Governance

AUGUST 2025

NEWFOUNDLAND AND LABRADOR

SUPPORT

Support for People and Patient-Oriented Research and Trials

Quality of Care NL

Proud to partner with Choosing Wisely Canada

Choosing Wisely NL

Contents

Who We Are

NL SUPPORT is Newfoundland and Labrador's SPOR SUPPORT unit.

SPOR = Strategy for Patient-Oriented Research

SUPPORT = Support for People and Patient-Oriented Research and Trials

It is one of 11 SPOR SUPPORT Units across Canada that provide specialized services to researchers, patients, clinicians, policy makers and SPOR-funded entities to conduct patient-oriented research.

NL SUPPORT provides expertise and training in knowledge translation, patient engagement and patient-oriented research, as well as access to expertise in research methodologies.

The NL SUPPORT team includes the research and evaluation program **Quality of Care NL** (QCNL) and receives support from the **Centre for Analytics, Informatics and Research** (CAIR).

Quality of Care NL is an applied health and social systems research and evaluation program aimed at improving social and health outcomes in Newfoundland and Labrador. A collaborative effort between the leading health care entities in the province, our goal is to improve the quality of care by facilitating change to ensure the right treatment gets to the right patient at the right time. QCNL leads the Learning Health System Core of the NL SUPPORT Unit.

The Centre for Analytics, Informatics and Research, a high-performance computing centre with the capacity to rapidly process and analyze vast amounts of data and provide secure storage with off-site backups, supports the work of the Data Platform and Services Core of the NL SUPPORT Unit. CAIR staff assist researchers with determining the best tools for analysis, troubleshooting issues, secure transfer of clinician specific data and results and back-up and data storage.

Each SPOR SUPPORT Unit must focus their work on four core components within their unique local contexts.

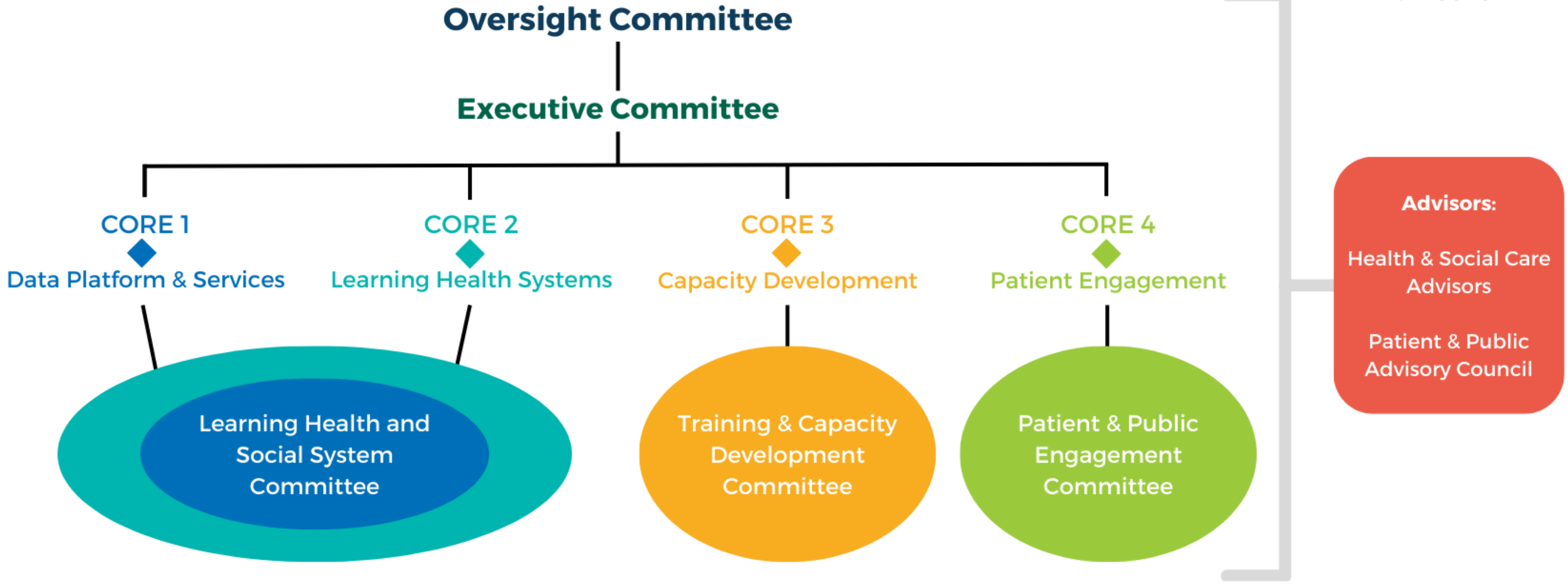
NL SUPPORT's governance structure is set up to facilitate its work and to make room for new opportunities for growth and sustainability. A diverse committee made up of staff members, patient and public partners and relevant local content experts supports each core component.

