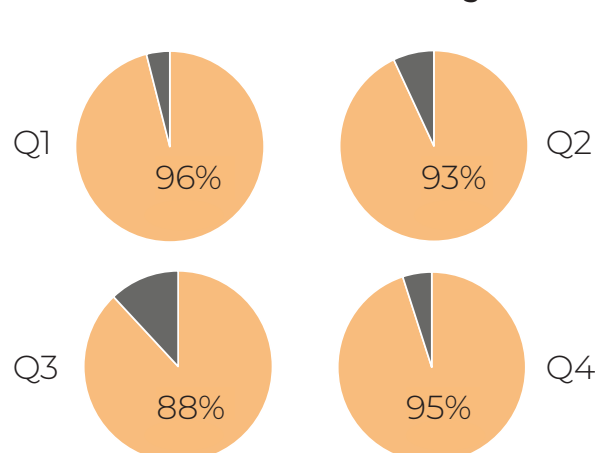
The first of its kind in Canada the IREE platform ensures that Indigenous voices, knowledges, values and rights as they relate to health research are respected, represented and inherent in all SCPOR activities, particularly in the areas of community & patient engagement.

- 17** research projects focused on or exclusively for Indigenous peoples as partners in the research
- 12** IPHRC / SCPOR new traineeships launched
- 14** IHAC members representing various community health organizations, governance bodies, Patient Partners and Knowledge Keepers
- 122** # of BRRIC training module attendees

BRRIC Training Module Attendance



% BRRIC Attendee Understanding



At SCPOR, Indigenous peoples are represented on the Oversight Committee, SCPOR management & staff, PPAC and IHAC, and Indigenous voice are engaged in a variety of activities:



Building Research Relationships in Indigenous Communities (BRRIC) training module provides participants with practical skills and best practices for engaging with indigenous peoples in order to produce research that is effective and benefits Indigenous communities.



Realizing Rights & Responsibilities in Indigenous Research (RIRRR), a companion workshop developed and delivered by the IREE team aims to educate, inform and promote Indigenous self-determination when engaging with researchers and research projects from outside of the community.



Knowledge Keepers serve as a resource for SCPOR researchers and staff seeking information and advice related to respectful Indigenous engagement. They also provide blessings, prayers and opening remarks to start meetings, events and training sessions off in a good way.



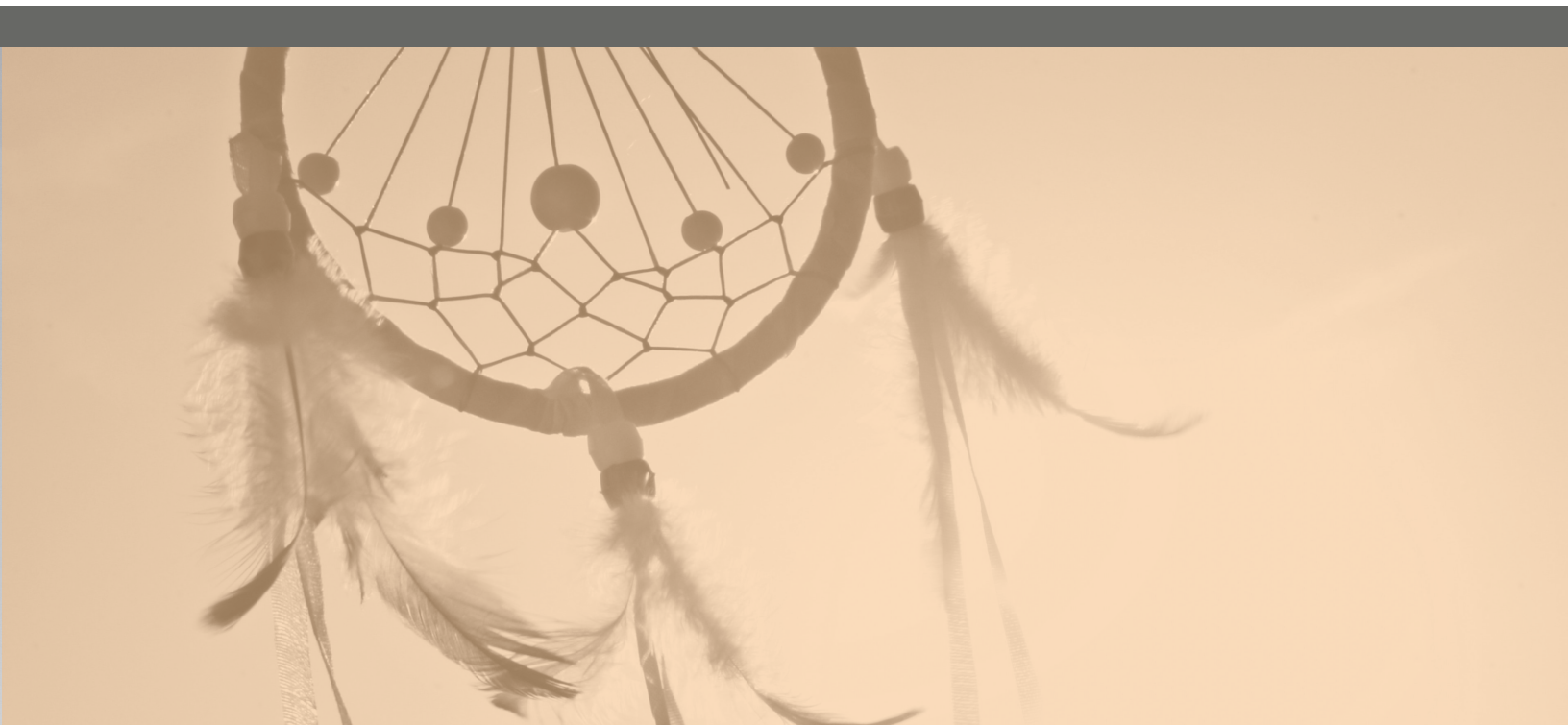
IREE staff provide a culturally safe environment that allows participants to ask questions and share stories in a safe space without fear of retribution or judgment.



