



**Implementing a patient  
navigation program for people  
with dementia**



**Healthcare  
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## **Acknowledgements**

This report was prepared by Dr Shelley Doucet, Dr Alison Luke, Grailing Anthonisen, and Jennifer Splane. We would like to gratefully acknowledge the contributions of the Centre for Research and Integrated Care (CRIC); Canadian Agency for Drugs and Technologies in Health (CADTH); Healthcare Excellence Canada; and the project’s Advisory Committee. Members of the Advisory Committee were Lisa Poole, Mary Beth Wighton, Stephanie Smith, Calvin Young, Jennifer Major, Camille Dulong, Nicole Pollack, and Neil Drimer.

*Healthcare Excellence Canada is an independent, not-for-profit charity funded primarily by Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.*

## **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 “how to” document serves as a framework for the development and implementation of a navigation program to serve those with dementia. This toolkit includes several documents to support this process, such as intake forms; information on setting up a patient and family advisory council; policy documents; and evaluation tools.

## **Introduction**

### **What is Patient Navigation?**

Patient navigation refers to a model of care that aims to guide and support patients and their caregivers as they move through the healthcare system. It does so by matching their unmet health needs to appropriate resources to bridge the gap in programs and services, improve access to care, and promote integration of services across various aspects of care. [1-3] Patient navigation can improve health outcomes, in part, by providing education, resources, and individualized care. [4-5] This patient-centred approach is increasingly employed across North America and abroad in different contexts and settings. [6-7]

Patient navigation is facilitated by patient navigators, which are positions that are generally categorized as professional or lay navigators. Professional navigators are healthcare workers with clinical experience, such as nurses or social workers, whereas lay navigators are individuals with lived experience (e.g., patients) or with a non-professional background and training (e.g., caregivers of someone with a health-related issue). [8-10] Patient navigators can have a range of titles, such as care navigator, system navigator, nurse navigator, and care coordinator. [10] Navigators serve clients through a variety of delivery formats, such as virtually and/or in-person, and they work across a range of settings, such as in the community or in hospitals. [10]

### **The Need for Dementia Patient Navigation Support**

Dementia is an umbrella term that covers more than a hundred diagnoses characterized by cognitive impairment.[11] These diagnoses include, but are not limited to, Alzheimer's disease, vascular dementia, Lewy body dementia, and mixed dementia. Dementia frequently results in degenerative brain function and causes symptoms like memory loss, communication difficulties, and declines in reasoning or other thinking skills. [11-12] Internationally, it is estimated that 50 million people live with dementia, with nearly 10 million new cases every year.[13]

Because dementia care is often fragmented, uncoordinated, and difficult to navigate, patient navigation may benefit individuals with dementia. [14-15] Moreover, the needs of people with dementia are individual and change over time according to their condition's different stages.[14] Throughout their care journey, 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.[14, 16] Patient navigation offers a way to integrate care and improve health outcomes for people living with dementia and their caregivers.

### **Toolkit Organization**

This toolkit serves as a guide or framework to help implement a patient navigation program for people with dementia, their caregivers, and members of the care team. It is organized into essential aspects for the implementation and operation of the program with

templates that may be easily adaptable to fit any patient navigation program. It also includes a guide for data collection to conduct program evaluation.

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## **Patient Navigation Program Team**

To implement a navigation program, it is essential to have a cohesive team with clear roles. Additionally, the navigator should have a delineated scope of practice. The following are examples of members of the navigation program team, with a description of roles. Note that not all roles are required, and some roles could be merged into one position depending on the size of the program (e.g., program director/manager and program coordinator). Note as well that health and social care providers can also be part of the team, such as when the program is embedded in a hospital or community care team.

