Newfoundland and Labrador Support for People and Patient-Oriented Research and Trials (SUPPORT) Unit Evaluation

Memorial University of Newfoundland

SUBMITTED By: Dig Insights
DATE: September 2019
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EXECUTIVE SUMMARY

Background

The Canadian Institute of Health Research (CIHR) identified the need for patient-oriented research (POR) in its 2009/10 Health Research Roadmap. As a result of this new focus, CIHR released Canada’s Strategy for Patient-Oriented Research (SPOR) in August 2011 which identified five initiatives to increase POR in Canada. One of these initiatives was building and resourcing SUPPORT (Support for People and Patient-Oriented Research and Trials) Units across Canada.

One SUPPORT Unit was established in Newfoundland and Labrador (NL) at Memorial University of Newfoundland (Memorial) in 2014. NL SUPPORT (also referred to as “the Unit”) is a methodological research support centre dedicated to supporting and developing the province’s capacity for POR. This center brings together patients, researchers, healthcare providers, IBM, and provincial and federal bodies to provide methodological support and research services for projects that have “a direct impact on patients’ lives, in ways that are important to patients and by making them partners in research.”

As a hub of expertise, NL SUPPORT performs six core functions: (1) data platforms and services; (2) methods support and development; (3) health system research, implementation research and knowledge translation, (4) pragmatic/real-world clinical trials; (5) career development in methods and health services research; and (6) consultation and research services. These six key areas were the cornerstones to NL SUPPORT’s service delivery model which included knowledge brokering and expertise through consultations and training as well as providing funding to conduct research.

Dig Insights was commissioned to undertake a summative evaluation of NL SUPPORT with the overall goal to examine the relevance, design, delivery, effectiveness and efficiency of the program in achieving its expected outcomes.

Methods of data collection used to undertake this evaluation included: a document review; literature review; administrative data analysis; key informant interviews; surveys (grant recipient, stakeholder, patient advisory council); and cases studies.

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1 http://www.nlsupport.ca/home.aspx
Key Findings

Relevance
1. NL SUPPORT strongly aligns with the objectives and priorities of its funders including CIHR, Memorial, IBM and the Government of Newfoundland and Labrador. This is supported through its commitment to fund projects that align with the healthcare needs identified by residents, funding projects aimed at increasing the effectiveness and efficiency of healthcare system (e.g., telehealth), and by enhancing the capacity of researchers and students in the province.

2. NL SUPPORT’s objectives were seen to be relevant to the needs of the healthcare community including, but not limited to patients, researchers and the residents of Newfoundland and Labrador. It was especially seen to be relevant in increasing researchers’ capacity to complete POR and engage patients in sharing their results.

Design and Delivery
1. NL SUPPORT was seen by stakeholders to be effectively designed through its interconnected governance structure with the TPMI Steering Committee and collaborative partnerships with Quality of Care/ Choosing Wisely NL, and CHIA. The Unit’s design also provides sufficient opportunities for residents across the province to direct research, as well as participate in knowledge translation (KT) through community events.

Patients engaged in NL SUPPORT felt that they had sufficient resources to effectively engage in the program. NL SUPPORT follows sector best practice through the integration of patient partners at the beginning of the project and through collaborating with other Units.

Researchers were satisfied with the design of the eight grants and the awards provided by NL SUPPORT. Engagement of the additional supports varied among survey recipients, with many not accessing support from CHIA. Researchers were overall positive about the support they received implementing POR and developing in KT.

To improve delivery moving forward, increased engagement of Regional Health Authorities (RHAs) from Central and Labrador-Grenfell and the Nunatsiavut Government, Qalipu First Nation, and Innu Round Table, and increased awareness of analysis capabilities available at CHIA was recommended.

Achievement of Outcomes:
1. NL SUPPORT has enhanced the research infrastructure throughout the province through the establishment of CHIA and its ongoing partnership with IBM. CHIA’s health information and data analytics platforms have provided faster computation, increased data storage security and the ability to create customizable software solutions. For
example, CHIA is working with IBM to develop an e-ordering platform to reduce unnecessary medical assessments.

Through its agreement with NLCHI, researchers have also benefited from **increased efficiency in accessing data**, with waiting times reduced to months instead of years. Despite this reduction in waiting time, researchers still require a more efficient process to access NLCHI data to reduce delays in research.

Despite these challenges, health research is seen to be more **responsive to the changing climate** of the province as a result of NL SUPPORT’s efforts as demonstrated by the Effects of Diagnostic Imaging Utilization Reports study.

2. As a result of NL SUPPORT researchers, students and healthcare professionals have **increased their knowledge and skills in POR and KT**. In advance of the Unit, researchers had limited or no knowledge on these topics. Through training, consultations and conducting POR research, researchers, students and healthcare professionals agreed that they have increased their knowledge on patient engagement and KT. Additionally, with over 250 tools created to date to support POR (e.g., training sessions, consultations, community events) there are ongoing resources to enable POR development in the future.

3. NL SUPPORT has **effectively engaged participants** in various capacities in POR through sitting on the TPMI Steering Committee, being a member of PAC or Patient Panels, or through the Friends Pool.

   As a result of participating in NL SUPPORT, attending training and accessing resources, participating in studies, patients identified developing key skills including critical thinking and confidence, as well as knowledge about the healthcare system. This personal and skill development has increased their capacity to engage in POR studies.

4. NL SUPPORT has **increased the occurrence of evidence-based research** across the province through providing 85 grants/awards and supporting over 135 projects in conducting POR. In addition to their funding, the inclusion of patients, collaboration of key stakeholders and leveraged internal expertise, and access to the improved infrastructure has facilitated innovative research that is responsive to patients’ opinions and perspectives.

   Nevertheless, it was found that that greater attention should be placed on funding projects outside of St. John’s and Eastern Health to ensure patients across the province can benefit from the research conducted.

5. Early signs indicate that NL SUPPORT has improved the efficiency of the healthcare system. This has been achieved through **improved analysis and efficiency accessing provincial level data** as a result of CHIA and its partnership with NLCHI; **increased knowledge of**
**POR and KT** by researchers, patients, healthcare professionals and students through its training and consultations; and **increased research** as a result of their funding dollars.

Additionally, the increased efficiency of the healthcare system can also be illustrated through the biomedical testing case study which resulted in approximate **annual cost avoidance** to Eastern Health of **$563,644** as a result of a change in ordering form and physician academic detailing.

The antibiotic case study further evidenced the effectiveness of POR and data analysis as a public, nurse and physician campaign led to a **reduction of 4,434 antibiotics** prescriptions by physicians annually.

6. The **transferability** of the knowledge and skills developed by students and patients as a result of engaging with NL SUPPORT has led to individual outcomes that were not intended at the beginning of their engagement with NL SUPPORT.

NL SUPPORT supports and services have made a PhD student better prepared for completing their comprehensive exams, as well as resulted in patients and their friends and family becoming more engaged in their healthcare and consultations with their physicians. The information learned through NL SUPPORT also has great transferability as a PAC member is now sitting on the Canadian Medical Association (CMA) Patient Voice Group with one student intending to integrate POR into her curriculum as she has recently secured a faculty position.

**Considerations**

Based on the findings from the report, the following considerations have been developed for NL SUPPORT to inform the design and delivery of the program moving forward.

1. **Establish core line funding**

   NL SUPPORT has facilitated an increase of stakeholder knowledge on POR and KT, improved efficiency of the data retrieval processes and has provided funding to 85 POR projects, many of which would have not been conducted without this funding. At the end of the first five years of funding, NL SUPPORT has been shown to empower patients, educate researchers on best practices and begun to improve efficiencies in the healthcare system.

   Stakeholders acknowledged that without NL SUPPORT in the future, the effectiveness of the established partnerships, and implementation of POR would likely be lost.

   NL SUPPORT should consider opportunities to obtain core funding through the Government of Newfoundland and Labrador. Core funding would ensure that the program’s objectives continue to be developed and met, and research would continue to
have the means and resources available to develop innovative projects which improve the healthcare system and lives of residents.

2. **Improve data retrieval from NLCHI**

   While the development of CHIA and the partnership with NLCHI has greatly increased the capacity for health research across Newfoundland and Labrador, there is still a delay in retrieving provincial level data from NLCHI causing some researchers to wait months for this data. This delay can impact the effectiveness of the research study as well as the timeliness of the results.

   Acknowledging that NLCHI is working towards creating their own Data Lab platform, NL SUPPORT, CHIA, Quality of Care and NLCHI should continue to discuss reviewing the process for researchers and healthcare professionals to access data. This will increase the efficiency of the process presently and the new Data lab platform when it is launched.

3. **Training to improve awareness of services / supports available with a focus on CHIA**

   Many stakeholders identified gaps in their knowledge surrounding POR and KT prior to accessing NL SUPPORT. As a result, NL SUPPORT offered a wide variety of services and supports including training, consultation services, assistance completing ethics application and facilitating meetings with potential collaborators; however, survey results indicate that there has been a fairly low engagement with these supports. In addition, it was also felt that CHIA’s software may not be being used to its full extent, likely attributed to the lack of knowledge of researchers about the full capacity of the system and how to best integrate it into their studies.

   To further increase the impact NL SUPPORT has had on the medical research field in the province, it is recommended that a greater focus be placed on increasing stakeholders’ awareness of their service offerings and its applicability to studies being conducted for wider reach.

4. **Increase regional and Indigenous representation at both the governance and projects funded level**

   NL SUPPORT is a provincial body that provides support to healthcare research across Newfoundland and Labrador.

   While efforts have been made to have provincial representation, both Central and Labrador-Grenfell RHAs are presently missing on the TPMI Steering Committee. This lack of representation reduces the opportunity for health research concerns related to these regions to be effectively raised when directing policy and funding decisions.

   This is further illustrated in the project funding, where only 5 projects have been specifically designed to address health concerns outside of the Avalon region or at the provincial level.
Similar trends have been seen with Indigenous communities in Newfoundland and Labrador. NL SUPPORT are making effort to recruit Indigenous individuals to join the PAC and disseminated the first Indigenous Community Grant in 2017, however there is no representation from Indigenous communities in the governance. This was further exemplified by the evaluator’s inability to connect with Indigenous representatives for the evaluation.

As each region and Indigenous community faces their own challenges when accessing healthcare, NL SUPPORT should consider new opportunities to secure representatives from the two RHAs and the Nunatsiavut Government, Qalipu First Nation, and Innu Round Table, as well as review their funding programs and priority setting initiatives to ensure that projects funded reflect the diversity of NL’s healthcare landscape.

5. **Reporting requirements should be added to the NUTRA grant for undergraduate students to increase student’s reflection on their experience and its importance for their future**

To facilitate greater implementation of POR research in the future, NL SUPPORT offered grants and awards to graduate and undergraduate students to complete or support a POR project.

The Educational Funding Award requires students to provide a written report at the end of their funding to demonstrate the impact the project has had on them. This opportunity provides students the ability to reflect on their experience and the applicability of their learning in the next phase of their journey.

In contrast, undergraduate students who secure NUTRA funding are not required to provide any written feedback on their experience. To ensure that students are provided the opportunity to reflect on their experience with POR and the lessons they learned through their placement, NL SUPPORT should consider reviewing its grant reporting requirements for NUTRA.
1.0 BACKGROUND

The Canadian Institute of Health Research (CIHR) identified the need for patient-oriented research (POR) in its 2009/10 Health Research Roadmap. The roadmap outlines its strategic direction over the next five years. POR is defined by CIHR as:

“...a continuum of research, from the initial studies in humans to comparative effectiveness and outcomes research, and the integration of this research into the healthcare system and clinical practice. It includes studies of therapies, diagnostic tools, pharmaceuticals, and prevention strategies as well as comparative evaluations of those interventions against each other and against existing practices. It concludes with the synthesis, dissemination and integration of evidence into the healthcare system and clinical practice. Patient-oriented research thus encompasses both clinical research and health services research, the synthesis, dissemination and integration of this new knowledge into the healthcare system and into clinical practice.”

As a result of this new focus, CIHR released Canada’s Strategy for Patient-Oriented Research (SPOR) in August 2011 which identified five initiatives to increase POR in Canada. One of these initiatives was building and resourcing SUPPORT (Support for People and Patient-Oriented Research and Trials) Units across Canada. CIHR envisioned these units as being centers of methodological support “including epidemiologists, biostatisticians, social scientists, health economists and clinical trialists, as well as research support staff to assist investigators design relevant research studies, conduct biostatistical analyses, manage data and biobanks, learn project management skills and meet all relevant regulatory standards.”

In 2013, two years after the release of SPOR, the first SUPPORT Units were established in Canada in Alberta, Manitoba, Ontario and the Maritimes. The following year in 2014, a SUPPORT Unit was established in Newfoundland and Labrador (NL) at Memorial University of Newfoundland and Labrador (Memorial).

**NL SUPPORT** (also referred to as “the Unit”) is a methodological research support centre dedicated to supporting and developing the province’s capacity for POR. This center brings together patients, researchers, healthcare providers, IBM, and provincial and federal bodies to provide methodological support and research services for projects that have “a direct impact on patients’ lives, in ways that are important to patients and by making them partners in research.”

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3 Ibid
4 Ibid
5 http://www.cihr-irsc.gc.ca/e/49964.html
6 NL Government: Departments of Health and Community Services and Tourism, Culture, Industry and Innovation, Eastern Health, Atlantic Canada Opportunities Agency, NL Centre for Health Information, Memorial University, and patients, Canadian Institute of Health Research (CIHR)
7 http://www.nlsupport.ca/home.aspx
The Unit has been funded by both financial and in-kind donations. Below are the contributions over the past five years (2014-2019)³:

**Financial**
- **CIHR** - $9,780,855
- **IBM** - $2,800,000
- **Government of Newfoundland and Labrador (GNL)** - $7,200,000⁹

**In-kind**
- **IBM** – In addition to funding, IBM also provided access to IBM software through an academic initiative for infrastructure development and creation of employment opportunities in the healthcare market.
- **Patient time** - Patients advised on research priorities and project design and implementation.
- **Memorial University** – Memorial faculty and staff provided advice and support on topics including research methodologies, approach, proposal development and project implementation. Memorial also provided space and amenities for NL SUPPORT at the Craig L. Dobbin Research Centre.

As a hub of expertise, NL SUPPORT performs six core functions: (1) data platforms and services; (2) methods support and development; (3) health system research, implementation research and knowledge translation, (4) pragmatic/real-world clinical trials; (5) career development in methods and health services research; and (6) consultation and research services (figure 1). These six key areas were the cornerstones to NL SUPPORT’s service delivery model which included knowledge brokering and expertise through consultations and training¹⁰ as well as providing funding to conduct research.¹¹

**Figure 1:** Core functions of NL SUPPORT.

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³ SUPPORT Performance Measurement Strategy
⁹ In particular the Department of Health and Community Services and the Department of Tourism, Culture, Innovation and Industry.
¹⁰ http://www.nlsupport.ca/Home.aspx
¹¹ http://www.nlsupport.ca/Funding.aspx
1.1 Governance of NL SUPPORT

NL SUPPORT is governed by the Translational and Personalized Medicine Initiative (TPMI) Steering Committee. TPMI provides support through integrating evidence with the goal of:

- Reducing inappropriate use of healthcare resources;
- Increasing efficiencies;
- Improving cost effectiveness; and
- Improving patient outcomes.

As an overarching body, the TPMI Steering Committee’s goal is to improve the healthcare delivery across the province by integrating evidenced-based principles.

Through a formal collaboration process with CIHR, GNL, Atlantic Canada Opportunities Agency (ACOA) and IBM, TPMI leveraged partner expertise and financial contributions (cash and in-kind) in order to establish and support initiatives with an overarching goal to ensure that “right intervention gets to the right patient at the right time.” The Vice President of Research of Memorial oversees TPMI with operational support from the Office of Research, Grant and Contract Services. Through the collaboration of all stakeholders (researchers, patients, Regional Health Authorities (RHAs), policy makers, private industry, funding agencies) the initiative is designed to support and improve the healthcare system in the province. To ensure key partners and stakeholders are engaged in the decision making, the TPMI Steering Committee is comprised of representatives of the following organizations:

- Memorial (five representatives12 and three votes13);
- IBM (maximum of two representatives and two votes);
- Regional Health Authority (RHA; one vote for each RHA, up to a maximum of four);
- NLCHI (one representative and vote);
- Department of Health & Community Services (DHCS; one representative and vote);
- Department of Tourism Culture Industry and Innovation (TCII; one representative and vote);
- Patients (three representatives and three votes); and
- Other stakeholders as agreed to by the Committee on an ad hoc basis (non-voting members).1415

TPMI oversees the work of NL SUPPORT, as well as the Centre for Health Information and Analytics (CHIA) and two research programs Quality of Care/Choosing Wisely NL and Translational Genomics16. While each initiative is unique in its programming, the organizations support each other where possible to extend the reach and effectiveness of each initiative.

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12 Representatives from Memorial include: TPMI Chief Scientific Officer, Dean of Medicine, Office of the Vice President Research, TPMI Translational Research lead, NL SUPPORT Scientific lead
13 Allocation of votes: One of which will be the Steering Committee’s Chair’s tie breaking vote, and one will be the VPR delegate to the Steering Committee
15 Approved terms of ref TPMI steering committee January 2018
16 While a component of TPMI and does receive some support, this is not a key function of NL SUPPORT and therefore will not be explored in the evaluation.
Centre for Health Information and Analytics
The CHIA has developed into one of the largest high-performance computing facilities in Atlantic Canada. CHIA functions as the data platform and services core of NL SUPPORT. Funded in the main by NL SUPPORT, CHIA provides next-generation health informatics and data analytics hardware and software to improve health data collection and analysis in NL’s healthcare sector. This is done through the rapid interrogation and integration of complex data from multiple organizations sourced from electronic medical record (EMR), picture archiving communication system (PACS), oncology patient information system (OPIS), Pharmacy, Laboratory, Financial and Administrative data from Newfoundland and Labrador Center for Health Information (NLCHI) and RHAs. The data includes molecular, epidemiological, psycho-social, and health risk data to facilitate “transformational change in health system utilization, costs and health outcomes”.17

Quality of Care / Choosing Wisely NL
With a focus on supporting the delivery of a more effective and sustainable healthcare system, Quality Care/ Choosing Wisely NL functions as the Health System Research, Implementation and Knowledge Translation Core of NL SUPPORT. It receives support from NL SUPPORT and other partners to conduct research and lead awareness and knowledge translation activities with healthcare stakeholders, including patients.18

The primary areas of focus for Choosing Wisely NL include:
- Appropriate use of antibiotics;
- Peripheral arterial disease;
- Imaging for lower back pain;
- Preoperative testing prior to low-risk surgeries;
- Appropriate use of antipsychotics;
- HLA-B27;
- Antibiotic overuse;
- IgE testing; and
- Proton Pump Inhibitors.19

Quality Care NL supports projects focusing on:
- Stroke prevention;
- Potentially unnecessary testing;
- Drug utilization;
- Long term care;
- Acute care;
- Imaging; and
- Cancer care.20

17 https://www.med.mun.ca/CHIA/Home.aspx
18 https://qualityofcarenl.ca/about/what-we-do/
19 https://choosingwiselycanada.org/campaign/nl/
20 https://qualityofcarenl.ca
1.2 Other Advisory Groups

**Patient Advisory Council**

To support the mandate of POR, NL SUPPORT established a Patient Advisory Council in 2015, which provides advice and patient perspectives on all aspects of research including priority setting, research programs, communications materials, and grant applications. According to its terms of reference, the council “will provide advice and guidance on the determination of patient-oriented research priorities and the engagement of patients in research projects.” The council is comprised of up to 25 patients representing a cross-section of the population of the province; the NL SUPPORT Director and Patient Engagement lead; and NL Primary and Integrated Healthcare SPOR Network Coordinator and Patient Engagement Lead.