Researchers are encouraged to follow cultural protocols, such as providing cloth and tobacco in exchange for knowledge and participation in research projects.



IHAC members are invited to provide feedback on Indigenous research projects and SCPOR initiatives





Data Services

Data Highlights.

Over the past year, data work plans were developed to execute the implementation of the data infrastructure, including data literacy and a data sharing framework. An environmental scan of local and national data literacy assets was completed, and a privacy consultant and data architect were added to the team.

The data team supported the SHA through the completion of a health networks evaluation, and continues to work on the Mental Health & Addictions research program.

Data Linkages for the following projects were made to administrative health databases:

- Canadian Mother-Child Cohort: Cough and cold products containing opioid and utilization patterns in the pediatric population
- Analysis of Linked Rural and Remote Memory Clinic and Administrative Health Data
- TRANS: Trans Research and Navigation Saskatchewan - Evaluating the Impact of Peer Navigators on the Health of People who are Trans and Gender Diverse
- Do Fluoroquinolones affect the Lens Zonules?
- Development and Evaluation of a Remote Robotic Ultrasound Clinic Model to Improve Access to Medical Imaging in Rural, Remote and Indigenous Communities

Future work plans include:



Coordinated data intake request process



Data/information governance framework



Centralized data repository with remote access



Data literacy supports throughout

Impact Stories

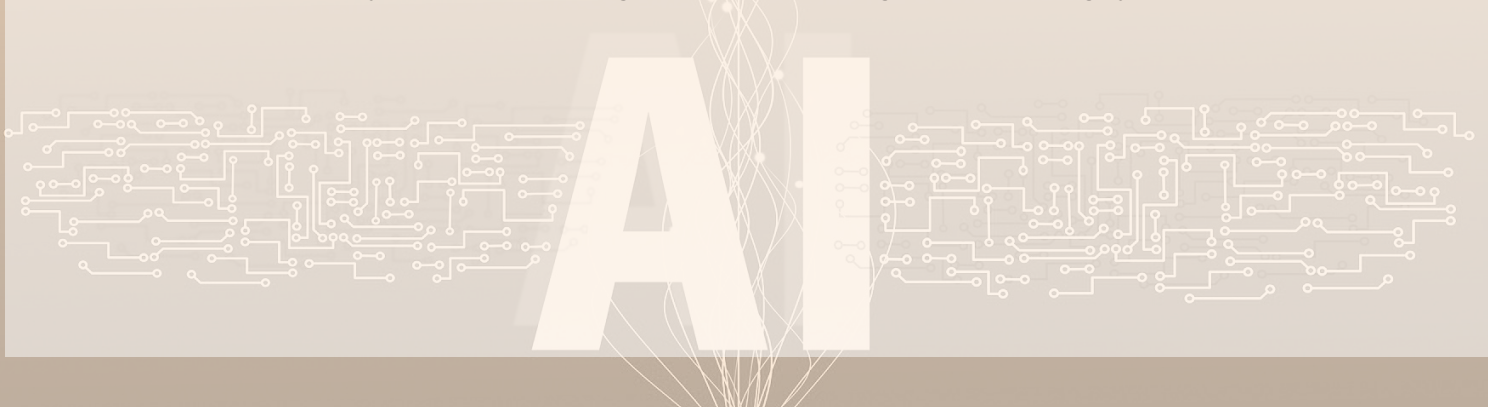
Improving Lung Cancer Diagnosis with Novel Artificial Intelligence Imaging Analytics **Principal Investigator: Paul Babyn**