### **Program Director or Manager**

- Oversees program operations and future directions
- Seeks funding for program sustainability
- Supervises staff, including trainees if applicable
- Oversees Patient and Family Advisory Council (PFAC)
- Oversees program budget
- Oversees research activities (if applicable)
- Oversees outreach activities

### **Administrative Assistant**

- Supports team's day-to-day administrative needs (e.g., order items, prepare expense claims)
- Assists with program budget
- Assists with scheduling meetings and appointments
- Prepares minutes of meetings
- Organize files and keep records
- Responds to general enquiries

### **Program Coordinator**

- Supports marketing (e.g., videos), social media (e.g., Facebook page), website
- Supports PFAC
- Supports patient navigator and other staff when needed
- Supports program capacity building
- Supports knowledge translation (e.g., help develop videos)
- Supports outreach activities

### **Patient Navigator**

- Responds to calls and emails from clients (e.g., people with dementia, caregivers, health professionals, and other stakeholders seeking navigational support)
- Screens and triages navigation requests, providing information and resources to determine the next best steps
- Identifies needs of clients (e.g., people with dementia, caregivers, health professionals, and other stakeholders seeking navigational support)
- Maintains case summaries

- Helps families understand the health, education, and social services available to meet their needs
- Connects clients with resources and services
- Facilitates and coordinates communication between people with dementia, caregivers, and members of the care team
- Promotes self-management through teaching people with dementia/caregivers how to navigate services and programs
- Advocates on the client's behalf as needed
- Acts as a resource for the care team, by working closely with the team to ensure that care remains integrated
- Stays up to date with the range of resources currently available for people with dementia and stays informed of any changes or additions
- Engages in outreach activities as a way to promote program and learn about services and resources that are available
- Maintains database of resources and services
- Identifies gaps and barriers to services and programs in NB and across Canada
- Visits, where necessary, specific communities and centres to both gather information and support families, health professionals, and/or stakeholders
- Collects a range of demographic, health and service use information from all contacts to complete database records that will allow for ongoing evaluation of the program (if necessary)
- Stores client data securely

#### **Patient and Family Advisory Council**

- Comprised of people with dementia and/or their caregivers who have extensive lived personal experience navigating the health and social resources and services for people with dementia and their caregivers
- Acts as a resource to the Patient Navigator and navigation team
- Ensures that materials are family-friendly
- Influences resource development
- Guides educational opportunities and best-practices

#### **Research Assistant or Research Coordinator** *(if applicable)*

- Leads the program's research and evaluation
- Helps prepare grant applications
- Supports day-to-day research (e.g. lit reviews, data analysis, data access, preparing presentations, research briefs, research and evaluation plans)
- Engages the patient and family advisory council in the research planning
- Conducts knowledge translation

## Patient and Family Advisory Council Overview

To help ensure that the navigation program meets the needs of persons with dementia and their caregivers, it is recommended that the program establish a *Patient and Family Advisory Council (PFAC)*. Members should include people with dementia and/or caregivers who have lived experience navigating the system. Either the patient navigator or the program coordinator will sit on the PFAC to act as a co-chair and support their work. They should meet on a designated schedule to advise the staff, patient navigators, and research team (if required). The PFAC may also engage in their own projects to build capacity in the community, including creating resources for families and caregivers, and developing and delivering workshops for care providers.

To learn more about setting up a PFAC, see:

Richard, J., Azar, R., Doucet, S., & Luke, A. (2020). Pediatric patient and family advisory councils: A guide to their development and ongoing implementation. *Journal of Patient Experience*.

The following are templates to establish a PFAC, including:

1. Contact Information Form
2. Volunteer Confidentiality Agreement
3. Terms of Reference

**Patient And Family Advisory Council**  
*Contact Information Form*

*Please note, the information you provide will not be distributed or shared with parties outside of [name of program]. It will be used primarily by our Patient Navigator (PN) and Program Coordinator. Other members of the team who will have access to this information and might wish to contact you include the Program's Administrative Assistant and Director.*

Date completed: \_\_\_\_\_

**Member Information**

Name: \_\_\_\_\_

Mailing Address: \_\_\_\_\_

\_\_\_\_\_

Email Address: \_\_\_\_\_

Home Phone: \_\_\_\_\_ Cell phone: \_\_\_\_\_

What is your preferred method of communication? \_\_\_\_\_

Languages spoken: \_\_\_\_\_

**Experiences/strengths**

Please provide a brief summary of your lived-experiences. Include things such as experience or knowledge of dementia programs/services, barriers/facilitators you've encountered in accessing care, health/social care-providers you've worked with, any advocacy roles you have played, etc.