An Oversight Committee focused on strategic program direction, sustainability planning, funding accountability, and approval of research and evaluation project proposals and knowledge translation products governs the work of these committees. A separate Executive Committee oversees human resource and operational matters.

NEWFOUNDLAND AND LABRADOR SUPPORT
Support for People and Patient-Oriented Research and Trials

Quality of Care NL

Governance Structure



Oversight Committee

Executive Committee

CORE 1
Data Platform & Services

CORE 2
Learning Health Systems

CORE 3
Capacity Development

CORE 4
Patient Engagement

Learning Health and Social System Committee

Training & Capacity Development Committee

Patient & Public Engagement Committee

Advisors:

Health & Social Care Advisors

Patient & Public Advisory Council

Terms of Reference

Oversight Committee

Purpose:
The Oversight Committee (The Committee) is responsible for providing strategic direction and funding accountability, contributing to setting program priorities, and ensuring program activities are aligned with program priorities, as well as developing and delivering a sustainability plan for the program beyond the period of CIHR funding.

Mandate:
The Committee has the mandate to:

- Provide overall governance and leadership on the strategic direction of the program.
- Approve the Terms of Reference of program Committees.
- Provide high level leadership (advice and guidance) to the Executive Committee regarding decisions related to program operations and required supports.
- Review project proposals, publications, knowledge translation plans and public engagement plans (note: The Committee may be requested to review documents via email between meetings).
- Advise on policies for scientific and technical interaction within research projects.
- Advise on frameworks for consultation with end-users.
- Provide conflict resolution on matters referred to the Oversight Committee by the Executive Committee.
- Contribute to and participate in strategic planning and prioritization processes.
- Facilitate communications between major internal and external stakeholders, including site partners, external funding agencies, data custodians, other national bodies, and partners ensuring that all necessary agreements are in place.
- Contribute to an annual review of progress towards program outcomes.
- Ensure milestones, objectives and goals set by Committee work plans are achievable and in line with the overall strategic direction of the project.
- Contribute to setting long-term strategic direction and making strategic investment decisions, including developing a sustainability plan for the program beyond the period of CIHR funding.

Membership:

Membership (Voting)

- Nominated Principal Applicant (Chair)
- Department of Health and Community Services Representative
- NL Medical Association Representative
- SPOR Primary Care Research network Representative
- Research, Initiatives and Services Representative
- NL Health Services
    - VP Quality and Learning Health Systems
    - Provincial Director Research and Innovation

    - Senior Director Planning Performance and Evaluation
    - VP Digital Health
- NL College of Family Physicians Representative
- NL Nurse Practitioner Association Representative
- Other Health Professional Representative
- Patient Representatives (3 total)
- Indigenous Communities Representatives (as appropriate)

Ex Officio Membership (Non-voting)

- Program Director (Secretariat)
- Faculty of Medicine Representative – Assistant Dean, Clinical Research
- Choosing Wisely Canada Representative
- Program Manager, Quality of Care
- Equity, Diversity and Inclusion lead
- Director, Analytics and Data Access – NLHS
- Other Representatives of appropriate stakeholders as agreed to by the Committee from time to time

Observer

- CIHR Representative

Rules of Procedure

Meetings

- The Chair and Vice-Chair will be appointed from the Oversight Committee membership following consultation with the Dean of Medicine.
- The Secretariat will provide support to the Oversight Committee and will distribute a draft agenda with relevant documents for the meeting no later than one week before an agreed meeting date.
- The Oversight Committee will meet regularly, not less than quarterly.
- The Oversight Committee will strive to work by consensus in drafting its advice and recommendations.
- A record of each meeting will be kept and will be circulated to the Oversight Committee members shortly after each meeting.
- Meetings will be scheduled one year in advance where possible.
- A quorum will be 50% of the voting membership plus one.
- Members may send delegates to represent them if they are unable to attend the meeting. Delegates will not have voting rights.

