

**Saskatchewan Centre for Patient-Oriented Research
Access and Procedures Guidelines**

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Saskatchewan Centre for Patient Oriented Care Access Guidelines and Procedures

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1. SCPOR Overview

VISION: Working together for a healthier Saskatchewan through patient-oriented research

MISSION: The Saskatchewan Centre for Patient-Oriented Research (SCPOR) will build capacity and engage collaborative teams to conduct responsive, equitable, innovative, patient-oriented research that continuously improves the care and health of Saskatchewan people

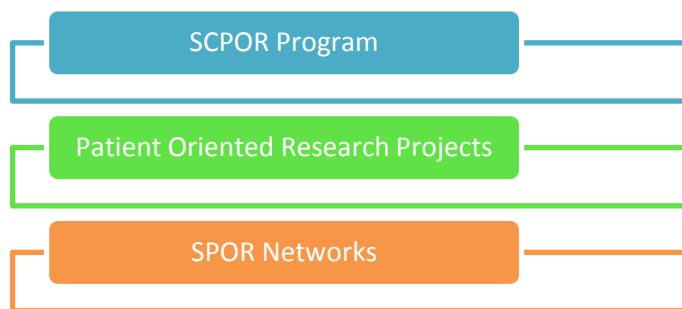
SCPOR teams start with the end in mind. They work with patients, families and caregivers to design research questions that are important to people living with health conditions. SCPOR connects patients, families and caregivers with teams of researchers, clinicians, and policy-makers to conduct research that is intended to improve the health and care of all Saskatchewan people. The research is informed from conception to implementation by all members of that team. For definitions of terms please refer to the Glossary (Appendix 1).

In order to make this happen, SCPOR brings together and is funded by the Canadian Institutes for Health Research (CIHR) plus nine (9) provincial partners. SCPOR partners are:

- University of Saskatchewan
- eHealth Saskatchewan
- Saskatchewan Health Quality Council
- Saskatchewan Health Research Foundation
- Ministry of Health
- Saskatoon Health Region
- Regina Qu'Appelle Health Region
- University of Regina
- Saskatchewan Polytechnic

2. Aim and Purpose of Saskatchewan Centre for Patient Oriented Care (SCPOR)

SCPOR is committed to supporting three areas of patient-oriented research in Saskatchewan:



SCPOR Program is a focused area of research where SCPOR will support several research projects in the same area, for example, mental health and addictions. The intent is to reduce the time it takes for research results to go from bench to bedside, and to nurture a collaborative effort that will result in greater improvements in the health of patients and/or improvements within the health

system. Research priorities and questions will be collaboratively determined by the research team which includes patients, families, clinicians, health system staff and researchers. SCPOR methodologists and trainees along with the research team will be supported with in-kind resources.

Patient-Oriented Research Projects:

- The Saskatchewan Health Research Foundation (SHRF) is a key partner in SCPOR. SHRF has allocated yearly funding awards to advance patient-oriented research. SCPOR will provide support to these teams in the areas of data services, patient engagement, methodology, knowledge translation and indigenous engagement and expertise.
- SCPOR will also support additional projects as capacity allows. The intake process for these projects is outlined below.

SPOR Networks address research priorities identified by patients and accelerate the translation of research findings into patient care and health care policy.

3. Authorization and Scope of Access Guidelines and Procedures

This document outlines the various procedures and requirements for accessing support from SCPOR. These guidelines and procedures may be amended from time to time in the future.

SCPOR is committed to supporting Patient-Oriented Research (POR) that aligns with Provincial and National Healthcare priorities. SCPOR will be faithful to the principles of transparent, supportive, equitable and facilitated access to support as outlined with the Business Plan and this document.

4. SCPOR Support for Program

Accepted teams working on the SCPOR Program in Mental Health & Addictions will receive:

- Patient Engagement support including recruitment, orientation, facilitation, mentorship and honorarium/expense coverage.
- Indigenous Research and Engagement Expertise support including community relationship building, assistance with drafting of research community agreements and a review of grant applications through an Indigenous lens.
- Data Services support including data access, data extraction & linkage, data analysis, and coaching in analysis plan development and data analysis ethics application process.
- Knowledge Translation & Capacity support including support for integrated knowledge translation planning and system engagement in implementation. Coaching, tools and resources for knowledge dissemination and communications.
- Methods support including access to SCPOR methodologists who can support the project, services from the CTSU, SSRL and ADRL, as well as access to trainee funding.

- SCPOR will also provide access to SPOR module training, relationship building with health system leaders, library services including systematic review support.

5. SCPOR Support for Projects

In order to answer requests for support efficiently we have initiated an intake process to ensure equitable access to SCPOR support.