**Patient Panels**

To ensure high patient engagement and avoid overburdening patients on the Advisory Council, Patient Panels were created in 2018. Available to principal investigators and project teams for Quality Care and Choosing Wisely NL projects, the patient panels provided patient insight and perspective throughout the project. The mandate of these panels is to:

- “Assist in all phases of research projects to ensure that the patients’ points of view are included;
- Assist in identifying patients to join research teams;
- Advise on how to create awareness and behavior change among patients and communities;
- Assist with knowledge translation: a research activity which aims to turn the knowledge gained in the process of research into actual products, policies or practices;
- Assist in the writing of lay summaries as required for funding applications, conference summaries, etc.; and
- Identify training and support needs for members of the Patient Panels and research groups and advise on how these needs may be met”.

The Patient Panels are comprised of patients, the Quality Care and Choosing Wisely NL Coordinators (chairs), the manager, and NL SUPPORT Patient Engagement Lead.

2.0 Evaluation Context

Since its implementation in 2014, NL SUPPORT has provided various support and services in attempts to facilitate POR across the province. To ensure the Unit was provided sufficient and appropriate supports to date, an external midterm evaluation was conducted in 2017. The results of the evaluation were positive and identified that the Unit had demonstrated “above average

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21 Quality of Care NL/Choosing Wisely NL, Patient Panel Terms of Reference
22 Ibid
performance\textsuperscript{23}, with minor recommendations related to design and delivery (e.g., clarification of governance structure, regional disparities).

As NL SUPPORT approaches the end of their five-year funding, a summative evaluation was required by CIHR. Memorial commissioned Dig Insights (Dig) to undertake a summative evaluation of NL SUPPORT. The overall goal of the final evaluation was to examine the relevance, design, delivery, effectiveness and efficiency of the program in achieving its expected outcomes.

To guide the evaluation, the following program logic model was developed to depict the intended outcomes and expected impact of NL SUPPORT (figure 2).

\begin{itemize}
  \item
\end{itemize}

\textsuperscript{23} Newfoundland and Labrador Support for People and Patient-Orientated Research and Trails (SUPPORT) Unit Mid Term Evaluation (2017)
Figure 2: Logic Model for NL SUPPORT.

*To grow, support and sustain the capacity for a collaborative, interdisciplinary and innovative patient-oriented research environment capable of addressing evolving health care questions, contributing to enhancing patients’ health care experience and improving health outcomes.*
3.0 EVALUATION METHODOLOGY

The team at Dig worked closely with NL SUPPORT to develop a participatory approach to complete the evaluation.

Building off the logic model, Dig developed an evaluation framework to direct the methodological approach for the evaluation including the data collection tools implemented and the analysis conducted. This was done through mapping each evaluation question to a specific performance indicator and a tailored methodology as seen in appendix A.

As seen below, a mixed/multi-method evaluation design was implemented for this evaluation which included a document review, literature review, administrative data analysis, key informant interviews, surveys and case studies.

3.1 Document Review

Dig conducted a document review to gain an understanding of the NL SUPPORT program and its requirements to assess alignment with its funders and stakeholders’ priorities, and to gather evidence of expected outcomes.

A full list of documents reviewed can be found in Appendix B, with some of the key documents listed below:

- Annual performance reports 2015-16, 2016-17, 2017-18;
- CIHR: Strategy for Patient-Oriented Research - Patient Engagement Framework;
- Interim mid-term evaluation;
- Steering Committee meetings notes;
- Patients Advisory Council minutes; and
- Quality Care /Choosing Wisely NL priorities.
3.2 Literature Review

A literature review was conducted to get an overview of the best practices of other SPOR units conducting POR across Canada. This information was also fundamental in understanding the relevance of the program and its key stakeholders.

A full list of reviewed literature can be found in Appendix C, with some of the most referenced documents listed below:


3.3 Administrative Data Analysis

NL SUPPORT’s administrative data was provided to Dig to analyze the effectiveness of the program’s design and outcomes achieved to date. This included data on:

- Funding allocated per grant;
- Annual NL SUPPORT performance data;
- Survey response data collected by NL SUPPORT;
- Knowledge translation products created;
- TPMI Education Fund funding;
- SHARE Summit presentations and data; and
- NL SUPPORT funded and supported research projects.

3.4 Key Informant Interviews

Key informant interviews were conducted to gather a deeper understanding and to explore any questions that emerged upon analysis of findings from other evaluation methods. In total 27 key informant interviews were conducted with key stakeholders including:

- NL SUPPORT staff (5);
- TPMI Steering Committee members (9);
- TPMI employees (3);
- Healthcare providers (2);
- Grant Recipients (6);
Detailed interview guides can be found in Appendix G. Interviews were conducted over the phone and lasted between 30 minutes and 1.5 hours in length.

### 3.5 Surveys

Surveys were completed with grant recipients, project stakeholders and the Patient Advisory Council to identify the strengths and weaknesses of the program design and delivery and to assess program outcomes. NL SUPPORT worked with Dig to select individuals to receive the appropriate survey. Detailed survey results can be found in Appendix D.

#### 3.5.1 Grant Recipient Survey

The online grant recipient survey was conducted from June 23rd to July 21st, 2019, with a response rate of 54%. Most respondents were students (57%) who received a Patient-Oriented Research Grant (52%) (table 1 and 2) and were at differing stages of completion of their research project (table 3).

<table>
<thead>
<tr>
<th>Table 1: Grant Survey: Recipients Profession (N=21)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Profession</strong></td>
</tr>
<tr>
<td>Student</td>
</tr>
<tr>
<td>Professor</td>
</tr>
<tr>
<td>Physician/ Healthcare professional</td>
</tr>
<tr>
<td>Researcher Associate</td>
</tr>
</tbody>
</table>

| Table 2: Grant Survey: Which of the following NL SUPPORT grants were you successful in obtaining? Select all that apply. (N=21)
<table>
<thead>
<tr>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Type of Grant</strong></td>
</tr>
<tr>
<td>NL SUPPORT Graduate Awards for Engagement/Educational Funding Award</td>
</tr>
<tr>
<td>Patient-Oriented Research Grant</td>
</tr>
<tr>
<td>SPARK Grant for Clinicians, Nurses and Allied Health Professionals</td>
</tr>
<tr>
<td>Development Grant</td>
</tr>
<tr>
<td>TPMI/NL SUPPORT Training and Travel Funding</td>
</tr>
<tr>
<td>NL SUPPORT Undergraduate Research Award (NUTRA)</td>
</tr>
</tbody>
</table>

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24 While survey was sent to Development grant and travel fund recipients, they did not complete the survey; the survey was not sent to Indigenous Grant recipients.
Table 3: Grant Survey: At what phase is your most complete NL SUPPORT-funded research project? Select all that apply. (N=21)

<table>
<thead>
<tr>
<th>Phase</th>
<th>% (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Planning</td>
<td>5% (1)</td>
</tr>
<tr>
<td>Implementation/data collection</td>
<td>19% (4)</td>
</tr>
<tr>
<td>Analysis</td>
<td>38% (8)</td>
</tr>
<tr>
<td>Reporting</td>
<td>19% (4)</td>
</tr>
<tr>
<td>Dissemination</td>
<td>14% (3)</td>
</tr>
<tr>
<td>Complete</td>
<td>5% (1)</td>
</tr>
</tbody>
</table>

3.5.2 Stakeholder Survey
An online survey for stakeholders was implemented from June 18th to July 17th, 2019. In total five respondents (response rate of 31%) completed the survey with individuals identifying themselves as executives, policy makers, practitioner and program administrator (table 4).

Table 4: Stakeholder Survey: What is your current role? Select all that apply. (N=5)

<table>
<thead>
<tr>
<th>Role</th>
<th>% (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health executive/manager</td>
<td>40% (2)</td>
</tr>
<tr>
<td>Policy maker</td>
<td>40% (2)</td>
</tr>
<tr>
<td>Healthcare practitioner</td>
<td>20% (1)</td>
</tr>
<tr>
<td>Health charity representative</td>
<td>20% (1)</td>
</tr>
<tr>
<td>Program Administrator</td>
<td>20% (1)</td>
</tr>
<tr>
<td>Patient – family rep</td>
<td>20% (1)</td>
</tr>
</tbody>
</table>

3.5.3 Patient Advisory Council (PAC) Survey
To collect feedback from the PAC, an online survey was open for 18 members to complete between June 18th to July 17th, 2019. In total, eight committee members completed the survey (response rate of 44%) with most members heavily involved in NL SUPPORT (on average participated in 3.75 different opportunities; table 5).

Table 5: PAC Survey: Can you tell me how you have participated in NL SUPPORT/Quality of Care/Choosing Wisely Newfoundland? Select all that apply. (N=8)

<table>
<thead>
<tr>
<th>Role</th>
<th>% (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Member of the Patient Advisory Council</td>
<td>100% (11)</td>
</tr>
<tr>
<td>Member of the Translational and Personalized Medicine Initiative (TPMI) Steering Committee</td>
<td>13% (1)</td>
</tr>
<tr>
<td>Patient partner in research</td>
<td>63% (5)</td>
</tr>
<tr>
<td>Patient partner in disseminating/sharing research results</td>
<td>38% (3)</td>
</tr>
<tr>
<td>Identification of Research priorities</td>
<td>25% (2)</td>
</tr>
<tr>
<td>Setting meeting agendas</td>
<td>25% (2)</td>
</tr>
<tr>
<td>NL SUPPORT training recipient</td>
<td>38% (3)</td>
</tr>
</tbody>
</table>
### 3.6 Case Studies

Building on the findings from the other lines of evidence and guided by three overarching outcomes of NL SUPPORT (best practices in healthcare delivery, use of data to encourage evidence-based practices and increasing capacity of various stakeholders), Dig conducted six case studies focusing on:

1. NL SUPPORT’s partnership with IBM;
2. Antibiotics campaign;
3. Applied Behavioural Analysis (ABA) Telehealth;
4. Medical test ordering;
5. Increasing capacity of graduate students to conduct POR through education and funding; and

To conduct each case study, Dig reviewed program documents, multimedia advertisements and administrative data provided by stakeholders to gather a deeper understanding of the project topic. Following the review of data, key informant interviews were conducted with stakeholders to probe deeper into their experience, outcomes achieved, best practices and next steps.

In addition to the nine original key informant interviews, 11 additional telephone interviews were conducted as part of the case study methodology. Interviews lasted between 30 minutes to 1 hour and 15 minutes.

Findings from the case studies are incorporated throughout this report.

### 3.7 Limitations

The following were limitations of the evaluation methodology:

**Interpretation on Survey Responses:** Due to the breadth of supports and services offered by NL SUPPORT, surveys were used to collect feedback from each group to ensure reach and a comprehensive understanding of the impact of the program. This approach was advantageous as it allowed all perspective from multiple groups. However, it is worth noting that survey results are based on relatively small sample sizes. When looking at survey responses in the report, readers should interpret the results in this context.

**Engagement of Indigenous Community:** Though the program, NL SUPPORT administered one Indigenous Community Grant in 2018. While effort was made to gather the perspective from the
Innu community in relation to the impact of the grant and how NL SUPPORT could further support Indigenous communities, there was no response to the invitation to take part in the evaluation. Consequently, there is no input from Indigenous communities in this evaluation report.

4.0 FINDINGS

This section presents the findings and supporting evidence from the evaluation of the NL SUPPORT.

4.1 Relevance

4.1.1 NL SUPPORT alignment with funders/partners’ priorities and objectives

**Finding:** NL SUPPORT strongly aligns with the objectives and priorities of its funders including CIHR, Memorial, IBM and the Government of Newfoundland and Labrador. This is supported through its commitment to fund projects that align with the healthcare needs identified by residents; funding projects aimed at increasing the effectiveness and efficiency of healthcare system (e.g., telehealth), and by enhancing the capacity of researchers and students in the province.

NL SUPPORT’s objectives were seen to be **relevant to the needs of the healthcare community** including, but not limited to patients, researchers and the residents of Newfoundland and Labrador. It was especially successful in engaging patients and sharing results to increase researchers’ capacity to complete POR.

NL SUPPORT is well aligned with the priorities of their main funders and partners including CIHR, Memorial, IBM and the Government of Newfoundland and Labrador. The Unit has prioritized funding projects and developing infrastructure to help to increase the effectiveness of the healthcare sector.

**CIHR:** With a mandate to “**excel, according to internationally accepted standards of scientific excellence, in the creation of new knowledge and its translation into improved health for Canadians, more effective health services and products and a strengthened Canadian healthcare system,**”\(^{25}\) CIHR established SUPPORT Units across the country to establish “**improved health outcomes and an enhanced healthcare system,**”\(^{26}\) through POR research.

NL SUPPORT directly aligns with CIHR’s mandate as they actively work with their key stakeholders, PAC and patient advisors to fund and support projects that align with healthcare needs that are important to the residents of Newfoundland and Labrador.

\(^{25}\) [http://www.cihr-irsc.gc.ca/e/7263.html](http://www.cihr-irsc.gc.ca/e/7263.html)

\(^{26}\) From: [http://www.cihr-irsc.gc.ca/e/48413.html](http://www.cihr-irsc.gc.ca/e/48413.html)
**Memorial University:** NL SUPPORT aligns with Memorial’s mission as an “an inclusive community dedicated to innovation and excellence in teaching and learning, research, scholarships, creative activity, service and public engagement.” The Unit provides funding, training and supports to facilitate innovative POR research at the University by both students and professors.

More specifically, NL SUPPORT’s work is relevant to the MUN Innovation: Re-Imagining Memorial University’s Innovation Support System strategy released in 2016. This strategy aims to “coordinate and enhance the suite of innovation supports across Memorial University to better support and empower students, faculty, staff, and external partners to create provincial, regional, and national prosperity through innovation.” As a part of this mission, Memorial has identified four key goals including “Interact”, which identifies the needs for strengthening relationships with external partners and “Invent”, which looks to enhance the suite of innovation supports at the university. NL SUPPORT contributes to both of these goals as it facilitates the collaboration and increased partnerships across various bodies both provincially (e.g., government officials, RHAs, Memorial) and nationally (e.g., IBM, other SUPPORT Units). Additionally, more specialized and complex computing software offered through CHIA provides researchers and students the platform to envision and create innovative tools to enhance research and service delivery in the healthcare sector.

> “The overall objective related to the creation of CHIA is the improvement of Memorial University’s computational capacity so as to position it on the leading edge of knowledge generation technology.”
>  
> - Stakeholder

**IBM:** IBM is founded on the goal of progress and that “application of intelligence, reason and science can improve business, society and the human condition.” This is further highlighted in the organization’s values which centers around client success and supporting innovation that matters for the world.

Through IBM’s partnership with NL SUPPORT, the organization is able to help develop software and system management to improve the efficiencies and scope of data analytics available in the province, as well as develop CHIA staff capacity to be able to conduct complex data analysis. The development of both resources and staff skills provide the framework to support future advancements in the healthcare sector and improve the lives of citizens in the province. This partnership also has the potential to develop new platforms or systems that IBM could sell for a fee or through service contracts to private industry and academic partners further enhancing the reach of this partnership and its alignment with IBM’s vision.

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27 [https://www.mun.ca/president/home/vision.php](https://www.mun.ca/president/home/vision.php)
28 From: [https://www.mun.ca/innovation/Charter.pdf](https://www.mun.ca/innovation/Charter.pdf)
30 2018 Implementation Plan
**Government of Newfoundland and Labrador:** Healthcare needs of residents of Newfoundland and Labrador remain a prevalent issue as they have one of the lowest life expectancies, highest rates of some chronic diseases (e.g., heart disease, diabetes, and several cancers) and highest incidence of system overuse in Canada.\(^{31}\) Between 2007 and 2017, healthcare spending in NL increased by $1 billion, despite the province having the highest public debt.\(^{32}\)

In attempts to address the financial challenges facing the province, the Government released *The Way Forward* document. In this document the Government indicated that one of their key objectives going forward is to “create better health outcomes through innovation”. The document also sets targets to bring NL rates more in line with Canadian averages by the year 2025 through investments in e-health infrastructure.

NL SUPPORT is in alignment with these commitments as they support the healthcare system in identifying practices that would help to improve health outcomes, while increasing efficiencies. An example of this is the NL SUPPORT funded project, “Effect of Diagnostic Imaging Utilization Reports.”\(^{33}\) This study aimed to determine the effectiveness of two versions of diagnostic imaging utilization feedback reports and in-person detailing sessions in changing physicians’ ordering practices of CT, x-rays and ultrasounds. This was seen to be beneficial for both the reduction of medical assessments conducted as well as reducing patients contact to potentially harmful radiation and unnecessary testing to follow up on inconsequential findings.

The Unit also funded the “Utilizing commercially available infrared thermometers to prevent foot ulcers in patients with diabetes - A mixed methods approach” project. This project aimed to determine the effectiveness of an inexpensive commercially available infrared thermometer (CAIT) to improve foot outcomes for individuals with diabetes, a key priority for the Government of NL.\(^{34}\)

*“NL SUPPORT is aligned with provincial priorities and that is in support of policymakers, they align with the Way Forward, for example, like my work around obesity. It is one of the strategic objectives of the province and policy-makers.”*  
- Stakeholders

Furthermore, the activities of NL SUPPORT are in line with the province’s *Health Innovation Action Plan*, which focuses on increasing the adoption of new processes and improved technologies in the healthcare sector to better manage costs, improve services, and provide better care while contributing to economic growth. The Health Innovation Action Plan also recommends a focus on improving the labour pool and increasing the capacity of big data analytics which are in line with NL SUPPORT activities of training and funding undergraduate and graduate students in POR and through CHIA’s work on big data analytics.

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\(^{31}\) Presentation to CIHR Overview of NL SUPPORT key achievements Nov 2019  
\(^{32}\) Ibid  
\(^{33}\) https://clinicaltrials.gov/ct2/show/NCT02917837  
\(^{34}\) https://clinicaltrials.gov/ct2/show/NCT03506776
4.1.2 Alignment of NL SUPPORT with healthcare needs across the province

**Finding:** NL SUPPORT’s objectives were seen to be relevant to the needs of the healthcare community including, but not limited to, patients, researchers and the residents of Newfoundland and Labrador. It was especially seen to be relevant in increasing researchers’ capacity to complete POR and engage patients in sharing their results.

The objectives of NL SUPPORT were viewed by all survey respondents to be relevant to the needs of researchers and patients across the province (figure 3). The objective to increase the capacity to fully engage patients in sharing results and researcher’s capacity to complete POR were identified as being the most relevant to these populations.

**Figure 3: PAC/ Grant/ Stakeholder Survey:** Below is a list of the objectives of NL SUPPORT. To what extent do you think these objectives are relevant to the healthcare field in Newfoundland and Labrador? (N=8, 5, 21)\(^{35}\)

<table>
<thead>
<tr>
<th>Objective</th>
<th>Grant</th>
<th>Stakeholder</th>
<th>PAC</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increasing partnerships across faculties, schools, and disciplines</td>
<td>81%</td>
<td>100%</td>
<td>80%</td>
</tr>
<tr>
<td>Improved access to health system level data</td>
<td>86%</td>
<td>80%</td>
<td></td>
</tr>
<tr>
<td>Improve the responsiveness of the healthcare system</td>
<td>76%</td>
<td>80%</td>
<td>100%</td>
</tr>
<tr>
<td>Increase researchers’ capacity to fully engage patients when sharing their research results</td>
<td>76%</td>
<td>100%</td>
<td>100%</td>
</tr>
<tr>
<td>Increase capacity of researchers to undertake Patient-Oriented Research</td>
<td>81%</td>
<td>80%</td>
<td>88%</td>
</tr>
<tr>
<td>Increase researchers’ capacity to plan Patient-Oriented Research</td>
<td>71%</td>
<td>80%</td>
<td>100%</td>
</tr>
</tbody>
</table>

\(^{35}\) PAC members were not asked for their opinion on the relevance of partnership across facilities and access to health system level data.
4.2 Design and Delivery

**Finding:** NL SUPPORT was seen by stakeholders to be **effectively designed** through its interconnected governance structure with the TPMI Steering Committee and collaborative partnerships with Quality of Care/Choosing Wisely NL, and CHIA. The Unit’s design also provides sufficient opportunities for residents across the province to direct research, as well as participate in knowledge translation (KT) through community events.

**Patients engaged in NL SUPPORT felt that they had sufficient resources to effectively engage in the program.** NL SUPPORT follows sector best practice through the integration of patient partners at the beginning of the project and through collaborating with other Units.