Accountability:

Committee

- The Oversight Committee will monitor team effectiveness on an annual basis (carry out an annual self-evaluation of its functions and operations).

- Be accountable collectively for the successful execution of its mandate.
- Report annually to its stakeholders.

Members

- Attend meetings on a regular basis.
- Review all necessary meeting material and be prepared to speak to the items on the agenda.
- Represent their organization at meetings of the Oversight Committee.
- Participate in the evaluation of team effectiveness of the Oversight Committee.
- Report regularly to their organization.

Approved 19th October 2023

Executive Committee

Purpose:
The Executive Committee (The Committee) is responsible for providing operational direction and support to program activities to ensure alignment with program priorities and for developing and monitoring the program budget.

Mandate:
The Committee has the mandate to:

- Design and develop program strategies, operational plans, human resources plans and program budgets aligned with program priorities for Oversight Committee and CAIR steering committee approval.
- Approve committee workplans and budgets based on the strategic direction set by the Oversight Committee and CAIR steering committee and by program priorities.
- Ensure Equity, Diversity and Inclusion issues are addressed.
- Assess human resources requirements.
- Coordinate all necessary data sharing agreements and policies.
- Advance all necessary conflicts to the Oversight Committee for resolution.
- Develop partnership models and frameworks.
- Approve program activities, proposals, funding opportunities and requests for program assistance including from other SPOR entities.
- Develop and deliver program evaluation activities.
- Develop and deliver prioritization processes.

Membership:

- Program Director (Chair)
- Program Manager (Secretariat)
- Nominated Principal Applicant
- Clinical Lead
- Systems officer, CAIR
- Scientific Lead
- Implementation Lead
- Patient representative
- Other representatives of appropriate stakeholders as agreed by The Committee from time to time

Rules of Procedure

Meetings

- The Committee will meet the first Thursday of every month.
- The Secretariat will provide support to the Committee and will distribute a draft agenda with relevant documents for the meeting no later than two days before an agreed meeting date.

- The Committee will strive to work by consensus in drafting its advice and recommendations.
- A record of each meeting will be kept and will be circulated to The Committee after each meeting.

Accountability

- The Committee is accountable to provide updates and recommendations to the Oversight Committee and CAIR Steering Committee.

Members

- Attend meetings on a regular basis.
- Review all necessary meeting material and be prepared to speak to the items on the agenda.

Review

These terms of reference will be reviewed as needed.

May 2023

Learning Health and Social System Committee

Background:
The NL SUPPORT/Quality of Care NL governance structure reflects the Canadian Institute of Health Research's Strategy for Patent-Oriented Research defined core components for SUPPORT Units; Data Platforms and Services, Learning Health System, Capacity Development, and Patient Engagement. Within the NL SUPPORT Unit, a Committee has been set up to lead each of the core component areas.

These Core Component Committees meet at least quarterly and are responsible for determining the direction and focus of work for the specific core, managing day-to-day operations, taking remedial actions where necessary and providing updates to the Executive Committee.

Purpose:
The Learning Health and Social System Committee (The Committee) is responsible for developing and delivering annual priorities to encourage and support the emergence of a learning health and social systems (LHSS) in the province.

Mandate:
The Committee has the mandate to:

- Facilitate discussions with decision and policy makers to encourage the development of LHSS.
- Contribute to the design, development, delivery and evaluation of the implementation of LHSS.
- Provide social and clinical expertise in process development and design related to LHSS.
- Contribute to and evaluate knowledge translation activities relevant to LHSS (multiway communication between knowledge user groups).
- Determine annual priorities aligned with NL SUPPORT/Quality of Care NL goals for Executive Approval.
- Provide feedback on project methodologies, manage project workflow and review project progress.
- Review requests for services and research/evaluation project proposals from partner agencies.
- Develop project proposals for Executive Committee approval, as needed.
- Ensure Inclusion, Diversity, Equity and Accessibility are considered and supported in all areas of work.
- Ensure lived experience and expertise of patients/families/citizens is considered and supported in all areas of work.
- Fulfill joint working requirements with other SPOR entities as directed by the Executive Committee.
- Identify partners and make connections to our social system.