Please provide any other skills that may be beneficial to [name of program] (graphic work, policy writing, communications, knowledge translation, etc.)

Please include any additional information you feel may be applicable to your role as a patient or family advisor.

**Patient And Family Advisory Council**  
*Volunteer Confidentiality Agreement*

[Name of program] is committed to ensuring that all patient and business information is maintained in a confidential and secure manner.

As a member of the Patient and Family Advisory Council (PFAC), I may be involved in informing the program, designing initiatives intended to influence best practices, and be privy to internal decisions and information. I will also be advising and consulting on cases with the Patient Navigator(s), as well as sharing lived-experiences.

*As a member of the PFAC, I will be expected to adhere to the following in terms of respecting confidentiality:*

1. The Patient Navigator may on occasion ask me to draw on my lived-experience and provide suggestions for resources and/or action in relation to a case. The Navigator will take care not to share identifying information. Should the individual/family be identifiable due to a rare circumstance, I will be asked to maintain strict confidentiality.
2. As a member of the Council, I will share personal experiences that help inform the program. I will not share details of other members' lived-experiences outside the context of the group.
3. In the case that a care provider is identified in PFAC discussions, I will keep information about said professional or circumstance confidential.
4. I will be involved in internal discussions and planning with [name of program] Leadership Team. I will respect this information as internal and private.
5. I agree that I will not discuss the details of my volunteer work with [name of program] with any representatives of the media, or partake in any official speaking engagements unless I have the permission of the [name of program] Leadership Team.
6. When my role as an PFAC member ends, I will respect the terms of this confidentiality agreement.

I have reviewed and understand the confidentiality agreement as written above and will abide by it.

Name: \_\_\_\_\_ Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## Patient and Family Advisory Council (PFAC)

### *Terms of Reference*

#### **Background**

##### **Patient and Family Advisory Council: Purpose**

The purpose of the Family and Patient Advisory Council (PFAC) is to ensure that the program's goals and outcomes align with the needs of the persons with dementia and their caregivers who use the program. The PFAC functions to share the expertise of people with lived experience to positively influence the implementation and evaluation of [name of program]. The involvement of people with lived experience helps ensure the needs of people with dementia, as well as their caregivers, are identified and met.

##### **Membership**

PFAC members have significant lived-experience receiving services within the health and social care system as a person with dementia, a caregiver, or other involved family member.

In addition, PFAC members typically deal with care providers across multiple sectors (health, social, educational) and often in more than one setting (e.g., within the local or regional setting). This experience provides PFAC members with a unique perspective to enrich the program's PFAC.

*Note: What works best for your PFAC may vary, but we have found that a PFAC comprised of 7 family/patient members is a good number.*

##### Co-Chairperson

*Note: A Co-Chairperson model may be used, with one Co-Chair being the patient navigator or program coordinator and the other being a PFAC member.* The PFAC Co-Chairperson is elected by the PFAC for a term of one year and is eligible to serve for additional terms. It is recommended that a maximum number of terms be set. Once the maximum terms have been served, the Co-Chairperson is invited to serve as a PFAC member for one additional year to facilitate transition with the incoming co-chair.

Duties assigned to the Co-Chairperson include, but are not limited to:

- Planning and leading monthly meetings;
- Following up on action items;
- Meeting with the advisory committee to discuss and plan PFAC strategies around the program's goals;
- Recruitment and retention of members.

##### Members

PFAC members share valuable expertise and experience to influence the program's implementation and evaluation (as required) in a variety of ways. This includes, but is not limited to:

- Participating in special projects and events;
- Providing design guidance and feedback on educational materials for families;
- Providing input on outreach initiatives and marketing of the program (e.g. promotional materials for the program, strategic ideas, etc.);
- Providing guidance and direction to the PN (as needed);
- Delivering feedback on the evaluation research plan (as needed)

All PFAC members are required to sign a confidentiality agreement.

