



**Exploring patient navigation for
people with dementia, their
caregivers, and the care team:**
Methodology to conduct a
needs assessment



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Executive Summary

As the number of Canadians with dementia sharply increases, patient navigation is a way to coordinate and integrate care for people with dementia and their caregivers and counter fragmented, uncoordinated, and often difficult to navigate systems. Part of what makes dementia care complex is that the needs of people with dementia are individual and change according to its different stages. Patient navigation programs for people with dementia have the potential to: 1) improve experiences with health and social care systems for people with dementia, their caregivers, and the care team through improving the integration and coordination of care; 2) increase access to resources and support; and 3) generally improve health outcomes for people with dementia and their caregivers. This document serves as a framework of how to conduct a needs assessment with the goal of implementing a patient navigation program for people with dementia, their caregivers, and members of the care team. This toolkit includes several documents to support this process, including interview questionnaires and consent forms.

Methodology: How to Conduct a Needs Assessment for a Dementia Navigation Program

The following is an example of a needs assessment protocol that you can adapt to your local context to explore the need and potential for a dementia navigation program.

Background

The number of Canadians with dementia is sharply increasing, with approximately nine people diagnosed every hour (Public Health Agency of Canada, 2019). New Brunswick, in particular, faces the challenge of having Canada's second oldest population, with 15,000 people living with dementia. In Canada, dementia care is fragmented, uncoordinated, and often difficult to navigate (Canadian Academy of Health Sciences, 2018; Moore et al., 2018). People with dementia, their caregivers, and the care team face many barriers, such as limited access to health and social care; a lack of knowledge and information about dementia and the available services; and high rates of burnout among caregivers (Canadian Academy of Health Sciences, 2018; Stephan et al., 2018). The Canadian Dementia Priority Setting Partnership's study showed that access to information and services post-diagnosis is a priority for Canadians affected by dementia⁵. Similarly, Canada's National Dementia Strategy emphasizes the importance of access to quality care from diagnosis through to end of life, building the capacity of care providers, and improving support for caregivers, including access to resources and supports to improve quality of life and care for people with dementia and their caregivers (Public Health Agency of Canada, 2019).

Part of what makes dementia care complex is that the needs of people with dementia are individual and change according to its different stages (Canadian Academy of Health Sciences, 2018). One solution to address the complex care needs of people with dementia and their caregivers is patient navigation. This model is increasingly being used across North America and abroad as a patient-centred approach that allows the timely movement of clients through a complex maze of fragmented services and programs across settings and sectors (Freeman & Rodriguez, 2011). The central premise of patient navigation is to proactively guide, support, and orient patients through the healthcare system, matching patients' unmet needs to appropriate resources to decrease fragmentation, improve access, and promote the integration of care (Fillion et al., 2012; Freeman & Rodriguez, 2011; McMullen, 2013). There is early evidence to support patient navigation as a feasible and cost-effective model for patients with dementia and their caregivers (Statistics Canada, 2017).

Our team has five years of expertise building an innovative patient navigation model of care called NaviCare/SoinsNavi. NaviCare/SoinsNavi is a free research-based patient navigation centre for children and youth aged 25 years or younger with health care needs and their families in New Brunswick. NaviCare/SoinsNavi aims to help facilitate more convenient and integrated care to support the physical, mental, emotional, social, cultural and spiritual needs of children/youth and their families through personalized supportive care. It is a community-based model of care that includes an individualized approach and a designated role to help coordinate and integrate care.

Methods

Operations Committee

An advisory committee will assume a leadership role overseeing the proposed project to ensure that it addresses the priorities of key stakeholder groups and that the research questions are completed within the allotted 3-month timeframe. The advisory committee will include representation from each of the following groups: people with dementia, their caregivers, decision-makers, and organizations focused on dementia/seniors (e.g., the Canadian Consortium on Neurodegeneration in Aging, Dementia Advocacy Canada, AgeWell).