**Researchers were satisfied with the design** of the eight grants and the awards provided by NL SUPPORT. Engagement of the additional supports varied among survey recipients, with many not accessing support from CHIA. Researchers were overall positive about the support they received implementing POR and developing KT.

To improve delivery moving forward, increased engagement of Regional Health Authorities (RHAs) from Central and Labrador-Grenfell and the Nunatsiavut Government, Qalipu First Nation, and Innu Round Table, and increased awareness of analysis capabilities available at CHIA was recommended.

Throughout the past five years, NL SUPPORT has continued to refine their design and delivery model to best reflect the needs of its Steering Committee, residents, patients, researchers, students, and healthcare providers.

**Governance Structure:** As explained in section 1.1, NL SUPPORT is governed by the TPMI Steering Committee. The interconnectedness of this governance structure with Quality of Care/Choosing Wisely NL, and CHIA was seen to an effective model as it has allowed NL SUPPORT to extend the reach of their efforts as they, where possible, collaborate with other initiatives. Through collaborating with Quality Care /Choosing Wisely NL, the Unit has been able to support the involvement of POR in over 55 projects and has been identified as a best practice by other Choosing Wisely programs across Canada for its ability to collect and share research that is meaningful to the residents and physicians in the province.36

> “If it wasn’t for NL SUPPORT we would not have the money or infrastructure - we would be at ground zero like all the other provinces Choosing Wisely programs. [...] Most people are doing CW off the side of their desk and we in NL have infrastructure and people fully dedicated to this work. We constantly hear we are doing so well.”
> - Stakeholder

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36 2017-2018 SPOR SUPPORT Unit Annual Performance Report
In addition to the initiatives, the TPMI Committee effectively provides patients an opportunity to share their opinion and contribute to the direction of the initiatives.

“Having patients sitting at this level is different for staff and physicians. I think in the beginning that was difficult for them to wrap their heads around. But now they acknowledge what patients have to say, what we bring. The 3 patients on TPMI are very vocal now.”
- Stakeholder

It was acknowledged by stakeholders that there was a lack of provincial wide representation on the committee as there are currently only representatives from Eastern and Western Health. While efforts have been made to secure a representative from the other RHAs (Central and Labrador-Grenfell) and engage representatives from the Nunatsiavut Government, Qalipu First Nation, and Innu Round Table, it was felt that additional effort is needed to ensure that the studies and direction of NL SUPPORT reflect the needs of the entire province. The inclusion of representatives from these groups would also provide them the opportunity to provide insight and resources to support the implementation of different research projects.

Residents: Since 2016\(^{37}\), NL SUPPORT has provided residents across Newfoundland and Labrador the opportunity to participate in the annual priority-setting process (table 6). Originally conducted through eight town hall events, residents are now able to provide feedback through paper and online surveys, which resulted in 981 responses collected in 2018 alone. Key informants viewed this to be an effective process to engage residents across the province and maintain the objectives of the Unit. Table 6 outlines the research priorities identified over the last three years.

“Only by embedding patient voices so thoroughly throughout our research initiative can we be sure that the impacts we are having are addressing the needs of patients, as identified by those patients, and most effectively fulfil the special obligation NL SUPPORT has to the people of Newfoundland and Labrador”
- 2016-2017 NL SUPPORT Annual Report

Table 6: Priority Research Themes

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary care</td>
<td>Mental health and addictions</td>
<td>Wait times</td>
</tr>
<tr>
<td>Access to support services</td>
<td>Wait times</td>
<td>Mental health and addiction</td>
</tr>
<tr>
<td>Wait times</td>
<td>Awareness of and access to community services and supports</td>
<td>Appropriate healthcare/ efficient use of resources</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Senior care/ long- term care</td>
</tr>
</tbody>
</table>

\(^{37}\) Eastern Health set the research priorities in 2015
Residents also have the opportunity to engage with the research completed as part of NL SUPPORT through the Health 4 All event.

First launched in fall 2017, the Health 4 All Festival provide families in the province the opportunity to communicate with researchers,primarily students, about their research and allow children to learn about health topics through fun and interactive activities. This was seen by stakeholders to be an effective event with over 200 in attendance. Since its first implementation the event has run annually with attendance reaching over 400 this year under the new “Terrific Scientific Health Discovery Day.”

Patients: To support the implementation of POR, NL SUPPORT has recruited patients from across the province using newspaper ads, social media, emails and brochures to join PAC, Patient Panels and/or to participate in the larger “Friends Pool”, which provides e-consultations for smaller projects or researchers needing periodic support. In recent years, NL SUPPORT has been effective in diversifying the engagement of patients to include youth, individuals with low income and those with a disability. However, there has been low engagement of Indigenous patients and NL SUPPORT has acknowledged that additional outreach activities are needed to engage this population.

Once recruited, NL SUPPORT provides patients the opportunity to avail of their supports including training, consultation services and if desired, are matched with a project to provide their perspective. Overall, patients surveyed were satisfied with the support provided by NL SUPPORT especially the information and training and the cash appreciation payment provided. (88%; figure 4).
A potential cause for the lower satisfaction in their participation in the research projects was explained by the case study patient. They shared that due to a principal investigator’s unfamiliarity with POR, they had little meaningful engagement with the project at the onset. This was later modified with NL SUPPORT providing the researcher additional guidance.

**Researchers/Students/Healthcare Providers:** To achieve its overall mandate, NL SUPPORT provided individuals interested in health research and POR the opportunity to access funding, additional supports and present at Research Day.

**Funding:** Over the course of the past five years, NL SUPPORT has offered eight different grants and awards to support students, research teams, Indigenous communities and staff on TPMI projects as seen below. A description of each award can be found in Appendix E.

- **Students**
  - Educational Funding Opportunities Award
  - Graduate Awards for Engagement
  - Undergraduate Training in Research Award
  - TPMI Training and Travel Funding
- **Research Teams**
  - Development Grants
  - SPARK Grants for Clinicians, Nurses and AHP
  - Patient Orientated Research Grants
- **Indigenous Communities**
  - Indigenous Communities Grants
The diversity of awards offered by NL SUPPORT was seen to be a strength of the program as it provided both current and future researchers, as well as individuals in the healthcare sector the opportunity to learn and develop skills in POR. Stakeholders also appreciated the varying financial incentive and flexibility as it allowed for various projects including smaller pilot projects to be funded and was seen to help raise the profile of POR in the province.

“NL SUPPORT helps researchers by placing focus on POR research. It has helped to percolate the knowledge and awareness amongst researchers through their grants.”

- Stakeholder

As seen in table 7, overall grant recipients were satisfied with grant design including application (100%), funding (75%-100%), and reporting/presentation (100%) requirements with the lowest satisfaction seen in the number and amount of grants being administered (75%). In addition to the guidelines, almost all grant recipients (95%) were also satisfied with how long it took for their application to be approved.
Table 7: Grant Recipient Survey: Guidelines for grants/awards

<table>
<thead>
<tr>
<th>Award/Grant</th>
<th>Application Requirements</th>
<th>Application Criteria</th>
<th>Maximum Funding Amount</th>
<th>Maximum Annual Grants</th>
<th>Reporting Requirements</th>
<th>Presentation Requirements</th>
</tr>
</thead>
<tbody>
<tr>
<td>NL SUPPORT Graduate Awards for</td>
<td>Application form CV University transcript 2 letters of reference CV of supervisor</td>
<td>NL SUPPORT committee will review applications to select winners based on their alignment with TPMI mandate 100% satisfied</td>
<td>$1,000 75% satisfied</td>
<td>No stated number</td>
<td>Final report 100% satisfied</td>
<td>Participate in Science, Health and Research Education (SHARE) Summit and potentially Health 4 All Festival 100% satisfied</td>
</tr>
<tr>
<td>Engagement</td>
<td>Description of project and career goals 100% satisfied</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educational Funding Award</td>
<td>Completion of online application Transcript 100% satisfied</td>
<td>- Relevance of the proposed research to the mandate and priority research themes</td>
<td>Masters - $14,000 75% satisfied</td>
<td>No stated number</td>
<td>Final report 100% satisfied</td>
<td>Participate in SHARE Summit and potentially Health 4 All Festival 100% satisfied</td>
</tr>
<tr>
<td>NUTRA</td>
<td>Supervisor Identification form Student application form Essay on interest in the summer project and how it will benefit career plans</td>
<td>NL SUPPORT committee will review applications to select winners based on their alignment with TPMI mandate 100% satisfied</td>
<td>$4,500 Stipend for up to 16 weeks 4 = total of $18,000</td>
<td>None</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>Development Grant</td>
<td>Completion of online application</td>
<td>- Relevance of the proposed research to the mandate and priority research themes</td>
<td>$20,000</td>
<td>5</td>
<td>End of term report</td>
<td>Participate in SHARE Summit</td>
</tr>
</tbody>
</table>

Recipients “a lot” and “somewhat” satisfaction with grants requirements is provided where available.
<table>
<thead>
<tr>
<th>Award/Grant</th>
<th>Application Requirements</th>
<th>Application Criteria</th>
<th>Maximum Funding Amount</th>
<th>Maximum Annual Grants</th>
<th>Reporting Requirements</th>
<th>Presentation Requirements</th>
</tr>
</thead>
</table>
| SPARK Grant for Clinicians, Nurses and Allied Health Professionals | 3-page summary of their study, research clearances and timeline 100% satisfied | - Planned incorporation of patients as partners  
- Planned integration of KT  
- Expertise and research experience, and past POR  
- Merit of the proposal and clarity of application 100% satisfied | $10,000 75% satisfied | 10 75% satisfied | 6-month progress report  
End of study report 100% satisfied | Participate in SHARE Summit and/or Health 4 All Festival 100% satisfied |
| Patient-Oriented Research Grant | Online application  
Must first submit an Expression of Interest before submitting the final application 100% satisfied | - Relevance of the proposed research to the mandate and priority research themes  
- Planned incorporation of patients as partners  
- Expertise and research experience, and past POR  
- Merit of the proposal and clarity of application 100% satisfied | $75,000 100% satisfied | 4 = Up to $300,000 per annum in funding 91% satisfied | Final report 100% satisfied | Participate in SHARE Summit and other public engagement events 100% satisfied |
| Indigenous Communities’ Grant | Online application | Projects must be led by an identified Indigenous community | $75,000 | 1 | Final Report | Participate in SHARE Summit and potentially Health 4 All Festival |
| TPMI/NL SUPPORT Training and Travel Funding | Description of reason and need for funding and its applicability to their project and career goals | Reviewed by TPMI Executive committee for applicability | Reflective of need | Reflective of need | None | None |
Additional Supports: To support funded and non-funded researchers, students and healthcare professionals, NL SUPPORT provided various training, and consultation services. As seen in figure 5, grant recipients were very satisfied with the support they received from the Unit in POR (33%) and in developing KT tools (e.g. educational material, online tools, journal articles).

Figure 5: Grant Recipient Survey: Below are some of the supports you could have received in addition to the funding from NL SUPPORT. How would you rate your experience with the supports you received from NL SUPPORT (including QoC/CW NL, and CHIA)? (N=21)

<table>
<thead>
<tr>
<th>Support</th>
<th>Very Good</th>
<th>Good</th>
<th>Poor</th>
<th>Very Poor</th>
<th>Not Applicable/Did not Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support in patient engagement in research project(s)</td>
<td>33%</td>
<td>43%</td>
<td>5%</td>
<td>19%</td>
<td></td>
</tr>
<tr>
<td>Support with the development of KT tools</td>
<td>33%</td>
<td>33%</td>
<td>5%</td>
<td>52%</td>
<td></td>
</tr>
<tr>
<td>Facilitation of meetings with knowledge users</td>
<td>24%</td>
<td>29%</td>
<td>5%</td>
<td>43%</td>
<td></td>
</tr>
<tr>
<td>Support to complete funding application(s)</td>
<td>24%</td>
<td>38%</td>
<td>10%</td>
<td>29%</td>
<td></td>
</tr>
<tr>
<td>Facilitation of meetings with potential collaborators</td>
<td>19%</td>
<td>24%</td>
<td>5%</td>
<td>52%</td>
<td></td>
</tr>
<tr>
<td>Consultation on methodology/research question</td>
<td>10%</td>
<td>29%</td>
<td>10%</td>
<td>52%</td>
<td></td>
</tr>
<tr>
<td>Assistance with an ethics application(s)</td>
<td>5%</td>
<td>24%</td>
<td>5%</td>
<td>67%</td>
<td></td>
</tr>
<tr>
<td>Support from CHIA</td>
<td>5%</td>
<td>19%</td>
<td>5%</td>
<td>71%</td>
<td></td>
</tr>
<tr>
<td>Support accessing data from NLCHI</td>
<td>14%</td>
<td>5%</td>
<td>81%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

While projects were in varying stages of completion and some survey respondents would not have required access to these supports and services based on the scope of their study, many of the respondents did not need or access services from NLCHI (81%) or CHIA (71%). This high response calls into question whether grant recipients were fully familiar with the services, capabilities and depth of data available at these organizations.

A further description of the training and consultation services is provided in section 4.3.2.

Research / Scientific Day: In addition to supports, NL SUPPORT hosted an annual Science, Health and Research Education (SHARE) Summit, previously called Research / Scientific Day. During this event researchers were able to present research or take part in panel discussions. In 2018 students presented posters and participated in "The Rewarding Success Practice Pitch Panel" where they were given five minutes to pitch their research to a panel of researchers, patients and other stakeholders.

39 https://www.mun.ca/sgs/contacts/AtlanticSummit.php
This annual event provided students and researchers the opportunity to gain experience sharing their study with the general public as well as becoming more aware of other research projects being conducted across the province. Over two thirds (68%) of respondents who completed the NL SUPPORT Summit feedback survey in 2018, found the event very valuable with the most preferred aspects being the presentations (individual or group) and panel discussions.

### 4.2.1 Best Practices

NL SUPPORT follows best practices as it continues to provide patients opportunities for meaningful engagement in research in the healthcare sector throughout the duration of projects and engages with other SUPPORT Units to leverage expertise and skill.

As POR is relatively new in the Canadian healthcare landscape, many best practices are still evolving. Nass, Levine, Yancy (2012) conducted an international analysis of the best practices to engage patients. From their study they determined that studies that involve patients in early stages of research are seen to be the most beneficial with the goal to establish patient-clinical partnerships.

> "Engaging patients in healthcare research makes (investments in) research more accountable and transparent, provides new insights that could lead to innovative discoveries, and ensures that research is relevant to patients’ concerns. The international experience with engaging citizens and patients in research has shown that involving them early in the design of studies, ideally as early as at the planning stage, leads to better results."
> - Nass, Levine, Yancy (2012)

NL SUPPORT follows this best practice by matching patients with researchers at the beginning of the project so patients can provide input during all phases of research, especially during the preliminary phase. The matching process also helps to ensure that individuals’ experiences are the best fit for the project to ensure a mutually beneficial partnership.

> “Emergency room department – came to us and we were able to provide an innovative idea of the model and gave her preliminary funding to be able to do a preliminary study to then leverage larger fund”
> - Stakeholder

In addition to international best practices, NL SUPPORT continues to collaborate with other SUPPORT Units across Canada to leverage their skills and expertise to support the implementation of both Units. As an example, NL SUPPORT is currently working with the Maritime SPOR SUPPORT Unit (MSSU) in the delivery of CIHR POR Foundations training to ensure that both SUPPORT Units are equipped to provide the training within their own geographical area. In addition, NL SUPPORT’s academic Patient Engagement Lead and PAC are working with Alberta’s Patient

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40 2018 SHARE Feedback
Engagement Acting Director and Lead and their PAC on a scientific publication that will describe both councils, their work, successes and challenges and will help build the evidence base for the use of councils in POR.

When asked to reflect on best practices from other jurisdictions, stakeholders agreed that NL SUPPORT was seen to be a leader compared to other units, especially in its patient engagement strategies which it has shared with other Units to help achieve a consistency of service.

“NL has been at the leading edge of POR compared to others in the field, now other provinces are catching up.”
- Stakeholder

4.3 Achievement of Outcomes

Over the past five years, the funding, support, services and opportunities provided by NL SUPPORT have resulted in the following achievements of outcomes:

- Enhanced research infrastructure;
- Increased capacity of researchers to conduct POR;
- Improved patient capacity for engagement;
- Increased evidence-based practice; and
- Improved health system efficiency.

4.3.1 Enhanced Research Infrastructure

**Finding:** NL SUPPORT has enhanced the research infrastructure throughout the province through the establishment of CHIA and its ongoing partnership with IBM. CHIA’s health information and data analytics platforms have provided faster computation, increased data storage security and the ability to create customizable software solutions. For example, CHIA is working with IBM to develop an e-ordering platform to reduce unnecessary medical assessments.

Through its agreement with NLCHI, researchers have also benefited from increased efficiency in accessing data, with waiting times reduced to months instead of years. Despite this reduction in waiting time, researchers still require a more efficient process to access NLCHI data to reduce delays in research.

Despite these challenges, health research is seen to be more responsive to the changing climate of the province as a result of NL SUPPORT’s efforts as demonstrated by the Effects of Diagnostic Imaging Utilization Reports study.

Over half of the stakeholder (60%) and most of the grant recipient survey respondents (43%) felt that NL SUPPORT has very much helped to improve the responsiveness of the research being
conducted as a result of the creation of CHIA and the improved efficiency accessing provincial data from NLCHI.

**CHIA:** The funding provided through NL SUPPORT and its stakeholders has funded the establishment of CHIA, a state-of-the-art health information and data analytics hardware and software platform. This new system facilitates the rapid interrogation and integration of complex source data from multiple partner organizations\(^4\) which was previously not feasible in the province.

Though CHIA’s high-performance computing version of SAS, complex statistical analysis is now being conducted on a system with up to 128 cores of computational power as compared to a desktop computer (average laptop is around 2 cores).

In addition, CHIA increases the efficiency of linking data sets together to be able to determine correlations and causations in provincial wide data. This was seen in the “Optimizing Drug Utilization in Newfoundland and Labrador through Patient Oriented Research-Demonstration Project.”\(^4\) This project demonstrated the ability to link necessary databases together to design and implement a study to optimize physician prescribing habits for seniors using data from Newfoundland and Labrador Prescription Drug Program (NLPDP).

“This initial phase of our drug utilization program aims to determine the feasibility regarding the linkage of several healthcare databases, demonstrate the capacity to conduct rigorous and policy relevant drug utilization research, and begin to explore optimal dissemination methods to inform policy makers of drug utilization.”
- 2015 NL SUPPORT Annual Report

In cases of appropriately consented information, the improved infrastructure has also helped to compile the data collected by researchers across Memorial into a centralized location and allow other researchers to access this information to reduce duplication and wasted resources when recollecting data.

“We are now able to provide adequate backup and saving of data collected by researchers instead of it sitting on 10-year-old computers under someone’s desk.”
- Stakeholder, case study

“MUN went from $0 to $10 million in hardware. People just didn’t know what to do. Over the past 5 years people have begun to determine the capacity of the system, however we need to build a system for what we need.”
- Stakeholder

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\(^4\) https://www.med.mun.ca/CHIA/Home.aspx
\(^4\) 2015-2016 Support Unit Annual Report
Researchers were also able to work with CHIA and IBM to develop customizable software platforms for their research. This was seen to be beneficial as researchers would work with IBM and CHIA staff at the onset of the research study to determine the best software approach for tracking and analyzing the data collected. This allowed the staff to be able to work on the new platform while the researchers were planning the study to mitigate delays that would have occurred otherwise as the researcher waited for their new system. Stakeholders did identify that there was less customized infrastructure created than expected, likely based off of researchers' lack of familiarity of CHIA's capacity.

“The results that are being produced through CW are very interesting. We have not seen enough commercialization, it would be the one shortcoming I would identify.”
- Stakeholder case study

“A lot of clinical people understand the innovations that are needed in the healthcare system, my role was just trying to help them understand how the technology would help them and how to use the technology as a tool to do your work better. That line has not been crossed by most people yet. Once they feel comfortable with the systems, the physicians will drive the change.”
- Stakeholder case study

Projects that Enhanced Infrastructure: In addition to supporting the implementation of projects, NL SUPPORT is presently working with CHIA to develop an e-ordering platform, where physicians would request medical tests. The system would be based on an algorithm that would question physicians ordering habits if it did not align with the patient's medical symptoms and/or test results. Physicians would be able to override the system if they felt the assessment was needed, however this two-step process is seen to be an effective method to reduce unnecessary assessments. This is platform is still in development.