### Terms

Terms are 1 year in duration. Terms are renewable up to a maximum of two times.

### Remuneration

Members are offered an annual remuneration. To receive remuneration, members are expected to attend monthly meetings. If a member is unable to attend one or more meetings per quarter, remuneration will be deducted accordingly. Exceptions will be granted for extenuating circumstances.

### **Meeting Procedures**

The PFAC meets a minimum of 10 times over a ten-month period. Occasionally, additional meetings are required. Video conferencing tools, such as Zoom, are used. It is expected that all members will participate via video (camera turned on) to enhance collaboration and interaction.

Monthly meetings are held the third week of the month at a set time for approximately 60 minutes. The date of the meetings is chosen by all members through a Doodle Poll which is sent to all members the first or second week of each month.

In the event a member cannot attend a meeting, they are to notify one of the Co-Chairpersons. Quorum is met when at least 50% of members, including Co-Chairs, are present.

The PFAC also arranges for an annual, in-person meeting.

Support for the PFAC, such as minute-taking and other meeting materials, is provided by the program's administrative support. However, voluntary participation of a PFAC member in a secretary-like role is both encouraged and welcomed. Meeting materials, including an agenda and the most recent meeting minutes, is circulated by e-mail to members approximately one week before the meeting date.

## **Outreach and Database of Programs**

Outreach to various stakeholders across the province is essential to the implementation of a patient navigation program. All members of the team (e.g., patient navigators(s), program coordinator, administrative assistant, and research assistant) should be involved in various forms of outreach and have actively built collaborative relationships across sectors. In addition to building partnerships, the patient navigator(s) should maintain regular contact with the programs and services they are referring clients to, which is imperative to understanding the resources available. Further, these programs and services identified can then be compiled by the navigator(s) into a resource database, which may be uploaded to the program's website to support widespread ease of access. To evaluate the effectiveness of the program's outreach (if necessary), a targeted outreach plan should be developed.

## **Process of Working with the Patient Navigator**

Patient navigators (professional or lay) assist patients, family members, and the care team by helping coordinate patient care; facilitating transitions in care (e.g. transitions from paediatric to adult services); connecting families with resources; helping families understand the health and social services available to meet their needs; and acting as a resource for the care team. The patient navigators also help facilitate the integration of services across various levels of care, settings, and sectors, and increase community capacity in the care of people with dementia. They identify barriers to services and programs for this population, advocate for system change, and develop evidence-based best practices. Clients (i.e., people with dementia, caregivers, care providers) can reach out with a specific concern or a general need for support that can be articulated into goals that are then prioritized during an ongoing relationship with their navigator.

The process of working with the navigator begins during the first interaction, with an assessment of the client's needs and collection of demographic information. Once unmet needs are identified by the client, with support from the navigator, goals are set to address those needs. The intervention, which involves providing personalized family-centred navigational support based on these identified goals, takes place during the navigator-client relationship. The patient navigators maintain communication with the client for support and will follow-up as needed; at which time it is common for new needs to be identified. The navigators often reach out to the client's care team to engage care providers and community stakeholders in finding a resolution to unmet needs or recognized barriers. If such system barriers and gaps in services exist and remain unresolved, they may be explored and documented to be shared with decision makers. Once the client's needs are resolved, the case can be archived, although not closed, and it is understood that the client can call back at any time should new needs arise.

The following are templates to implement the patient navigation program:

1. Intake Form: Person with Dementia or Caregiver
2. Intake Form: Care Provider
3. Care Provider Referral Form
4. Third Party Authorization for Release of Information

## *Intake Form: Person with Dementia and Caregivers*

When doing intake, only relevant or necessary information should be collected. This information can vary by program. Below is a suggested list of information you may want to collect.