With increased use of cross-sectional imaging modalities such as computed tomography, a common problem in medical imaging is the inability to accurately classify a lung nodule as either benign (noncancerous) or malignant (cancerous). This project aims to identify groups of cancerous nodules early so that patients can be treated sooner, and for patients with benign nodules, avoid undue risk from biopsies and relieve the mental stress of thinking they may have cancer. The patient- and clinician-identified research objectives of this project are to: evaluate the accuracy of artificial intelligence (AI) imaging analytics in the diagnosis of lung cancer; assess how we can better empower patients in the management of their lung nodules; and determine whether AI has the potential to reduce health care costs in the provincial health care system.

In preparation for this project, the research team, with support from SCPOR, identified and invited 17 patients from urban, rural, and remote communities across Saskatchewan to participate in a workshop to learn about their perceptions regarding AI and what their priorities were for AI in radiology. While some patients initially expressed ambivalence in placing trust in something that was unknown to them, upon learning more about AI, patients identified many priority areas in which it could improve radiology. These priorities included improving access to medical imaging and reducing wait times; reducing time to diagnosis; increasing diagnostic accuracy; improving communication with healthcare providers; and empowering patients. This information will be used to inform the clinical implementation of AI and explore the implications of using AI for lung cancer diagnosis in the healthcare system.

The multidisciplinary team includes two Patient Partners, researchers, clinicians, policy advisors, radiologists and one SCPOR funded trainee. The project is funded by a SHRF/SCPOR Sprout Grant and the team is creating industry collaborations with start-up tech companies to discover how they can best use AI in radiology in Saskatchewan, Canada, and beyond. Team members expressed that Patient Partners have been invaluable in bringing patient perspectives to the project. Empowered through shared decision-making, Patient Partners were intimately involved in identifying research objectives and curating interview questions. Patient Partners also played a critical role in identifying themes at a knowledge exchange workshop hosted by the multidisciplinary team.

Findings from the team's research have been published in the Journal of the American College of Radiology and Healthcare Management Forum and have been presented at the Radiological Society of North America Scientific Assembly and Annual Meeting, Canadian Association of Radiologists Annual Scientific Meeting, Centre for the Study of Science and Innovation Policy Research Forum, and the SCPOR supported Saskatchewan Health Research Showcase. The project is in the data collection and analysis phase. An incremental step to initiating change in practice, initial project findings have created awareness and interest nationally and internationally with respect to the potential cost impact on the health care system when adding AI to a current lung nodule scoring system.



Impact Stories

Saskatchewan Farmer and Rancher Mental Health (FARMh) Principal Investigator: Michelle Pavloff

When Michelle Pavloff sat down at a farm-to-table restaurant to meet with her patient-oriented research (POR) team for the first time, she didn't know just how significant the input from her patient family partners would be, nor what an impact farm culture would have on the direction of her project.

As Principal Investigator on the Saskatchewan Farmer and Rancher Mental Health (FARMh) Initiative, Michelle was interested in learning what programs, resources and interventions would help support farmers and ranchers who, globally, were found to have higher rates of psychological distress, depression and suicide when compared with the general population. It would be Michelle's first-time conducting patient-oriented research, and in true-POR form, she invited patient family partners to join her team at the outset of the research process. Even though Michelle had some initial ideas for the project, she soon learned the input of patient family partners would prove invaluable in leading the direction of the research.