“Through research being conducted we can create an algorithm to ensure physicians are ordering tests effectively. It will also help with the flow of data as it moves through the system.”
- Stakeholder

Access to Data: Moreover, in addition to having a new information hub to store researcher data, NL SUPPORT established a partnership with NLCHI to assist researchers in accessing provincial level healthcare more effectively as a result of signed agreement between NLCHI and Memorial. As a result, researchers now wait a few of months to access data, which is greatly reduced from the previous timeline of over a year. This improved efficiency to access to data was seen to be an asset for researchers as they are now able to conduct research in a more timely and relevant manner. For example, researchers have begun to conduct analysis to determine diagnostic trends across the province as a result of increased ease and ability to access the data faster with a TPMI project.

“Due to the increased access to data we are conducting rural urban comparative analysis in diagnostic trends looking at healthcare utilization and misuse of different procedures and
prescriptions. We are not trying to reinvent the wheel with what has been done but trying to establish those databases. “

- Stakeholder

While researchers were able to access NLCHI data more effectively, stakeholders and case study participants did acknowledge that the timeline to receive data from NLCHI (a few months) still impacted the effectiveness of the research and the responsiveness of the findings. For example, in 2018 the average request to access data was 19.35 weeks with a quarter of studies taking over 26 weeks to access data.

NLCHI has begun to improve the efficiency of their data retrieval process on their end through creating Data Lab, an online portal that will allow researchers to access data on this platform. However, this new feature is already delayed (anticipated completion date was April 2018) with no finite date of being launched.

Due to the uncertainty around the launch and services offered by Data Lab, IBM and CHIA staff are working together with NLCHI to determine more effective approaches in data retrieval. For example, a case study participant highlighted the effort they are making to increase NLCHI’s awareness of machine learning as a potential solution to increase efficiency.

“Soon I am going to give talk to NLCHI about machine learning. I will spend my time helping them understand what is possible and how it can be applied to health data.”

- Stakeholder case study

“People still think the process is slow and there is a heavy administrative burden. We are working well together and we know who to talk to at NLCHI, know which questions to ask, we describe the projects. There is still some work to do but we are making inroads there.”

- Stakeholder

Impact of Infrastructure and Data Access: The benefits of improved infrastructure and efficiency of accessing data trickled down to impact the responsiveness of research studies being conducted and their ability to share meaningful results to stakeholders through effective KT. This is illustrated in the project example below.

**Project Example: Effects of Diagnostic Imaging Utilization Reports**

Physicians in Newfoundland and Labrador order almost twice as many diagnostic imaging than the Canadian provincial average. This can have an impact on the healthcare system beyond increased cost, as individuals are exposed to potentially harmful radiation and may lead to further unnecessary testing.

Through working with CHIA, a “report card” was developed for family physicians in the province that illustrated how many tests are being ordered compared to others in the region. The report
card was sent to physicians to inform them on their ordering habits for CTs, ultrasounds and plain x-rays per 100 patients.

Without the ability to create a software system and establish partnerships to access this information and send it to physicians in a responsive manner, this project would be unable to occur.

“CHIA is responsible for evaluating changes in practice as a result of sharing the information by analyzing the data on an ongoing basis to identify practice changes on an individual Doctor and aggregate basis.”
- Stakeholder case study

4.3.2 Increased Capacity of Researchers to Conduct POR

**Finding:** As a result of NL SUPPORT researchers, students and healthcare professionals have increased their knowledge and skills in POR and KT. In advance of the Unit, researchers had limited or no knowledge on this information. Through training, consultations and conducting POR research, researchers, students and healthcare professionals agreed that they have increased their knowledge on patient engagement and knowledge translation. Additionally, with over 250 tools created to date to support POR (e.g., training sessions, consultations, community events) there are ongoing resources to enable POR development in the future.

NL SUPPORT was seen by survey recipients to be very successful at increasing researchers’ knowledge of KT, how to meaningfully engage patients, and their capacity to complete POR as seen in the figure 6. A description of these achievements can be seen below in this section.
**Figure 6: Survey Data**: To what extent did the support you received from NL SUPPORT/Quality of Care/Choosing Wisely NL contribute to the achievement of the following outcomes? (Grant recipients N=21, Stakeholders N=5, PAC = 8)  

As POR is relatively new to the Canadian health research industry, at the onset of their grant many researchers, students and healthcare professionals noted they had not used POR previously, with many unfamiliar with the concept.

“I had not used POR in other research before I got funding.”  
- Stakeholder

“I had originally planned to engage patients in my study, but I was not planning to conduct patient-oriented research until I learned about what it was when I was applying for the grant.”  
- Student case study

Researchers and healthcare professionals also identified having limited experience conducting KT activities as any research was primarily focused on publication or influencing policy in a report.

“A lot of people in my area have a scientific lens, and what NL SUPPORT did was change our approach 180 degrees to make it more approachable. For example, usually we use scientific wording as we are presenting resources for physicians. This causes a problem – we have done research but no one but physicians understand what we did.”  
- Stakeholder

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44 Not applicable removed for tabulation
Training: This lack of awareness of POR research and KT was further identified by the SPOR National Steering Committee in 2016, which discovered that only half of the surveyed respondents actively involved patients or the public in their research or decisions about their research.\(^\text{45}\) As a result of this need for formalized training in POR and KT, NL SUPPORT has offered 72 courses\(^\text{46}\) in-person and online over the past five years (figure 7) on topics including:

- Bootcamp for POR grant applicants;
- Writing in plain language;
- Knowledge Translation: Beyond Publication;
- POR in practice; and
- Grant writing and funding opportunities in POR.

In total, 1,023 people have attended a training session and are now more knowledgeable about POR and KT.

“Webrinars they were hosting have been really great. Normally what they will do is structure webinars in ways that apply for different grants that are active at the time. Also use grants to identify issues for researchers in NL, for example how to pitch your project to industry.”

- Stakeholder

Figure 7: Administrative Data: Training and capacity activities and attendance annually, 2016-2019\(^\text{47,48,49,50}\)

\(^{45}\) Training and capacity building plan version 4.0 (2016)
\(^{46}\) 72 is total number of courses, the content was often duplicated annually
\(^{47}\) Newfoundland and Labrador SUPPORT Unit performance monitoring report 2017
\(^{48}\) SPOR SUPPORT Unit Annual Performance Report 2015
\(^{49}\) SPOR SUPPORT Unit Annual Performance Report 2016
\(^{50}\) NL SUPPORT 2018-2019 SUPPORT Unit Reporting Template
Consultations: In addition to training, NL SUPPORT has provided consultation services to researchers on an array of topics to support their skill development including:

- Data platform and services;
- Methods support and development services (e.g., study design);
- Knowledge translation;
- Health systems research;
- Real-world clinical trials;
- Training and capacity development; and
- Patient engagement.

Most of the grant survey respondents (80%) who accessed consultations found them to be helpful as they were able to receive personalized support from members from NL SUPPORT’s team to support their research implementation. In total 709 consultation sessions (figure 8) were conducted with a steady growth year over year.

**Figure 8: Administrative Data:** Consultation completed annually

<table>
<thead>
<tr>
<th>Year</th>
<th>Consultations</th>
</tr>
</thead>
<tbody>
<tr>
<td>2015/16</td>
<td>17</td>
</tr>
<tr>
<td>2016/17</td>
<td>167</td>
</tr>
<tr>
<td>2017/18</td>
<td>181</td>
</tr>
<tr>
<td>2018/19</td>
<td>344</td>
</tr>
</tbody>
</table>

Through training and consultation support, researchers, students and healthcare professionals shared they were able to develop their POR skills including how to engage patients in a meaningful way. Many researchers acknowledged that this is a lifelong skill and viewed NL SUPPORT as the starting point.

“I attended courses on skill building, grant writing, POR, and making a business case. They helped me develop skills on a broad range of things.”
- Stakeholder

“Through NL SUPPORT I learned about meaningful patient engagement and the problems I had with my original study. I am now submitting a new research proposal to address the gaps in my original study.”
- Student case study
“Through this process I see it is more ethical and relevant to individuals in the community. I see it as a skill set that I need to build over time”
- Stakeholder

**Knowledge Translation:** To foster an improved understanding of KT, NL SUPPORT created opportunities for researchers, students and healthcare professionals to engage with the public through community events (SHARE Summit, Health 4 All), as well as supported them in the creation of internal and project specific tools and resources.

“I learned that I need to use better ways to communicate my findings if I want to make change. The training on KT was helpful on knowing how to explain your research to your audience and in 5 minutes.”
- Student case study

In the community events, researchers, students and healthcare professionals had the opportunity to share their research through presentations, posters, a pitch competition,\(^{51}\) as well as create engaging interactive events for children to learn about their research.

“It was a lot of prep to explain what my research is to children and adults. I created a poster for adults and created a mini market for children to use positive reinforcement on what food they should pick for a picnic. It was a great experience.”
- Student case study

In addition to these events, NL SUPPORT created 34 KT resources including educational materials and online tools that researchers are able to access to improve the effectiveness of their own study. NL SUPPORT also supported researchers, students and healthcare professionals to create an additional 46 tools and resources.

![chart showing KT resources](chart)

PAC (63%) and stakeholders (80%) acknowledged that research results are now more accessible, with researchers seeing this as a valuable tool that they have developed to extend their research in the future.

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\(^{51}\) Students were able to present their research in a 5-minute pitch during the Summit
Below is an example of a YouTube video created to share knowledge from an NL SUPPORT/Choosing Wisely project with Paddy Daly from VOCM: https://www.youtube.com/watch?v=rMvzd8BD7w&feature=youtu.be.

“Prior to NL SUPPORT research was siloed with researchers only publishing studies, with many of the findings staying internally. Now we are focusing on how we share the knowledge. We now think how can we engage the community and use our findings to improve communities. We are also starting to allocate funding to consider knowledge translation – something we never did before.”
- Stakeholder

“NL SUPPORT brought us outside of our box, they helped us realize how we should extend outreach”. Now we use YouTube videos – we have put out paid sponsors; people see our videos and have started to make changes”
- Stakeholder

**Student Skill Development:** The enhanced capacity of POR research was further demonstrated through the student case study participants, who shared that the ability to engage in the multiple community events, conduct POR research and leverage resources and supports was invaluable to their learning.

**Case Study: Graduate Students**

Before accessing funding from NL SUPPORT, the three graduates were unfamiliar with POR and were introduced to the topic by their graduate supervisor who recommended applying for this grant.

Since receiving funding, the students attended many of the online and in-person training sessions, with two sharing that they had earned the certificate offered by NL SUPPORT. Students shared that through this opportunity they had learned about how to implement POR and engage patients in meaningful ways.
Participating in the SHARE Summit, in particular the Practice Pitch Panel, was seen to be a valuable experience to communicate their research in common language and receive feedback on their research from experts in the field.

The Health for All Festival was further seen as a highlight as they were able to communicate their research in a fun and engaging medium for children, with one creating a market where children were able to shop for food that they would take on a picnic to reinforce healthy eating.

As a result of this opportunity, all students were able to see the value of POR research and were planning on incorporating POR in future research with one student planning to incorporate it in her future curriculum, as she recently secured a position as a professor.

In addition to the funding provided to graduate students, undergraduate students were provided the opportunity to learn about POR during an up to 16-week placement with a professor through the NUTRA program. While the program was perceived to be an important program to introduce students to POR early in their career, a few stakeholders believed that a more intentional reflection on their experience in the program would be beneficial to students. Following the same model of Undergraduate Student Research Awards (USRA) by Natural Science and Engineering Research Council (NERSC), stakeholders recommended adding a final report requirement to this placement.

Next Steps: As a result of this increased training, opportunities and consultation services, most stakeholders (80%) had a better understanding and improved capacity to conduct POR with 67% of all grant recipients feeling comfortable implementing POR in the future.

67% of grant recipients feel comfortable Implementing POR in the future

“From one to ten, I am a 15! I now know how to effectively engage with patients and the advantage they provide my research. I even went with my supervisor to give a three-hour workshop in Ottawa about patient orientated research.”
- Student case study

“Without NL SUPPORT I would keep carrying on doing what I do and POR would just be something that I had heard about. It’s critical to have the Unit at Memorial.”
- Stakeholder
4.3.3 Improved Patient Capacity for Engagement

Finding: NL SUPPORT has effectively engaged participants in various capacities in POR through sitting on the TPMI Steering Committee, being a member of PAC or Patient Panels, or through the Friends Pool.

As a result of participating in NL SUPPORT, attending training and accessing resources, participating in studies, patients identified developing key skills including critical thinking and confidence, as well as knowledge about the healthcare system. This personal and skill development has increased their capacity to engage in POR studies.

Over three quarters of the grant recipient survey respondents (76%) felt that NL SUPPORT has helped to improve patients’ capacity to engage in the research process through the opportunity to participate in research, attend training, the Summit and community events as explained below.

As a cornerstone to its delivery, NL SUPPORT has actively recruited and engaged patients, starting with only two patients in its first year to its present complement of52:

- 3 patients on TPMI Steering Committee;
- 21 patients on PAC; and
- 15 patients on Patient Panels.

For those interested in providing ad hoc advice, NL SUPPORT developed a Friends Pool. This opportunity allows patients the ability to provide e-consultations to smaller projects or researchers who need periodic support. This allows patients the ability to engage in medical research without requiring a significant investment of time.

Case study patients shared that many of them joined NL SUPPORT to give back to the healthcare system that supported their family members and/or themselves.

“ Wanted to give back following our experience with our son many years ago.”
- Patient case study

Despite having limited knowledge of health research when joining NL SUPPORT, recent patients actively sought out opportunities to learn more about POR through NL SUPPORT (e.g., training, community events, Summit). This training was seen to be beneficial to the patients as it provided them a foundation to base their role on as they worked with researchers on projects.

52 Note: Patients can be on multiple opportunities below; these are not exclusive positions.
“I had the opportunity to learn about healthcare research including why and how research is done. How patients are (or are not) involved through working on my project, attending the fair, taking online courses and attending Summit 2018”
- Patient case study

To date patients have provided feedback on over 135 projects directly funded by NL SUPPORT or in partnership with Quality of Care / Choosing Wisely NL, with many patients supporting multiple projects at one time. In addition to NL SUPPORT projects, patient partners have also supported CIHR funded projects with one patient supporting a five province SUPPORT project focusing on case management to avoid hospitalization. Patients have also been given the opportunity to attend conferences across Canada to showcase the work they have completed with NL SUPPORT and as a learning opportunity.

As a result of these projects and their work on PAC, Patient Panels, and/or TPMI, patients were able to further develop their critical thinking skills and confidence as they became more comfortable sharing their perspectives at roundtables with academics and researchers. This increased confidence was further supported by patients finally feeling that their voices and perspectives were valued in healthcare research.

“10 years ago we would recommend adding patient in the research team and pay them and it was never taken up – it was a pipe dream in conferences and now it is going forward”
- Stakeholder

Through this positive experience, patients shared that they feel empowered and have an improved capacity to contribute to POR research, with patients now taking a more active role in research. One patient is now a co-primary investigator on a study and another patient in the final year of their undergrad at Memorial hoped that this experience and their increased awareness of the healthcare sector will be beneficial as they apply and hopefully attend medical school in the fall.

“We are doing our own research projects now! A patient is now a principal investigator on research and we are looking at bringing humanity to the hospital bedside. This process has also empowered patients – there are 2 dozen of us involved in the community and getting out and doing things and making changes!”
- Patient case study

Case Study: John⁵³, PAC Member

John first engaged in NL SUPPORT for multiple reasons including a way to give back to the health system that supported his son, to explore the feasibility of sustainable health care and to be involved in something that interested him (e.g., policy analysis, strategic planning).

⁵³ Pseudonym used
Since joining NL SUPPORT three years ago, John has been an active member. He has been able to regularly attend meetings, provided his perspective during the 2018 Summit, at other community events, and on proposals and has presented about POR at a conference in Ottawa.

John has also had the opportunity to be the NL patient representative for a national study which examines POR in five provinces.

Through these opportunities, John has noticed positive shift in health research with patients being seen as a valuable member at the research table. Patients have helped researchers develop a better understanding of the benefits of involving patients in research.

Over the years, John has been able to become more educated about healthcare issues, priorities and activities, which he believes has increased his capacity to engage in research and provide more meaningful support to projects.

4.3.4 Increased Evidence-Based Research

Finding: NL SUPPORT has increased the occurrence of evidence-based research across the province through providing 85 grants/awards and supporting over 135 projects in conducting POR. In addition to their funding, the inclusion of patients, collaboration of key stakeholders, and leveraged internal expertise, and access to the improved infrastructure has facilitated innovative research that is responsive to patients’ opinions and perspectives.

Nevertheless, it was found that that greater attention should be placed on funding projects outside of St. John’s and Eastern Health to ensure patients across the province can benefit from the research conducted.

Survey recipients considered NL SUPPORT to be very successful at increasing the effectiveness of the research with all stakeholders acknowledging the Unit helped to increase their network of researchers and their ability to conduct interdisciplinary work (figure 9). While a lower number of survey grant respondents felt that the support received from NL SUPPORT helped to support innovation, increase their ability to conduct interdisciplinary work and increase their network of researchers, only a few respondents felt that this was not being achieved (11%, 10%, and 10%, respectively). 54

A description of these achievements can be seen below.

54 Remaining respondents selected somewhat and not sure.
**Figure 9: Survey Data:** To what extent did the support you received from NL SUPPORT/Quality of Care/ Choosing Wisely NL contribute to the achievement of the following outcomes? (Grant recipients N= 21, Stakeholders N=5, PAC = 8)

![Survey Data Chart]

**Funding:** Through administering almost $2 million in funding, NL SUPPORT has contributed funding to 85 POR research projects through 6 project specific grants (table 8). All projects funded related to the priority research themes identified in partnership by residents from across the province. A list of projects funded can be found in Appendix F.

**Table 8: Administrative Data:** Number of awards and grants administered 2014-2019

<table>
<thead>
<tr>
<th>Grants/Award</th>
<th>Number of Applications</th>
<th>Number Funded</th>
<th>Amount to Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educational Funding Award</td>
<td>-</td>
<td>43</td>
<td>$737,617</td>
</tr>
<tr>
<td>Undergraduate Training in Research Award</td>
<td>-</td>
<td>4</td>
<td>$18,000</td>
</tr>
<tr>
<td>Patient-Oriented Research Grant</td>
<td>47</td>
<td>20</td>
<td>$883,107</td>
</tr>
<tr>
<td>SPARK Grant for clinicians/nurse/allied health professionals</td>
<td>24</td>
<td>15</td>
<td>$110,000</td>
</tr>
<tr>
<td>Developmental Grant</td>
<td>4</td>
<td>2</td>
<td>$19,988</td>
</tr>
<tr>
<td>Indigenous Communities Grant</td>
<td>3</td>
<td>1</td>
<td>$75,000</td>
</tr>
</tbody>
</table>

NL SUPPORT’s impact on facilitating effective research across the province is further increased through its partnership with Quality of Care / Choosing Wisely NL where they are able to support over 50 projects including:

- Stoke Prevention Public Campaign;

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55 Not applicable removed for tabulation
• CT Scanning Public Campaign; and
• Access to Colonoscopy.

Through both Quality of Care / Choosing Wisely NL and grant/award funded projects, NL SUPPORT has supported over 135 projects.

**Over 135 projects supported**

**Geographical Diversity:** Through a review of grants/awards administered by NL SUPPORT it was identified that there is limited representation of projects outside of Eastern Health and Memorial. As seen in the table below, there were only four grants (11%) that were specifically focusing on Western or Labrador-Grenfell or Indigenous communities, with none directly related to Central Health. It is important to note that while many of the projects were provincial in scope, these areas of the province experience additional challenges in accessing healthcare services due to expanding rural areas and increased prevalence of Indigenous communities.

"More than half the population lives on the Avalon. Once you get outside of that, the population is very small and rural and healthcare services are less robust.”