Membership:

- Program Director (Chair)
- Administrative Assistant (Secretariat)
- Nominated Principal Applicant
- NL SUPPORT Implementation Lead
- Project Coordinator
- Health Policy Analyst
- Communications Advisor
- Patient Engagement Lead
- Social and Health System Clinical Leads
- NLCAHR Representative
- Senior NLHS Representative
- NLHS Digital Health Representative
- NLHS Innovation Team Representative
- Implementation Science Lead
- Equity, Diversity and Inclusion Representative
- Patient Representative (Minimum 2 positions)
- Other representatives of appropriate knowledge user groups as agreed by The Committee from time to time.

Rules of Procedure

<u>Meetings</u>

- The Committee will meet the first Wednesday of every month, with additional meetings scheduled as needed with approval of the Committee.
- The Secretariat will support the Committee and will distribute a draft agenda with relevant documents for the meeting no later than 2 days before an agreed meeting date.
- The Committee will strive to work by consensus in drafting its advice and recommendations.
- A record of each meeting will be kept and will be circulated to The Committee after each meeting.

<u>Accountability</u>

- The Committee is accountable to provide updates and recommendations to the Executive Committee.

<u>Members</u>

- Attend meetings on a regular basis.
- Review all necessary meeting material and be prepared to speak to the items on the agenda.

<u>Review</u>

These terms of reference will be reviewed as needed.

December 2024

Training & Capacity Development Committee

Background:
The NL SUPPORT/Quality of Care NL governance structure reflects the Canadian Institute of Health Research's Strategy for Patent-Oriented Research (SPOR) defined core components for SUPPORT Units; Data Platforms and Services, Learning Health System, Capacity Development, and Patient Engagement. Within the NL SUPPORT Unit, a Committee has been set up to lead each of the core component areas.

These Core Component Committees meet regularly and are responsible for determining the draft work plan for the specific core, managing day-to-day operations, taking remedial actions where necessary and providing updates to the Executive Committee.

Purpose:
The Training and Capacity Development Committee (The Committee) is responsible for developing and delivering an annual training and capacity development workplan to enhance skills and address identified knowledge gaps for all knowledge users and partners to facilitate a culture of Patient-Oriented Research.

Mandate:
The Committee has the mandate to:
- Design, develop, deliver and evaluate an annual training and capacity development workplan and budget aligned with program priorities for Executive Committee approval.
- Coordinate an annual training needs assessment.
- Manage requests for services and assign resources as appropriate.
- Capture and report training activities and outcomes.
- Collaborate with national SPOR entities with a focus on the National Training Entity.
- Monitor the delivery of the Patient Engagement in Health Research credit course.
- Ensure Inclusion, Diversity, Equity and Accessibility are considered and supported in all areas of work.
- Ensure lived experience and expertise of patients/families/citizens is considered and supported in all areas of work.
- Fulfill joint working requirements with other SPOR entities as directed by the Executive Committee.

Membership:
- Operational Lead, Engagement and Capacity Development (Chair/Secretariat)
- Administrative Staff Specialist I (Secretariat support)
- Program Director
- Training and Capacity Lead
- Patient Engagement Academic Lead
- Scientific Lead
- Implementation Lead

- Knowledge Translation Lead
- Communications Advisor
- Patient and Public Advisory Council Representatives (minimum of 2 positions)
- Inclusion, Diversity, Equity and Accessibility Committee Representative
- Indigenous Representative(s)
- Other representatives of appropriate knowledge user groups as agreed by The Committee from time to time

Rules of Procedure

Meetings

- The Committee will meet the second Tuesday of every second month.
- The Secretariat will support the Committee and will distribute a draft agenda with relevant documents for the meeting no later than two days before an agreed meeting date.
- The Committee will strive to work by consensus in drafting its advice and recommendations.
- A record of each meeting will be kept and will be circulated to The Committee after each meeting.