### **Referral and Intake**

Date referral was received:

Initial contact made by [name of program]:

Enrolment date:

Referral source (How did they hear about your program?):

Is this the first time calling [name of program]?

Consent Obtained:

### **Person with dementia Information**

Name:

DOB or age:

Medicare: *only if necessary*

### **Caregiver Information**

Name:

Relationship to person with dementia:

Primary caregiver:

Email:

Phone:

- Can we leave a voicemail?

Address:

Preferred language:

### **Care Provider Information**

Family doctor/Nurse practitioner:

Specialists:

Other care providers (i.e., social worker, OT, PT, SLP):

Involvement in community organizations/programs/services:

### **Reason for Call**

Diagnosis:

Date of Diagnosis:

Intake Discussion:

### **Goal**

Identified goal:

### **Plan**

Insert agreed upon plan:

**Additional Demographic Data** (if required): You may also want information for evaluation purposes such as education, income, employment status, relationship status, and gender identity (for both person with dementia and caregiver)

## *Intake Form: Care Provider*

When doing intake, only relevant or necessary information should be collected. This information can vary by program. Below is a suggested list of information you may want to collect.

### **Referral and Intake**

First contact with [name of program]:

Initial contact made by [name of program]:

Enrolment date:

Referral source (How did they hear about us?):

Is this your first time calling [name of program]?

Consent obtained:

### **Care Provider Information**

Name:

Area of work/specialty:

Organization:

Phone:

Email:

Preferred Language:

### **Care Provider Information**

Reason for call:

What barriers are you experiencing to accessing resources and/or services to meet your person with dementia's needs:

Other information:

Is your client aware of [name of program]?

### **Goal**

Identified goal:

### **Plan**

Insert agreed upon plan:

**Additional Demographic Data** (if required): You may also want information for evaluation purposes such as education, income, employment status, relationship status, and gender identity (for both person with dementia and caregiver)



*Third Party Authorization for Release of Information*

Patient Navigator, [name of program]  
[Contact information]

Client Information:

Name of Patient: \_\_\_\_\_ DOB: \_\_\_\_\_

Name of Substitute Decision Maker: \_\_\_\_\_ \*

Address: \_\_\_\_\_

\_\_\_\_\_

Phone #: \_\_\_\_\_

\*Substitute Decision Maker will be asked to provide the patient navigator with copies of 2 pieces of government-issued ID for verification of identification.

\_\_\_\_\_

I, \_\_\_\_\_, give consent to the [name of program]  
*Substitute decision maker's name*

service to speak to and share the person under my care's information with health care providers and other agencies for the purpose of informing, advocating for and discussing cases with third parties and linking the person I care for with appropriate services. This includes sending and gathering information and documentation, and speaking with these parties.

\_\_\_\_\_

*Name of Health Care Provider / Agency*

I understand that I can limit or withdraw consent at any time, and that only necessary information will be shared.

Substitute Decision Maker Signature: \_\_\_\_\_

Date: \_\_\_\_\_

## **How to Conduct Patient Navigation: A Policy Guide**

The development of program policies and procedures facilitate the smooth operation of the patient navigation program. These documents will standardize the clinical operations of the program and systematize the collection of client data for research purposes, while protecting the individualized nature of care. The following pages provide templates for policies and procedures related to ongoing navigation, program disenrollment, recording system gaps and barriers, and outreach. These policies and procedures include:

1. Caregiver Intake
2. Person with Dementia Intake
3. Active Navigation: Person with Dementia and Caregiver
4. Disenrollment: Person with Dementia and Caregiver
5. Care Provider Intake
6. Active Navigation: Care Provider
7. Disenrollment: Person with Dementia and Caregiver
8. Tracking Significant Gaps and Barriers
9. Program Outreach

## *Caregiver Intake*

### **Policy**

1. Standard of intake for all caregivers (CG) that call the program.
2. Completed in the [name of program] intake platform.
3. Data can only be provided by the legal caregiver.
4. Goals can be made to support persons with dementia, family, or caregiver.
5. Confidentiality will be maintained at all times.