Before contacting SCPOR and to assess if the proposed project is patient-oriented, please review the SCPOR website and information slides on SCPOR, POR and SCPOR resources. There are three ways to access SCPOR support:

1. *Information Gathering & Education*

- To learn more about the Saskatchewan Centre for Patient Oriented Research or how to engage in patient oriented research we encourage you to attend the following training opportunities.
 - Essentials of Patient Oriented Research (the presentation is available for delivery to your team upon request)
 - POR Modules (dates listed on the website)
 - Visit www.scpor.ca

2. *Submit a general inquiry to scpor@usask.ca*

All potential applicants are strongly encouraged to contact SCPOR prior to submitting an intake form to determine the feasibility of any potential support request, to determine if the proposed research is already underway, complies with POR criteria, is aligned with health system priorities, etc. SCPOR will not consider projects which are not POR. Patients and families must be meaningfully engaged on the research team.

- Within 7 days, a SCPOR staff member contact you and either answer your question directly, connect you with a specific team member or schedule you to attend a consultation session.
- To initiate this discussion please call or send a brief outline of the proposed project and potential support required to scpor@usask.ca using the Notification of Intent Form (Appendix 6). Your enquiry will be acknowledged and reviewed by the relevant support team member(s) and a response will be provided within 4 weeks.
- SCPOR Connection (consultation) sessions are hosted monthly. Refer to the SCPOR website: www.scpor.ca

3. *Complete the Intake Request Form.*

- To request formal SCPOR support for a project, please complete the Intake Form (Appendix 3).
- SCPOR will acknowledge receipt of the intake form within 5 business days of receipt.
- Evidence of secured funding and ethics review board approval are a condition of support.


Upon receipt of an Intake Request Form, the following process will occur:

5.1. Administrative Review


- Intake review will occur on the 3rd Thursday of every month. Deadlines for submission will be posted on the at SCPOR website: www.scpor.ca
- The Intake Review Committee will comprise of – SCPOR Platform Leads, Financial Manager, Executive Director, Administrative support, a member of the SCPOR Patient & Family Advisory Council and a member of the SCPOR Indigenous Advisory Circle.

5.1.1. SCPOR recognizes that Patient Engagement may fall along a spectrum. Although the ultimate goal is full engagement during the complete cycle from idea generation to implementation, the support provided may be for projects where the patient engagement is lower on the spectrum. Below is the IAP2’s Public Participation Spectrum which will help define the level of patient engagement in the project:

IAP2’S PUBLIC PARTICIPATION SPECTRUM



The IAP2 Federation has developed the Spectrum to help groups define the public’s role in any public participation process. The IAP2 Spectrum is quickly becoming an international standard.



	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
PUBLIC PARTICIPATION GOAL	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.
PROMISE TO THE PUBLIC	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision. We will seek your feedback on drafts and proposals.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will work together with you to formulate solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.

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The administrative review will utilize the following detailed screening questions to help determine the project's level of patient engagement:

Patient-Oriented

- Does the project engage patients as partners?
- Is the team multi-disciplinary?
- Does the project aim to improve patient outcomes as defined by patients?
- Does the project aim to apply the knowledge as opposed to merely create the knowledge?
- Does the project focus on patient-identified (or at least patient-endorsed) priorities?

Indigenous Engagement

- If the research project engages Indigenous patients, is the engagement meaningful (ex. partners, co-decision makers, co-investigators)?
- If the research project does not engage Indigenous patients and/or communities, is there a clear rationale?
- Does the project follow the principles, policies and frameworks for respectful engagement in research with Indigenous patients and/or communities (ex. Tri-Council Statement – Chapter 9, OCAP, community research agreements, etc.)?
- Does the research move beyond a typical deficit model to also include a strengths-based approach (ex. only focusing on the high rates of diabetes in the Indigenous population vs. building on traditional Indigenous healthy living activities as a means of diabetes prevention)?
- Does the project focus on Indigenous-identified research priorities?

Feasible

- Is the request complete?
- Has the project been funded?
- Are the supports requested within the role of SCPOR?
- Does each platform have the knowledge, staff and time to the requested work?
- Inclusion of the research protocol that relates directly to the submitted intake form.
- Status of the ethical approval for the specific research protocol being submitted.
- Affiliation of Applicant with a recognized Institution.
- Are requested supports available and to what extent via the various Platforms.

Aligned with SCPOR

- Is the request aligned with the current SCPOR priorities?
- If accepted, is SCPOR aligned with priority areas including balance between Regina/Saskatoon, urban/rural, etc.
- Are there any flags or issues with this project/work going forward?
- Is this a researcher/ student that is currently SCPOR supported?