Accountability

- The Committee is accountable to provide updates and recommendations to the Executive Committee.

Members

- Attend meetings on a regular basis.
- Review all necessary meeting material and be prepared to speak to the items on the agenda.

Review

These terms of reference will be reviewed as needed.

April 2025

Patient and Public Engagement Committee

Background:
The NL SUPPORT/Quality of Care NL governance structure reflects the Canadian Institute of Health Research's Strategy for Patent-Oriented Research defined core components for SUPPORT Units; Data Platforms and Services, Learning Health System, Capacity Development, and Patient Engagement. Within the NL SUPPORT Unit, a Committee has been set up to lead each of the core component areas.

These Core Component Committees meet monthly (or every second month) and are responsible for determining the draft work plan for the specific core, managing day-to-day operations, taking remedial actions where necessary and providing updates to the Executive Committee.

Purpose:
The Patient and Public Engagement Committee (The Committee) is responsible for developing and delivering an annual patient/public engagement workplan, including Indigenous community engagement, to ensure that relevant lived/living experience perspectives are represented throughout the governance structure, provide opportunities for meaningful engagement, and encourage patient/public participation in program activities.

Mandate:
The Committee has the mandate to:

- Design and develop an annual patient/public engagement workplan and budget aligned with program priorities for Executive Committee approval.
- Coordinate the Patient and Public Advisory Council as necessary.
- Ensure patient/public representation at all levels of program governance.
- Develop patient/public recruitment and retention strategies.
- Develop processes to integrate relevant lived/living experience perspectives into projects.
- Promote patient/public engagement networks nationally.
- Coordinate requests for services and assign resources as appropriate.
- Review and update Patient Partner Appreciation Guidelines for approval by the Patient and Public Advisory Council.
- Report on patient/public engagement activities for funding agencies and partners.
- Ensure the Patient and Public Advisory Council is apprised of all work of the Committee.
- Ensure relevant lived/living experience perspectives are integrated into program decision making and deliverables.
- Ensure Inclusion, Diversity, Equity, and Accessibility are considered and supported in all areas of work.
- Ensure lived experience and expertise of patients/families/citizens is considered and supported in all areas of work.
- Fulfill joint working requirements with other SPOR entities as directed by the Executive Committee.

Membership:

- Operational Lead, Engagement and Capacity Development (Chair/Secretariat)
- Administrative Staff Specialist (Secretariat support)
- Program Director
- Patient Engagement Lead
- Scientific Lead
- Implementation Lead
- Patient Engagement Academic Lead
- Knowledge Translation Lead
- Communications Advisor
- Patient and Public Advisory Council Representatives (minimum of 2 positions)
- Inclusion, Diversity, Equity and Accessibility Committee Representative
- Indigenous Representative(s)
- Other representatives of appropriate knowledge users as agreed by The Committee from time to time

Rules of Procedure

Meetings

- The Committee will meet at least quarterly.
- The Secretariat will support the Committee and will distribute a draft agenda with relevant documents for the meeting no later than two days before an agreed meeting date.
- The Committee will strive to work by consensus in drafting its advice and recommendations.
- A record of each meeting will be kept and will be circulated to The Committee after each meeting.

Accountability

- The Committee is accountable to provide updates and recommendations to the Executive Committee.

Member Responsibilities

- Attend meetings on a regular basis.
- Review all necessary meeting material and be prepared to speak to the items on the agenda.

Review

These terms of reference will be reviewed as needed.

April 2025

Patient and Public Advisory Council

Background:
In 2011 the Canadian Institutes for Health Research, Canada's federal funding agency for health research, announced a new national health care initiative: The Strategy for Patient-Oriented Research. The purpose of this strategy was to enhance Canadian capacity for patient-oriented research, a movement which had already grown in other parts of the world. Part of the strategy was to establish specialized research support units referred to as Support for People and Patient-Oriented Research and Trials (SUPPORT) units across Canada. The Strategy for Patient-Oriented Research Framework was released in 2014, after which SUPPORT Units began to be established across Canada through funding partnerships between CIHR and provincial governments, universities, and hospitals, among others. One of the objectives of these units is to recognize the importance and value of engaging patients and the public as members of research teams, not study participants, through all stages of health research.

