

# Saskatchewan Centre for Patient-Oriented Research



Annual Report  
2019-2020

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Engaging Patients. Supporting Researchers.  
Improving Health Together.

# SCPOR Partners

The Saskatchewan Centre for Patient-Oriented Research (SCPOR) is a partnership of eight Saskatchewan organizations. Our partners play a key role in supporting patient-oriented research (POR) across Saskatchewan. The partner organizations provide financial and in-kind support, with representatives from each partner organization participating on the Oversight Committee (OC) and in a variety of other programs. Together, we work to provide the services and supports needed to further patient-oriented research in Saskatchewan.



# Oversight Committee



**Cliff Ballantyne**

Patient Partner

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

**Sandra Blevins**, Dean, School of Nursing  
and School of Health Sciences  
Saskatchewan Polytechnic

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

**Phoebe De Ciman**, Director,  
Learning and Labour Market Priorities,  
Ministry of Advanced Education  
Government of Saskatchewan

**Heather Dyck**

Patient Partner

**Marg Friesen**, Minister of Health  
Métis Nation - Saskatchewan

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

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

**Malcolm King**, Scientific Director  
SCPOR

**Gabe Lafond**, Executive Director,  
First Nations and Métis Health  
Saskatchewan Health Authority

**Jackie Mann**, Executive Director  
SCPOR

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

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

**Dolores Pahtayken**

Patient Partner

**David Pratt**, Vice-Chief  
Federation of Sovereign Indigenous Nations

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

**Tracey Sherin**

Chief Executive Officer  
Health Quality Council

**Candace Skrapek**

Patient Partner

**Preston Smith**

Dean of Medicine  
University of Saskatchewan

**Tanya Verrall**, Director,  
Analysis and Research Partnerships  
Health Quality Council

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

# Patient Partner Advisory Committee



**Cliff Ballantyne**  
**Janet Barnes**  
**Heather Dyck**

**Diana Ermel**  
**Kathy Evans**  
**Janet Gunderson**

**Dale Hall**  
**Colleen Hamilton**  
**Maggie King**  
**J. Tyler Moss**

**Margaret Larocque**  
**Janice Osecap**  
**Candace Skrapek**  
**Lynn Thompson**



# Indigenous Health Advisory Council

**Louise Bird**  
Patient Partner

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

**Curtis Delorme**, *Youth Department -  
Team Lead, Health Services*  
File Hills Qu'Appelle Tribal Council

**Jessica Dieter**  
Patient Partner

**Terri Hansen-Gardiner**  
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

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

**Judy Pelly**  
Knowledge Keeper

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

# Message from the Directors



We are proud to have witnessed the significant progress made in the advancement of patient-oriented research throughout Saskatchewan in 2019/20. The engagement and widespread participation of Patient Partners through SCPOR activities have been key factors in our success. The leadership and participation of SCPOR partners and partner organizations have been remarkable throughout the year, particularly with their participation in drafting SCPOR's grant submission for SPOR Phase II.

Our mid-point evaluation confirmed that we are heading in the right direction. External reviewers provided us with a comprehensive review, making note of achievements including, "SCPOR and its Partners have encouraged POR and begun to engender a culture of patient engagement in health research."

Through the year, SCPOR's partner organizations contributed a variety of ways. Eleven SPROUT grants were issued with Saskatchewan Health Research Foundation (SHRF), while the Saskatchewan Health Authority (SHA) supported fourteen health research projects, and both the SHA and the Saskatchewan Health Quality Council (HQC) supported several appropriateness of care projects. The first Saskatchewan research showcase and award show was hosted in Regina by the SHA, SHRF and SCPOR. Our work with three partner educational institutions: University of Saskatchewan (USask), University of Regina (URegina) and Saskatchewan Polytechnic (Sask Polytech), saw success in the support of more than seventy new traineeships in POR. In partnership with HQC and eHealth, SCPOR was able to advance the Mental Health and Addictions Program of Research, which includes the linking of key databases within our province.

The depth and breadth of work with our Patient Partners continued to grow. The Indigenous Health Advisory Council (IHAC) was successfully re-launched. With representation from all key

Indigenous organizations and stakeholders, this new team quickly got to work, advising SCPOR on key initiatives, such as our two learning modules; Building Research Relationships with Indigenous Communities (BRRIC) and Realizing Indigenous Rights and Responsibilities in Research (RIRRR).

The SCPOR Patient Partner Advisory Committee (PPAC) identified and solved the need for a better mechanism for connecting Patient Partners with researchers by co-developing the Patient & Researcher Connection Site (P&RCS). Among other projects, Patient Partners were actively engaged in the Patient Partner Experience Evaluation project as well as the USask Respiratory Research Centre and James Lind Alliance project focusing on obstructive sleep apnea.

We were thrilled to see the growth of the Associated Researcher Alliance (ARA) this year, from 22 to 83 members. Many researchers presented at and participated in events focused on growing capacity in patient-oriented research in Saskatchewan.

In the next year, we will focus on finalizing our SPOR Phase II grant submission, and continuing the key planned activities within our strategic plan.

Finally and most importantly, we want to express our gratitude to all of the Patient Partners, researchers, partner organizations and staff who have been dedicated to advancing patient-oriented research in Saskatchewan.