- Stakeholder

**Table 9: Administrative Data:** Number of awards and grants outside of Memorial and Eastern Health

<table>
<thead>
<tr>
<th>Grants/Award</th>
<th>Number Funded</th>
<th>Number of Grants Outside of Memorial and Eastern Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient-Oriented Research Grant</td>
<td>20</td>
<td>2 (Western NL)</td>
</tr>
<tr>
<td>SPARK Grant for clinicians/nurse/allied health professionals</td>
<td>15</td>
<td>1 (Labrador Grenfell)</td>
</tr>
<tr>
<td>Development Grant</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Indigenous Communities Grant</td>
<td>1</td>
<td>1 (Labrador-Grenfell, Indigenous)</td>
</tr>
</tbody>
</table>

**Completion of Projects:** Three-quarters of grant recipient respondents shared that they would have not been able to conduct this research without this funding (figure 8). Subsequently grant recipients shared that they would have had to find funding elsewhere (57%) or have reduced the amount of patient engagement (52%) in their study.
**Figure 8: Grant Recipient Survey:** If you had not received this grant, how do you think your research study would have changed? *Select all that apply.* (N = 21)

<table>
<thead>
<tr>
<th>Change in Research Study</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Would not have been able to conduct this research</td>
<td>67%</td>
</tr>
<tr>
<td>Would have had to find funding elsewhere</td>
<td>57%</td>
</tr>
<tr>
<td>Would not have built as much capacity for POR</td>
<td>52%</td>
</tr>
<tr>
<td>Research would have been delayed</td>
<td>43%</td>
</tr>
<tr>
<td>Would have had to scale back patient engagement</td>
<td>38%</td>
</tr>
<tr>
<td>Would have undertaken a smaller research project</td>
<td>38%</td>
</tr>
<tr>
<td>Would not have been able to hire staff</td>
<td>33%</td>
</tr>
<tr>
<td>Would not have been engaged patients at all</td>
<td>33%</td>
</tr>
<tr>
<td>Would not have been able to engage to collaborators</td>
<td>24%</td>
</tr>
<tr>
<td>Nothing/no changes</td>
<td></td>
</tr>
</tbody>
</table>

“*Their funding has helped to fill a void – to explore topics that physicians identify that isn’t as established to get full dollar amount*”
- Stakeholder

“*Yes, without the Unit we would not be doing what we are doing. Not every province has the capacity to tap into national funding trends and lead the $1-2M dollar projects.*”
- Stakeholder

**Inclusion of POR:** Stakeholders acknowledged that having the patient perspective during their study helped to modify the scope, design and implementation.

“*Originally my research was data driven by cost – looking at the economic factors and solely looking at the cost to decision makers. Including patients helped me realize that there are costs to mothers when deciding whether or not to breastfeed. It helped me identify drivers that I may have not realized.*”
- Student case study
“We had a program designed to help people stop smoking and by having a participant engaged we changed the language that we used to engage them in the process. We learned what patients wanted to use and what was meaningful to them”

- Stakeholder

The patient’s perspective was also vital in the effectiveness of the KT activities. For example, “cost savings” was the original language that was going to be used when discussing the impact that changes in medical testing would have on the healthcare system. However, through engaging with patients it was determined that this phrasing had a negative connotation as patients perceived that this meant that they were not getting the quality of healthcare service that they deserved. Based on this advice, the wording was changed to “cost avoidance” which has been positively received by the province.

“People think healthcare is free and they want it all (all the tests) and don’t want to be denied services which they think when you say savings. Cost avoidance means money can be reallocated else where.”

- Stakeholder

Despite the value that patients provided to the research study, over half (57%) of the grant recipients acknowledged that without this funding they would have not implemented POR, with 24% unsure if they would have implemented POR. This potential exclusion of patients in research further highlights the importance of NL SUPPORT funding in completing POR research in the province.

In addition to accessing the patient perspective, NL SUPPORT has facilitated the collaboration of key stakeholders and leveraged internal expertise to enhance the quality of research being conducted in the province.

For example, one stakeholder acknowledged that they would have had difficulty recruiting physicians to participate in their study. Through connecting with NL SUPPORT, they were able to connect with Newfoundland and Labrador Medical Association (NLMA) which was vital to completing their study.

“NL SUPPORT has been helpful – there was a physician study where we knew we were going to have trouble recruiting people. They put us in contact with NLMA. I don’t know how else we could have done the study.”

- Stakeholder

Researchers connected with NL SUPPORT were also able to leverage the expertise of their staff, including KT, patient engagement, and bio statistics through consultations as explained in section 4.3.2 to support the implementation of their study. The ability to leverage their knowledge was seen to be a significant asset as it made the research more effective by following best practices, as well as allowed researchers to extend their analysis beyond those they are familiar with, for example social return on investment.
Innovative Research: As a result of access to improved infrastructure, additional funding, patient advice, leveraged expertise and consultations, researchers were able to conduct innovative research studies including “Patshitinikutau Natukunisha Tshishennuat Uitshuau (A Place for Elders to Spend their Last Days in Life): Developing an Innu Approach to Palliative Care” which was identified as an area with limited prior research on. In addition, NL SUPPORT funded the innovative study, “Making the link: A mixed-method exploration of the impact of using telehealth to facilitate Applied Behavioural Analysis (ABA) orientation for families in rural areas of Western NL” which utilized telehealth to increase efficiency in ABA treatment as seen in the case study below.

Case Study: Making the link: A mixed-method exploration of the impact of using telehealth to facilitate ABA orientation for families in rural areas of Western NL.

Traditionally ABA services had been offered to parents and caregivers of children with Autism Spectrum Disorder in the Western region using face-to-face modalities. Senior executives at the Western RHA wanted to explore the best options for connecting with children and families directly in their homes, rather than having staff travel across the region or only connecting with parents using recognized Telehealth centres, which may still have been a fair driving distance away.

To increase access, Western RHA introduced at home telehealth options during the following three phases of the process:
- During delivery of the three-day ABA training;
- For ongoing mentorship and support for the Child Management Specialists; and,
- To support and follow up with families and home therapists in each child’s home.

Patients were engaged in every stage of research, which was a new approach for Western RHA. Staff identified that this approach helped to engage families in the study and made it meaningful for them, and plan on utilizing POR in the future where applicable.

Patient-Oriented research was a new practice as far as including patients through the process. They have been involved in research projects before, where they were subjects as opposed to involving them in the design of the research, that part was new to us.

- Stakeholder case study
The study was successful in demonstrating that at-home telehealth could be used in all three phases of ABA treatment and resulted in increased efficiencies for the client and providers in all phases.

### 4.3.5 Improved Health System Efficiency

**Finding:** Early signs indicate that NL SUPPORT has improved the efficiency of the healthcare system. This has been achieved through improved analysis and efficiency accessing provincial level data as a result of CHIA and its partnership with NLCHI; increased knowledge of POR and KT by researchers, patients, healthcare professionals and students through its training and consultations; and increased research as a result of their funding dollars.

Additionally, the increased efficiency of the healthcare system can also be illustrated through the biomedical testing case study which resulted in approximate annual cost avoidance to Eastern Health of $563,644 as a result of a change in ordering form and physician detailing.

The antibiotic case study further evidenced the effectiveness of POR and data analysis as a public, nurse and physician campaign led to a reduction of 4,434 antibiotics prescriptions by physicians annually.

NL SUPPORT was developed as methodological research support centre dedicated to supporting and developing the province’s capacity for POR. As a result of this Unit and its work, the hope is that through better integration of trained researchers, enhanced research infrastructure, and evidence-based research that includes patient engagement that there will be an impact on the health care system as a whole. Although it has only been five years, and given the complexity of the health care system, results of this evaluation show that NL SUPPORT’s early efforts have started to impact parts of the health care system.

First and foremost, the creation and addition of CHIA has greatly improved the efficiency of data sharing and analysis, and not just for academics, but healthcare professionals. As explained earlier, this has allowed researchers the ability to access provincial data and complete complex analysis more effectively, allowing for research and subsequent KT to be conducted more effectively and provide feedback in a timely manner.

Next, training and consultations for healthcare professionals, researchers, students and patients within the province on POR and subsequent relevant topics (e.g., KT, statistical analysis) have helped to increase attendee’s knowledge of these topics. This increased knowledge in partnership with additional funding has increased the number of POR studies being conducted in the province.

At the project level, the focus on funding projects that align with residents’ identified priorities helped to ensure that the studies are meaningful to the healthcare landscape in NL and are aimed at improving the effectiveness of the system.
Through the implementation of innovative projects and improved KT developed through NL SUPPORT, stakeholders acknowledged there have been preliminary improvements to the healthcare system, primarily highlighted by stakeholders through the biochemical testing and antibiotic cases studies seen below.

As seen in figure 9, most of the survey respondents considered NL SUPPORTS system level impact to be considerable. In fact, only one person across all surveys felt that NL SUPPORT has not contributed at all to the outcomes below.

**Figure 9: Survey Data:** To what extent did the support you received from NL SUPPORT/Quality of Care/ Choosing Wisely NL contribute to the achievement of the following outcomes? (Grant recipients N= 21, Stakeholders N=5, PAC = 8)\(^{56}\)

This impact on the healthcare system was further illustrated by following case studies, biomedical testing and antibiotic utilization.

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\(^{56}\) Not applicable removed for tabulation
**Case Study: Biochemical Testing**

Eastern Health originally identified that physicians were over ordering unnecessary medical tests. For example:

- LDH testing is only useful for hemolytic anemia and cell growth disorders; there is little need for it in family practice.
- Creatine kinase is a useful test in patients with a high index of suspicion for muscle disease; it is no longer needed for monitoring asymptomatic patients on statins.
- Serum Ferritin is a useful iron status test where hemochromatosis or hypoferritinemia are suspected as a cause of symptoms; it is not useful in patients with normal hemoglobin and normal MCV/MCHC.
- Blood urea is not a useful test to measure kidney function in stable patients.⁵⁷

To reduce the ordering of these tests, in 2016 Eastern Health created a new requisition form which omitted blood urea, AST and LDH and tested to see whether this form would help to reduce physicians ordering habits. To support the implementation of the new form, Quality of Care NL conducted detailing across the province to discuss the need for ordering these tests. Through comparing the number of tests physicians ordered during the last six months of 2015 and 2017, researchers identified a strong decrease in number of physicians who order more than 200 blood urea, creatine kinease and AST tests in a year (figure 10).

As a result of this simple change in testing form and analysis, Eastern Health experienced an approximate annual cost avoidance of $563,644 and improved efficiency of the healthcare sector as a result of the decreased number of tests ordered.

“Prior to this study there were 0.5 million tests occurring annually across NL and likely 90% of those were unnecessary. While they only cost $1 or $2 a test, that add ups. So we analyzed the info and tests that a doctor sends and made changes to the forms in attempts to reduce test ordering.”

- Stakeholder case study

“The blood testing – I changed my practice overnight as I learned it was virtually useless.”

- Stakeholder

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**Figure 10: Administrative Data:** Percent of doctors who ordered more than 200 tests during last six months of 2015 and 2017

<table>
<thead>
<tr>
<th>Test</th>
<th>2015</th>
<th>2017</th>
</tr>
</thead>
<tbody>
<tr>
<td>AST Test</td>
<td>1.20%</td>
<td>5.50%</td>
</tr>
<tr>
<td>Creatine Kinase Test</td>
<td>11.90%</td>
<td>20.30%</td>
</tr>
<tr>
<td>Ferritin Test</td>
<td>21.30%</td>
<td>21.30%</td>
</tr>
<tr>
<td>Blood Urea Test</td>
<td>14.00%</td>
<td>54.60%</td>
</tr>
</tbody>
</table>

**Case Study: Antibiotic Prescriptions**

NL has the highest rate of antibiotic use in the country at 955 antibiotics per 1000 people (19% more prescriptions than the next highest province). This was concerning as overuse of antibiotics can lead to the development of resistance to hard to treat infections, so much so that the World Health Organization created a global action plan in 2015.

Through a collaboration with NL SUPPORT, Choosing Wisely and CHIA, data was obtained from the NLPDP on physicians’ prescription habits for patients aged 65 years and older in 2016. This data was then analyzed against provincial wide best practices and was confidentially sent to each physician with some physicians receiving in clinic visits to further explain the study. Due to the success of this physician campaign, a nurse practitioner campaign was launched in 2018.

Understanding that patients play an active role in the consumption of antibiotics, researchers worked with NL SUPPORT and patient advisors to develop a public campaign. Using fact sheets, posters and videos, effort was made to increase patient’s awareness of the health ramifications of overconsumption of antibiotics.

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An example of a video campaign can be found at: https://www.youtube.com/watch?v=rMvzd8BPD7w&feature=youtu.be.

As a result of the effective physician nurse and patient campaign, there has been a reduction of 4,434 antibiotics prescribed by physicians between 2016 and 2017 alone as seen in figure 11.

Figure 11: Administrative Data: Number of antibiotic prescriptions ordered by physicians in a fiscal year

While these studies have been effective in making change in the healthcare services in NL, stakeholders did acknowledge that with greater time and more research completed, they were optimistic that greater healthcare efficiencies would be achieved.

“This is exactly what we want, implementation of research finding into practice. It takes on average 17 years to change practice in healthcare.”
- Stakeholder case study

“It takes a long time for it to trickle down and make the full impact.”
- Stakeholder
4.3.6 Unintended outcomes

**Finding:** The transferability of the knowledge and skills developed by students and patients as a result of engaging with NL SUPPORT has led to individual outcomes that were not intended at the beginning of their engagement with NL SUPPORT.

NL SUPPORT supports and services have made a PhD student better prepared for completing their comprehensive exams, as well as resulted in patients and their friends and family becoming more engaged in their healthcare and consultations with their physicians. The information learned through NL SUPPORT also has great transferability as a PAC member is now sitting on the Canadian Medical Association (CMA) Patient Voice Group with one student intending to integrate POR into her curriculum as she has recently secured a faculty position.

In addition to the outcomes anticipated by NL SUPPORT, there were a few unanticipated outcomes that occurred as a result of the program.

1. As a result of the KT training, one student shared that they were better prepared for the comprehensive exams as they were better able to explain their research in plain language.
2. A case study patient acknowledged that through learning about the program they have encouraged their friends to be more assertive when having one-on-one consultations with their doctor and advocate for themselves.
3. Patients on the advisory committee are also able to take advantage of external opportunities including the Canadian Medical Association (CMA) Patient Voice Group as well as multi-province SUPPORT projects.
4. A student who was funded by NL SUPPORT has since secured a faculty position in pharmacy and intends to embed the information she learned about POR into her future curriculum to support her students.

“Patient orientated research is not going away. As a future professor I will need to help my students engage with it. I cannot afford not to. It has helped me and my research already.”

- Student case study
5.0 CONCLUSION AND CONSIDERATIONS

5.1 Conclusion

NL SUPPORT is an effective program which aligns strongly with the objectives and priorities of CIHR and its funding partners. By enhancing the capacity of researchers and students in the province through funding, training, resources and knowledge translation, NL SUPPORT has supported and grown its network of partners across the province and is considered a leader in implementing POR.

NL SUPPORT’s interconnected governance structure with TPMI Steering Committee, Quality of Care/Choosing Wisely NL and CHIA has been effectively designed. Through partnerships such as IBM and the creation of CHIA, NL SUPPORT has upgraded the research infrastructure resulting in increased efficiency of big data analysis. While delays accessing NLCHI provincial data are an ongoing limitation, NLCHI is looking to improve data sharing in the future. Research has already become more responsive to the province’s changing healthcare sector. Engagement of RHAs from Western and Labrador-Grenfell have ensured that the distribution of NL SUPPORT have included the diverse and rural populations of NL.

By increasing capacity of researchers and students to conduct POR studies, NL SUPPORT has increased the occurrence of evidence-based research across NL by supporting over 135 POR projects. The inclusion of patients, collaboration with key stakeholders and leveraging internal expertise has facilitated innovative research that is responsive to patient’s perspectives and healthcare needs identified by residents across the province. Students and residents are able to participate in the Unit’s knowledge translation events which provide further opportunity for widespread engagement.

Through effectively engaging patients through PAC, Patient Panels and the Friends Pool, NL SUPPORT has provided opportunities and resources to patients to become involved in POR, increase patient knowledge about the healthcare system and increase patient capacity to engage in POR studies.

While NL SUPPORT has shown efficiency and innovation in the healthcare sector, stakeholders acknowledge it takes more than five years to establish sustainable change. To ensure this, further funding is needed to determine full system level changes and to ensure sustainability. To assist NL SUPPORT in continuing to meet its objectives, the following considerations have been established.
5.2 Considerations

Based on the findings from this evaluation, the following five recommendations were developed for consideration by NL SUPPORT to inform future decision making.

1. **Establish core line funding**
   NL SUPPORT has facilitated an increase of stakeholder knowledge on POR and KT, improved efficiency of the data retrieval processes and has provided funding to 85 POR projects, many of which would have not been conducted without this funding. At the end of the first five years of funding, NL SUPPORT has been shown to empower patients, educate researchers on best practices and begun to improve efficiencies in the healthcare system.

   Stakeholders acknowledged that without NL SUPPORT in the future, the effectiveness of the established partnerships, and implementation of POR would likely be lost.

   NL SUPPORT should consider opportunities to obtain core funding through the Government of Newfoundland and Labrador. Core funding would ensure that the program’s objectives continue to be developed and met, and research would continue to have the means and resources available to develop innovative projects which improve the healthcare system and lives of residents.

2. **Improve data retrieval from NLCHI**
   While the development of CHIA and the partnership with NLCHI has greatly increased the capacity for health research across Newfoundland and Labrador, there is still a delay in retrieving provincial level data from NLCHI causing some researchers to wait months for this data. This delay can impact the effectiveness of the research study as well as the timeliness of the results.

   Acknowledging that NLCHI is working towards creating their own Data Lab platform, NL SUPPORT and CHIA and NLCHI should continue to discuss reviewing the process for researchers and healthcare professionals to access data. This will increase the efficiency of the process presently and the new platform when it is launched.

3. **Training to improve awareness of services / supports available with a focus on CHIA**
   Many stakeholders identified gaps in their knowledge surrounding POR and KT prior to accessing NL SUPPORT. As a result, NL SUPPORT offered a wide variety of services and supports including training, consultation services, assistance completing ethics application and facilitating meetings with potential collaborators; however, survey results indicate that there has been fairly low engagement with these supports. In addition, it was also felt that CHIA’s software may not be being used to its full extent, likely attributed to the lack of knowledge of researchers about the full capacity of the system and how to best integrate it into their studies.
To further increase the impact NL SUPPORT has had on the medical research field in the province, it is recommended that a greater focus be placed on increasing stakeholders’ awareness of their service offerings and its applicability to studies being conducted for wider reach.

4. **Increase regional and Indigenous representation at both the governance and projects funded level**

   NL SUPPORT is a provincial body that provides support to healthcare research across Newfoundland and Labrador.

   While efforts have been made to have provincial representation, both Central and Labrador-Grenfell RHAs are presently missing on the TPMI Steering Committee. This lack of representation reduces the opportunity for health research concerns related to these regions to be effectively raised when directing policy and funding decisions.

   This is further illustrated in the project funding, where only 5 projects have been specifically designed to address health concerns outside of the Avalon region or at the provincial level.

   Similar trends have been seen with Indigenous communities in Newfoundland and Labrador. NL SUPPORT has made effort to recruit Indigenous individuals to join the PAC and disseminated the first Indigenous Community Grant in 2017, however there is no representation from Indigenous communities in the governance. This was further exemplified by the evaluators’ inability to connect with Indigenous representatives for the evaluation.

   As each region and Indigenous community faces their own challenges when accessing healthcare NL SUPPORT should consider new opportunities to secure representatives from the two RHAs and the Nunatsiavut Government, Qalipu First Nation, and Innu Round Table, as well as review their funding programs and priority setting initiatives to ensure that projects funded reflect the diversity of NL’s healthcare landscape.

5. **Reporting requirements should be added to NUTRA grant for undergraduate students to increase student’s reflection on their experience and its importance for their future**

   To facilitate greater implementation of POR research in the future, NL SUPPORT offered grants and awards to graduate and undergraduate students to complete or support a POR project.