Participants

We are recruiting people with dementia; caregivers of people with dementia; health and social care providers; decision makers/health administrators, and other stakeholders from organizations focused on dementia/seniors in New Brunswick. Dementia is a diagnosis that is associated with memory loss, and often problems with thinking and reasoning, or even personality changes. The most common cause of dementia is Alzheimer's disease, but there are several other types, such as vascular and mixed dementias. The diagnosis may or may not be specified further than dementia. Caregivers are people who provide care support for individuals and are not paid but may receive a pension or government allowance to help them in this caregiving role. Caregivers may or may not live with the person they are supporting and could be a family member, friend, or neighbour. Health and social care providers are individuals who work in the health or social care system, providing essential services that promote health and deliver health care services to individuals, families, and communities, specifically those who work with people with dementia. Decision-makers/health administrators include individuals who make important decisions or are in managerial/supervisory roles in their organizations, programs, or departments, such as the GNB's Departments of Health and Social Development; professional associations (e.g., NB Medical Society, Nursing Association of New Brunswick); and regional health authorities (i.e., Horizon and Vitalité). Other stakeholders include individuals and community organizations, like Dementia Advocacy Canada and the Alzheimer Society of New Brunswick, who are involved in dementia-related organizations and projects, such as advocacy, research or outreach. In order to participate, individuals must belong to one of the five groups mentioned above, be over the age of 19, reside in New Brunswick, and be capable of communicating in English or French. Our team will seek representation from diverse regions and groups throughout the duration of this research project.

Focus Group and Individual Interview Procedure

The examination of how patient navigation can be implemented for people with dementia, their caregivers, and the care team in the New Brunswick context will take place between [timeframe]. Our aim is to recruit approximately 30 participants for individual interviews and 30 participant for focus groups. We will organize approximately 5 focus groups for people with dementia/caregivers and care providers. Each focus group will include approximately 4-8 participants (patients and/or their caregivers). Focus groups can be implemented in English or French depending on participant preference.

Recruitment of people with dementia and their caregivers will proceed over 3 months through several organizations, such as community organizations, memory clinics, nursing homes, seniors' centers, and public announcements and advertisements. Care providers and decision-

makers/health administrators will be recruited through targeted communications, such as emails, phone calls and flyers, as well as e-newsletters from organizations, such as Centre for Research in Integrated Care and Primary and Integrated Health Care Innovations (PIHCI) Network. Other stakeholders will be recruited through targeted emails and phone calls to multiple organizations that provide support for people with dementia and their caregivers, as well as press releases and advertisements in local newspapers, as well as the e-newsletters.

Participants will be invited to take part in an audio recorded focus group or individual interview held over the Zoom video-conference platform by an experienced interviewer. All participants will be presented with an informed consent form prior to beginning the interview. The participant will be informed about the purpose of the study and they will be asked to indicate their willingness to participate.

Because all focus groups and individual interviews will take place virtually (i.e., through the Zoom video-conference platform) all participants' consent will be obtained verbally. Participants will be emailed the consent form before the interview and the facilitator will review the informed consent form with each participant and obtain audio recorded verbal consent before proceeding with the interview. These focus groups and individual interviews will be audio-recorded and transcribed to ensure data accuracy. Each participant will receive a \$20 honorarium for their participation.

Focus Group and Individual Interview Analysis

All participant data, audio recordings, and transcripts will be de-identified and stored on a secure UNB drive to which access is limited only to members of the research team. Data will be stored for 7 years, at which time it will be destroyed through permanent deletion and/or confidential shredding. Qualitative data management will be done with the assistance of NVivo software. The content of the focus groups will be transcribed by a member of the research team, and thematic analysis will be conducted to identify commonly occurring questions that the participants have with respect to services, programs and the delivery of health services.

The interviews and focus groups will be analyzed using the six phases of thematic analysis as outlined by Braun and Clarke (Braun & Clarke, 2011). These include 1) familiarizing yourself with your data; 2) generating initial codes; 3) searching for themes; 4) reviewing themes; 5) defining and naming themes; and 6) producing the report (Braun & Clarke, 2011).