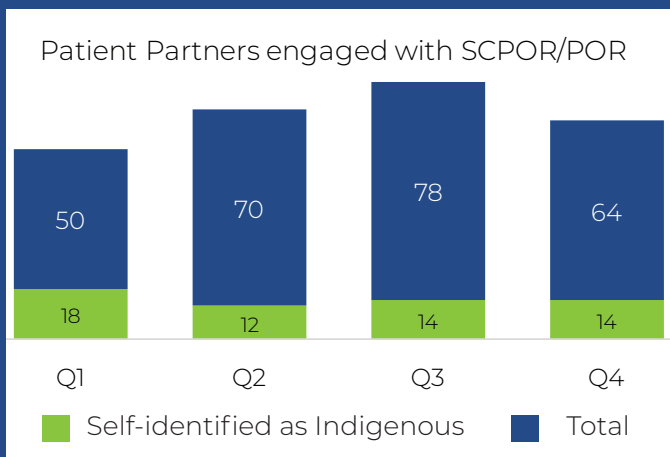
**Jackie Mann,**  
Executive Director

**Malcolm King,**  
Scientific Director

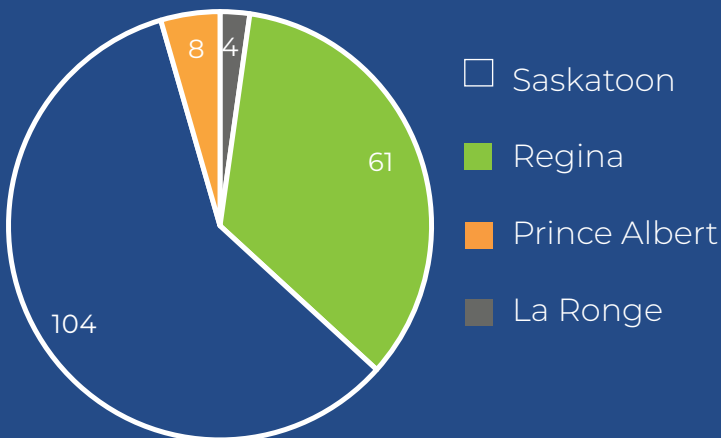
 **SCPOR** Saskatchewan Centre for  
Patient-Oriented Research

# Patient Engagement

**Better Impact Database** was used to assess Patient Partner representation in an effort to increase the diversity in SCPOR's pool of Patient Partners. A target of increasing both male Patient Partners as well as those under the age of 50 was identified. Four new PPAC members and two new OC members were added, and both committees achieved increased Indigenous representation in 2019/20.



**SPOR Module Training** was provided in various locations throughout the province. There were 177 participants who increased their understanding of patient-oriented research throughout the year.



**Patient Partners were at the core of the work SCPOR does everyday.** The Patient Engagement Platform ensured Patient Partners continued to play a significant role in health research by surrounding them and the entire research team and health system with supports that encourage patient engagement through every phase of a research project.

**Patient Partners were actively engaged through SCPOR.** Last year, we engaged 130 Patient Partners, 99 new, of whom 40 self-identified as Indigenous.



**PEADA - the Patient Engagement Application Development Award**, which supports research teams to engage Patient Partners from the grant development phase of their research projects, supported 26 teams in 2019/20. Sask Polytech showed their support for the program by stating, "Without PEADA funding, our team would not have been successful in securing a Sprout Grant. These funds directly contributed to our patient family partners having the opportunity to build our proposal and grant application through four face to face meetings with the team."



**STEP - SCPOR Trainee Engagement with Patients Funding**, supports SCPOR trainees by providing funds to support patient engagement activities. This may include Patient Partner honouraria as well as expenses such as travel for research team meetings. Two STEP funded projects were completed with eight more in progress.



**The Patient Partner Experience Evaluation Project**, which was published in the Longwoods Health Care Quarterly Journal, provided SCPOR with valuable information from the Patient Partner perspective. We learned that Patient Partners want greater role clarity at the beginning of their research projects and regular updates throughout. Patient Partners feel the best part of engagement is feeling like valued members of the team. This feedback led us to provide coaching to POR teams with specific attention in these areas.

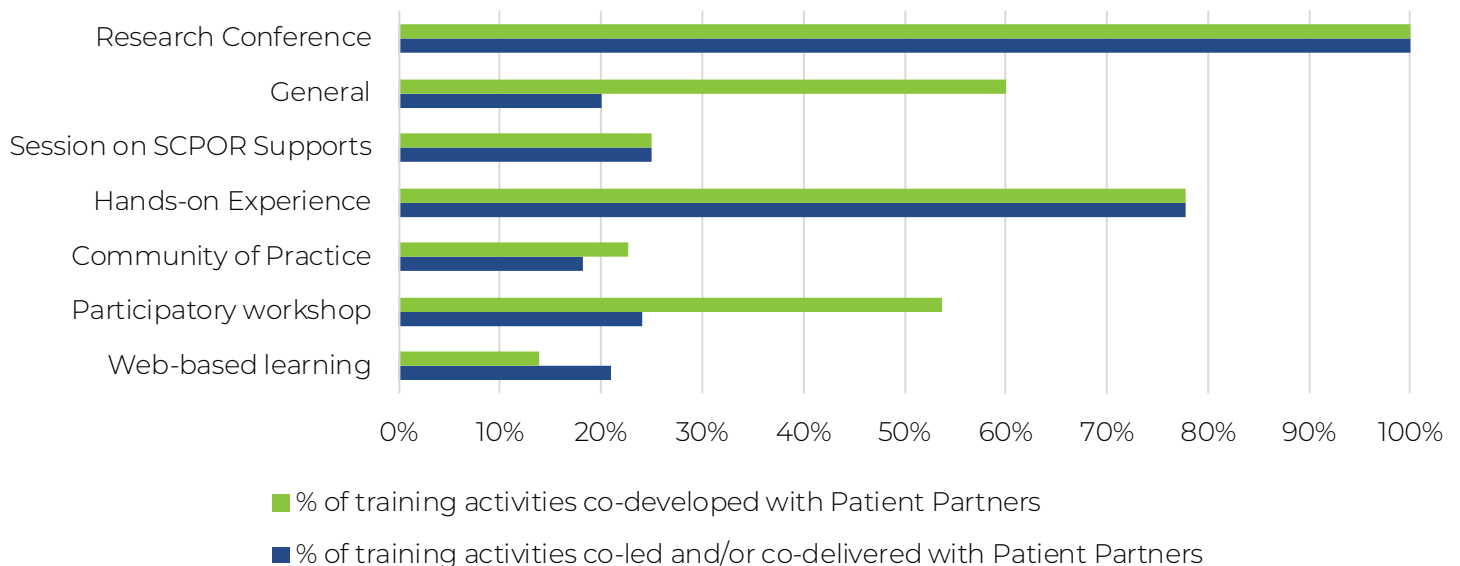
**Patient Partners identified obstructive sleep apnea as a priority** and worked with the USask Respiratory Research Centre and James Lind Alliance to identify treatment evidence gaps to produce a list of top priorities for research.