   The Educational Funding Award requires students to provide a written report at the end of their funding to demonstrate the impact the project has had on them. This opportunity provides students the ability to reflect on their experience and the applicability of their learning in the next phase of their journey.
In contrast, undergraduate students who secure NUTRA funding are not required to provide any written feedback on their experience. To ensure that students are provided the opportunity to reflect on their experience with POR and the lessons they learned through their placement, NL SUPPORT should consider reviewing its grant reporting requirements for NUTRA.
APPENDIX A: EVALUATION MATRIX
<table>
<thead>
<tr>
<th>Evaluation Question</th>
<th>Indicator</th>
<th>Methodologies</th>
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</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Doc Review</td>
</tr>
<tr>
<td><strong>Relevance</strong></td>
<td>Level of alignment between SUPPORT activities and CIHR and other funders/partners’ strategic objectives and priorities.</td>
<td>X</td>
</tr>
<tr>
<td>1. To what extent does NL SUPPORT align with CIHR and other funders/partners’ priorities and objectives (public/private partners for IBM, GNL, and other provincial and federal agencies)?</td>
<td>Level of alignment between SUPPORT and GNL strategic objectives and priorities.</td>
<td>X</td>
</tr>
<tr>
<td></td>
<td>Level of alignment between the NL SUPPORT Unit program and jurisdictional priorities, roles and responsibilities</td>
<td>X</td>
</tr>
<tr>
<td>2. To what extent is NL SUPPORT aligned with the needs of healthcare stakeholders and patients?</td>
<td>Level of alignment between Unit’s activities and needs of healthcare stakeholders and patients.</td>
<td>X</td>
</tr>
<tr>
<td><strong>Design and Delivery</strong></td>
<td></td>
<td>Doc Review</td>
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<tr>
<td>Evaluation Question</td>
<td>Indicator</td>
<td>Methodologies</td>
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<tr>
<td>3. To what extent do elements of the design (e.g., planning processes, organizational structure) enable effective delivery of the activities to meet unit objectives?</td>
<td>Perception of the effectiveness and flexibility to be responsive to evolving needs, objectives and/or regional differences</td>
<td>Data Review</td>
</tr>
<tr>
<td></td>
<td>Perceptions of the effectiveness of the planning and governance processes</td>
<td>Lit Review/Secondary Research</td>
</tr>
<tr>
<td></td>
<td>Evidence of effectiveness and flexibility to be responsive to evolving needs, objectives and/or regional differences</td>
<td>Admin Data</td>
</tr>
<tr>
<td></td>
<td>Evidence of the effectiveness of the planning and governance processes</td>
<td>Stakeholder Surveys</td>
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<tr>
<td></td>
<td>Evidence of effectiveness of the planning and governance processes</td>
<td>KI Interviews</td>
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<td></td>
<td>Evidence of effectiveness of organizational structure</td>
<td>Case Studies</td>
</tr>
<tr>
<td></td>
<td>Perceived appropriateness of the unit activities</td>
<td></td>
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<tr>
<td>4. To what extent are the key activities delivered as intended?</td>
<td>Evidence of delivery of key activities in line with plans.</td>
<td></td>
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<td>5. Are there alternative Best practices/lessons</td>
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<tr>
<td>Evaluation Question</td>
<td>Indicator</td>
<td>Methodologies</td>
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<tr>
<td></td>
<td>delivery methods or models that could achieve objectives more effectively and/or efficiently?</td>
<td>Doc Review</td>
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<tr>
<td></td>
<td>learned from other POR units</td>
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</tr>
<tr>
<td></td>
<td>Best practices/lessons learned from stakeholders</td>
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</tbody>
</table>

**Effectiveness**

6. To what extent has the unit been effective at achieving expected immediate and intermediate outcomes?

6.1 Immediate Outcomes include:

- Improved access to data to inform decisions
- Existing expertise is leveraged
- Increased knowledge of meaningful patient engagement practices
- Increased collaborations between stakeholders

- Levels of engagement across stakeholder groups
- Levels of engagement across diverse and/or vulnerable groups
- Level of leveraging of expertise
- Perceptions of effectiveness of training and other support activities
- Level of engagement of patients in all phases of research (from planning to implementation, analysis and dissemination)
- Level of knowledge translation activities

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Methodologies</th>
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<tbody>
<tr>
<td>Levels of engagement across stakeholder groups</td>
<td>Doc Review</td>
<td>X</td>
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<td>Levels of engagement across diverse and/or vulnerable groups</td>
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<td>Level of leveraging of expertise</td>
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<td>Perceptions of effectiveness of training and other support activities</td>
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<td>X</td>
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<td>Level of engagement of patients in all phases of research (from planning to implementation, analysis and dissemination)</td>
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<td>Level of knowledge translation activities</td>
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<td>X</td>
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<td>X</td>
<td>X</td>
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<tr>
<td>Evaluation Question</td>
<td>Indicator</td>
<td>Methodologies</td>
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<tr>
<td>Increased Knowledge Translation and Exchange capacity</td>
<td>Level of knowledge exchange activities (e.g. consulting, collaboration with decision-makers)</td>
<td>Doc Review</td>
<td>Lit Review/Secondary Research</td>
<td>Admin Data</td>
<td>Stakeholder Surveys</td>
</tr>
<tr>
<td>6.2 Intermediate Outcomes include:</td>
<td>Level of collaboration amongst stakeholders</td>
<td>X</td>
<td>X</td>
<td>X</td>
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<tr>
<td>Improved patient capacity for engagement</td>
<td>Level of awareness of SPOR among stakeholders</td>
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<td>Improved POR research capacity</td>
<td>Level of engagement of partners</td>
<td>X</td>
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<td>Improved infrastructure and support services</td>
<td>Level of skills or competency development</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A collaborative, multi-disciplinary POR community</td>
<td>Impact of skill or competency development on career</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Improved responsiveness</td>
<td>Level of use of and impact of data platform and services</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Improved ability to innovate</td>
<td>Number of real-life clinical trials</td>
<td>X</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Increased evidence-based practice</td>
<td>Level of stakeholders’ use or plans to use evidence from research</td>
<td>X</td>
<td></td>
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<td></td>
<td>Level of improved and/or increased collaboration</td>
<td>X</td>
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<td>Evaluation Question</td>
<td>Indicator</td>
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<td>Doc Review</td>
<td>Lit Review/Secondary Research</td>
<td>Admin Data</td>
<td>Stakeholder Surveys</td>
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<tr>
<td>among stakeholders</td>
<td></td>
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<td>Level of responsiveness</td>
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<td>Level of innovation</td>
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<td></td>
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<td>X</td>
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<tr>
<td>7. To what extent is the unit on track to achieve expected intermediate and long-term outcomes?</td>
<td>Alignment of activities to achieve outcomes</td>
<td></td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>8. Did the activities of the unit lead to any unintended impacts or outcomes?</td>
<td>Evidence of unintended impacts or outcomes</td>
<td></td>
<td>X</td>
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<td>X</td>
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<tr>
<td>Efficiency</td>
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<tr>
<td>9. Were the resources and funding dollars used in a timely and cost-effective manner?</td>
<td>Perception of timeliness of resource and funding allocation</td>
<td></td>
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</tbody>
</table>
APPENDIX B: DOCUMENTS REVIEWED
Dig Insights reviewed the following 58 documents as apart of the evaluation:

1. 2017 -2018 Training Plan
2. 2018 Training plan
3. 2019 Training Plan
4. Annual performance reports 2015-16, 2016-17, 2017-18
5. CIHR: Strategy for Patient-Oriented Research - Patient Engagement Framework
6. CIHR: What is the Strategy for Patient-Oriented Research?
7. Choosing Wisely Annual Work Plan 2018 2019
8. Choosing Wisely Quarterly reports 2018
9. Commercialization agenda
10. Communication plan antibiotics
11. Communications plan stroke
12. Description of certificate programme
13. Economic Assessment survey
14. Ethics and patient engagement guidelines
15. Giving Patients a Voice - Evaluation study of patient engagement in research
17. Health 4 All Festival guide 2018
18. Interim mid-term evaluation
19. Kelly and Balsom clinician grant report
20. KT presentation SPOR Summit
21. KT products summary
22. KT webinar - beyond publications
23. Memorial University of Newfoundland: Welcome to the Center for Health Informatics and Analytics (CHIA)
24. MOU with ARNNL
25. MOU with NLMA
27. NLCHI contract (being renewed)
28. NL SUPPORT implementation plan 2018
29. NL SUPPORT presentation to CIHR SPOR steering committee
30. NL SUPPORT presentation to grant facilitators
31. NL SUPPORT website link – [http://www.nlsupport.ca/home.aspx](http://www.nlsupport.ca/home.aspx) note funding and training opportunities
32. Patient Advisory Council minutes May 2018 – Jan 2019 x 4
33. Patient Advisory Council terms of reference
34. Patient appreciation guidelines
35. Patient pitch
36. Patient recruitment brochure
37. Patient reviewer orientation presentation patient reviewers
<table>
<thead>
<tr>
<th></th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>38.</td>
<td>POR training evaluation</td>
</tr>
<tr>
<td>39.</td>
<td>Priority setting results</td>
</tr>
<tr>
<td>40.</td>
<td>Priority setting survey</td>
</tr>
<tr>
<td>41.</td>
<td>Response to interim mid-term evaluation</td>
</tr>
<tr>
<td>42.</td>
<td>Rewarding Success Pitch panel</td>
</tr>
<tr>
<td>43.</td>
<td>SHARE summit agenda</td>
</tr>
<tr>
<td>44.</td>
<td>Steering Committee minutes – April 2018 – Jan 2019 x 4</td>
</tr>
<tr>
<td>45.</td>
<td>Steering committee papers on POR grants awarded 2018</td>
</tr>
<tr>
<td>46.</td>
<td>Steering committee paper on Development grants 2018</td>
</tr>
<tr>
<td>47.</td>
<td>Steering Committee terms of reference</td>
</tr>
<tr>
<td>48.</td>
<td>Summary of the number of clinician grants funded</td>
</tr>
<tr>
<td>49.</td>
<td>Summary of the number of students who received funding</td>
</tr>
<tr>
<td>50.</td>
<td>TPMI / NL SUPPORT structure diagrams (triangles)</td>
</tr>
<tr>
<td>51.</td>
<td>Training services survey</td>
</tr>
<tr>
<td>52.</td>
<td>QCNL / CWNL priorities - Priority matrix partner agencies</td>
</tr>
<tr>
<td>53.</td>
<td>QCNL / CWNL working group terms of reference</td>
</tr>
<tr>
<td>54.</td>
<td>QCNL partner confidentiality form</td>
</tr>
<tr>
<td>55.</td>
<td>QCNL Patient panels terms of reference</td>
</tr>
<tr>
<td>56.</td>
<td>Quality of care website link – <a href="https://qualityofcarenl.ca/">https://qualityofcarenl.ca/</a> note Resources link for campaigns and practice points</td>
</tr>
<tr>
<td>57.</td>
<td>QCNL / CWNL working group minutes Nov 2018 – Jan 2019 x 2</td>
</tr>
<tr>
<td>58.</td>
<td>Value Assessment Survey</td>
</tr>
</tbody>
</table>
APPENDIX C: LITERATURE REVIEW


IMPACT Awards: Ontario SPOR SUPPORT Unit. Retrieved from https://ossu.ca/for-researchers/impact-awards/


Memorial University: Centre for Health Informatics and Analytics. Retrieved from https://www.med.mun.ca/CHIA/Home.aspx


Memorial University. MUNInnovation: Re-imaging the innovation support system at Memorial University. Initiative Chapter, Draft, v. 1.6, September 22, 2016. Retrieved from https://www.mun.ca/innovation/Charter.pdf


APPENDIX D: SURVEY RESULTS
Relevance
Which of the following NL SUPPORT grants were you successful in obtaining? Select all that apply. (N=21)

<table>
<thead>
<tr>
<th>Grant Description</th>
<th>%</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>NL SUPPORT Graduate Awards for Engagement/Educational Funding Award</td>
<td>38%</td>
<td>8</td>
</tr>
<tr>
<td>Patient-Oriented Research Grant</td>
<td>52%</td>
<td>11</td>
</tr>
<tr>
<td>SPARK Grant for Clinicians, Nurses and Allied Health Professionals</td>
<td>19%</td>
<td>4</td>
</tr>
<tr>
<td>Development Grant</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Indigenous Communities’ Grant</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>TPMI/NL SUPPORT Training and Travel Funding</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>NUTRA</td>
<td>5%</td>
<td>1</td>
</tr>
</tbody>
</table>

Below is a list of the objectives of NL SUPPORT. To what extent do you think these are relevant to the work in your field? (N=21)

<table>
<thead>
<tr>
<th>Objective</th>
<th>A lot</th>
<th>Somewhat</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increasing capacity to plan Patient-Oriented Research</td>
<td>71%</td>
<td>24%</td>
<td>5%</td>
<td>-</td>
</tr>
<tr>
<td>Increasing capacity to undertake Patient-Oriented Research</td>
<td>81%</td>
<td>19%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Increasing capacity to fully engage patients in the dissemination of research results</td>
<td>76%</td>
<td>24%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Increasing ability to complete real world clinical trials</td>
<td>76%</td>
<td>14%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Improved access to health system level data</td>
<td>86%</td>
<td>10%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Increasing partnerships across faculties, schools, and disciplines</td>
<td>81%</td>
<td>19%</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Grant Design and Delivery

How satisfied were you with the design of the NL SUPPORT Graduate Awards for Engagement/Educational Funding Award in regard to the following aspects? (N=8)

<table>
<thead>
<tr>
<th>Aspect</th>
<th>A lot</th>
<th>Somewhat</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>Application requirements (e.g., proposal, proposal summary, online submission)</td>
<td>75%</td>
<td>25%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>The application criteria (e.g., having to be a researcher, nurse, Indigenous)</td>
<td>50%</td>
<td>38%</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>The amount of funding you received from the grant</td>
<td>63%</td>
<td>13%</td>
<td>25%</td>
<td>-</td>
</tr>
<tr>
<td>The number of grants available during one fiscal year</td>
<td>13%</td>
<td>50%</td>
<td>25%</td>
<td>-</td>
</tr>
</tbody>
</table>
How satisfied were you with the design of the Patient-Oriented Research Grant in regard to the following aspects? (N=11)

<table>
<thead>
<tr>
<th>Aspect</th>
<th>A lot</th>
<th>Somewhat</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>Application requirements (e.g., proposal, proposal summary, online submission)</td>
<td>82% (9)</td>
<td>9% (1)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>The application criteria (e.g., having to be a researcher, nurse, Indigenous)</td>
<td>45% (5)</td>
<td>45% (5)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>The amount of funding you received from the grant</td>
<td>55% (5)</td>
<td>36% (4)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>The number of grants available during one fiscal year</td>
<td>36% (4)</td>
<td>45% (5)</td>
<td>9% (1)</td>
<td>-</td>
</tr>
<tr>
<td>Final reporting requirement (i.e., the report you submit at the conclusion of your research)</td>
<td>55% (6)</td>
<td>35% (4)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Receiving feedback on your application during the review process (e.g., peer review, panel review)</td>
<td>55% (6)</td>
<td>36% (4)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Presentation requirements (e.g., presenting at the annual Scientific Day (SHARE) and/or Health 4 All Festival / Terrific Scientific)</td>
<td>82% (9)</td>
<td>9% (1)</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

How satisfied were you with the design of the SPARK Grant for Clinicians, Nurses and Allied Health Professionals in regard to the following aspects? (N=4)

<table>
<thead>
<tr>
<th>Aspect</th>
<th>A lot</th>
<th>Somewhat</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>Application requirements (e.g., proposal, proposal summary, online submission)</td>
<td>75% (3)</td>
<td>25% (1)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>The application criteria (e.g., having to be a researcher, nurse, Indigenous)</td>
<td>50% (2)</td>
<td>50% (2)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>The amount of funding you received from the grant</td>
<td>50% (2)</td>
<td>25% (1)</td>
<td>25% (1)</td>
<td>-</td>
</tr>
<tr>
<td>The number of grants available during one fiscal year</td>
<td>25% (1)</td>
<td>50% (2)</td>
<td>25% (1)</td>
<td>-</td>
</tr>
<tr>
<td>Final reporting requirement (i.e., the report you submit at the conclusion of your research)</td>
<td>100% (4)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Receiving feedback on your application during the review process (e.g., peer review, panel review)</td>
<td>75% (3)</td>
<td>25% (1)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Preliminary reporting requirement (i.e., the report(s) submitted during your research)</td>
<td>25% (1)</td>
<td>25% (1)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Presentation requirements (e.g., presenting at the annual Scientific Day (SHARE) and/or Health 4 All Festival / Terrific Scientific)</td>
<td>50% (2)</td>
<td>50% (2)</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>
How would you rate the time it took for you to find out if your grant application was approved? (N=21)

<table>
<thead>
<tr>
<th></th>
<th>Very Good</th>
<th>Good</th>
<th>Poor</th>
<th>Very Poor</th>
</tr>
</thead>
<tbody>
<tr>
<td>% (N)</td>
<td>33% (7)</td>
<td>57% (12)</td>
<td>5% (1)</td>
<td>-</td>
</tr>
</tbody>
</table>

**Supports**

Below are some of the supports you could have received in addition to the funding from NL SUPPORT. How would you rate your experience with the supports you received from NL SUPPORT (including QoC/CW NL, and CHIA)? (N=21)

<table>
<thead>
<tr>
<th>Support</th>
<th>Very Good</th>
<th>Good</th>
<th>Poor</th>
<th>Very Poor</th>
<th>Not applicable/Did not use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultation on methodology/research question</td>
<td>10% (2)</td>
<td>29% (6)</td>
<td>10% (2)</td>
<td>-</td>
<td>52% (11)</td>
</tr>
<tr>
<td>Support to complete funding application(s)</td>
<td>24% (5)</td>
<td>38% (8)</td>
<td>10% (2)</td>
<td>-</td>
<td>29% (6)</td>
</tr>
<tr>
<td>Support from CHIA</td>
<td>5% (1)</td>
<td>19% (4)</td>
<td>5% (1)</td>
<td>-</td>
<td>71% (15)</td>
</tr>
<tr>
<td>Assistance with an ethics application(s)</td>
<td>5% (1)</td>
<td>24% (5)</td>
<td>5% (1)</td>
<td>-</td>
<td>67% (14)</td>
</tr>
<tr>
<td>Support accessing data from NLCHI</td>
<td>-</td>
<td>14% (3)</td>
<td>-</td>
<td>5% (1)</td>
<td>81% (17)</td>
</tr>
<tr>
<td>Support with the development of Knowledge Translation tools</td>
<td>33% (7)</td>
<td>33% (7)</td>
<td>5% (1)</td>
<td>-</td>
<td>52% (11)</td>
</tr>
<tr>
<td>Facilitation of meetings with potential collaborators</td>
<td>19% (4)</td>
<td>24% (5)</td>
<td>5% (1)</td>
<td>-</td>
<td>52% (11)</td>
</tr>
<tr>
<td>Facilitation of meetings/introductions to knowledge users such as decision-makers/policy makers</td>
<td>24% (5)</td>
<td>29% (6)</td>
<td>5% (1)</td>
<td>-</td>
<td>43% (9)</td>
</tr>
<tr>
<td>Support in ensuring patient engagement in research project(s)</td>
<td>33% (7)</td>
<td>43% (9)</td>
<td>5% (1)</td>
<td>-</td>
<td>19% (4)</td>
</tr>
</tbody>
</table>

How useful was the NL SUPPORT/QoC/CW NL training you participated in? (N=21)