"Early on, our patient family partners identified that we really need to figure out what farm culture is and what it means to be part of the farm community," says Michelle. "That really drove the way we designed the program and data collection, and hopefully will inform some of our findings. We've been able to take the patient family partners ideas and run with them. Others on the research team are humbled by the expertise and input our patient family partners offer."

Patients as partners in research

Patient-oriented research engages patients, their families, and caregivers as partners on the research team. POR teams are multi-disciplinary – Michelle's team includes researchers, healthcare providers, and industry partners in addition to patient family partners.

Thanks to supports like SCPOR's Patient Engagement Application Development Award (PEADA) funding, which supports research teams in engaging patient family partners in the grant development phase of their research, patient family partners were recruited at the onset of the project. "PEADA funding was so instrumental in us getting that Sprout Grant," Michelle acknowledges. "That face-to-face engagement to have those half day meetings was really important for establishing relationships within the team."

Confirms Justine Lustig, patient family partner on the team, "Overall, I have felt really included and valued. It's been empowering to be heard in a room full of researchers. There was a lot of shop talk between the researchers, and I'd be like hey – I'm a farmer, I don't know what that means, and they were really good at explaining what they were talking about."

Justine grew up on a grain farm and later ran a cattle ranch with her husband. Her interest in the project came from her desire to end the stigma around mental health and ensure access to those in need of support. "I see a lot of my family members and relatives being very stoic and silent about their mental health, and they're all farmers. It's exciting to be part of something that's going to make an impact on people like my dad."

Patient family partner Shari Laventure, who has spent her whole life in the farm industry, reached out to take part in Michelle's research project because of her own personal experiences, having lost her younger brother to suicide. She wanted to be part of a solution that better supported the farmer/rancher population in the mental health system.

As partners on the research team, Shari, Justine and other patient family partners have contributed throughout the project, from identifying priorities and opportunities for knowledge translation to interviewing participants. They've also played a major role in ensuring farm culture was considered throughout.

Farm Culture

Interpersonal interaction plays a significant role in farm culture. Says Michelle, “Patient family partners really advocated for going to the farms to collect data - build relationships as part of the culturally appropriate way to collect data.”

Many interviews that were initially intended to take place in person on the farms and ranches had to occur on the phone due to COVID restrictions. Despite that, the one-on-one connection between participants and patient family partners have proven to be impactful. Adds Shari, “I’m a pretty strong person. After some of these calls, I really had to do a check on myself. Hearing the passion and sometimes the hopelessness in their voices; hearing the gratitude that there’s someone out there trying to do something and make a difference - it’s humbling. Afterwards, I’m emotionally exhausted – elated, as well, because they were so open to sharing. These interviews are going to direct us in the ways we need to go.”

Farm culture has played a role beyond the research itself, as was evident by an initiative aimed to raise funds for the project. When a group got together to syndicate a heifer sale, it helped the team see how much support their research had from the farming and ranching community.

“It’s a common way for people to donate – a real grass roots effort to support a project,” says Justine. “If there’s a lot of movement behind the project, they’ll increase the value of this animal to show their support. The fact that people just kept bidding and driving up the price of this animal shows that there’s actually more support for this than we thought there was!”

While part of farm culture brings people and communities together, another aspect holds many back. The team acknowledges a reluctance for this population to seek help for mental health support and recognizes that simply having the systems in place isn’t always enough to support farmers and ranchers. Says Michelle, “The problem is that farmers and ranchers are not always going to seek mental health services. This leads to either staying at home to struggle alone, dying by suicide, or not having the capacity to be productive in their work.”

Another issue stems from the fact that there is no nine to five in this industry, and it can lead to farmers and ranchers delaying their health care. As Justine states, “There should be continuing education for people who are working in rural settings to learn about farmers. You can’t just tell them to take a week off work, because they have to get the wheat in the bin. Some of them are not going to come into the doctor until it’s too late. An injury can turn into a mental health problem because it makes them feel unproductive.”

“The goal,” adds Shari, “is we develop for Saskatchewan farmers and ranchers a safe place where they are going to get the help they may be scared to ask for. There’s a lot of stigma, especially in the rural community. It’s farm culture – it’s not the same as everywhere else.”