Online Survey Procedure

For those who cannot participate in the focus groups or individual interviews, we will distribute an online self-report survey. We will target people with dementia; their caregivers; health and social care providers; decision-makers; and other stakeholders and organizations focused on dementia/seniors in New Brunswick. The survey will include both closed-ended and open-ended questions to explore which key/necessary elements are required for the successful implementation of a patient navigation program for people with dementia, their caregivers, and the care team in New Brunswick. This survey will be distributed to participants electronically via a link to the online survey platform Qualtrics. For researchers at Canadian institutions using Qualtrics, data is stored in a Canadian data centre and backed up in Canada. The survey link for this study will not collect the user's IP Address and location data based on that IP Address, as the

“anonymize responses” function has been enabled. This function renders the IP Address irretrievable once the response is collected. This survey can be completed online at the participant’s convenience and will take approximately 15 minutes. A consent form will be presented first to each participant, explaining the purpose of the study. Participants must consent to participate before starting the online survey, and participants must be over 19 years of age to complete the survey online. Participants will complete a series of demographic questions first and then be asked a series of questions about programs and services currently available and what health service delivery needs are being met and/or left unmet. Participants will have the option to answer survey questions via telephone with a research team member. After completing the survey, participants will have the option to be entered into a raffle for one of two \$100 gift cards as compensation for their time. A sample size of approximately 100 respondents overall is desired for this stage of the current study.

Online Survey Analysis

Electronic data will be stored on the research team’s password protected shared drive (UNB’s secure drive). Data will be stored for 7 years; at which time it will be destroyed through permanent deletion. Demographic information (i.e., age, gender, region) will be used for descriptive purposes. Like the interviews and focus groups, the questionnaires will be analyzed using the six phases of thematic analysis as outlined by Braun and Clarke (Braun & Clarke, 2011). These include 1) familiarizing yourself with your data; 2) generating initial codes; 3) searching for themes; 4) reviewing themes; 5) defining and naming themes; and 6) producing the report (Braun & Clarke, 2011).

Interview Guides

The following documents are interview guides to conduct a needs assessment, which you can adapt to your local context.

Person Living with Dementia Interview Guide

Hello, my name is [name]. I am a [position] at [institution or organization]. I am conducting interviews with people with dementia and their caregivers in the province.

I would like to thank you for agreeing to participate in this interview. Before we start, let's review the consent form. If you have any questions, please do not hesitate to ask.

(Review consent form)

The study we are doing will explore how we can improve care for people with dementia and their caregivers. We are specifically interested in exploring how patient navigation services can help support people with dementia, their caregivers, and members of the care team. Patient navigation refers to a model of care that helps guide people through the healthcare system, matching their unmet needs to appropriate resources, services, and programs.

I will be asking you approximately 14 questions about your needs and experiences in relation to navigating health and social care services in the province. To give you an example of what we mean, health care services can include emergency care, diagnostic care, and treatment. Social care can include services such as home support and long-term care. By navigating, we are referring to your experiences accessing services and programs to meet your needs. If you do not want to, or are unable to answer a question, please let me know and we can move to the next question. Please also let me know if you want to stop the interview. You can do so at any time.

Before we begin, I'd like to remind you that we are interested in learning about your experiences while navigating health and social care resources, services, and programs, including any challenges you face, as well as any potential solutions you might have to address these challenges. We also want to know what has worked well and what has been helpful during your journey. When answering the questions, please think about the aspects of your condition and needs, whether they be physical, emotional, social, gender, language, cultural, educational, or financial. If you have no further questions, then we can begin. I am now turning on the recording device.

Questions

1. Can you please describe your experiences navigating health and social care services and programs when getting a dementia diagnosis or since you were diagnosed with dementia?
 - a. **Probe:** What are some of the barriers you have experienced when accessing services and resources? What has worked well for you?
2. After your diagnosis – who was the main person in either the health or social system that you relied on the most to provide you with information?