- 5.1.2. Should any issues be identified during the administrative review, SCPOR will advise the applicant. The applicant will be required to address any issues identified, to the satisfaction of SCPOR, before the intake process will be advanced.
- 5.1.3. SCPOR Oversight Committee, Patient & Family Advisory Council and the Indigenous Advisory Council will be kept apprised of approved/ denied projects.
- 5.1.4. The SCPOR Executive Director, or designate, will send a letter to the applicant outlining the decision regarding approval (approval, approval pending conditions or rejection) and, if appropriate, the conditions which would permit approval of the Research Proposal.

5.2. Letter of Support

- 5.2.1. SCPOR is willing to provide a Letter of Support to potential applicants to assist with funding applications. Potential Applicants who receive a letter of support from SCPOR are still required to complete the intake form and follow the remainder of the access process once funding is in place. If funding has already been secured or is not necessary, a letter of support is not required to submit an intake form.
- 5.2.2. Potential Applicants who require a Letter of Support to complete funding applications are not guaranteed to receive set levels of in-kind support from SCPOR. This letter is simply an expression that SCPOR is in support of the application in that it is POR and is willing to further consider application for SCPOR support. SCPOR will review the request within 5 business days of receipt and will notify the applicant if there are any substantial issues. If there are none, or once they are resolved, a letter of support will be produced.
- 5.2.3. Evidence of ethical approval for a Research Proposal is not required to receive a letter of support.
- 5.2.4. It should be noted that a letter of support does **not** guarantee access to SCPOR resources.
- 5.2.5. Upon request, the letter of support can include the value of the SCPOR supports and resources. SCPOR will NOT be invoicing for these supports however these values can be included in requests which require budget documentation (either as fee for service or in-kind contributions).

6. SCPOR Resources

Access to SCPOR resources must be requested using the formal intake review process described in this document and is subject to the terms and conditions of the SCPOR Access Guidelines and Procedures.

6.1. Patient Engagement and Empowerment Platform Supports:

6.1.1. *SPOR Module 1& 2*

- Honoraria/expenses for patient/family advisors to attend SPOR Module 1 & 2 training is covered and processed by SCPOR.
- All other teams members may attend at no cost. Travel and accommodation expenses for research team members who are not patient/family advisors are the responsibility of the attendee.

6.1.2. *Patient & Family Advisor Recruitment Support*

- Patient Engagement Platform staff will provide templates for recruitment materials and will distribute recruitment materials to patient/family advisor networks in Saskatchewan.
- Patient Engagement Platform staff will support in interviewing and selecting patient/family advisors.
- Patient Engagement Platform staff will provide orientation on the role of patient/family advisors.

6.1.3. *Patient & Family Engagement Plan Development*

- Patient Engagement Platform staff will support teams to co-develop patient engagement plans with research teams members (including patients).

6.1.4. *Honoraria and Expense Processing*

- SCPOR will support teams by facilitating the processing of honoraria and expense reimbursement to patient/family advisor team members.
- Teams are to budget hours/ expenses for PFA's.

6.1.5. *Patient & Family Engagement Facilitation*

- Patient Engagement Platform staff will support research team in planning, hosting and facilitating patient engagement or community engagement workshops, events, meeting, etc.
- Cost may include request for meeting space, refreshments, etc.

6.2. Indigenous Research and Engagement Expertise Platform Supports:

6.2.1. *Indigenous Community Engagement*

- Assistance with drafting of community research agreements.
- Assistance with linking to Indigenous CBOs, communities and organizations to explore potential research partnerships.
- Facilitation of initial partnership-building with Indigenous CBOs, communities and organizations.
- Ongoing assistance as needed/requested with relationship-building and constructive "problem-solving".

6.2.2. *Indigenous Patient & Family Advisors*

- Assistance with identification and recruitment of Indigenous patient and family advisors as research team members
- Teams are to budget for honoraria/expenses for PFAs.

6.2.3. *Knowledge Keepers (elders)*

- Assistance with identification and recruitment of Indigenous Knowledge Keepers (elders) as research team members.
- Assistance with support of Indigenous Knowledge Keepers (elders) as research team members.
- Teams are to budget for honoraria/expenses for Knowledge Keepers.

6.2.4. *Indigenous lens review of grant application*

- Assistance with reviewing research grant application with an Indigenous lens to ensure it supports effective community engagement and is consistent with ethics of Indigenous research.

6.2.5. *Essentials of Indigenous Research & Engagement 101 Module Training*

- A half-day of module training delivered by SCPOR's Indigenous Research & Engagement Expertise (IREE) Platform about the fundamentals of engaging in effective research relationships with Indigenous communities.
- Delivering training in Indigenous Research & Engagement (i.e. Essentials of Indigenous Research & Engagement Module Training).
- Delivering Advanced Training in Ethics of Indigenous Research & Engagement.

6.3. Methods Platform Supports:

6.3.1. *Methods Plan Development*

- Assistance to teams in developing or building of methods for use within rural and remote communities.

