

**Terms of Reference of the NL SUPPORT and Quality of Care NL  
Patient and Public Advisory Council**

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## 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](#). 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.

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). [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 and includes the Newfoundland and Labrador chapter of [Choosing Wisely Canada](#) (Choosing Wisely NL). The [Centre for Analytics, Informatics and Research](#) (CAIR), 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 NL SUPPORT.

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.

These Terms of Reference identify the purpose, structure, and operating rules of the Patient and Public Advisory Council.

## Unit Structure

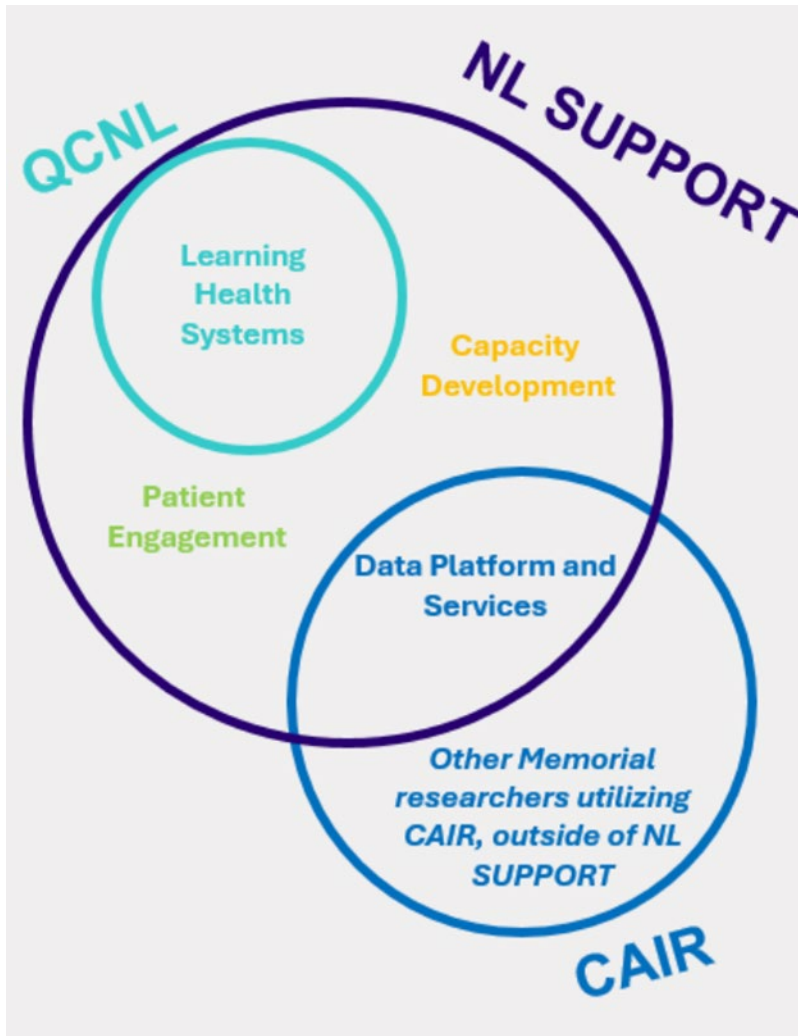


Figure 1. NL SUPPORT Unit's structure

## 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
- Patient and Public Advisory Council (PPAC) Chair(s)\*
- 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)

*\*Up to two Patient and Public Advisory Council (PPAC) members may serve as Chairs at any given time.*

## 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.**

## Chair(s) Responsibilities

In addition to fulfilling all regular PPAC member responsibilities, the PPAC Chair(s) will:

- Attend Patient and Public Engagement Core Component Committee meetings and work with members to set PPAC agendas
- Facilitate virtual and in-person PPAC meetings (at least 4 per year but may include additional meetings if additional time is needed to address PPAC priorities/suggested work)
  - Examples of facilitating: lead meetings and make sure they proceed according to the agenda; make sure that all members have equal opportunities to contribute to the discussion; etc.

Additional aspects of the role may include:

- Lead work to collect and appropriately apply PPAC member advice within the NL SUPPORT/Quality of Care NL structure
- Assist with recruitment and onboarding of new PPAC members
- Work with Unit staff to mediate disputes or personality conflicts among Council members to ensure team cohesion
- Meet with Unit staff and PPAC members as necessary to address breaches of the Patient Partner Confidentiality Agreement
- Work with Unit staff to adapt the role of PPAC Chair over time to reflect learnings throughout each term

These responsibilities are subject to change depending on the experiences of PPAC members, Chair(s), and Unit staff. This role will also reflect individual Chair(s)'s goals and Chairing style, with Unit staff working to support the development of the role in response to Chair and PPAC member suggestions.

## Rules of Procedure

- The NL SUPPORT Patient and Public Advisory Council (PPAC; 'the Council') will be chaired by members of the Council. The Chair(s) will be decided on through a nomination and adjudication process occurring no less than annually. Chairs can self-nominate or be nominated by a peer (with agreement from the nominee). Chairs will be determined by majority vote of the Council and will serve a one-year term. The position will be reposted as necessary when a year-long term is not possible. Up to two PPAC members may serve in this role at a time. Further details regarding the Chair(s) nomination and selection process are provided in the **PPAC Chair(s) Nomination and Decision Process** section of this document
  - Staff support to Chairs can be provided as needed. If the Chair(s) is/are 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

## PPAC Chair(s) Nomination and Decision Process

Up to two PPAC members can serve as Chair at the same time. Having two Chairs provides extra support and helps members who are new to the role build their leadership skills. If only one person is nominated, we will continue with one Chair and keep the second Chair position open for anyone who shows interest throughout the year. If someone expresses interest in becoming second Chair during the year, the rest of the group will be given the opportunity to nominate alternative second Chairs at the time of the expression of interest and any candidates will go through the nomination process outlined below. If no potential second Chair expresses interest during the year, the opportunity will be offered again at the end of the current Chair's term.

Nominations for the Chair position(s) will be accepted at least once a year, when the current Chair's term is nearing completion. Unit staff or the current Chair(s) will let members know when nominations are open, either at a PPAC meeting or by email, and will clearly state the deadline for submitting nominations. Chair(s) and Unit staff will work to ensure that there is enough overlap between the outgoing and incoming Chair(s) to support a smooth transition and provide time and support for the handover.

When a nomination period opens, nominations will be accepted via email to appropriate Unit staff (i.e. the Operational Lead). Anyone nominating a peer must carbon copy the nominee. After the nomination period ends, if more than three candidates are nominated, Unit staff will collate nominee names into a survey to be distributed to the group, so that members can vote for their preferred candidates anonymously. Chair(s) will be determined by majority vote, unless fewer than three are nominated, in which case nominees will be appointed directly.

**Should any PPAC member wish to express concerns about a current Chair throughout the course of that Chair's term, Unit staff will work with the member to address their concerns in a way that is agreeable to them. This may include mediating a meeting between the member and the Chair and/or working with the other Chair and the member to determine acceptable solutions.**

## 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 13, 2026

## 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](#)). In the context of Patient-Oriented Research and related work, 'patient engagement' approaches may also include engaging with anyone with relevant lived/living experience relative to the project topic. 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.