**The Patient & Researcher Connection Site (P&RCS)** was launched in November of 2019, to increase opportunities for Patient Partners and research teams to engage. In the 2019/20 fiscal year, 31 opportunities were posted, and of those surveyed, 58% of respondents indicated the P&RCS facilitated a connection to a POR team.



**SCPOR shared their secrets to supporting Patient Partners** with the Maritime SPOR SUPPORT Unit. Discussion covered the experience of supporting Patient Partners, particularly through honouraria reimbursement, PPAC development, and specific support of Indigenous Patient Partners. SCPOR shared resources with the Maritime SUPPORT Unit, such as our honouraria policy and advice on internal processes that are used to reimburse Saskatchewan Patient Partners. This information helped the Maritime SUPPORT unit expand their own reimbursement policy and processes so they could provide greater support to their own Patient Partner community.

**Patient Partners were engaged in all areas of SCPOR support and services.** The following shows Patient Partner engagement in the development and delivery of training activities.





# Methods

## The Affiliated Researcher Alliance

(ARA) provides services, supports and opportunities to researchers and connects them with patients, the healthcare system, decision makers and other researchers in POR. In 2019/20, the ARA grew from 22 to 83 researchers!



**12** # of events hosted by Methodologies Platform

# of attendees at Methods Platform events

**436**

**4** # of Meet & Eat events

# of attendees at Meet & Eat events

**129**

**190** # of researchers engaged at Methods Platform events

SCPOR is dedicated to supporting POR researchers through workshops, the Affiliated Researcher Alliance network and collaboration with relevant partners, as well as opportunities designed to advance our members and patient-oriented research!

The Methods Platform focuses on **building research collaborations**. We hosted several networking events throughout the year, and utilized computer algorithms to match participants and encourage meaningful connections. A searchable database highlighting expertise of ARA members was developed, and accessed over 500 times! Through the database, 63 targeted connections were made between members, relevant services and researchers with complimentary skill sets.



SCPOR, in collaboration with Patient Partners, held several workshops over the past year to **build capacity and expertise in patient oriented research methodologies**. These included *Utilizing Sharing Circles as a Research Methodology*, which was co-developed by a local First Nations Knowledge Keeper Rose Roberts, Pragmatic Clinical Trials and Accessing the Network of Networks (N2).

## Highlighting work of local researchers

In 2019/20, five short videos featuring the research projects of Colleen Dell, Donna Goodridge, Brenna Bath, Heather Hadjistavopoulos and Cathy Arnold were produced and received over 1,100 views! Videos can be seen on SCPOR's YouTube channel.

Through its affiliation with SCPOR, **Canadian Hub for Applied and Social Research (CHASR)**, formerly USask Social Sciences Research Laboratories (SSRL), provides in-kind support to teams conducting POR across Saskatchewan. In 2019/20, there were 130 unique POR research studies conducted that received support such as the provision of equipment to conduct data collection activities, survey design consultation, administration, analysis and interpretation, the provision of space to conduct research projects or experiments, transcription support services and the development of maps, geographic information systems (WebGIS) or other cartographic approaches.



Another SCPOR affiliate, **the Advanced Diagnostic Research Laboratory (ADRL)**, focused on research priorities for delivering optimal care to Saskatchewan cancer patients. In 2019/20, great progress was made in targeting the right treatment for the right patient by implementing methods to safely limit toxic therapy in low risk acute leukemia patients. Through the breakdown of complex health care barriers, test turnaround times were shortened from 6 weeks to 16 days for lung cancer patients, providing faster access to life prolonging treatments.

Tests were developed to risk stratify lymphocytic leukemia patients and develop non-invasive blood based monitoring of lung cancer myeloma and acute leukemia patients, validating new and cutting edge tests to ensure they are both appropriate and robust for research and clinical application. High sensitivity monitoring tests, capable of detecting recurrence at the 1 in 100,000 cell level compared to the 1 in 100 cell level using conventional approaches were used to avoid unnecessary acute leukemia treatments. This technology could allow patients to minimize or go off treatment earlier than with traditional detection methods, sparing them unnecessary side effects.

In 2019, processes were streamlined to identify Lynch Syndrome, a hereditary cancer syndrome, and quickly refer potential candidates for confirmatory testing and genetic counseling.

**A variety of communication mediums are used to get the POR message out.** The ARA Alert, an email newsletter targeted to ARA members, issued 21 newsletters last year, providing a useful resource to highlight upcoming events, share relevant news and feature ARA members and their contributions to POR. This complemented four quarterly editions of the SCPOR SCOOP, an email newsletter sent to a more general audience. SCPOR also utilized Twitter, YouTube, Facebook Groups, email and their website to share stories of POR, events, news and other relevant information to those interested in patient-oriented research.



# Knowledge Translation (KT)

KT produced by others supported by SCPOR  
 KT produced by SCPOR

## Thesis

3

## Video, Photovoice, Radio

24

11

## Newsletters, Infographics, Press Releases

5

4

## Online Knowledge Translation Tools

7

## KT Related Webinars

11

## KT Related Meetings

22

2

## KT Related Workshops

13

2

## Social Media Campaign

5

2

## Educational Materials

13

## Reports/ Technical Reports

11

## Books / Book Chapters

6

## Plain Language Publications

8

7

## Conference or Symposia Presentations

152

10

## Peer-Reviewed Journal Articles

161

1

## SCPOR launched a POR knowledge translation community of practice

that included multi-disciplinary, diverse stakeholders. Significant achievements were made in knowledge translation amongst SCPOR stakeholders.

## SCPOR Rapid Realist Systematic Review

addressed the questions, “how, why, for whom and under what circumstances does patient-oriented research impact a healthcare system?” using a realist lens. The review protocol was submitted to the Canadian Medical Association Journal.

**SCPOR Rapid Systematic Review** set out to determine Patient Partners’ perspectives on meaningful engagement utilizing a rapid systematic format. Patient engagement was extensive and an abstract was submitted to Cochrane Colloquium 2020.