6.3.2. *Methods Consultation*

- Guidance, support and consultation in the following methodological areas:
 - Quantitative and qualitative research
 - Biostatistics
 - Epidemiology
 - Health economics
 - GIS and cartography
 - Social network analysis
 - Indigenous research

6.3.3. *Real-World Clinical Trials*

- Consultation to provide advice on optimal real-world clinical trial and realist innovative trial designs, ethical considerations and efficient trial and data management.
- Consultation includes liaison with the Health Region to make arrangements for delivery of the Clinical Trial.
- Other supports available include Health Region operational approval applications, research ethics applications, participant consent forms, Health Canada Clinical Trial Applications and grant writing support.

6.3.4. *Social Sciences Research Laboratories*

- Consultation with specialists with backgrounds and training in social science research methodologies such as quantitative and survey research; qualitative research; experimental research; GIS and cartography; and social network analysis, among others (see <http://srl.usask.ca/> for more information).
- Provide access to specialized research infrastructure (computers, equipment and software).
- Provide access to research space (specific and multi-purpose).
- Providing access to the following shared research infrastructure:
 - Community-Based Observation Laboratory (COL) provides portable technology and software to assist researchers in the collection and analysis of observational research data;
 - Experimental Decision Laboratory (EDL) that assists researchers in conducting applied behavioural experiments including a SMART Board, computer station lab, portable eye tracking systems and laptops/iPads for mobile data collection;
 - EEG Hyperscanning Laboratory (EHL) provides the technology and knowledge base for conducting neuroscientific research measuring brain activity;

- Qualitative Research Laboratory (QRL) provides resources for researchers conducting qualitative and exploratory research;
- Spatial Analysis for Innovation in Health Research Laboratory (SAFIHR) to assist researchers in the creation, management, analysis and presentation of spatial information;
- Survey and Group Analysis Laboratory (SGAL) provides a wide range of supports to researchers in conducting telephone, online and mixed-mode surveys including development, creation of survey, recruitment of participants for online surveys, completion of telephone surveys, data analysis and reporting among other supports;
- Social Network Laboratory (SNL) provides support and resources to researchers in conducting social network analysis and interpretation; and
- Video Therapy Analysis Laboratory (ViTAL) provides researchers with the space and technology to assist researchers in the collection and analysis of qualitative and intervention research data.

6.3.5. *Advanced Diagnostics Research Laboratory*

- Provide researchers with bioassay methods development and/or analysis consultation and access to state-of-the-art diagnostic and monitoring testing for Saskatchewan cancer patients using new technology platforms such as 10-color flow cytometry and Next Generation Sequencing (NGS).

6.4. Data Services Platform Supports:

6.4.1. *Data Consultation*

- Consultation with the research team to determine available data sources and advise on data access procedures.
- Consultation with the research team to determine the supports required from the data services platform (for example, data extraction and linkage, analyst support, database development, etc.)
- Data platform staff will assess feasibility of proposed analysis.

6.4.2. *Data De-identification*

- Prepare a dataset for linkage and analysis by removing personal identifying information and replacing it with encrypted identifiers or anonymous study numbers.

6.4.3. *Data Extraction and Linkage*

- Prepare a research dataset by extracting data from relevant sources, linkage, data cleaning, and derived variable creation. Dependent on the situation, the dataset may be provided to the research team, stored in a secure data access area for analysis by the research team, or analyzed by a Platform staff member.

6.4.4. *Data Analysis*

- An experienced data analyst, based on the analysis plan created with the research team, will conduct the analysis and prepare outputs that will be provided to the researcher.

6.4.5. *GIS and Cartography*

- Mapping services are available. Data can be provided to the platform from the research team, or the use of existing data sources, as determined by the data consultation, can be visualized, analyzed, and interpreted by using location as the key index variable to understand relationships, patterns, and trends.

6.4.6. *Facilitation of Data Sharing Agreements*

- Platform staff will assist the research team and data trustee to ensure that the necessary data sharing agreements and approvals are obtained. Please note: for data sources not currently held by the Data Services Platform, if data access or extraction fees are charged by the data provider, these costs are not covered by the Data Services Platform and are the responsibility of the research team.

6.5. Knowledge Translation, Training and Capacity Building Platform Supports:

6.5.1. *KT Consultation*

- Assistance to teams in identifying relevant knowledge users within the health system.

6.5.2. *KT Plan Development*

- Assistance to teams in developing a KT plan that appropriately engages knowledge users and includes integrated and end-of-grant KT strategies.

6.5.3. *Stakeholder Engagement*

- Assistance to teams in planning, hosting, and facilitating knowledge exchange and/or knowledge dissemination events.

6.5.4. *Knowledge Synthesis*

- Resources, tools and consultation services to assist with conducting a literature search and producing an evidence synthesis.