3. What was the role of your primary care provider (i.e., your family doctor or nurse practitioner) in supporting you to navigate the system?
4. Were you seen by a specialist to assist with the diagnosis of your dementia? If yes – what role did they play in helping you navigate health and social care services?
5. What type of follow up in the healthcare system did you have for your dementia?
 - a. **Probe:** Was it with your primary care provider? Was it with a specialist? Or was it with both?
6. Were you followed in a specific Geriatric Medicine Clinic or Memory Clinic?
7. Are you ever unclear about which services are available to you? If so, can you describe your experiences?
 - a. **Probe:** Have you ever wondered who to ask for help? In the past, how did you find answers to your questions?
8. What could have improved your experiences navigating health and social care services and programs?
9. If a dementia navigation program were to be implemented in the province, what services would you hope this program would offer?
10. Where would it be helpful to receive this navigational support?
 - a. **Probe:** In the hospital, the home, in a clinic, in a community space or somewhere else?
 - b. **Probe:** Virtual delivery, face-to-face or a combination of the two?
11. Who would be helpful to provide this navigational support?
 - a. **Probe:** After the participant has had time to answer, introduce the role of a formal patient navigator. There are a variety of people who can fill the role of “patient navigator”. They can be professional navigators, such as nurses or social workers, trained lay navigators, or peer navigators, who are individuals with lived experience with a health issue or with caregiving for someone with a health issue. Ask within this context their thoughts on who would be helpful in the role of a patient navigator.
12. Can you think of any challenges with implementing a dementia patient navigation program in the province? Any opportunities?
13. Do you have any additional suggestions about how the system can be improved to make it easier for people with dementia to navigate services and programs in the province?
14. Is there anything else you would like to add before we end our discussion?

(Turn off device)

Caregiver Individual Interview Guide

Hello, my name is [name]. I am a [position] at [organization or institution]. I am conducting interviews with people with dementia and their caregivers in the province.

I would like to thank you for agreeing to participate in this interview. Before we start, let's review the consent form. If you have any questions, please do not hesitate to ask.

(Review consent form)

The study we are doing will explore how we can improve care for people with dementia and their caregivers. We are specifically interested in exploring how patient navigation services can help support people with dementia, their caregivers, and members of the care team. Patient navigation refers to a model of care that helps guide people through the healthcare system, matching their unmet needs to appropriate resources, services, and programs.

I will be asking you approximately 14 open ended questions about your needs and experiences in relation to navigating health and social care services in the province. To give you an example of what we mean, health care services include emergency care, diagnostic care, and treatment. Social care can include services such as home support and long-term care. By navigating, we are referring to your experiences accessing services and programs to meet your needs while caring for someone with dementia. If you do not want to answer a question, please let me know and we can move to the next question. Please also let me know if you want to stop the interview. You can do so at any time.

Before we begin, I'd like to remind you that we are interested in learning about your experiences while navigating health and social care resources, services, and programs, including any challenges you face, as well as any potential solutions you might have to address these challenges, in the context of being a caregiver for a person with dementia. If you have no further questions, then we can begin. I am now turning on the recording device.

Questions

1. Can you please describe your experiences navigating health and social care services and programs when caring for a person with dementia?
 - a. **Probe:** What are some of the barriers you experience when accessing services and resources? What has worked well for you?
2. After there was a diagnosis – who was the main person in either the health or social system that you relied on the most to provide you with information?
3. What was the role of your primary care provider (i.e. your family doctor or nurse practitioner) in supporting you to navigate the system?
4. Did the person you care for see a specialist to assist with the diagnosis of their dementia? If yes – what role did they play in helping you navigate health and social care services?
5. What type of follow up in the healthcare system did the person you care for have for their dementia?
 - a. **Probe:** Was it with their primary care provider? Was it with a specialist? Or was it with both?