## Patient Partners Score the POR Workshop

In November 2019, Janet Gunderson, Patient Partner, and Kate Dunn, Knowledge Translation Specialist, joined the Alberta SUPPORT Unit’s META Workshop series, where they delivered a 3-hour workshop titled “Patients Score the POR: Working Together to Review Grants.” Workshop participants were provided an overview of the Patient-Oriented Research Level of Engagement Tool (PORLET) and discussed tips on how Patient Partners can be supported to review and provide feedback on grant applications.



## Appropriateness of Care

**Collaboration with HQC** led to the development of a measurement plan for the provincial appropriateness of care team to identify areas for improvement, shifts in pathways for treatment and intervention in methods used when performing hip replacement in Prince Albert, Saskatoon and Regina.

**In collaboration with SHA**, several appropriateness of care projects were completed:

- *The development and provision of clinician reports that provided timely, relevant practice information to individual clinicians that stimulated dialogue moving towards consistent high-quality care.* The behavioural practice pathway changes and the implementation of combined CT/MRI checklists for lumbar spine investigation led to reductions in inappropriate testing, providing increased availability of resources for more timely access to CT/MRI patients.
- *The provision of support to clinicians who are engaged in developing quality improvement skills through the Clinical Quality Improvement Program (CQIP).* Projects have the potential to be replicated across the system, and clinicians to become future coaches, mentors and faculty for CQIP.
- *The support and development of the Pain Pathway*, which is foundational for a provincial pain pathway.
- *Support of a project aiming to optimize access to care for Saskatchewan neuro-oncology patients to standardize the optimal path patients take through their neuro-oncological journey*, which will lead to a decrease in system costs and in-patient stay duration, and standardize admission processes.

## Implementation Research

Key achievements include:

- The implementation and evaluation of a culturally relevant approach for chronic back pain management within a Northern Saskatchewan Indigenous community. This project involved Knowledge Keepers and community members as research partners to assist in applying Cree perspectives and experiences to inform and co-create a technology-assisted model of care in a culturally appropriate manner.
- Co-creation and implementation of electronic health records in communities to benefit patient access to health data. Utilizing a Plan-Do-Study-Act method, Patient Partners with researchers implemented and evaluated how this technology impacts patients and end-users of electronic health records.

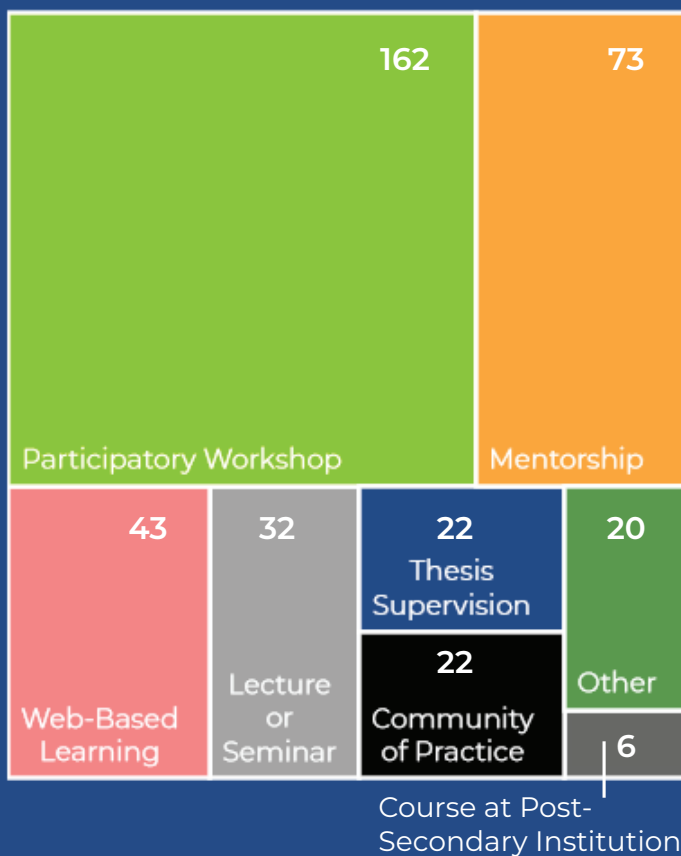
## Health System Research

Key achievements include collaboration on numerous high priority provincial projects led by the SHA Research Department, including:

- The Health Network Evaluation, which examined large-scale restructuring of provincial health care
- Mental Health Capacity Building initiative in collaboration with Ministries of Health and Education
- Roots of Hope National Suicide Demonstration Project, which engaged numerous Northern community members
- Frailty Screening Patient Partner identification and proposal development
- Working with Indigenous community representatives to evaluate the new Canadian diabetic screening guidelines for youth, 8-18 years.

# Training & Capacity Development

## Training & capacity building activities



**70+** POR traineeships with USask, URegina & Sask Polytech

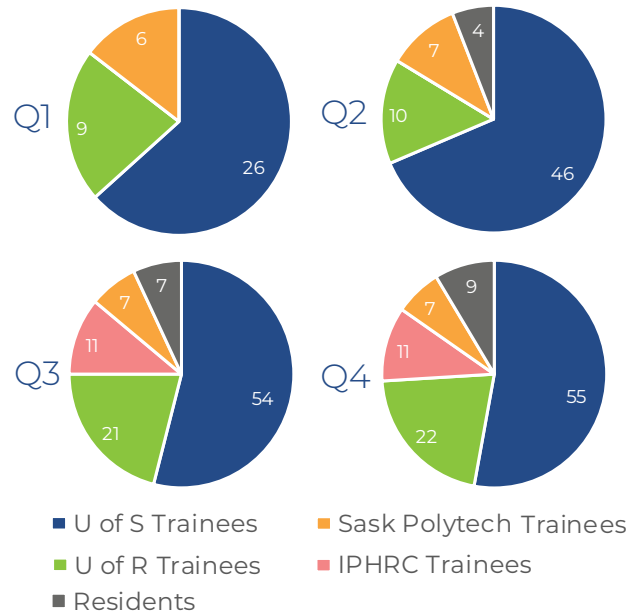
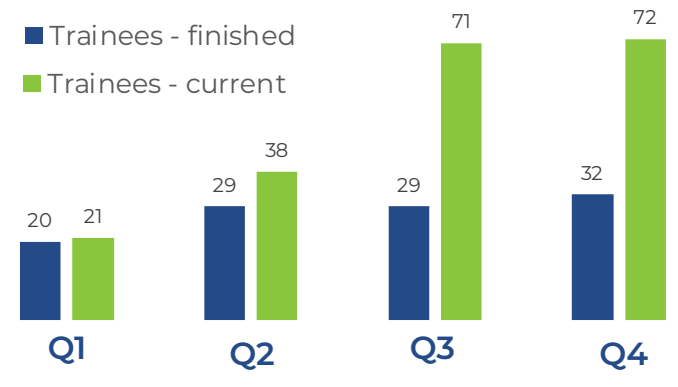
**6** trainees took part in Pecha Kucha presentations