6.5.5. *Health-System Implementation*

- Assistance to teams in identifying/developing appropriate implementation strategies, and then evaluating those strategies.

6.5.6. *Dissemination and Communications*

- Provision of resources, tools and consultation services to assist with developing KT materials and multimedia tools.

6.5.7. *Traineeship Funding*

- Matching funds are available to support research assistantship(s)
- Rates based on institutional standards
- Note: This funding is separate from a “SCPOR Traineeship” and trainees cannot be receiving funding from both concurrently.

6.5.8. *Training & Professional Development*

- Resources, tools, and ongoing learning opportunities for teams to develop competency in various areas related to patient-oriented research.
- Training is available through N2’s Collaborative Institutional Training Initiative (CITI) program.

6.5.9. *Network of Networks (N2) Research Support*

- N2 provides a common platform for sharing best practices, resources and research-related content to ensure efficient and high-quality research, integrity of clinical practices and accountability.
- Available to all researchers at SCPOR-affiliated institutions.

- N2's research support tools are available on the N2 website. Tools include standard operating procedures, quality assurance resources and research privacy guidelines.
- More information can be found at: <http://n2canada.ca>. If you would like to access N2's online training or the research support tools, please email the contact for SCPOR's membership in N2, Scott Corley, at scott.corley@usask.ca.

6.6. Execution of Agreements

- 6.6.1.** Upon approval of the Research Proposal, the required agreements appropriate to the research proposal will be executed.

6.7. Post Approval

- 6.7.1.** If an Approved Research Project is scheduled to extend beyond one year, an annual Progress Report (Appendix 4) will be required. SCPOR will send reminders for submission of the Progress Report form approximately one month in advance of the due date. Proof of a current annual renewal from the relevant ethical review board must also be submitted with the Progress Report form. If SCPOR does not receive the annual Progress Report form within 30 days following the due date, all supports will be subject to cancellation.
- 6.7.2.** Changes to the Approved Project e.g. supervisor, institution, support, etc. must be communicated via a completed Change Form (Appendix 5).

6.8. Project Completion

- 6.8.1.** On Approved Research Project Completion, SCPOR will request submission of a Final Report.
- 6.8.2.** SCPOR will give reasonable consideration to written requests (containing an appropriate explanation) for an extension of time limits described in these guidelines.

6.9. Denial of Support

A proposal maybe denied approval for several reasons, for example:

- 6.9.1.** The ability of the applicant to execute the Research Proposal is in doubt or the Research Proposal is considered inadequate during the review conducted by SCPOR. The applicant will have to show evidence of expertise, resources, financing and the ability to execute the Research Proposal to its successful completion.
- 6.9.2.** There are ethical or legal issues with the Research Proposal.

6.9.3. The Research Proposal does not comply with SCPOR's criteria for POR.

6.10. Audits

6.10.1. On reasonable notice to the applicant, and in order to confirm or investigate compliance with the agreed support, SCPOR may itself or via appropriate third parties audit compliance to signed agreements, use of funds or resource. SCPOR or the Audit Requester e.g. CIHR, will bear the costs of such audits unless a material default within the procedures and processes of the applicant is discovered, in which case the applicant will be obliged to reimburse the reasonable costs of SCPOR and any relevant third parties.

6.10.2. If SCPOR deems it appropriate, SCPOR will make recommendations to the applicant to improve their compliance with the Approved Project Agreement and expects that the recommendations will be implemented by the applicant within 15 business days.

7. Access Limitations

7.1. Requests to access the SCPOR Resource at the individual Research Participant level for non-research related uses including by law enforcement bodies or governmental agencies, will be considered in consultation with Legal and Privacy portfolios and in accordance with Saskatchewan's Health Information Act and the Freedom of Information and Protection of Privacy Act.

7.2. Disclosure to Law Enforcement

7.2.1. Information may be disclosed if it relates to the commission of an offence, when there is immediate harm to the subject individual or others; or when law enforcement presents a subpoena for the information. When there is a situation of immediate harm the amount of information disclosed shall be considered in consultation with Legal and Privacy Portfolios, and shall be the minimum amount to prevent harm. When law enforcement presents a subpoena, SCPOR shall redirect law enforcement to the Information Privacy Office and contact the Office to inform them of the pending request.

7.3. Support may not be used for any other purpose other than for the Approved Research Project. The applicant must inform SCPOR of any changes in purpose to the Approved Research Project for continued approval via a Change form. The Change form will be reviewed by the SCPOR Executive Director or delegate. If the change is deemed to be fundamental, the applicant may be required to submit a new application and supporting documentation to SCPOR, and to go through the access review process as previously described.