6. Were they followed in a specific Geriatric Medicine Clinic or Memory Clinic?
7. Are you ever unclear about which services are available to you and the person you care for? If so, can you describe your experiences?
 - a. **Probe:** Have you ever wondered who to ask for help? In the past, how did you find answers to your questions?
8. What could have improved your experiences navigating health and social care services and programs?
9. If a dementia navigation program were to be implemented in the province, what services would you hope this program would offer?
10. Where would it be helpful to receive this navigational support?
 - a. **Probe:** In the hospital, the home, in a clinic, in a community space or somewhere else?
 - b. **Probe:** Virtual delivery, face-to-face or a combination of the two?
11. Who would be helpful to provide this navigational support?
 - a. **Probe:** After the participant has had time to answer, introduce the role of a formal patient navigator. There are a variety of people who can fill the role of “patient navigator”. They can be professional navigators, such as nurses or social workers, trained lay navigators, or peer navigators, who are individuals with lived experience with a health issue or with caregiving for someone with a health issue. Ask within this context their thoughts on who would be helpful in the role of a patient navigator.
12. Can you think of any challenges with implementing a dementia patient navigation program in the province? Any opportunities?
13. Do you have any additional suggestions about how the system can be improved to make it easier for people with dementia and their caregivers to navigate services and programs in the province?
14. Is there anything else you would like to add before we end our discussion?

(Turn off device)

Care Provider Individual Interview Guide

Hello, my name is [name]. I am a [position] at [institution or organization]. I am conducting interviews with health and social care providers involved in the care of people with dementia and their caregivers in the province.

I would like to thank you for agreeing to participate in this interview. Before we start, let's review the consent form. If you have any questions, please do not hesitate to ask.

(Review consent form)

The study we are doing will explore how we can improve care for people with dementia and their caregivers. We are specifically interested in exploring how patient navigation services can help support people with dementia, their caregivers, and members of the care team. Patient navigation refers to a model of care that helps guide people through the healthcare system, matching their unmet needs to appropriate resources, services, and programs.

I will be asking you approximately 14 open ended questions. We are interested in learning about your experiences, including any challenges you face, while supporting people with dementia and their caregivers in the navigation of health and social care resources, services and programs, as well as any potential solutions you might have to address these challenges. If you do not want to answer a question, please let me know and we can move to the next question. Please also let me know if you want to stop the interview. You can do so at any time.

If you have no further questions, then we can begin. I am now turning on the recording device.

Questions:

1. Can you please describe your role in caring for people with dementia and their caregivers?
2. How would you describe your experiences supporting people with dementia and their caregivers as they navigate health and social care services and programs?
3. When you are caring for people with dementia and their caregivers, what are some of your needs as a care provider helping patients and their families navigate the health and social care services and programs?
4. Are you ever unclear about which services are available for this population? If so, can you describe your experiences?
 - a. **Probe:** Have you ever wondered who to ask for help? In the past, how did you find answers to your questions?
5. What currently works well when you require support to help your patients with dementia and their families navigate health and social care services and programs?
6. What could improve your experiences supporting this population when navigating health and social care services and programs?
7. If a dementia navigation program were to be implemented in the province, what services would you hope this program would offer?
8. Where would it be helpful to receive this navigational support?

- a. **Probe:** In the hospital, the home, in a clinic, in a community space or somewhere else?
9. What is the best way to receive support or help to navigate the system?
 - a. **Probe:** Virtual delivery, face-to-face or a combination of the two?
10. Who would be helpful to provide this navigational support?
 - a. **Probe:** After the participant has had time to answer, introduce the role of a formal patient navigator. There are a variety of people who can fill the role of “patient navigator”. They can be professional navigators, such as nurses or social workers, trained lay navigators, or peer navigators, who are individuals with lived experience with a health issue or with caregiving for someone with a health issue. Ask within this context their thoughts on who would be helpful in the role of a patient navigator.
11. Do you foresee any challenges with implementing a dementia patient navigation program in the province? Any opportunities?
12. Do you have any additional suggestions about how the system can be improved to make it easier for people with dementia and their caregivers to navigate services and programs in the province?
13. Who would you suggest that we interview in the province who work with people living with dementia, their caregivers or care providers about this project?
 - a. **Probe:** Mention the other stakeholder groups, such as decision-makers, health administrators, or other stakeholders
14. Is there anything else you would like to add before we end our discussion?

(Turn off device)

Decision Maker/Health Administrator Individual Interview Guide

Hello, my name is [name]. I am a [position] at [institution or organization]. I am conducting interviews with people with dementia, their care partners, and those involved in their care in the province.