<table>
<thead>
<tr>
<th>Training Type</th>
<th>Very</th>
<th>Somewhat</th>
<th>A little</th>
<th>Not at all</th>
<th>Not applicable/Did not use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Newsletter</td>
<td>19% (4)</td>
<td>24% (5)</td>
<td>14% (3)</td>
<td>-</td>
<td>43% (9)</td>
</tr>
<tr>
<td>YouTube videos (NLSUPPORT or MUN medicine)</td>
<td>19% (4)</td>
<td>5% (1)</td>
<td>14% (3)</td>
<td>-</td>
<td>62% (13)</td>
</tr>
<tr>
<td>Peer reviewed publications</td>
<td>14% (3)</td>
<td>10% (2)</td>
<td>10% (2)</td>
<td>-</td>
<td>67% (14)</td>
</tr>
<tr>
<td>Plain language publications (e.g., Antibiotic Use, Stroke Prevention)</td>
<td>29% (6)</td>
<td>-</td>
<td>5% (1)</td>
<td>-</td>
<td>67% (14)</td>
</tr>
<tr>
<td>NL SUPPORT website</td>
<td>57% (12)</td>
<td>24% (5)</td>
<td>10% (2)</td>
<td>-</td>
<td>10% (2)</td>
</tr>
<tr>
<td>Patient Engagement resources</td>
<td>57% (12)</td>
<td>24% (5)</td>
<td>5% (1)</td>
<td>-</td>
<td>14% (3)</td>
</tr>
<tr>
<td>Knowledge Translation plans/resources</td>
<td>43% (9)</td>
<td>24% (5)</td>
<td>5% (1)</td>
<td>-</td>
<td>43% (9)</td>
</tr>
</tbody>
</table>
Outcomes

At what phase is your most complete NL SUPPORT-funded research project? select all that apply.
(N=21)

<table>
<thead>
<tr>
<th>Phase</th>
<th>% (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Planning</td>
<td>5% (1)</td>
</tr>
<tr>
<td>Implementation/data collection</td>
<td>19% (4)</td>
</tr>
<tr>
<td>Analysis</td>
<td>38% (8)</td>
</tr>
<tr>
<td>Reporting</td>
<td>19% (4)</td>
</tr>
<tr>
<td>Dissemination</td>
<td>14% (3)</td>
</tr>
<tr>
<td>Complete</td>
<td>5% (1)</td>
</tr>
</tbody>
</table>

To what extent did the supports you received from NL SUPPORT/QoC/CW NL (including the grant) contribute to your achievement of the following outcomes? (N=21)

<table>
<thead>
<tr>
<th>Outcome</th>
<th>A lot</th>
<th>Somewhat</th>
<th>A little</th>
<th>Not at all</th>
<th>Not sure</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support Patient-Oriented Research</td>
<td>76% (16)</td>
<td>19% (4)</td>
<td>5% (1)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Leverage existing expertise in Patient-Oriented Research</td>
<td>48% (10)</td>
<td>24% (5)</td>
<td>-</td>
<td>5% (1)</td>
<td>-</td>
<td>24% (5)</td>
</tr>
<tr>
<td>Build Patient-Oriented Research capacity</td>
<td>71% (15)</td>
<td>14% (3)</td>
<td>5% (1)</td>
<td>5% (1)</td>
<td>5% (1)</td>
<td>-</td>
</tr>
<tr>
<td>Increase knowledge of meaningful patient engagement activities</td>
<td>48% (10)</td>
<td>19% (4)</td>
<td>10% (2)</td>
<td>5% (1)</td>
<td>10% (2%)</td>
<td>10% (2%)</td>
</tr>
<tr>
<td>Increase your network of researchers or collaborators</td>
<td>52% (11)</td>
<td>33% (7)</td>
<td>5% (1)</td>
<td>5% (1)</td>
<td>5% (1)</td>
<td>-</td>
</tr>
<tr>
<td>Increase your ability to conduct inter-disciplinary work</td>
<td>52% (11)</td>
<td>38% (8)</td>
<td>5% (1)</td>
<td>5% (1)</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Increase knowledge translation and exchange capacity</td>
<td>52% (11)</td>
<td>19% (14)</td>
<td>5% (1)</td>
<td>5% (1)</td>
<td>-</td>
<td>19% (4)</td>
</tr>
<tr>
<td>Increase uptake of research results in the healthcare system</td>
<td>38% (8)</td>
<td>19% (4)</td>
<td>10% (2)</td>
<td>-</td>
<td>14% (3)</td>
<td>19% (4)</td>
</tr>
<tr>
<td>Improve patient capacity to engage in the research process</td>
<td>48% (10)</td>
<td>29% (6)</td>
<td>5% (1)</td>
<td>5% (1)</td>
<td>14% (3)</td>
<td>-</td>
</tr>
<tr>
<td>Support research that has the potential to improve the health of individuals, families and communities</td>
<td>76% (16)</td>
<td>19% (4)</td>
<td>-</td>
<td>5% (1)</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>
Support innovation  
<table>
<thead>
<tr>
<th>A lot</th>
<th>Somewhat</th>
<th>A little</th>
<th>Not at all</th>
<th>Not sure</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>43% (9)</td>
<td>24% (5)</td>
<td>5% (1)</td>
<td>5% (1)</td>
<td>10% (2)</td>
<td>14% (3)</td>
</tr>
</tbody>
</table>

Improve the responsiveness of your research to emerging patient issues and concerns  
<table>
<thead>
<tr>
<th>A lot</th>
<th>Somewhat</th>
<th>A little</th>
<th>Not at all</th>
<th>Not sure</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>43% (9)</td>
<td>33% (7)</td>
<td>5% (1)</td>
<td>5% (1)</td>
<td>-</td>
<td>14% (3)</td>
</tr>
</tbody>
</table>

Allowed me/my team to apply for additional funding  
<table>
<thead>
<tr>
<th>A lot</th>
<th>Somewhat</th>
<th>A little</th>
<th>Not at all</th>
<th>Not sure</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>29% (6)</td>
<td>10% (2)</td>
<td>14% (3)</td>
<td>-</td>
<td>29% (6)</td>
<td>19% (4)</td>
</tr>
</tbody>
</table>

Allowed me/my team to obtain additional funding  
<table>
<thead>
<tr>
<th>A lot</th>
<th>Somewhat</th>
<th>A little</th>
<th>Not at all</th>
<th>Not sure</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>10% (2)</td>
<td>24% (5)</td>
<td>10% (2)</td>
<td>5% (1)</td>
<td>24% (5)</td>
<td>29% (6)</td>
</tr>
</tbody>
</table>

If you had not received this grant, how do you think your research study would have changed? Select all that apply. (N = 21)  
<table>
<thead>
<tr>
<th>% (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Would not have been able to conduct this research</td>
</tr>
<tr>
<td>Would have undertaken a smaller research project</td>
</tr>
<tr>
<td>Research would have been delayed</td>
</tr>
<tr>
<td>Would not have been engaged patients at all</td>
</tr>
<tr>
<td>Would not have been able to engage to collaborators</td>
</tr>
<tr>
<td>Would not have been able to hire staff/other researchers</td>
</tr>
<tr>
<td>Would have had to scale back patient engagement</td>
</tr>
<tr>
<td>Would not have built as much capacity for patient engagement</td>
</tr>
<tr>
<td>Would have had to find funding elsewhere</td>
</tr>
<tr>
<td>Nothing/no changes</td>
</tr>
</tbody>
</table>

If you had not received support from NL SUPPORT, do you think you would be implementing Patient-Oriented Research in your research program? (N=21)  
<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>% (N)</td>
<td>19% (4)</td>
<td>57% (12)</td>
</tr>
</tbody>
</table>

How comfortable do you feel implementing Patient-Oriented Research in your future research? (N=21)  
<table>
<thead>
<tr>
<th>Very</th>
<th>Somewhat</th>
<th>A little</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>% (N)</td>
<td>67% (14)</td>
<td>33% (7)</td>
<td>-</td>
</tr>
</tbody>
</table>

Did you experience any unanticipated results (positive or negative) from your collaboration with NL SUPPORT? (N=21)  
<table>
<thead>
<tr>
<th>Yes</th>
<th>No</th>
<th>Not sure</th>
</tr>
</thead>
<tbody>
<tr>
<td>% (N)</td>
<td>10% (2)</td>
<td>48% (10)</td>
</tr>
</tbody>
</table>
# NL SUPPORT

## Stakeholder Survey

### Relevance

What is your current role? *Select all that apply.* (N=5)

<table>
<thead>
<tr>
<th>Role</th>
<th>% (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health executive/manager</td>
<td>40% (2)</td>
</tr>
<tr>
<td>Policy maker</td>
<td>40% (2)</td>
</tr>
<tr>
<td>Healthcare practitioner</td>
<td>20% (1)</td>
</tr>
<tr>
<td>Health charity representative</td>
<td>20% (1)</td>
</tr>
<tr>
<td>Program Administrator</td>
<td>20% (1)</td>
</tr>
<tr>
<td>Patient – family rep</td>
<td>20% (1)</td>
</tr>
</tbody>
</table>

Below is a list of the objectives of NL SUPPORT. To what extent do you think these objectives are relevant to the healthcare field in Newfoundland and Labrador? (N=5)

<table>
<thead>
<tr>
<th>Objective</th>
<th>A lot</th>
<th>Somewhat</th>
<th>A little</th>
<th>Not at all</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increasing capacity to plan patient-oriented research</td>
<td>80% (4)</td>
<td>20% (1)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Increasing capacity to undertake Patient-Oriented Research</td>
<td>80% (4)</td>
<td>20% (1)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Increasing capacity to fully engage patients in the dissemination of research results</td>
<td>100% (5)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Increasing ability to complete real world clinical trials</td>
<td>80% (4)</td>
<td>20% (1)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Improved access to health system level data</td>
<td>80% (4)</td>
<td>20% (1)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Increasing partnerships across faculties, schools, and disciplines</td>
<td>100% (5)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

### Supports

How would you rate your experience with the supports you received from NL SUPPORT (including Quality of Care, Choosing Wisely NL, and the Centre for Health Informatics and Analytics)? (N=5)

<table>
<thead>
<tr>
<th>Support</th>
<th>Very good</th>
<th>Good</th>
<th>Poor</th>
<th>Very poor</th>
<th>Not applicable/ did not use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consultation on methodology/research question</td>
<td>40% (2)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>60% (3)</td>
</tr>
<tr>
<td>Support to complete funding application(s)</td>
<td>20% (1)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>80% (4)</td>
</tr>
<tr>
<td>Support from the Centre for Health Information and Analytics</td>
<td>40% (2)</td>
<td>20% (1)</td>
<td>-</td>
<td>-</td>
<td>40% (2)</td>
</tr>
<tr>
<td>Assistance with an ethics application(s)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>100% (5)</td>
</tr>
<tr>
<td>Support accessing data from NLCHI</td>
<td>20% (1)</td>
<td>40% (2)</td>
<td>-</td>
<td>-</td>
<td>40% (2)</td>
</tr>
<tr>
<td>Support with the development of Knowledge Translation tools</td>
<td>40% (2)</td>
<td>40% (2)</td>
<td>-</td>
<td>-</td>
<td>20% (1)</td>
</tr>
<tr>
<td>Facilitation of meetings with potential collaborators</td>
<td>80% (4)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>20% (1)</td>
</tr>
<tr>
<td>Facilitation of meetings/introductions to knowledge users such as decision-makers/policy makers</td>
<td>60% (3)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>40% (2)</td>
</tr>
<tr>
<td>Support in ensuring patient engagement in research project(s)</td>
<td>60% (3)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>40% (2)</td>
</tr>
</tbody>
</table>

How useful was the NL SUPPORT/Quality of Care/Choosing Wisely NL training you participated in? (Training and webinar titles are listed below) (N=5)

<table>
<thead>
<tr>
<th>Training Title</th>
<th>Very</th>
<th>Somewhat</th>
<th>A little</th>
<th>Not at all</th>
<th>Not applicable/ did not use</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bootcamp for POR grant applicants</td>
<td>20% (1)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>80% (4)</td>
</tr>
<tr>
<td>Recruiting Patient Partners for Research Projects</td>
<td>40% (2)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>60% (3)</td>
</tr>
<tr>
<td>Learn How to Pitch Research Ideas to Funding Agencies, Investors, and Beyond</td>
<td>40% (2)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>60% (3)</td>
</tr>
<tr>
<td>Lessons in Innovation: From Research to Start-Up</td>
<td>20% (1)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>80% (4)</td>
</tr>
<tr>
<td>The Art of Pitching Your Research to Non-Academic Funding Bodies</td>
<td>-</td>
<td>20% (1)</td>
<td>-</td>
<td>-</td>
<td>80% (4)</td>
</tr>
<tr>
<td>New Models for Research in the New Era of Health Innovation</td>
<td>20% (1)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>80% (4)</td>
</tr>
<tr>
<td>The Basics of SPSS</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>100% (5)</td>
</tr>
<tr>
<td>Biostatistics: Sample Size &amp; Power</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>100% (5)</td>
</tr>
<tr>
<td>Knowledge Translation: Beyond Publications</td>
<td>20% (1)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>80% (4)</td>
</tr>
<tr>
<td>Writing In Plain Language</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>100% (5)</td>
</tr>
<tr>
<td>Let’s Talk Policy: Translating Research Into Policy</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>100% (5)</td>
</tr>
<tr>
<td>Grant Writing and Funding Opportunities in POR</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>100% (5)</td>
</tr>
<tr>
<td>Business Case Development for Your Research</td>
<td>-</td>
<td>20% (1)</td>
<td>-</td>
<td>-</td>
<td>80% (4)</td>
</tr>
<tr>
<td>Patient-Oriented Research in Practice</td>
<td>20% (1)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>80% (4)</td>
</tr>
</tbody>
</table>
How useful were the following NL SUPPORT/Quality of Care/Choosing Wisely NL resources you accessed? (N=5)

<table>
<thead>
<tr>
<th>Resource</th>
<th>Very</th>
<th>Somewhat</th>
<th>A little</th>
<th>Not at all</th>
<th>Not applicable – did not access</th>
</tr>
</thead>
<tbody>
<tr>
<td>Newsletter</td>
<td>40% (2)</td>
<td>40% (2)</td>
<td>-</td>
<td>-</td>
<td>20% (1)</td>
</tr>
<tr>
<td>YouTube videos (NLSUPPORT or MUNmedicine)</td>
<td>40% (2)</td>
<td>20% (1)</td>
<td>-</td>
<td>-</td>
<td>40% (2)</td>
</tr>
<tr>
<td>Peer reviewed publications</td>
<td>20% (1)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>80% (4)</td>
</tr>
<tr>
<td>Plain language publications (e.g., Antibiotic Use, Stroke Prevention)</td>
<td>80% (4)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>20% (4)</td>
</tr>
<tr>
<td>NL SUPPORT website</td>
<td>60% (3)</td>
<td>40% (2)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Patient Engagement resources</td>
<td>40% (2)</td>
<td>40% (2)</td>
<td>-</td>
<td>-</td>
<td>20% (1)</td>
</tr>
<tr>
<td>Knowledge translation plans/resources</td>
<td>80% (4)</td>
<td>20% (1)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Outcomes

To what extent did the support you received from NL SUPPORT / QoC/CW NL contribute to your achievement of the following outcomes? (N=5)

<table>
<thead>
<tr>
<th>Outcome</th>
<th>A lot</th>
<th>Somewhat</th>
<th>A little</th>
<th>Not at all</th>
<th>Not sure</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improve access to data to make decisions / progress research</td>
<td>60% (3)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>40% (2)</td>
</tr>
<tr>
<td>Increase understanding of the benefits of patient-oriented research</td>
<td>80% (4)</td>
<td>20% (1)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Leverage existing expertise in patient-oriented research</td>
<td>60% (3)</td>
<td>40% (2)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Build Patient-Oriented Research capacity</td>
<td>80% (4)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>20% (1)</td>
</tr>
<tr>
<td>Increasing network of collaborators</td>
<td>100% (5)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Create new or improve existing partnerships with researchers</td>
<td>60% (3)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>40% (2)</td>
</tr>
<tr>
<td>Make research results more accessible (e.g. plain language)</td>
<td>80% (4)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>20% (1)</td>
</tr>
<tr>
<td>Increase uptake of research results with decision-makers</td>
<td>80% (4)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>20% (1)</td>
</tr>
<tr>
<td>Improve access to research that has the potential to improve the health of individuals, families and communities</td>
<td>60% (3)</td>
<td>20% (1)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>20% (1)</td>
</tr>
<tr>
<td>Support innovation</td>
<td>60% (3)</td>
<td>20% (1)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>20% (1)</td>
</tr>
<tr>
<td>charts</td>
<td>A lot</td>
<td>Somewhat</td>
<td>A little</td>
<td>Not at all</td>
<td>Not sure</td>
<td>Not applicable</td>
</tr>
<tr>
<td>--------</td>
<td>-------</td>
<td>----------</td>
<td>----------</td>
<td>------------</td>
<td>---------</td>
<td>----------------</td>
</tr>
<tr>
<td>Improve the responsiveness of your organization to emerging patient issues and concerns</td>
<td>60% (3)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>40% (2)</td>
</tr>
</tbody>
</table>

Are you aware of other results (positive or negative)? (N=5)

<table>
<thead>
<tr>
<th>charts</th>
<th>Yes</th>
<th>No</th>
<th>Unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>% (N)</td>
<td>-</td>
<td>20% (1)</td>
<td>80% (4)</td>
</tr>
</tbody>
</table>
Experience with Patient Advisory Committee

Can you tell me how you have participated in NL SUPPORT/Quality of Care/Choosing Wisely Newfoundland? *Select all that apply.* (N=8)

<table>
<thead>
<tr>
<th>Activity</th>
<th>% (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Member of the Patient Advisory Council</td>
<td>100% (11)</td>
</tr>
<tr>
<td>Member of the Translational and Personalized Medicine Initiative (TPMI) Steering Committee</td>
<td>13% (1)</td>
</tr>
<tr>
<td>Patient partner in research</td>
<td>63% (5)</td>
</tr>
<tr>
<td>Patient partner in disseminating/sharing research results</td>
<td>38% (3)</td>
</tr>
<tr>
<td>Identification of research priorities</td>
<td>25% (2)</td>
</tr>
<tr>
<td>Setting meeting agendas</td>
<td>25% (2)</td>
</tr>
<tr>
<td>NL SUPPORT training recipient</td>
<td>38% (3)</td>
</tr>
<tr>
<td>Trained other patients</td>
<td>13% (1)</td>
</tr>
<tr>
<td>Trained Researchers/healthcare providers</td>
<td>13% (1)</td>
</tr>
<tr>
<td>Member of other committees</td>
<td>50% (4)</td>
</tr>
</tbody>
</table>

Please rate your experience with the following aspects of the Patient Advisory Committee: (N=8)

<table>
<thead>
<tr>
<th>Aspect</th>
<th>Very good</th>
<th>Good</th>
<th>Poor</th>
<th>Very Poor</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information and training you received</td>
<td>88% (7)</td>
<td>13% (1)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Your participation on research projects</td>
<td>38% (3)</td>
<td>25% (2)</td>
<td>-</td>
<td>-</td>
<td>38% (3)</td>
</tr>
<tr>
<td>Support you received from NL SUPPORT</td>
<td>88% (7)</td>
<td>13% (1)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Ability to fully participate in meetings</td>
<td>75% (6)</td>
<td>25% (2)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Honorarium/ Appreciation for your time</td>
<td>88% (7)</td>
<td>13% (1)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Compensation for travel</td>
<td>63% (5)</td>
<td>13% (1)</td>
<td>-</td>
<td>-</td>
<td>25% (2)</td>
</tr>
</tbody>
</table>

In your opinion, how well do the following NL SUPPORT/Quality of Care/Choosing Wisely objectives meet the needs of patients and/or researchers? (N=8)

<table>
<thead>
<tr>
<th>Objective</th>
<th>A lot</th>
<th>Somewhat</th>
<th>A little</th>
<th>Not at all</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increase researchers’ capacity to plan Patient-Oriented Research</td>
<td>100% (8)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Increase capacity of researchers to undertake Patient-Oriented Research</td>
<td>88% (7)</td>
<td>13% (1)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Increase researchers’ capacity to fully engage patients when sharing their research results</td>
<td>100% (8)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>
Outcomes

To what extent do you think the activities of NL SUPPORT, including the participation of patient partners in research projects, is helping achieve the following outcomes? (N=8)