**53** attended video production viewing party

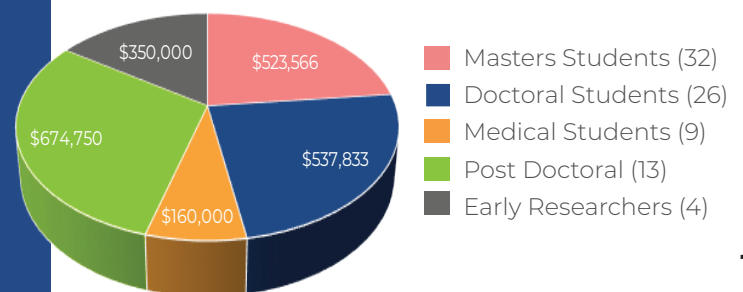
**11** Sprout Grants issued to trainee research teams

**Training and capacity development** took flight this past fiscal year. Traineeships more than tripled from 33 to 104, with trainees representing diverse backgrounds from different institutions throughout the province. While undertaking POR within their programs, trainees build significant POR capacity in our next generation of researchers.

## 2019/20 SCPOR Traineeships



## 2019/20 SCPOR Awarded Funding



SCPOR provided many **training and mentoring opportunities** in the 2019/20 fiscal year:

- A **Video Production Workshop** attracted 53 participants with top videos shown at a viewing party.
- The **Knowledge Translation Community of Practice** provided opportunities for collaboration and reciprocal capacity development among participants.
- **2019 Research Showcase**, in collaboration with SHA and SHRF, provided the opportunity for the Saskatchewan health research community to come together to share and learn from one another through informative sessions and poster presentations. Six trainees took part in Pecha Kucha style presentations, sharing 20 slides lasting 20 seconds each in a well received, innovative presentation opportunity.
- **The Patient Partner Reviewer Orientation** was moved online in an effort to expand reach, especially to those in rural and remote areas, and included interactive websites and animated videos. The PORLET was presented with Patient Partners at two conferences.
- **Building Research Relationships with Indigenous Communities (BRRIC) Module training** continued to be conducted regularly throughout the year, providing a history of Indigenous Health and research in Saskatchewan along with practical skills and best practices for engaging with Indigenous peoples, to produce research that is effective and benefits Indigenous communities.

**The SCPOR and SHRF Sprout Grants program** cultivates POR in Saskatchewan and furthers the work of SCPOR and SHRF to build capacity and collaborations to conduct responsive, equitable, innovative and patient-oriented research that improves the care and health of Saskatchewan people. In 2019/20, eleven sprout grants were awarded.

In what participants called “unique, fun, engaging, imaginative and educational,” **SCPOR launched its first escape room** for the purpose of teaching fundamentals of POR. Teams worked collaboratively to solve a series of puzzles focusing on components of the PORLET with 33 participants attending the launch!



SCPOR Trainee Dr. Linzi Williamson, who has been supported for both a Doctoral and Post-Doctoral traineeship, was awarded the **CIHR POR Transition to Leadership Award** in 2020. This award exemplifies the importance of continued capacity development in others to garner strength in POR for the next generation of researchers.

# Data Services

## Mental Health & Addictions

This fiscal year marked the official launch of SCPOR's Mental Health & Addictions (MHA) Program. On September 30, 2019, Patient Partners, researchers, health system decision makers and SCPOR staff came together to learn about the program, its components and embedded supports and discuss emerging research ideas and patient priorities. Initial areas of focus were identified by the SCPOR Oversight Committee.

One of the priorities of the program was the development of key data infrastructure - a **new MHA database** that would build linkage between standard administrative health data and four stand-alone MHA databases:

- Mental Health Information System (MHIS)
- Mental Health & Addictions Information System (MHAIS)
- The Alcohol, Drug and Gambling System (ADG)
- The Addictions and Mental Health Information System (AMIS)

SCPOR was part of a data sharing agreement committee, working towards a multi-organizational data sharing agreement to enable this work.

A second priority was the **launch of MHA research projects**. SCPOR currently supports two projects in areas such as research design, ethics applications, data access and Patient Partner recruitment and support.

## Provincial Data Infrastructure

SCPOR's Data Services platform, in collaboration with Patient Partners and other partner organizations, developed plans to advance the provincial data infrastructure for health research in Saskatchewan. eHealth and HQC made significant contributions through the data and technology related services provided to researchers.

SCPOR's data platform engaged with a provincial Data and Analytics Oversight Group (DAOG), that included key health system and government decision makers as well as researchers and Patient Partners, to develop a shared vision and goals, province-wide. A visioning session led to the identification of three key priorities that SCPOR continued to focus on:

- Enhancing data infrastructure
- Developing a data management framework
- Developing a data literacy program

Working groups including representatives from SCPOR and our partner organizations were formed and demonstration projects will be utilized to show the progress being made in these three priority areas.



## Data Support Request Process (DSRP)

In 2019/20, SCPOR's Data Services supported 17 projects who reached out for support through the DSRP, two of which were completed within the fiscal year. HQC played a significant role in synthesizing data for research teams to access, and provided support in ethics approval, and data extraction and analysis.

## Health Networks Evaluation

With the recent restructuring to a single, provincial health authority, Health Networks, which are comprised of collaborative teams of health professionals providing fully integrated services, were established to ensure the alignment of health services that best fit the needs of individuals and communities.