I would like to thank you for agreeing to participate in this interview. Before we start, let's review the consent form. If you have any questions, please do not hesitate to ask.

(Review consent form)

The study we are doing will explore how we can improve care for people with dementia and their caregivers. We are specifically interested in exploring how patient navigation services can help support people with dementia, their caregivers, and members of the care team. Patient navigation refers to a model of care that helps guide people through the healthcare system, matching their unmet needs to appropriate resources, services, and programs.

I will be asking you approximately 12 open ended questions. If you do not want to answer a question, please let me know and we can move to the next question. Please also let me know if you want to stop the interview. You can do so at any time.

If you have no further questions, then we can begin. I am now turning on the recording device.

Questions:

1. Can you please describe your role as a decision maker in context of dementia care in the province?
2. What is your understanding of the barriers and facilitators to navigating health and social services in the province for people with dementia, their caregivers, and the care team?
 - a. **Probe:** What parts of the health and social system seem to be working well at this time to provide navigational support for people with dementia, their caregivers, and the care team?
 - b. **Probe:** What parts of the health and social system do not seem to be working well to provide navigational support for people with dementia, their caregivers, and the care team?
3. What could improve the experiences of people with dementia, their caregivers, and the care team when navigating health and social care services and programs?
4. What is your understanding of current initiatives underway or being explored to improve patient navigation for this population?
5. If a dementia navigation program were to be implemented in the province, what services would you hope this program would offer?
6. Where would it be helpful to receive this navigational support?
 - a. **Probe:** In the hospital, the home, in a clinic, in a community space or somewhere else?
7. What is the best way to receive support or help to navigate the system?
 - a. **Probe:** Virtual delivery, face-to-face or a combination of the two?
8. Who would be helpful to provide this navigational support?

- a. **Probe:** After the participant has had time to answer, introduce the role of a formal patient navigator. There are a variety of people who can fill the role of “patient navigator”. They can be professional navigators, such as nurses or social workers, trained lay navigators, or peer navigators, who are individuals with lived experience with a health issue or with caregiving for someone with a health issue. Ask within this context their thoughts on who would be helpful in the role of a patient navigator.
9. Do you foresee any challenges with implementing a dementia patient navigation program in the province? Any opportunities?
10. Do you have any additional suggestions about how the system can be improved to make it easier for people with dementia and their caregivers to navigate services and programs in the province?
11. Who would you suggest that we interview in the province who work with people living with dementia, their caregivers or care providers about this project?
 - a. **Probe:** Mention the other stakeholder groups, such as care providers or other stakeholders
12. Is there anything else you would like to add before we end our discussion?

(Turn off device)

Other Stakeholders Individual Interview Guide

Hello, my name is [name]. I am a [position] at [institution or organization]. I am conducting interviews with stakeholders involved in programs or services for people with dementia and their caregivers in the province.

I would like to thank you for agreeing to participate in this interview. Before we start, let's review the consent form. If you have any questions, please do not hesitate to ask.

(Review consent form)

The study we are doing will explore how we can improve care for people with dementia and their caregivers. We are specifically interested in exploring how patient navigation services can help support people with dementia, their caregivers, and members of the care team. Patient navigation refers to a model of care that helps guide people through the healthcare system, matching their unmet needs to appropriate resources, services, and programs.

I will be asking you approximately 11 open ended questions. If you do not want to answer a question, please let me know and we can move to the next question. Please also let me know if you want to stop the interview. You can do so at any time. If you have no further questions, then we can begin. I am now turning on the recording device.