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>A lot</th>
<th>Somewhat</th>
<th>A little</th>
<th>Not at all</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Improve the responsiveness of the healthcare system</td>
<td>63% (5)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>38% (3)</td>
</tr>
<tr>
<td>Build capacity for patients to participate in the research process</td>
<td>100% (8)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Support innovation</td>
<td>75% (6)</td>
<td>25% (2)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Increase uptake of research results in the healthcare system</td>
<td>63% (5)</td>
<td>38% (3)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Support the presentation of research results in formats that are accessible to patients</td>
<td>63% (5)</td>
<td>38% (3)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Increase use/application of research results</td>
<td>50% (4)</td>
<td>50% (4)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Support the development of research that is relevant to patient concerns and priorities</td>
<td>88% (7)</td>
<td>13% (1)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Support research that has the potential to improve the health of individuals, families and communities</td>
<td>88% (7)</td>
<td>13% (1)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>
APPENDIX E: DESCRIPTION OF GRANTS AND AWARDS
**Educational Funding Award:** Aligned with TPMI’s mandate to foster an atmosphere or learning, capacity and suitability within patient-centric research, the Educational Funding Opportunities Award provides graduate students who are conducting translational, applied or other POR as a part of their thesis with additional funding (up to $14,000 master students and $18,000 for PhDs). This award is seen to help students develop necessary skills to be competitive in the workforce upon graduation.\(^{59}\)

**Graduate Awards for Engagement:** This award is given to up to 5 graduate students each year (maximum $1,000) to cover some costs related to POR including compensation, field travel, patient engagement/appreciation, administrative tasks (e.g., printing, photocopying, postage) and obtaining copyright releases and payment.\(^{60}\)

**Undergraduate Training in Research Awards (NUTRA):** This grant was designed to provide undergraduate students interested in conducting research the ability to work with a MUN facility member on POR. The grant provides a stipend funding for up to 16 weeks.\(^{61}\)

**Development Grant:** The Developmental Grant seeks to support an individual or group of researchers who are conducting POR in alignment with the mandates and priorities set by NL SUPPORT. Successful applicants will receive up to $20,000 to be used for the implementation of POR including access to, or stage and analysis of data, clerical staff/research assistants or consultants, necessary medical procedures, compensation for research subjects and field travel costs.\(^{62}\)

**SPARK Grant for Clinicians, Nurses, AHP:** The SPARK Grant offers up to $10,000 for clinical, nurse or allied health-professional-led small patient-orientated quality improvement, evaluation projects. A maximum of 10 grants are administered each year with funding to be used for implementation of POR including access to and analysis of data, clerical staff/research assistants or consultants, necessary medical procedures, compensation for research subjects and field travel costs.\(^{63}\)

**Patient Orientated Research Grants:** Similar to the SPARK grant, this award provides a maximum of $75,000 per individual or group, with a maximum of $300,000 awarded per year to support researchers conducting a research project on NL residents that incorporates POR and is in alignment with NL SUPPORT mandates and priorities. These grants are designed to defray the


\(^{60}\)http://www.nlsupport.ca/getdoc/2a9ee10a-1591-453f-b752-e705b0c562fb/NL-SUPPORT-PE-Awards-Guide.aspx

\(^{61}\)http://www.nlsupport.ca/getdoc/c7e17cdd-deb9-4199-b77b-c87b1d461d56/NUTRA.aspx

\(^{62}\)http://www.nlsupport.ca/getattachment/99b82d10-35d3-4187-8dad-552e0b5f7f2/NL-SUPPORT-Development-General-Information.pdf.aspx

\(^{63}\)http://www.nlsupport.ca/getdoc/2e514175-c3d5-4d21-9463-41eb3b4feb0d/Clinician-AHP-Grants.aspx
normal direct costs of research including personnel costs, supplies and expendable materials, equipment, computing costs, research travel, and dissemination and communications.\textsuperscript{64}

**Indigenous Communities Grants:** The Indigenous Communities Grant supports health research projects in the communities of the Mi’kmaq, Inuit and Innu people of Newfoundland and Labrador. The grant offers a total of $75,000 which can be awarded to one project or divided among multiple projects each year. Similar to other NL SUPPORT grants, the Indigenous Communities Grant focuses on projects who include POR, but also supports community research that seeks to improve the health and/or wellbeing of Indigenous People of Canada.\textsuperscript{65}

**TPMI Training and Travel Fund:** The TPMI/NL SUPPORT Training and Travel Funding was developed to assist staff and student career development through funding for training and travel for students and staff working on TPMI projects. Career development funding can be used for conference attendance, courses available within the province and outside of the province.\textsuperscript{66}

\textsuperscript{64} http://www.nlsupport.ca/getattachment/56183082-8531-4c34-8711-1339b02131da/NL-SUPPORT-Award-Guide-(2).pdf.aspx
\textsuperscript{65} http://www.nlsupport.ca/Home/Indigenous-Communities-Grant.aspx
\textsuperscript{66} http://www.nlsupport.ca/Home/Training-and-Travel-Funding.aspx
APPENDIX F: PROJECTS FUNDED
**Patient Orientated Grants Funded:**

- Diagnostic imaging utilization
- Optimizing medication therapy outcomes for high risk patients transitioning from acute to primary care
- Making decisions about surgical treatment: using digital stories to explore the experiences of breast cancer patients
- Utilizing commercially available infrared thermometers to prevent foot ulcers in patients with diabetes - A mixed methods approach
- Making the link: A mixed-method exploration of the impact of using telehealth to facilitate ABA orientation for families in rural areas of Western NL
- Evaluating a cardiovascular screening intervention to promote healthy aging.
- Why don’t BRCA carriers in NL receive adequate screening and prevention?
- Family centred care (FCC) to meet the emotional, psychological and developmental needs of infants’ mental health (pre-natal to 36 months)
- Exploring health services options through a patient-led study in response to a growing wait list for bariatric surgery as a treatment for severe obesity in NL
- Young adults with cancer in their prime (YAC PRIME): A patient oriented collaborative study
- The Eastern Health Diversity Project: Examining needs and establishing priorities
- Using mixed methods to assess upskilling physiotherapists to implement the evidence-based Back Skills Training Program into routine practice: a pragmatic cluster randomized controlled trial and interview study
- The Development of Strategies to Foster Awareness and Accessibility of Services for Seniors Living with Hearing Loss in the Province of NL
- The Determinants of Nutrition Influencing Community-dwelling Older Adults living in Western NL: Community Engagement and the Role of Nursing Practice
- The time is now: Linking evidence to action for a comprehensive approach to suicide prevention in Newfoundland and Labrador

**SPARK Grants Funded:**

- Impact of a deprescribing intervention on nursing home residents: an RCT
- A Functional Approach to Inpatient Rehabilitation of the Elderly; Does Task-Oriented Practice Promote Quicker Recovery of Function in Slow-Stream Rehabilitation Patients?
- Knowledge of and Adherence to radiographic guidelines for low back pain
- Non-medical management of chronic constipation in northern Newfoundland and Labrador
- Efficacy and cost-effectiveness of an intensive individualized smoking cessation support program delivered by pharmacists
- Implementing the Frazier Free Water Protocol (FFWP) with Oral Care to Improve Hydration and Quality of Life in Long Term Residents
• Vulvodynia: Addressing patient-identified gaps in primary care provider knowledge of a condition with significant impact on quality of life
• Engaging Patients as Partners: Developing A Post-Operative Total Joint Surgery Rehabilitation Resource
• Identifying Missed Appointment Statistics for Government Assisted Refugees to Improve Access to Care
• Beyond weight-loss: the physiological and psychological effects of a community-based exercise program on fertility
• Can Preoperative Ostomy Education Improve the Postoperative Outcomes for Patients Undergoing Colorectal Surgery Requiring Stoma Formation in Eastern Health?
• Impact of nurse practitioner-led clinics on chronic disease management in Newfoundland and Labrador
• Studying Fetal Surveillance to Understand how Nurses’ Work is Organized
• Using 3D-printed models to improve patient education surrounding testicular cancer
• The prevalence and patterns of use of point of care ultrasound (POCUS) in Newfoundland and Labrador -- an environmental scan

Development Grant Projects Funded
• Engaging patients with MS to uncover the neuroscience of hand impairment
• The Iowa infant feeding attitude scale (IIFAS) -- assessing its clinical application

Indigenous Grant Project Funded
• Patshitinikutau Natukunisha Tshishennuat Uitshuau (A Place for Elders to Spend their Last Days in Life): Developing an Innu Approach to Palliative Care
APPENDIX G: KEY INFORMANT INTERVIEW GUIDES
INTRODUCTION

Hello,

Memorial University has hired my firm, Dig Insights, to carry out the evaluation of the Newfoundland and Labrador Support for People and Patient-Oriented Research and Trials (NL SUPPORT) Unit. The purpose of the evaluation is to understand how NL SUPPORT activities are delivered, early results, as well as any lessons learned or improvements required.

Today we are looking to speak to you to better understand your experience and knowledge of NL SUPPORT. This interview should take approximately 30 minutes of your time.

This interview is completely voluntary. All of your answers will remain confidential and will only be used for research and program planning purposes. You will not be personally identified in any reports, and your answers will be combined with others in the final analysis.

I would also like to record this interview to ensure I do not miss any key information that you provide during the interview. The recording will remain confidential and only reviewed by the evaluation team. Are you okay with me recording the interview?

Do you have any questions before we begin?

BACKGROUND AND RELEVANCE

1. Can you briefly tell me about your knowledge of and involvement in NL SUPPORT and/or Quality of Care / Choosing Wisely NL activities? For example, did you apply for grants, use the research originating from the Unit, participate in training, etc.

Relevance

NL SUPPORT is a methodological research support centre dedicated to supporting and developing the province’s capacity for POR. This is achieved by bringing together patients, researchers, healthcare providers, IBM, and provincial and federal bodies67 to provide methodological support and research services for projects that have “a direct impact on patients’ lives, in ways that are important to patients and by making them partners in research.”68 This objective was being supported through:

67 NL Government: Departments of Health and Community Services and Tourism, Culture, Industry and Innovation, Eastern Health, Atlantic Canada Opportunities Agency, NL Centre for Health Information, Memorial University, and patients, Canadian Institute of Health Research (CIHR)
68 http://www.nlsupport.ca/home.aspx
• Effective patient engagement being the cornerstone of health research facilitated by NL SUPPORT;
• Research addressing the knowledge, evidence and decision support needs of the patients;
• Ensuring a critical mass of specialized and multidisciplinary methodological expertise in patient-oriented research and that this expertise is then applied;
• Decision makers and investigators identifying and designing relevant research studies as well as building skills and use of biostatistical analyses, data management, project management skills and ensuring that the selected studies meet all relevant regulatory standards;
• Methods development, expertise and knowledge translation and exchange in comparative effectiveness research being advanced and the next generation of methodologists developed; and
• Enabling timely access to linked health system data being provided and integrated into existing or new databases.

2. How well do the Unit’s activities address the needs of stakeholders such as yourself?
   • Are you aware of groups whose needs are less well served by NL SUPPORT?
   • Are there any unmet needs that would be relevant for NL SUPPORT to address? If so, how could the Unit best address those needs?

Outcomes

3. Now I am going to read you a description of the NL SUPPORT Unit’s expected short-term outcomes.

Probe: for the why/how on each outcome which is RELEVANT to this stakeholder based on their area of knowledge and interaction with NL SUPPORT

The short-term outcomes for the Unit include improved access to data to inform decisions, existing expertise being leveraged, increased knowledge of meaningful patient engagement practices for stakeholders, increased collaborations between stakeholders, and increased knowledge translation and exchange capacity.

a. Overall, to what extent do you feel the NL SUPPORT Unit has been successful in:
   • Improving access to data to inform decisions?
   • Leveraging existing expertise?
   • Increased knowledge of meaningful patient engagement practices?
   • Increasing collaborations between stakeholders?
   • Increasing knowledge translation and exchange capacity?

b. Do you feel these outcomes vary depending upon core function/region?
4. Next, let’s discuss the intermediate outcomes of the unit. The **intermediate outcomes** include improved patient capacity for engagement, improved POR research capacity, improved infrastructure and support services, a collaborative, multi-disciplinary POR community, improved responsiveness, improved ability to innovate and increased evidence-based practice.

*Probe: for the why/how on each outcome*

a. Overall, to what extent do you feel the NL SUPPORT is meeting or on track to meet these outcomes?
   - Improved patient capacity for engagement?
   - Improved POR research capacity?
   - Improved infrastructure and support services?
   - A collaborative, multi-disciplinary POR community?
   - Improved responsiveness?
   - Improved ability to innovate?
   - Increased evidence-based practice?

b. Do you feel these outcomes vary depending upon core function/region? (Note – repeat outcomes as necessary)

5. One of the larger, overarching goals for NL SUPPORT is to contribute to improved health system efficiency.
   - Based on your experience with the unit, how do you feel NL SUPPORT is contributing to the efficiency of the health system to date?
   - What you feel its impact will be in the future?
   - How do you see the activities contributing to improved health outcomes for residents of Newfoundland and Labrador?

*Cost-Effectiveness*

6. Do you have other comments or suggestions that would help us in this evaluation?

Thank you for your time!
Hello,

Memorial University has hired my firm, Dig Insights, to carry out the evaluation of the Newfoundland and Labrador Support for People and Patient-Oriented Research and Trials (NL SUPPORT) Unit. The purpose of the evaluation is to understand how NL SUPPORT activities are delivered, early results, as well as any lessons learned or improvements required.

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Do you have any questions before we begin?

**BACKGROUND AND RELEVANCE**

7. Can you tell me about your current role in NL SUPPORT?
   a. How long have you been in this role?

**Relevance**

8. How well do you feel NL SUPPORT is meeting the needs of the following stakeholder groups?
   - Provincial/territorial departments and agencies;
   - Patients;
   - Researchers and/or health practitioners;
   - Policy makers/decision-makers; and
   - Private sector stakeholders.

9. Are there any unmet needs that would be relevant for NL SUPPORT to address? If so, how could those needs best be addressed?
10. Is the current design and delivery of the Unit effective? What about the planning processes?
   - How did changes made as a result of the previous evaluation influence the effectiveness of the activities?

11. Thinking about similar units in other jurisdictions that you are familiar with, are there any lessons learned or best practices that NL SUPPORT could adopt which would lead to improvements?
   - Are there any other changes that you think would improve the design and delivery of the unit?

**Outcomes**

12. Now I am going to read you a description of the NL SUPPORT Unit’s expected short-term outcomes.

*Probe: for the why/how on each outcome*

The **short-term outcomes** for the Unit include improved access to data to inform decisions, existing expertise being leveraged, increased knowledge of meaningful patient engagement practices for stakeholders, increased collaborations between stakeholders, and increased knowledge translation and exchange capacity.

   c. Overall, to what extent do you feel the NL SUPPORT Unit has been successful in:
      - Improving access to data to inform decisions?
      - Leveraging existing expertise?
      - Increased knowledge of meaningful patient engagement practices?
      - Increasing collaborations between stakeholders?
      - Increasing knowledge translation and exchange capacity?

   d. Do you feel these outcomes vary depending upon core function/region?

13. Next, let’s discuss the intermediate outcomes of the unit. The **intermediate outcomes** include improved patient capacity for engagement, improved POR research capacity, improved infrastructure and support services, a collaborative, multi-disciplinary POR community, improved responsiveness, improved ability to innovate and increased evidence-based practice.

*Probe: for the why/how on each outcome*

   c. Overall, to what extent do you feel the NL SUPPORT is meeting or on track to meet these outcomes?
      a. Improved patient capacity for engagement?
b. Improved POR research capacity?
c. Improved infrastructure and support services?
d. A collaborative, multi-disciplinary POR community?
e. Improved responsiveness?
f. Improved ability to innovate?
g. Increased evidence-based practice?

•

d. Do you feel these outcomes vary depending upon core function/region? *(Note – repeat outcomes as necessary)*

14. One of the larger, overarching goals for NL SUPPORT is to contribute to improved health system efficiency.
   a. Based on your experience with the unit, how do you feel NL SUPPORT is contributing to the efficiency of the health system to date?
   b. What you feel its impact will be in the future?
   c. How do you see the activities contributing to improved health outcomes for residents of Newfoundland and Labrador?

15. Have you observed any unintended results of NL SUPPORT activities? If so, what are those?

**Cost-Effectiveness**

16. Can you think of any changes to NL SUPPORT which would allow it to better achieve its objectives with the same or lower levels of funding or support?
   • Do you think the Unit is achieving good value for money? Why is that?

17. Do you have other comments or suggestions that would help us in this evaluation?

    **Thank you for your time!**
Hello,

Memorial University has hired my firm, Dig Insights, to carry out the evaluation of the Newfoundland and Labrador Support for People and Patient-Oriented Research and Trials (NL SUPPORT) Unit. The purpose of the evaluation is to understand how NL SUPPORT activities are delivered, early results, as well as any lessons learned or improvements required.

Today we are looking to speak to you to better understand your experience and knowledge of NL SUPPORT. This interview should take approximately 30 minutes of your time.

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I would also like to record this interview to ensure I do not miss any key information that you provide during the interview. The recording will remain confidential and only reviewed by the evaluation team. Are you okay with me recording the interview?

Do you have any questions before we begin?

**BACKGROUND AND RELEVANCE**

*Relevance*

18. Can you tell me about your current involvement with the TPMI Steering Committee?
   - Why did you join the TPMI Steering Committee?
   - How long have you been in this role?
   - Is there alignment between your organization and the Committee’s goals and objectives for NL SUPPORT (including Quality of Care / Choosing Wisely NL and the Centre for Health Information and Analytics)?

*Design and Delivery*

19. Is the current design of the governance structure effective? What about the planning processes?
   - How did changes made as a result of the previous evaluation influence the effectiveness of the governance structure and functioning of the Committee?
   - Can you recommend other changes which would improve effectiveness?
20. How well do you feel NL SUPPORT (including Quality of Care / Choosing Wisely NL and the Centre for Health Information and Analytics) are meeting the needs of the following stakeholder groups?
  - Provincial/territorial departments and agencies;
  - Patients;
  - Researchers and/or health practitioners;
  - Policy makers/decision-makers; and
  - Private sector stakeholders.

21. Are there any unmet needs that would be relevant for NL SUPPORT to address? If so, how could those needs best be addressed?

Outcomes

22. Now I am going to read you a description of the NL SUPPORT Unit’s expected short-term outcomes.

Probe: for the why/how on each outcome

The short-term outcomes for the Unit include improved access to data to inform decisions, existing expertise being leveraged, increased knowledge of meaningful patient engagement practices for stakeholders, increased collaborations between stakeholders, and increased knowledge translation and exchange capacity.

  e. Overall, to what extent do you feel the NL SUPPORT Unit has been successful in:
     - Improving access to data to inform decisions?
     - Leveraging existing expertise?
     - Increased knowledge of meaningful patient engagement practices?
     - Increasing collaborations between stakeholders?
     - Increasing knowledge translation and exchange capacity?

  f. Do you feel these outcomes vary depending upon core function/region?

23. Next, let’s discuss the intermediate outcomes of the unit. The intermediate outcomes include improved patient capacity for engagement, improved POR research capacity, improved infrastructure and support services, a collaborative, multi-disciplinary POR community, improved responsiveness, improved ability to innovate and increased evidence-based practice.

Probe: for the why/how on each outcome

  e. Overall, to what extent do you feel the NL SUPPORT is meeting or on track to meet these outcomes?
• Improved patient capacity for engagement?
• Improved POR research capacity?
• Improved infrastructure and support services?
• A collaborative, multi-disciplinary POR community?
• Improved responsiveness?
• Improved ability to innovate?
• Increased evidence-based practice?
•
  f. Do you feel these outcomes vary depending upon core function/region? (Note – repeat outcomes as necessary)

24. One of the larger, overarching goals for NL SUPPORT is to contribute to improved health system efficiency.
   • Based on your experience with the unit, how do you feel NL SUPPORT is contributing to the efficiency of the health system to date?
   • What you feel its impact will be in the future?
   • How do you see the activities contributing to improved health outcomes for residents of Newfoundland and Labrador?

25. Have you observed any unintended results of NL SUPPORT activities? If so, what are those?

  **Cost-Effectiveness**

26. Can you think of any changes to NL SUPPORT which would allow it to better achieve its objectives with the same or lower levels of funding or support?
   • Do you think the Unit is achieving good value for money? Why is that?

27. Do you have other comments or suggestions that would help us in this evaluation?

  **Thank you for your time!**