8. Disclaimers and Limitations of Liabilities

- 8.1.** It is not the responsibility of SCPOR to inform applicants of any in progress, approval pending or approved intellectual property claims or proprietary rights of any third parties.
- 8.2.** The Approved User will indemnify SCPOR against all losses (whether direct or indirect, reasonably foreseeable or specifically contemplated by all parties), damages, costs, expenses (including but not limited to reasonable legal costs and expenses) that it incurs directly as a result of: i) any material breach of the Agreement by the applicant; or ii) any negligence or willful default of the applicant.
- 8.3.** SCPOR will retain copies of all intake forms, review forms, minutes/proceedings of review process meetings, and all associated correspondence or other relevant documents on file at SCPOR offices in Saskatoon, SK, Canada (or in a secure off-site storage facility). Records will be stored securely in electronic or paper format. Records will be retained for the duration of SCPOR.

9. Confidentiality

9.1. Research Participants

Protecting the confidentiality of Research Participants is a primary concern for SCPOR.

9.2. Research Proposals

- 9.2.1.** All information on Research Proposals submitted to SCPOR will be kept confidential. Once access to SCPOR support is granted, the following information on each Approved Research Project will become publicly available and may be published in a variety of places including, but not limited to, the SCPOR website:
 - i) Title of the Approved Research Project
 - ii) Name(s) of the applicant(s) involved, their academic credentials and professional experience
 - iii) Name(s) of the employer(s) and/or Institution(s) with which they are affiliated
 - iv) Scientific abstract provided by the applicant
 - v) Lay summary provided by the applicant
 - vi) Scheduled project start date and end date
 - vii) Source of funding for the Approved Research Project

- 9.2.2.** At the conclusion of an Approved Research Project, a scientific and lay summary of the findings submitted by the applicant may also be added to the publicly available information about SCPOR.

10. Publications

Approved Users of SCPOR's support are encouraged to publish their research results so as to benefit the scientific community, the health system and the general population.

- 10.1.** SCPOR will appreciate oversight of a final version of any meeting abstracts, conference presentations, online reports/blogs, or other outputs, other than manuscripts submitted for peer-review, prior to publication. SCPOR will not undertake a formal peer-review of the draft manuscripts, but will review all draft manuscripts to determine if:
- i) Any confidential and/or proprietary information has been disclosed
 - ii) The manuscript may bring SCPOR into disrepute
 - iii) The scope of the reported project is compliant with the Approved Research Project

Authors are not duty bound to follow any advice provided unless confidentiality, IP rights, Indigenous Collective Rights, SCPOR reputation and/or adherence Agreements appear to have been compromised.

- 10.2.** SCPOR reserves the right to work with the applicant to develop a communications strategy that may be deployed when a manuscript is published. This approach is not intended to introduce a delay in publication but rather to ensure that SCPOR is in a position to respond effectively to any queries they may receive from Research Participants, the media or any other bodies or persons.
- 10.3.** SCPOR would like to have all work linked to SCPOR to be easily identified, including in electronic searches. SCPOR encourages applicants to include 'SCPOR (Saskatchewan Centre for Patient Oriented Research)' as keywords and in the abstract.
- 10.4.** All Publications based on SCPOR support should clearly acknowledge SCPOR's funders, Research Participants and staff. The following acknowledgement must be included as is (or in a modified form to fit the journal requirements) in all Publications and presentations using the SCPOR Resource:

"SCPOR is only possible due to the commitment of its research participants, its staff and its funders: *Canadian Institutes of Health Research (CIHR), University of Saskatchewan, eHealth Saskatchewan, Saskatchewan Health Quality Council, Saskatchewan Health Research Foundation, Ministry of Health, Saskatoon Health Region, Regina Qu'Appelle Health Region, University of Regina, Saskatchewan Polytechnic* and substantial in kind funding. The views expressed herein represent the views of the author(s) and not of SCPOR or any of its funders."

- 10.5.** SCPOR has authorship and acknowledgement guidelines for Publications to assist applicants in preparing Publications or presentations based on SCPOR support.

11. Future Amendments to the SCPOR Access Guidelines and Procedures

- 11.1.** SCPOR Access Guidelines and Procedures will be revised as needed. Researchers are directed to contact SCPOR for the most recent version by emailing scpor_info@usask.ca.

12. Document Development

During this document's original development, access policies from the following were consulted:

- Alberta Tomorrow Project
- Canadian Institutes Health Research
- University of Regina
- University of Saskatchewan

Appendix 1: Glossary

Applicant: A researcher who wishes to conduct research relevant to POR and who is applying for access to the SCPOR resources. All applicants must be affiliated with an academic or research Institution and be eligible to receive ethical approval from a recognized ethics review board.

Approved Research Project: A Research Proposal that has been approved for access to SCPOR Resource(s).