SCPOR, along with health system partners, co-led the evaluation of the Health Networks. The goals of this project included identifying the critical components and assessing their development, as well as their impact on the system and patient experience and outcomes. In the 2019/20 fiscal year, SCPOR data services played a major role in the development of a proposal for an outcome evaluation, including a patient engagement strategy and supported the design and implementation of a developmental evaluation focused on discrete geographical areas of Saskatchewan, design of a knowledge translation component and the development of Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs) within the context of Health Networks.

## Real World Clinical Trials

**Clinical Trial Support Unit (CTSU)** provided support to 30 **Real World Clinical Trials**. This enabled patients to receive state of the art treatment delivered in a rigorous and well-monitored manner. Participant physicians received training in leading edge strategies, proliferating knowledge to colleagues and throughout the system. The pragmatic clinical trials that were supported include:

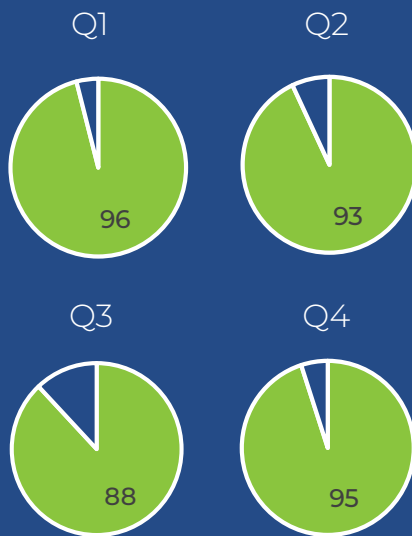
- ***Cannabidiol (CBD) in Children with Refractory Epileptic Encephalopathy. A Phase I Open Label Dose Escalation Study.*** A survey of parents of children with drug-resistant epilepsy who were using CBD-enriched products to treat their children's seizures found 84% of parents reported a decrease in seizure frequency, with over half reporting their children became seizure free or had a greater than 80% reduction in seizures. Despite a strong desire of families to use these products, there is little clinical data regarding the safety and efficacy of these compounds, which this pragmatic clinical trial seeks to address.
- ***PRE-GAiN Bone Health Pilot Study - Physiologic Replacement of Estrogen for Girls and Adolescent Females with Anorexia Nervosa for Bone Health Pilot Study.*** Anorexia nervosa (AN) is a condition of severe low body weight, often occurring in adolescence at a critical time for bone development. Adolescent females with AN are at increased risk of bone loss and bone fragility (osteoporosis), due to hormonal changes that occur in response to inadequate nutritional intake. Estrogen deficiency is thought to be a major contributor to the bone loss. Currently, no effective therapy exists for preventing and treating osteoporosis in AN. This pragmatic clinical trial will examine new evidence important for bone strength and fragility prevention for at-risk Saskatchewan female adolescents, aged 12-20 years.



# Indigenous Research & Engagement Expertise

**Building Research Relationships with Indigenous Communities (BRRIC) Module training** continued to be conducted regularly throughout the year, providing a history of Indigenous health and research in Saskatchewan. Included are policies and frameworks guiding research with Indigenous communities, such as OCAP™, Truth and Reconciliation Commission Calls to Action, Tri-Council Policy Statement Chapter 9 and protocol on respectfully and meaningfully engaging communities in research.

BRRIC Participants were surveyed following their training to gauge their understanding of material presented in the course. The green pie slices indicate the percentage of attendees that left the course with understanding of the material.



As Canada's first SPOR SUPPORT unit with a dedicated Indigenous Research and Engagement Expertise (IREE) Platform, SCPOR ensured Indigenous voices, knowledge, values, and rights as they relate to health research were respected, represented and inherent in all SCPOR activities, particularly in the areas of community and patient engagement. The IREE Platform supported and utilized Indigenous methodologies in all their work, both internal and external to SCPOR.

Knowledge Keepers provided opening/closing prayers at all major SCPOR gatherings while also actively engaging as participants/team members. The platform staff established a culturally safe environment for participants and utilized Indigenous storytelling techniques to engage participants and incorporated pipe ceremonies and other appropriate cultural protocols when pursuing new partnerships with Indigenous communities/organizations.

Indigenous communities are actively and meaningfully engaged as partners in respectful research projects/programs and decision-making processes that directly benefit Indigenous patients and their communities. The **Realizing Indigenous Rights & Responsibilities in Research (RIRRR)** workshop was developed by the IREE Platform with input from IHAC. Training was provided to Indigenous communities in an effort to build research capacity and self-determination in research. SCPOR researchers engaged with Indigenous communities are advised to build their relationships "in a good way" by adhering to communities' cultural protocols, conducting reciprocal research and creating spaces for Indigenous communities/Patient Partners to lead or co-lead research.



**Indigenous representatives** serve on all governance and management levels of SCPOR including the SCPOR Oversight Committee (3), SCPOR Staff (six staff members and two Knowledge Keepers on contract, including three members of the SCPOR Management team), Patient Partner Advisory Committee (six Indigenous members of 14 total) and 38 out of 259 (approximately 15%) Patient Partners self-identify as Indigenous.



In December 2019, the **Indigenous Health Advisory Council (IHAC)** was established to provide guidance to the IREE Platform and SCPOR as a whole. Membership included representatives from: Federation of Sovereign Indigenous Nations (FSIN), Métis Nation – Saskatchewan (MNS), Métis Addictions Council Inc., All Nations Healing Hospital, Battle River Treaty 6 Health Centre, Saskatchewan Health Authority – First Nations and Métis Health Services, Northern Inter-tribal Health Authority (NITHA), in addition to four Indigenous Patient Partners and two Knowledge Keepers.

SCPOR also provided support for Indigenous researchers and trainees developing their capacity to lead research programs, thus mentoring the next generation of Indigenous patient-oriented researchers. Collaboration with Saskatchewan Indigenous Mentorship Network led to sharing programs and services, such as BRRIC and other training workshops, and in Fall 2019, the **IPHRC/SCPOR Trainee Awards Program** was executed with subsequent orientation, activities, workshops and mentorship provided to trainees.



