



The Development of a Patient Advisory Committee to Inform a Mixed Methods Study About the Care Needs of Individuals With Diabetes in Newfoundland and Labrador

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INTRODUCTION

This project focuses on the development of a **Patient Advisory Committee (PAC)** that will inform a patient-oriented, mixed methods, multi-phase study. The goal of the study is to develop an intervention that will improve the process and resources available for diabetes care and management for residents of Newfoundland and Labrador living with diabetes.

A **patient** in this context is: “overarching and is inclusive of individuals with personal experience of a health issue and informal caregivers, including family and friends” (Canadian Institute of Health Research, 2019)

OBJECTIVES

1. To engage patient partners living with diabetes to form a PAC to help inform a research study.
2. To recruit and engage community group representatives of individuals in underserved populations living with diabetes.
3. To engage key stakeholders to inform a PAC to help inform a research study.
4. To draw on PAC members' expertise in living with diabetes and/or diabetes care in the development of PAC terms of reference, goals and objectives, and development of research questions for a research study.
5. To mentor an undergraduate nursing student about the importance of patient engagement, collaboration with community partners, and development of a PAC.

GOALS BASED ON MUN'S PUBLIC ENGAGEMENT FRAMEWORK

1. To make a positive difference in our communities, province, country, and world.
2. To develop and improve processes, tools, and resources to recognize and understand public needs, opportunities and priorities.
3. To mobilize knowledge, expertise, and resources in support of the public good: social, health, economic, cultural, and environmental.

TEAM MEMBER CONTRIBUTIONS

There are mutual contributions in this project.

Memorial University Faculty of Nursing Faculty members:

- Expertise concerning diabetes pathophysiology and pharmacology
- Expertise concerning research methods
- Infrastructure to conduct meetings

PAC members:

- Experience and expertise living with diabetes
- Experience and expertise providing care for/working with individuals/support persons with diabetes

POTENTIAL BENEFITS FOR TEAM MEMBERS AND MUN

There are mutual benefits for MUN and PAC Team Members.

MUN:

- Contribute to the goals of the Public Engagement Framework and the Research Strategy Framework in the Well-being, Health, and Biomedical Discovery research theme
- Collaboration of MUN Faculty of Nursing faculty members with patient partners/organizations outside the university

PAC Team Member:

- Increased understanding of the needs of individuals living with diabetes
- Experience in contributing to a research project and knowledge translation activities
- Quality improvement of processes for individuals living with diabetes to improve quality of life and health outcomes

PLAN TO DEVELOP PAC

Recruitment for the PAC began with invitations extended to:

- Community groups (e.g., Stella's Circle, The Gathering Place)
- Individuals/support persons with diabetes identified by NL Support
- Certified Diabetes Educators (CDE) (Diabetes Center and in the Community)
- Wound Care Clinic Nurses with Eastern Health

Meeting 1 (October 19 and 26/22):

- Review of CIHR definition of “patient” as guiding the project.
- Discussion of the following concerning individuals with diabetes in NL:
 - priority needs
 - gaps in care/services
 - barriers in diabetes management
 - facilitators of effective diabetes management
 - community agencies currently providing services
 - feasibility and sustainability of a program to address priority needs
 - key stakeholders of a potential program

Meeting 2 (November 9 and 16/22):

- Review discussion points from Meeting 1
- Develop Terms of Reference for PAC
- Determine which Patient Partners were interested in participating in the research study versus PAC, or both



MEETING 1 DISCUSSION

Issues & Gaps in Care/Services

- Access to primary healthcare provider
- Issues with:
 - medication management
 - cost and navigation of healthcare system
 - Insulin Pump Program
 - financial coverage of medications according to best practices recommendations (both government and insurance coverage)
- Lack of advocacy for healthy public policy
- Lack of knowledge/implementation of diabetes care

Barriers

- Large caseload that limits provider's time to deal with patients in depth (“putting out fires”, CDE)
- Financial barriers to cover services (e.g., optometrist, foot care)
- Gap in healthcare provider knowledge about diabetes best care practices
- Limitations in CDE scope of practice regarding prescribing medications
- Patients cannot self-refer to CDE
- Inconsistency in documentation and medical record storage

Facilitators

- CDEs
- Navigators
- Virtual appointments
- Collaborative Team Clinics
- Diabetes care checklists/flowsheet

Key Stakeholders

- Individuals with diabetes
- Nurses, CDEs
- Physicians/Specialists
- Foot Care Specialists
- Pharmacists Social Workers

MEETING 2 DISCUSSION: THE PAC TERMS OF REFERENCE

Mandate: The goal of the Diabetes Care Needs Research Study PAC is to provide an increased understanding of the needs of individuals who are living with diabetes in NL and to provide advice and make recommendations to the research team.

Scope: The PAC will advise the research team on matters related to conducting the research study in the areas of research question development, recruitment, data collection, analysis, and dissemination (i.e., knowledge translation).

Membership: Members of the PAC will represent patients with diabetes and community groups that support individuals living with diabetes in NL PAC. members may be added or removed at the discretion of the research team. The PAC members will not have responsibility for conducting the study and the information associated with it.

Chair: A member of the research team will act as chair of the PAC.

Responsibilities: Specific responsibilities of the Advisory Committee include:

- Inform the development of goals and objectives of the research study.
- Inform the formulation of research questions.
- Provide advice to the research team.
- Make recommendations that considers factors related to feasibility and sustainability.
- Review documents in relation to the study.
- Communicate in a respectful and collegial manner that values the perspectives of all members.

Meetings:

- Meetings will be held as required, but not less than once per quarter and take place in person or virtually.
- Members will be reimbursed reasonable travel costs associated with the meetings in accordance with the MUN Guidelines.
- A member of the research team or research assistant will be responsible for taking and distributing the minutes.
- The meeting agenda will be prepared and distributed by the chair.
- Between meetings members will communicate by email/phone.

Duration:

The Advisory Committee will remain in place for the duration of the research project (potentially 2-3 years).

LESSONS LEARNED and NEXT STEPS

- Completing this project during the pandemic was challenging as we had to revise our plans and schedule several times and adjust to public health guidelines. Our initial plans included four in-person meetings with lunch provided in April 2022. We ended up having four virtual meetings in October and November and providing a gift card to participants as a thank you for their time.
- We are very pleased with the connections we made with this engagement project and what we have learned about the needs of individuals living with diabetes in NL. We look forward to working with the PAC in 2023 as we move forward with conducting a mixed-methods research study to develop and test the effectiveness of a program to meet the needs of individuals living with diabetes in NL.

ACKNOWLEDGEMENTS AND CONTACT INFORMATION

Patient Partners: Mr. Matthew Keough, Ms. Cris Carter, Ms. Beverly Lethbridge NP RN CDE, Ms. Alicia Angel BN RN CDE, Ms. Melissa Ingram BN RN CDE

Research Assistant: Sarah Antle BA BEd, MUNFON 3rd Year Accelerated Student

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REFERENCES

Canadian Institute of Health Research. (2019). *Patient engagement*. Retrieved from <https://cihr-irsc.gc.ca/e/45851.html>

MUN Public Engagement Framework <https://www.mun.ca/publicengagement/public-engagement-at-memorial/the-public-engagement-framework/>