Approved Research Project Completion: The date of closure of the research protocol with the relevant ethics review board or 6 months post publication whichever comes first.

Co-Applicant: An individual from an academic or research Institution responsible for the supervision of a trainee (including a post-doctoral fellow) who is applying for access to SCPOR resources

Data: The information derived from questionnaires or forms completed by Research Participants, or obtained by linkage with administrative health databases.

Indigenous: Is used to refer to the people and peoples who identify their ancestry with the original inhabitants of Canada, the United States, Australia, New Zealand, and other countries. Indigenous is also used as an adjective to describe things that belong to these peoples (like Indigenous knowledges). In the Canadian context, an Indigenous person is defined as an individual identifying as either First Nations (status or non-status), Metis, or Inuit, who may be located on-reserve or in a rural or an urban area within Canada.

Institution: The academic or research organization with whom the Approved User is affiliated for the purpose of the Approved Research Project.

Oversight Committee: A group of funding partner representatives and patients from a range of disciplines and institutions who work collaboratively to develop and implement strategies to advance the aim of SCPOR.

Multidisciplinary Team: A group of patient-oriented research team members from a range of disciplines and institutions who work collaboratively to develop research. The team will include patients and family members, decision makers (including policy makers and health authority leaders), researchers, clinicians, methodologists and health care practitioners. The team members are engaged appropriately throughout the research process.

POR: Patient Oriented Research refers to the continuum ranging from the initial human studies of a new drug or device to research evaluating the implementation of simple or complex interventions in the health-care system.

Publications: Include but are not limited to, articles published electronically or otherwise in peer-reviewed journals, abstracts, reviews, books, posters, online reports and any other written and/or verbal presentations of an Approved Research Project.

Results: Any findings generated by the Approved User pursuant to the Approved Research Project.

SCPOR: Saskatchewan Centre for Patient Oriented Research.

SCPOR Access Guidelines and Procedures: A document that outlines SCPOR's general principles and guidelines on access to support.

SCPOR Funding Partner: National or Provincial organization which has come together to fund the operation of SCPOR.

SCPOR Trainee: Includes postdoctoral fellows, graduate students, medical residents, research assistants and graduate assistants receiving SCPOR funding.

Appendix 2: SCPOR Conflict of Interest Considerations

Introduction

These considerations aim to ensure that SCPOR's decision making processes for access to SCPOR support are conducted in accordance with the highest standards of integrity. The key guiding principle is the promotion of high quality patient oriented research which will impact the health system and care for all Saskatchewan citizens.

Application of Considerations

These considerations apply to:

- Any individual involved in the review process
- SCPOR Oversight Committee members and all SCPOR staff

Each individual covered by these considerations has an ongoing responsibility to comply with their terms. In complying with these terms, an interpretation should be taken which ensures adherence to both the spirit and the letter of these guidelines.

Guiding Principles

Decisions concerning applications for SCPOR support should be guided by SCPOR's Access Guidelines and Procedures and should be made free from external influences (such as related academic interests or positions of responsibility held outside of SCPOR).

Individuals must be alert to the risk of a conflict of interest arising, and appreciate that this is an ongoing responsibility. They must not make any academic or financial gain as a result of involvement in SCPOR's decision making processes.

A conflict of interest in this context specifically includes academic, financial, or other conflicts which (directly or indirectly) might interfere with, limit or compromise the ability of the individual to review Research Proposals to use SCPOR support in an objective manner.

Managing Conflicts

If an individual identifies an actual, potential or perceived conflict of interest with any Research Proposal under review, they should disclose the nature and extent of this conflict to SCPOR Executive Director immediately.

Individuals should declare all direct and indirect academic interests in relation to a Research Proposal, including (but without limitation) being involved in the preparation of the Research Proposal, being involved in a "competing" research activity, and/or being a in current collaboration or co-investigation with the applicant or other investigators named on the Research Proposal.

If an individual has a commercial interest in the applicant institution and/or funding organization for the applicant Institution, this should be disclosed to SCPOR's Executive Director.

Disclosures of conflict of interest may either be specific to a particular application or may be general with respect to an applicant, applicant institution and/or funding organization. A general disclosure will exempt an individual from making repeat disclosures in respect to future applications involving that individual, Institution and/or funding organization.

Any applicant or other person who considers that a conflict of interest exists should disclose their concern to SCPOR's Executive Director.

Conflict Action Points

Prior to beginning the expedited review process, Oversight Committee, or designate, will request that reviewers declare any actual, potential or perceived conflicts of interest related to the Research Proposals that are under consideration.

In the event that a disclosure is made by any individual involved in the review process, it will be for the Oversight Committee, or designate, to determine whether it is a material conflict of interest.