# Impact Stories

## Partnering with Patients to Expand Internet-Delivered Cognitive Behaviour Therapy in Saskatchewan to include Programs Addressing Alcohol Misuse and Sleep Problems

**Researcher:** Heather Hadjistavropoulos



The SCPOR/SHRF Leadership Grant provides patient-oriented research leaders funding to conduct research and facilitate meaningful uptake. Dr. Heather Hadjistavropoulos and her team embody the purpose of the grant, as was affirmed by SHRF honouring them with an award of excellence at the Saskatchewan Research Showcase and Santé event in November 2019, in recognition of the highest patient and peer review scores for the 2018/19 Leadership Grant.

Mental health problems are prevalent and disabling, but often untreated. Internet-delivered cognitive behaviour therapy overcomes barriers to face-to-face therapy by delivering patient-friendly treatment materials over the internet. The *Partnering with Patients to Expand Internet-Delivered Cognitive Behaviour Therapy in Saskatchewan to include Programs Addressing Alcohol Misuse and Sleep Problems* research project aims to develop and evaluate two new internet-therapy programs: one for alcohol misuse and one for sleep problems. These programs were identified as priorities by patients, health care providers, and decision makers in order to overcome barriers to accessing services for these conditions that result in high cost for patients as well as the health care system.

From day one, the multidisciplinary Patient-Oriented Research Steering Committee, composed of four Patient Partners, two internet-therapist providers (social work/psychology), two healthcare administrators/managers, and two trainees, worked to develop terms of reference whereby decisions are made by consensus, and Patient Partner factors weigh heavily in decision making. As the project moves forward, Patient Partners will continue to be involved in all aspects of the project.

This project has had one year of funding and has demonstrated significant contributions to the goals of SCPOR. The team has achieved great success in creating collaborations with the SHA, multiple physicians in the province and experts on alcohol and sleep courses. Knowledge translation products include: 8 presentations, 2 media stories, 1 peer-reviewed journal article, 1 conference presentation and 2 other publications in educational material and the project is now at the data collection phase.

The research has significant potential to improve:

1. Patient access to care;
2. Patient outcomes;
3. Healthcare system decision-making; and
4. Capacity for patient-oriented research.

## Understanding and advocating for Miyo-Mācihowin (good health and well-being) among Indigenous Peoples living with Inflammatory Bowel Disease.

Researcher: Juan-Nicolas Pena-Sanchez



Inflammatory Bowel Disease (IBD) is a chronic condition, usually diagnosed in early adulthood, with significant life-threatening disease-related complications and reductions in quality of life, if left untreated. There is little to no evidence regarding IBD among Indigenous peoples in Canada.

Together, the team developed four guiding research objectives:

1. Build partnerships with Indigenous patients;
2. Determine the number of existing and new cases of IBD among Indigenous peoples in Saskatchewan;
3. Explore the perceptions of living with IBD; and
4. Understand Indigenous explanations of healthcare for IBD.

The multidisciplinary patient-oriented research steering committee is composed of Indigenous Patient Partners, a gastroenterologist, decision makers, and Indigenous and non-Indigenous researchers. The concept of this research project was initiated when an Indigenous patient with IBD shared their experiences with a research team member. Since then, Patient Partners have been active research team members who have participated in all research meetings and contributed to the progress of the project and knowledge translation activities.

During its first year of funding, this project has demonstrated significant contributions to the goals of SCPOR. The unit is especially proud of the teamwork involved in creating multiple knowledge translation products. Patient Partners have co-presented at a national conference; at the Canadian Association of Health Services and Policy Research Conference in Halifax, 2019, and future plans include presentation at the Canadian Digestive Disease Week, Gather for miyomahcihowin, the European Crohn's and Colitis Organization Conference, and International Congress of Qualitative Inquiry. Additional translation activities include three abstracts accepted for oral poster presentation at upcoming national and international meetings to share preliminary results and multiple media stories.

Currently the project is at the data collection phase. The project steering committee will collaborate on interpreting, sharing results, and developing future research. The research has significant potential to contribute to an area of research with minimal understanding, inform new research projects, and change potential misconceptions. In addition, the team hopes to develop subsequent studies on the topic involving additional Canadian provinces.

SHRF presented the whole team with an award of excellence at the Saskatchewan Research Showcase event and Santé Awards in November 2019 for the highest patient and peer review scores for the Sprout Grant review 2018-2019 year.

# Impact Stories

## Individualized behaviour change strategies for physical activity in Multiple Sclerosis

**Researcher:** Sarah Donkers



Saskatchewan has one of the highest rates of Multiple Sclerosis (MS) worldwide. A recent survey estimated approximately 80% of persons living with MS recognize the importance of physical activity, but often indicate a lack of support, including limited access to professionals knowledgeable about MS and physical activity. The primary objective of this research project is to determine if individual behaviour change strategies delivered by neuro physiotherapists increased physical activity in MS.

Throughout the first year of this project, three crucial collaborations have been made. First, this research project set out to train 14 physiotherapists across the province to deliver the intervention. As a result, an organic community of practice of neurorehab physiotherapist was formed. Second, collaborations with the MS Society has allowed the team to share resources, update programs and resource documents. Finally, the collaboration with the SHA has created dialogue on future funding to address gaps in MS services that were identified through this project.

This research team is made up of four Patient Partners, multiple health researchers, decision makers, health care providers, and MS experts, representing a strong multi-disciplinary approach to patient-oriented research. Patient Partners have been involved as equal decision makers throughout the project. They have selected the outcome measures, helped prepare and edit all ethics and communication documents, and the protocol paper and abstract. Patient Partner team members are acknowledged in protocol papers and as authors on abstracts (as per their personal preferences).

Knowledge translation products include a peer reviewed journal article, education reports, media stories, and multiple presentations.

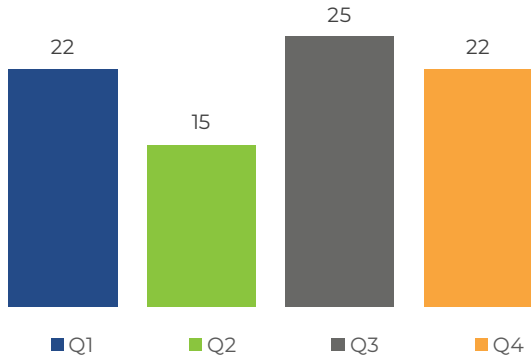
The long-term goal of this research is to lessen the burden of MS by identifying new opportunities for increasing physical activity. Intermediate reports suggest this research project has the potential to influence practice and policy in healthcare delivery in Saskatchewan.