Questions:

1. Can you please describe your role in the context of dementia care in the province?
2. What is your understanding of the barriers and facilitators to navigating health and social services in the province for people with dementia, their caregivers, and the care team?
3. What could improve the experiences of people with dementia, their caregivers, and the care team when navigating health and social care services and programs?
4. What is your understanding of current initiatives underway or being explored to improve patient navigation for this population?
5. If a dementia navigation program were to be implemented in the province, what services would you hope this program would offer?
6. Where would it be helpful to receive this navigational support?
 - a. **Probe:** In the hospital, the home, in a clinic, in a community space or somewhere else?
7. What is the best way to receive support or help to navigate the system?
 - a. **Probe:** Virtual delivery, face-to-face or a combination of the two?
8. Who would be helpful to provide this navigational support?
 - a. **Probe:** After the participant has had time to answer, introduce the role of a formal patient navigator. There are a variety of people who can fill the role of "patient navigator". They can be professional navigators, such as nurses or social workers, trained lay navigators, or peer navigators, who are individuals with lived experience with a health issue or with caregiving for someone with a health issue. Ask within this context their thoughts on who would be helpful in the role of a patient navigator.

9. Do you foresee any challenges with implementing a dementia patient navigation program in the province? Any opportunities?
10. Do you have any additional suggestions about how the system can be improved to make it easier for people with dementia to navigate services and programs in the province?
11. Is there anything else you would like to add before we end our discussion?

(Turn off device)

Informed Consent Forms

The following are consent form templates, which you can adapt according to your local context.

Survey Informed Consent Form

You Are Invited to Take Part in a Survey About Implementing Patient Navigation for People with Dementia, their Caregivers, and the Care Team in [location]

Thank you for choosing to participate in our survey!

Before starting, we ask that you read the following information about this study. Informed consent is an important part of participating in research.

Who can take part in this survey?

People with dementia, caregivers of people with dementia, health or social care providers involved in the care/support of a person with dementia in New Brunswick, decision makers/health administrators, and other stakeholders from organizations focused on dementia/seniors in [location], and over the age of [age of majority].

Why is this survey important?

The results of the survey will tell us about the needs of people with dementia, their caregivers, and health and social care providers and tell us how best implement patient navigation in New Brunswick.

What is involved if I take part in this survey?

You will be asked to complete a survey that will include some questions about you, as well as questions about your experiences either providing care, receiving care, or administering programs and services for people with dementia and their caregivers. This survey will take about 15 minutes to complete.

You can enter a raffle for one of two \$100 gift cards to Amazon as a thank you for your time today. Because it is uncertain how many individuals will enter the draw, the odds of winning will depend on the number of eligible entries that are received.

- Your participation is completely voluntary.
- You may stop participating in this study at any time with no consequences.
- You can refuse to answer any questions you are not comfortable answering and still complete the survey.
- Participating in this survey will not affect or change your current care and treatment.
- By agreeing to participate, you are not waiving any legal rights to potential research harm.

Will my answers be kept confidential?

Your name will not be connected to your survey responses. All electronic copies of study materials and data will be stored for 7 years on a secure drive, after which it will be deleted/destroyed. The drive where data will be stored is located at [institution or organization] and is password protected.

The online survey platform Qualtrics hosts this questionnaire. Qualtrics data is stored in a Canadian data centre and backed up in Canada. The survey link for this study will not collect your IP Address and your IP Address is irretrievable.

Who can I contact for more information?

If you have any questions about your participation in this study or if you would like more information about the outcome of this study, please contact the study coordinator, [name and contact information].

If you would like to speak to someone not involved in the study, you may contact the Ethics Board representative, [name and contact information].

Who is supporting this research?

[Insert name and contact information for leadership team here].

This project has been reviewed by the Research Ethics Board of [institution] and is on file as REB#xxxx-xxx.

By clicking “Next,” I confirm that I have read the information on the INFORMED CONSENT FORM and volunteer to participate in this study

Focus Group Consent Form

You are invited to take part in this focus group to help us learn more about implementing patient navigation for people with dementia, their caregivers, and the care team

Who can take part in this focus group?

People with dementia, caregivers of people with dementia, health or social care providers involved in the care/support of a person with dementia in [location], decision makers/health administrators, and other stakeholders from organizations focused on dementia/seniors in [location], and over the age of [age of majority].

Why is this focus group important?

By participating, you will tell us what is important to you about improving the care of people with dementia in [location]. The results of the focus groups will inform the development and implementation of a patient navigation program for people with dementia, their caregivers, and members of the care team.