In the event of a material conflict of interest, the individual must not take part in any decisions relating to that Research Proposal. In particular, the individual must not:

- be involved in the review of the Research Proposal nor any appeals or conditions which may be imposed, and;
- be involved in the decisions about the Research Proposal, and;
- receive any further papers or information concerning the Research Proposal, and;
- attend those parts of any meetings in which the Research Proposal is discussed.

Conduct

All reviewers, support staff and any other individuals convened to review a Research Proposal, must agree to uphold the confidentiality of:

- information and documents distributed prior to the meeting, brought to the attention of members during the meeting or relating to participation at the meeting, and;
- deliberations and the minutes pertaining to the review meeting.

These considerations will be subject to periodic review. Individuals should be familiar with the most recent version of the considerations.

If individuals have any queries or concerns regarding the application of these considerations, they should consult with SCPOR's Executive Director.

Appendix 3: SCPOR Intake Form Template

([Click here](#) to obtain current form)



SCPOR Request Form

The purpose of this form is to have standard information for your request to SCPOR so we can provide the appropriate assistance. Please complete all sections of the form to the best of your knowledge. Once the form is completed, please email it to scpor_info@usask.ca to submit your request.

Contact Information	
Date (dd/mm/year):	<input type="text"/> Name: <input type="text"/>
Email Address:	<input type="text"/>
Phone Number:	<input type="text"/>
Contact Organization:	<input type="text"/>
Do you identify as a:	<input type="checkbox"/> Clinician <input type="checkbox"/> Decision Maker/Policy Maker <input type="checkbox"/> Patient/Patient and Family Advisor <input type="checkbox"/> Trainee <input type="checkbox"/> Researcher <input type="checkbox"/> Other <input type="text"/>

Access the Full Form via the website link above.

Appendix 4: SCPOR Progress Report Form Template



The purpose of this form is for researchers to provide SCPOR an update with the progress of their SCPOR-funded patient-oriented research projects to date. The Annual Progress Report is required for all projects that have been awarded SCPOR support.

The Annual Progress Report is due on March 31st each year. It is the researcher's responsibility to ensure the annual report is completed and returned to SCPOR at scpor_info@usask.ca (Please note this form is for SCPOR purposes only and does not replace other required reporting.)

Researcher Name: _____ Date: _____

Project Name: _____ Program Start Date: _____

Location: _____ Expected Date of Completion: _____

Progress Report

1. Please provide a description of the completed research, the remaining research and a tentative timeline for completion.
2. How do you plan to or how have you engaged with patients in your project?
3. How do you plan to or how have you engaged with health system leaders/decision makers in your project?

4. What are your expected research impacts?

5. Please provide your plans for knowledge translation activities and any completed knowledge translation activities to date. Activities may include community events, newsletters, videos, publishing a journal article, presenting at conferences, etc.

6. Please describe any highlights and/or challenges you have experienced in your project thus far.

7. Please comment if your research project has continued as planned and outlined in the research proposal approved by SCPOR. Note that any significant change to the project is subject to approval by SCPOR and may require further information beyond this form.

SAMPLE FORM
Not for submission

Signatures

Researcher Signature: _____

SCPOR Signature: _____

Appendix 5: SCPOR Change Form Template



Name of approved user(s):

Title of approved research project:

Request number assigned by
SCPOR:

1. List and describe the change(s) to the approved project:

2. Justify why the proposed change(s) is/are needed:

3. Was an ethical amendment needed in order to accomplish the change(s):

Yes No

If yes, please attach the approval of the amendment from the relevant ethics review board.

If no, please explain why an amendment was not submitted to the relevant ethics review board:

Name of Approved User

Signature

Date (D/M/Y)

Your personal information is collected under the legal authority of section 33(c) of the Freedom of Information and Protection of Privacy Act. This information will be used by or disclosed for the purpose of SCPOR research administration and reporting. For questions, concerns or more information about the collection, use or disclosure of your personal information, please contact SCPOR's Executive Director at 1-306-966-7256 or via email at scpor_info@usask.ca

Appendix 6: SCPOR Notification of Intent Form Template



Notification of Intent Form

Name of applicant(s) and institution(s):

Mailing address:

Email address of applicant(s):

Phone number(s) of applicant:

Potential title of research proposal:

Name(s) of funding organization(s) from which applicant is seeking a grant:

Type of grant sought:

Short summary of research proposal (maximum 300 words):

Type(s) and characteristics of support that may be requested from SCPOR:

Name of Applicant

Signature

Date (D/M/Y)

Your personal information is collected under the legal authority of section 33(c) of the Freedom of Information and Protection of Privacy Act. This information will be used by or disclosed for the purpose of SCPOR research administration and reporting. For questions, concerns or more information about the collection, use or disclosure of your personal information, please contact SCPOR's Executive Director at 1-306-966-7256 or via email at scpor_info@usask.ca