

**Specialized Services for Children and Youth (SSCY)
Research and Evaluation Committee
Research Access Overview and Checklist**

Review the SSCY Research and Program Evaluation Access Guideline and this condensed overview to ensure all required documentation is submitted to the SSCY Research and Evaluation Committee when applying for research access at SSCY Centre.

Contact the SSCY Centre Research Coordinator, Elizabeth Hammond, with any questions ehammond@rccinc.ca or (204) 451-5702.

Please submit all required documents to the SSCY Centre Research Coordinator:

Via email: ehammond@rccinc.ca or

Via mail: Attn Elizabeth Hammond, 1155 Notre Dame Ave, Winnipeg, MB, R3E 3G1

The SSCY Network is an alliance of government departments, the Winnipeg Regional Health Authority (WRHA) and various service provider agencies, and consists of both co-locating and non co-locating partners. SSCY Centre, located in Winnipeg at 1155 Notre Dame Ave., houses the co-locating partners. **The SSCY Research and Evaluation Committee is responsible for reviewing and approving proposals for all research that is conducted at SSCY Centre (including recruitment and data collection), involves electronic medical records covered by the SSCY Data Sharing Agreement, or that is about the SSCY Network.** For research conducted at a SSCY Network partner facility that is not SSCY Centre, the PI is responsible for obtaining all required approvals. The PI may consult with the SSCY Research and Evaluation Committee for clarification or guidance regarding which approvals are required and how to obtain them.

Research Access Application Procedure Overview and Checklist

- Submit a completed SSCY Research Access Application Form, signed signature page from the SSCY Research and Program Evaluation Access Guideline, and a copy of the:
 - o Research protocol
 - o Participant informed consent form (ICF)
 - o Participant assent form
 - o Questionnaires or other materials to be given to participants
 - o Advertisements to be posted at SSCY Centre or on the SSCY Network website
 - o Budget
 - o Current Principal Investigator CV
 - o REB submission form
 - o REB certificate of final approval (you may submit to the SSCY Research and Evaluation Committee before final REB approval is received, but access will not be granted until the REB certificate of final approval is submitted)
 - o Health Canada Letter of No Objection, if applicable
 - o Clinical Trials Registry number, if applicable

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- The SSCY Research and Evaluation Committee will review all proposals with an emphasis on issues such as merit of the proposal, alignment with SSCY Network's mission and values, benefits and risks to the participants, research design, credentials of the researchers, presence of ethical approval, impact on the organization's resources, and involvement of appropriate SSCY Network partners.
 - You will be notified in writing regarding the outcome of this review
 - Approved studies will receive a SSCY Research Access Number, which should be included on all future correspondences
- Submit a copy of all REB correspondence that results from a major protocol or informed consent/assent change or update to the approval status of the project (including the updated protocol, informed consent form or assent form), all Adverse Event reporting forms, all protocol deviation reporting (minor and major), the REB Annual Study Status Reports and Certificates of Annual Approval, and the Final Study Status Report
- Submit a copy of any report or publication arising from research conducted at the SSCY Centre, with electronic medical records covered by the SSCY Data Sharing Agreement, or about the SSCY Network
- Notify the SSCY Centre Research Coordinator in writing at least two weeks in advance of any media presentation or publication involving results from research conducted at the SSCY Centre, with electronic medical records covered by the SSCY Data Sharing Agreement or about the SSCY Network
- PI(s) may be asked to participate in a variety of KT activities at SSCY Centre (including but not limited to: posters, presentations, pamphlets, etc)
 - Researchers will be expected to share results appropriately with a variety of stakeholders, which can include SSCY Centre clients, families or therapists, members of the SSCY Network, policy makers, other researchers and interested community members
- Information regarding past, ongoing and future research projects may be shared at SSCY Centre and on the SSCY Network website

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Research vs Quality Improvement/Program Evaluation:

Research: A class of activities designed to contribute to generalizable knowledge, including testing the application of new knowledge that is to be performed at SSCY Centre or using electronic medical records covered by the SSCY Data Sharing Agreement, or that is about the SSCY Network.

Quality Improvement: A range of activities conducted to assess, analyze, critique and improve current processes of health care delivery and services performed at SSCY Centre. Quality Improvement is also referred to as quality assurance/assessment, audit or performance measurement.

Program Evaluation: The systematic collection and analysis of information about programs at SSCY Centre, focused on a broad range of topics including accessibility, comprehensiveness, integration, cost, efficiency and effectiveness, and designed for uses such as management, accountability and planning.

If a Quality Improvement or Program Evaluation project at SSCY Centre involves human participants and meets any of the following criteria, it shall require approval through the SSCY Research and Evaluation Committee:

- presents a risk or burden to participants which is above minimal risk or an increase over accepted standard of care
- requires participants to take medication, undergo invasive procedures, protocols, psychometric testing or provide biological samples or give sensitive information, that is not routine to the program, service or care provided
- is intended to be published in peer-review literature
- is not a SSCY Network quality improvement plan
- has the potential to infringe on the privacy rights or professional reputation of participants

A Quality Improvement or Program Evaluation project that does not fall within the above parameters shall be approved through internal processes such as standards committees, quality councils or management committees. Publication or presentation of Quality Improvement or Program Evaluation results outside of SSCY Centre shall require the approval of the Department Head and the SSCY Research and Evaluation Committee.