This project was one of nine projects that received funding from SCPOR and SHRF under the Sprout Grant. The goal of this funding opportunity was to create new knowledge, increase collaboration, support emerging research and increase chances for further funding.

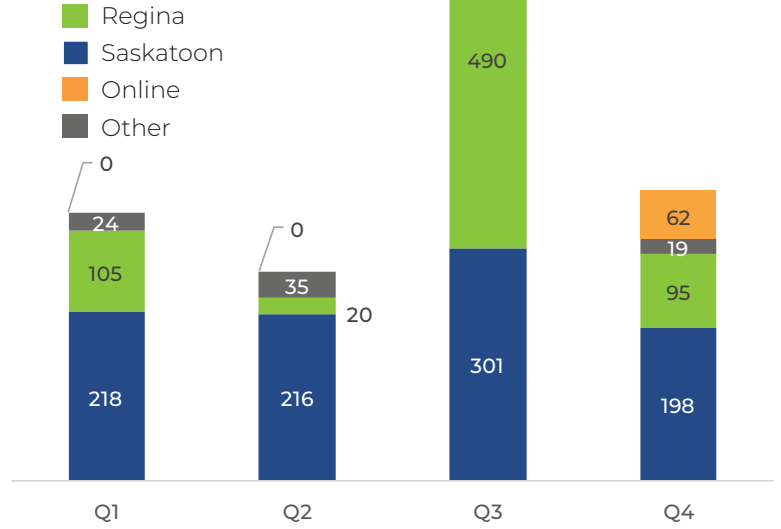
## SCPOR Events

SCPOR hosted 84 events in the 2019/20 fiscal year in locations throughout the province.

### # of SCPOR Events



### # of attendees at SCPOR Events



## SCPOR Support Requests

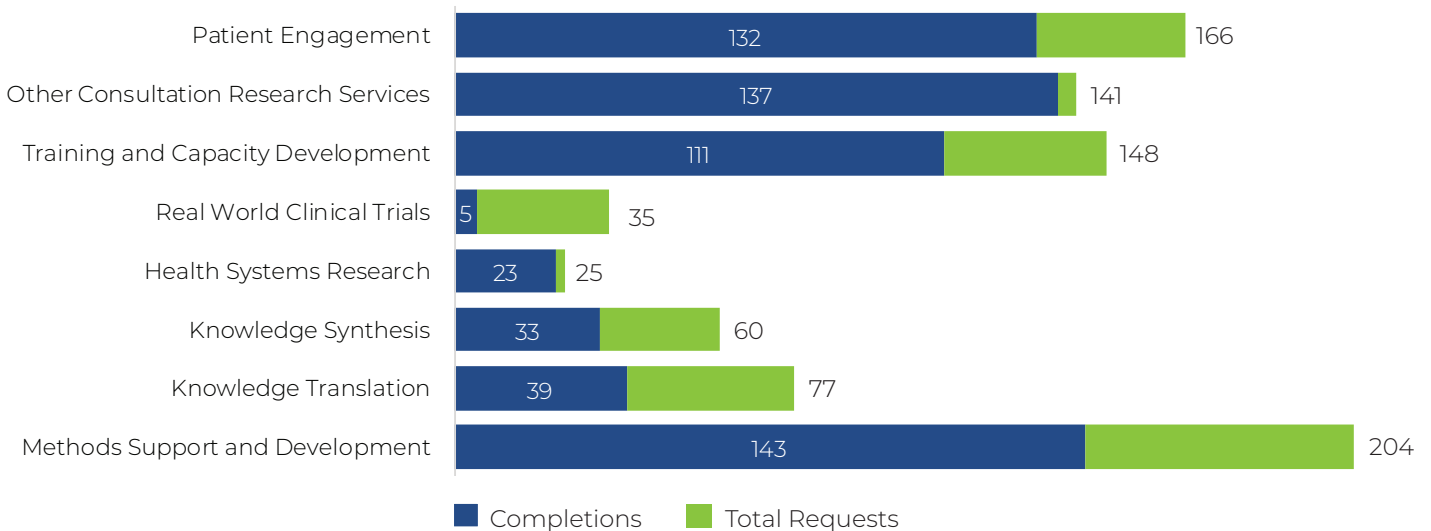
This past year, SCPOR experienced decreased Detailed Support Requests. This was the result of increases in Just Do It Support Requests.

Just Do It support requests allowed SCPOR to respond with increased flexibility and cohesion, and allowed us to expand relationships cross-provincially and nationally.

### Who is Making Support Requests?



### 2019/20 Support Requests





# SCPOR

## 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.

## Strategic Priorities

# 2

### Structures and processes support and sustain POR

- Capability and capacity for researchers, patients, families and health system decision-makers to engage in POR are improved
- Data infrastructure and training are in place to improve access to data for research, analysis and improvement of patient outcomes
- Patients, families, academics and health system leaders recognize and understand SCPOR's role in Saskatchewan
- SCPOR is a high performing, integrated collaborative team
- Academic productivity and performance are improved
- SCPOR is sustainable beyond 2022

# 4

### Indigenous communities, researchers and trainees are supported and self-determining in POR

- Indigenous communities are actively and meaningfully involved as partners in respectful, reciprocal research projects/programs and decision-making processes that directly benefit their members
- Trainees involved in Indigenous health research at the undergraduate, graduate and post-doctoral levels are successfully completing their academic programs and obtaining meaningful employment related to their fields
- Indigenous researchers have the capacity to lead research programs, grants and centres while mentoring the next generation of researchers

# 1

### Patient-identified priorities drive research

- Researchers and SCPOR partners address priorities and outcomes identified by patients, families and communities
  - Patients, families and communities are engaged as co-designers and collaborators in patient-oriented research

# 3

### Facilitated research has a direct impact on key health system priorities

- Mental Health and Addictions care and services are improved based on the outcomes of the SCPOR research program findings
  - Health system performance is improved



# SCPOR

Saskatchewan Centre for  
Patient-Oriented Research

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