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

Terms of Reference of the NL SUPPORT and Quality of Care NL

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.

Unit Structure

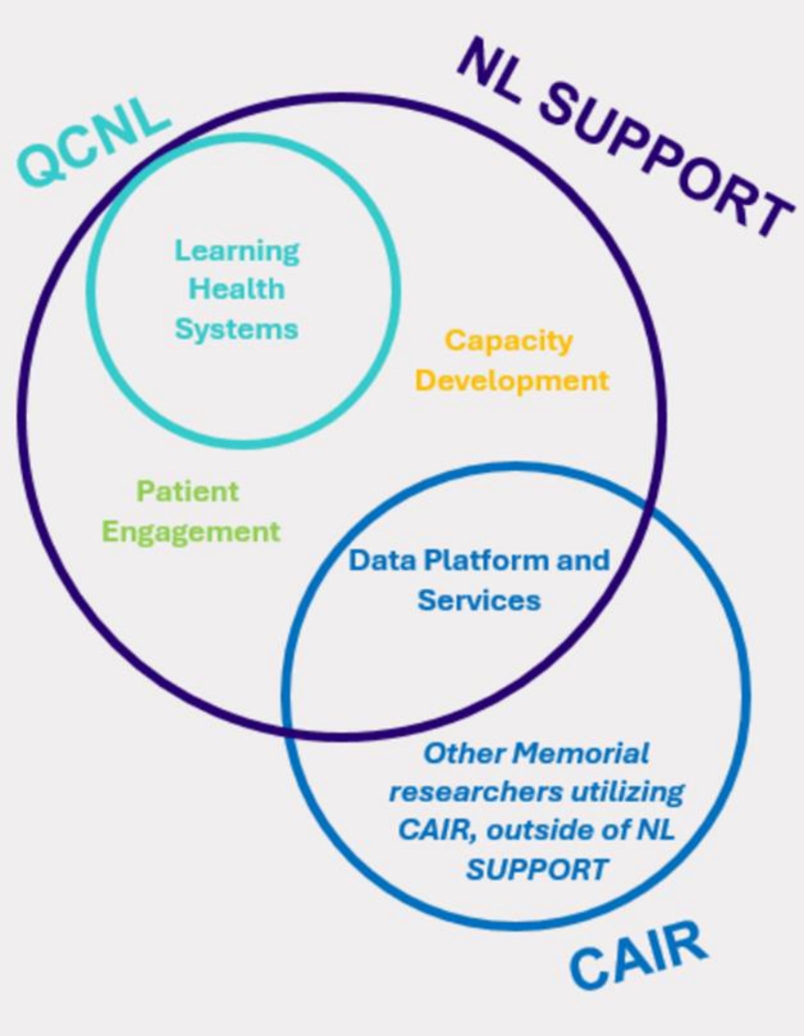

Figure 1. NL SUPPORT Unit's structure

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
- 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

- 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.