Why the research matters

At the end of the day, the research is about helping the people who need support. Says Shari, “Hopefully we’re able to get the supports and the help needed. My goal every day when I wake up, because I lost a younger sibling to mental health, is to maybe save one life. If I can accomplish that, then I’ll be happy.”

“There was a recent survey about burnout in the farm sector, and there are an alarming number of farmers that feel acutely stressed all the time and burnt out,” adds Justine. “I hope that through this research, we can show healthcare providers how important it is to learn about the communities they’re working in so they can be more prepared to help the people they’re trying to support.”

As their first patient-oriented research project, the team has fully embraced the concept. Says Justine, “I can’t believe that research is usually done without patients included because how could a room of full researchers actually know what’s helpful unless they ask the people that they’re trying to help? I want to do whatever I can to help POR become more mainstream because it’s the only way research should be done.”

Michelle agrees. “I would not do another project again that was not POR. I found it a very enriching experience to work with people with lived experiences on the team. Their ideas are better than mine and they’re contributing more than I could ever have imagined. This has been a very enriching experience for me.”

Impact Stories

Towards Improving the Quality of Life for Long Term Care Residents: Exploring the Current Factors Affecting Healthcare Provision and Health Outcomes **Principal Investigator: Roslyn Compton**

Relationships play a significant role in patient-oriented research (POR). Whether it is the relationship between research team members, with participants or even with the research itself, different relationships provide different perspectives. What Roslyn Compton and her team have learned while researching in long-term care (LTC) in Saskatchewan is that relationships are at the core of everything they do, and that by focusing on the dynamics each relationship brings to the team, they are able to learn more and achieve more meaning in their work.

Roslyn Compton's research project was driven by the needs of family members looking for the best care places for older adults. Adds Alison Craswell, "Roslyn wanted to improve access to healthcare for people in long-term care. Our model here in Australia included a nurse practitioner student, homegrown within the LTC facility, which was something Roslyn thought would work in the regional and rural areas of Saskatchewan."

The pre-existing relationship Compton held with Craswell and her team in Australia had provided her with a successful research example in the LTC system. Affirms Craswell, "This research is aiming to replicate the heart of the Australian study, including talking to older people in terms of their needs – learning what works for them and their families."

As the project started to take shape, Compton affirmed her commitment to POR. As a POR team, each member, regardless of their role, is an equal partner on the team. "I'm the co-lead - Principal Investigator is just a title," says Compton. "The project is co-led by all of us – not just me. Our team practices true patient-oriented research."

Comprised of seven to eight core members that sometimes evolves to 12-15 members, the team includes Resident Family Partners, researchers, research assistants, policy makers, physicians and other health system staff. Says Compton, "We have people that come and go, people that stay. We accommodate all those needs. Some Family Partners come and go based on interests or health factors, because given the nature of our research, they include a lot of older adults."

"Sometimes roles and boundaries overlap," adds Allison Cammer, dietician, and researcher on the team. "I'm here as a researcher, but we've had a family member in long-term care, so it's been a personal journey as well. It allows us to wear different hats and we can honour the different experiences we each bring to the table."

Marilyn Barlow, who joined the team as a Resident Family Partner, and is now a Resident Family Partner Research Assistant, agrees. "I'm a retired nurse, and I thought I could bring my voice to the table. My mother is independent living at home, but at some point, we're all going to need to depend on long-term care."

And what the team has learned is that long-term care requires so much more than physical care. While the goal, in the words of Roslyn, may be, "get the data to provide the evidence to change the model to meet the needs of residents, families and staff" - something that sounds simple, straightforward, and rather quantitative - the reality is that meaningful long-term care is about more than numbers and calculations. "The true focus of the study has been quality of life," says Compton. "And the processes that we've established revolve around quality of life for the residents and family members and making sure quality of life is integral to new models of care in long-term care."

The team agrees. "One of the things that was really important to the Resident Family Partners was that we include quality of life as an index," says Katie Ottley, a Psychology PhD student and research assistant. "There was significant time put into coming up with a quality-of-life measure."