The Newfoundland and Labrador SUPPORT Unit (NL SUPPORT; 'the Unit') was established in May 2014. The NL SUPPORT team includes the research and evaluation program Quality of Care NL (QCNL) and the supporting infrastructure for the Centre for Analytics, Informatics and Research (CAIR). Quality of Care NL, a collaborative effort between the leading health care entities in Newfoundland and Labrador, leads the Learning Health System Core of the NL SUPPORT Unit. A second round of funding (*The Strategy for Patient-Oriented Research Phase II, or SPOR II)* was awarded in 2021, allowing NL SUPPORT to continue to support and build capacity for patient-oriented research in the province of Newfoundland and Labrador. An important part of the organizational structure of NL SUPPORT was the formation of a Patient and Public Advisory Council (PPAC; 'the Council'). This Council is comprised of - and led by - a group of patient/public advisors/partners. The PPAC continues to be an integral part of the Unit in SPOR II, through their representation within the governance of NL SUPPORT and overall work of NL SUPPORT in the area of patient/public engagement.

This Terms of Reference identifies the purpose, structure, and operating rules of the Patient and Public Advisory Council.

Purpose:
The Patient and Public Advisory Council will provide advice and guidance on the work of NL SUPPORT and Quality of Care NL in the determination of patient-oriented research priorities, the engagement of patients in research projects, and public outreach activities, such as antibiotics awareness week.

Mandate:
The Patient and Public Advisory Council has the following mandate:

- Review research priorities and advise on the prioritization of research topics
- Identify opportunities for, facilitate and lead patient-initiated research

- Assist in planning research projects to ensure that the patients' points of view are included
- Review funding proposals and advise on funding priority
- Assist in identifying patients to join research teams
- Assist in the recruitment and retention of patient partners to the Council
- Assist in the orientation and mentoring of incoming members
- Advise on how to involve patients and the community in research and priority setting
- Assist with knowledge translation
- Assist in the writing of lay summaries for funding applications, journal articles. press releases, infographics, and other communications materials
- Identify training and capacity development needs for members of the Patient and Public Advisory Council, patient partners, and research groups
- Advise on how these needs may be met and participate in training delivery and other capacity development initiatives/programs
- Assist the Unit in contributing to the development of a Learning Health and Social System in Newfoundland and Labrador
- Network nationally to promote patient/public engagement and identify common themes and issues across Canada and internationally
- Assist in and advise on addressing Inclusion, Diversity, Equity and Accessibility in the work of the Council, NL SUPPORT and Quality of Care NL
- Other appropriate tasks as needed

Please note that individual members of the Council may choose to be more/less involved in certain activities outlined above depending on personal interest and capacity.

Membership:

- Up to 25 patients representing a sociodemographic, cultural, and geographical cross section of the population of the province
- NL SUPPORT/Quality of Care NL Director
- NL SUPPORT Scientific Lead
- Manager Quality of Care NL
- NL SUPPORT/Quality of Care NL Communications team
- NL SUPPORT/Quality of Care NL Patient/Public Engagement leads
- Representative from NL Centre for Applied Health Research (NLCAHR)

Members' Responsibilities:
It is the responsibility of all Patient and Public Advisory Council Members to:

- Attend Patient and Public Advisory Council meetings
- Read and respond to meeting materials before and after meetings
- Keep other Council members informed of health research related opportunities (both internal and external) that they are involved in

- Consider participation in NL SUPPORT Core Component Committees: Communications, Learning Health and Social System, Patient Engagement and Training and Patient-Oriented Research Skills
- Provide content (such as patient partner highlights) for the NL SUPPORT newsletter
- Consider responding to opportunities for patient partner engagement
- Use lived experience to speak to universal themes in health research in NL
- Adhere to the CIHR SPOR Guiding Principles of: inclusiveness, support, mutual respect and co- building
- Advocate for patient/public engagement in health research in Newfoundland and Labrador

Patient and Public Advisory Council members are required to sign a Patient Partner Confidentiality Agreement. Failure to comply with this agreement will result in a meeting with the Council Chair(s) and Unit staff, and could result in a discontinuation of your membership in the PPAC.