What can I expect from taking part in this focus group?

You will be asked to take part in a focus group with individuals in your stakeholder group (e.g., people with dementia, or decision makers). The focus groups will be audio recorded. The group will have a facilitator who will ask questions about your experiences with the care of people with dementia.

- Your participation is completely voluntary.
- You may stop participating in this study at any time.
- Participating in this focus group will not affect or change your current care and treatment or affect your employment.
- We will let you know of any changes to the study that could affect your participation and you may be asked to verbally consent to a new informed consent form.
- By agreeing to participate, you are not waiving any legal rights to potential research harm.

You will receive a \$20 gift card to Amazon for taking the time to participate in this focus group.

Will my answers be kept confidential?

If you decide to participate, any information that could identify you will be removed from the data that is collected and will be kept separately. The focus group facilitator will only collect the information they need for this study and only members of the researcher team will have access to study records. Audio-recordings will be transcribed by a member of the research team and any information that could identify you will be removed. All electronic copies of study materials and data collected from you will be kept for a maximum of seven years on a secure drive that is password-protected and located at [location]. Your name will not be included in any presentations or publications; however, quotations without names or other identifiers will be used.

What will happen to the results?

The information learned during this focus group will be explored along with those from other focus groups in New Brunswick. The research team will examine how patient navigation can be implemented for people with dementia, their caregivers, and the care team in the New Brunswick context.

Who can I contact for more information?

If you have any questions about your participation in this study or if you would like more information about the outcome of this study, please contact the study coordinator, [name and contact information].

Who is supporting this research?

[Insert name and contact information for leadership team here].

This project has been reviewed by the Research Ethics Board of [institution] and is on file as REB#xxxx-xxx.

If you agree to take part in the study, as described above, please state the following: “My name is [name] and I give my consent to participate in this study”.

Individual Interview Consent Form

You are invited to take part in an interview to help us learn more about implementing patient navigation for people with dementia, their caregivers, and the care team

People with dementia, caregivers of people with dementia, health or social care providers involved in the care/support of a person with dementia in [location], decision makers/health administrators, and other stakeholders from organizations focused on dementia/seniors in [location], and over the age of [age of majority].

Why is this interview important?

By participating, you will tell us what is important to you about improving the care of people with dementia in [location]. The results of the interview will inform the development and implementation of a patient navigation program for people with dementia, their caregivers, and members of the care team.

What can I expect from taking part in this interview?

You will be asked to take part in an interview about navigation and people with dementia. The interview will have to be audio recorded. The interview will have an interviewer who will ask questions about your experiences with the care of people with dementia.

- Your participation is completely voluntary.
- You may stop participating in this study at any time.
- Participating in this interview will not affect or change your current care and treatment or your employment.
- We will let you know of any changes to the study that could affect your participation and you may be asked to verbally consent to a new informed consent form.
- By agreeing to participate, you are not waiving any legal rights to potential research harm.

You will receive a \$20 gift card to Amazon for taking the time to participate in this interview.

Will my answers be kept confidential?

If you decide to participate, any information that could identify you will be removed from the data that is collected and will be kept separately. The interviewer will only collect the information they need for this study and only researchers related with this study will have access to study records. Audio-recordings will be transcribed by a member of the research team and any information that could identify you will be removed. All electronic copies of study materials and data collected from you will be kept for a maximum of seven years on a secure drive that is password-protected and located at [location]. Your name will not be included in any presentations or publications; however, quotations without names of other identifiers will be used.

What will happen to the results?

The information learned during this interview will be explored along with those from other interviews in [location]. The research team will examine how patient navigation can be implemented for people with dementia, their caregivers, and the care team.

Who can I contact for more information?

If you have any questions about your participation in this study or if you would like more information about the outcome of this study, please contact the study coordinator, [name and contact information].

Who is supporting this research?

[Insert name and contact information for leadership team here].

This project has been reviewed by the Research Ethics Board of [institution] and is on file as REB#xxxx-xxx.

If you agree to take part in the study, as described above, please state the following: “My name is [name] and I give my consent to participate in this study.”

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