Resident Family Partners collect most of the data from residents and their family members using the InterRAI Self-Reported Quality of Life Survey for Long-Term Care facilities (Nursing Homes)© (InterRAI QoL-LTCF©) and interviews. The experience has been mutually beneficial. While the residents and family members provide the team with the data they need, the Resident Family Partners are helping to affirm the resident and family experiences and are expressing – either directly or indirectly – that their input matters.

"It's important to get the residents' perspectives," says Barlow. "That's what intrigued me the most about this project, is that we'd be interviewing the residents. And what I found when I was completing the [InterRAI QoL-LTCF©] quality-of-life questionnaire with the residents, even some of those living with dementia, is that the responses were meaningful. People would thank me for asking them questions. It's not the physical needs – it's the emotional needs that matter most to them – the relationships and validating some of their responses. You can say to the residents, 'Yes, I've heard that a lot.' It makes them feel like they're not alone."

"We rely on our Resident Family Partners to really see and understand the residents," says Compton. "It's the notes in the margin – the little comments made on the InterRAI QoL-LTCF© tool that have been significant in determining the story – not just the numbers."

Resident Family Partners have also played a large role in knowledge translation. The team agrees that POR is about more than academic outcomes – sometimes it's necessary to get information out there in the moment, for example, through conversations or other less formal mediums, such as posters or newsletters, rather than waiting for a publication. "The more you become aware of a situation, the easier it is for you to talk," explains Barlow. "Even engaging with people in my social network or opening up conversations with my mom – those conversations can be hard. But relating it to the research – how do you feel about it? – has made it easier to have the conversation."

Change has also come from resident suggestions during the interviews. Says Barlow, "I've been able to relay a couple of things the residents have suggested to the managers at the long-term care home, and they have followed through. Having the ability to do that really feels like you're making a difference!"

Adds Ottley, "A resident might be nervous to pass on a message that says something negative but sharing it with an external entity, like the Resident Family Partner, doesn't assume the same level of risk. It becomes a way we can affect change right now to improve quality of life."

Whether influencing change on the spot or seeking new opportunities to share their findings, the team has worked together to bring ideas to fruition.

Says Cammer, "The POR team pushes for non-traditional risk taking. Taking leaps, knowing you're supported by the team. For example, Roslyn and Marilyn had a courageous conversation on agism for the human rights commission, with Marilyn bringing that real life perspective based on what she heard from the residents. We've also utilized video – a very non-traditional way to help demystify research."

At the end of the day, it's all about meaningfulness. As Cammer puts it, "It all boils down to - this has to be meaningful to researchers, residents and their families, and the long-term care system. Researchers, Resident Family Partners, decision makers from the health authority, all trying to make a difference - that's key to why this works. That 'meaningful' speaks to engagement."

However, what's meaningful to one may not be meaningful to another. Ottley, who admits to often having a quantitative focus, states, "Data can be perceived so differently. Resident Family Partners read graphs very differently from what I read as a researcher. When analyzing and displaying data, sometimes we have to make compromises that ensures the integrity of the research but also meets the needs of both the research community and those with lived experiences."

Adds Compton, "It's not easy to write POR. Trying to translate language that is understood and acceptable as quality by all members of the team – it can be interpreted differently, priorities about what should be included are different. That whole process has been significant in the fact that you don't just get to put an article out there – you need to ensure everyone sees themselves in the writing – it takes a lot of negotiation."

And that's where teamwork and supports from organizations like SCPOR become essential. "It's a very respectful team," says Cammer. "What I found most valuable is keeping our direction and focus on what we should be accountable to in the research. Our team helps to maintain that focus and reminds us why those things are important and what we should be doing. The nature of POR, the SCPOR training we've received and the PORLET [SCPOR's Patient-Oriented Research Level of Engagement Tool] all help us keep our eyes on the prize and ensure the work remains meaningful."

Now, more than ever, relationships within the team have become significant. Cammer states, "COVID-19 has had such a demoralizing effect, and especially on long-term care. It would be very easy to become desolate about it but working with Resident Family Partners helps us remember that there's a reason we're doing this and that there's hope. It's been very helpful in terms of research – in terms of everything, really!"

Compton sums up the importance of the team and the relationships they've built, both internal and external to the team. "Building relationships – they're so valuable. We have built a team that is passionate about the research – it's not just research for research's sake. It's not just about the outcome, but also the journey."