Rules of procedure for the Patient and Public Advisory Council:

- The Chair/Co-Chair will be members of the Council. Chairs can self-nominate or be nominated by a peer (with agreement from the nominee). Chairs to be determined by majority vote of the Council. Chairs will serve a one-year term. The position will be reposted as necessary when a year-long term is not possible
    - Staff support to Chairs can be provided as needed. If the Chair/Co-Chair is unable to chair, the invitation to chair will be circulated to the members of the Council. If a patient/public partner is unable to chair, a staff member will cover
- Secretariat support will be provided by Unit staff
- The Patient and Public Advisory Council will meet regularly, not less than quarterly
- Two Patient and Public Advisory Council meetings per year will be face-to-face, the rest will be conducted via teleconference or videoconference
- Patient and Public Advisory Council members will be invited to identify agenda items, including identifying visiting speakers, research topics/projects of interest, etc.
- A draft agenda with relevant documents for the meeting will be distributed no later than one week before an agreed meeting date
- A record of each meeting will be kept and will be circulated to Patient and Public Advisory Council members shortly after each meeting
- Length of term: two-years, with opportunities for continued membership (if mutually agreeable to both the member and Unit staff)
- Staff will reach out to members on a regular basis to review interest and provide opportunities for feedback about members' experiences of engagement. Inactive members for the previous 6 months (no participation in PPAC activities – meetings, email correspondence) will be contacted to review their continued membership on the Council. No response to this contact will be considered confirmation of a desire to step down from the Council

Decision Making:

- A quorum will be 50% of the membership plus one, if quorum is not achieved it will be at the discretion of the Chair(s) whether the meeting should proceed. Note that staff votes cannot overpower partner votes
- The Patient and Public Advisory Council will strive to work by consensus in drafting its advice
- Where consensus cannot be reached, the Chair(s) can choose to move to a vote, which will take place by show of hands or secret ballot whenever the Council feels that is necessary (individual members are invited to call for secret ballot whenever necessary to no contention)
- Votes will pass through majority agreement with the Chair(s) holding the casting vote
- Staff members of this Council will each get one vote

Review:
The terms of reference will be reviewed on an annual basis.

Authority:
The Patient and Public Advisory Council acts as an advisory body to NL SUPPORT and Quality of Care NL.

Date:
May 30, 2025

Glossary of Terminology

The Canadian Institutes of Health Research developed a glossary which provides lay language definitions for frequently used health research terms. Terms accompanied by (SPOR) have been defined in the context of Canada's Strategy for Patient-Oriented Research (SPOR). NL SUPPORT has developed definitions (below) for terms where none existed within SPOR and/or where we wanted to clarify a term's use in our specific context.

Patient

Patient is used as an overarching term inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends (CIHR, 2015; Patient Engagement Framework). We encourage Council members to substitute the term patients for the term that they prefer.

Patient Engagement

Meaningful and active collaboration in governance, priority setting, conducting research and knowledge translation. Depending on the context, patient-oriented research may also engage people who bring the collective voice of specific, affected communities.

Patient-Oriented Research

Refers to a continuum of research that engages patients as partners, focusses on patient-identified priorities and improves patient outcomes. This research, conducted by multidisciplinary teams in partnership with relevant stakeholders, aims to apply the knowledge generated to improve healthcare systems and practices.

Knowledge Translation

Knowledge Translation (KT) has a range of definitions, but within the Canadian Institutes of Health Research (CIHR) it is described as a process of summarizing, distributing, sharing, and applying the knowledge developed by researchers to improve the health of Canadians, and strengthen the health care system through the use of more effective health services, products, and standards of practice.

Integrated KT is a form of KT where researchers and knowledge users (e.g. policymakers, patients, clinicians) work together to determine research questions, decide on methodology, collect data, develop tools, interpret findings, and disseminate research results. This approach is intended to produce research findings that are more likely to be relevant to, and used by, the end users than studies designed and conducted by researchers alone.

Patient-Initiated Research

Patient-initiated research is research that engages patients at the highest level of patient engagement and provides patient partners with more autonomy than traditional patient-oriented research. In this instance, patients devise the research question and begin exploring how to study this question on their own. Through the help of a team with varied expertise in the necessary research area, these patients go on to co-conduct and co-lead the research project.