### **Procedure**

1. CG contact is initiated by phone, email, fax, or social media to any Patient Navigator (PN). The method and type of communication should be tracked and tallied at the end of every month.
  - The PN must make two attempts to contact the CG to complete the intake. If the CG does not respond, the case will remain unopened until the CG calls back.
  - When a referral is received, the PN will contact the referring Care Provider (CP) to inform them that the referral was received.
  - If a referral is received and only one of the following boxes is checked, the PN can assume that both boxes have been checked, as they are similar.
    - The person with dementia (PWD)/family has consented to this referral
    - The PWD/family has consented to be contact by a PN
2. The research consent and intake assessment are completed and recorded by the intaking PN using the intake platform.
3. Intake data will be stored by case number.
4. Consent
  - 4.1. Recorded consent is obtained before intake assessment data is collected.
  - 4.2. A CG unwilling to consent to the [name of program] research will not participate in the [name of program] service (*if applicable*).
  - 4.3. A record will be kept of CG that have not consented to research (*if applicable*).
5. Assessment
  - 5.1. Collection of the demographic data.
  - 5.2. Collection of goal ratings as indicated by the caregiver.
    - Note: Goals can be for PWD, CG, other family members.

6. Once intake assessment has been completed, an initial 'welcome' e-mail will be sent by PN within one business day.
7. Case will be assigned to one of [name of program] PNs based on current caseload
  - 7.1. The PN that completes the phone enrolment will add said case to their caseload.
8. Returning patient
  - 8.1. The cases of a returning patient will be numbered with a new numeric code and this will be linked to all their old case files.

## *Person with Dementia Intake*

### **Policy**

1. Standard of intake for all persons with dementia (PWD) that call the program.
2. Completed in the [name of program] intake platform.
3. Data can only be provided by the PWD.
4. Goals can be made to support PWD or caregiver (CG).
5. An ACG can be any other family member in the PWD's circle of care.
6. Confidentiality will be maintained at all times.

### **Procedure**

1. PWD contact is initiated by phone, email, fax, or social media to any Patient Navigator (PN).
  - 1.1. The PN must make two attempts to contact the Y in order to complete the intake. If the Y does not respond, the case will remain unopened until the Y calls back.
  - 1.2. When a referral is received, the PN will contact the referring care provider (CP) to inform them that the referral was received.
  - 1.3. If a referral is received and only one of the following boxes is checked, the PN can assume that both boxes have been checked, as they are similar.
    - The patient/family has consented to this referral
    - The patient/family has consented to be contacted by a PN
2. The research consent and intake assessment are completed and recorded by the intaking PN.
3. Intake data will be stored by case number [name of program] intake platform.
4. Consent
  - 4.1. Recorded consent is obtained before intake assessment data is collected.
  - 4.2. A PWD unwilling to consent to the [name of program] research will not participate in the [name of program] service (*if applicable*).
  - 4.3. A record will be kept of PWD that have not consented to research (*if applicable*).
5. Assessment
  - 5.1. Collection of the demographic data.
  - 5.2. Collection of goal ratings as indicated by the PWD.
    - Note: Goals can be for PWD, CG, family, or other caregivers

6. Once intake assessment has been completed, an initial 'welcome' e-mail will be sent by PN within one business day
7. Case will be assigned to one of [name of program] PNs based on current caseload
  - 7.1. The PN that completes the phone enrolment will add said case to their caseload
8. Returning patient
  - 8.1. The cases of a returning patient will be numbered with a new numeric code and this will be linked to all their old case files.

## *Active Patient Navigation: Person with Dementia/Caregiver*

### **Policy**

1. Standard of active navigation for all persons with dementia (PWD) and caregivers (CG) who call the program.
2. Collection of data to be stored on the [name of program] intake platform.
3. Collection of data can be performed by any [name of program] Patient Navigator (PN).
4. All communication and research time will be tracked for evaluation (*if applicable*).
5. Confidentiality will be maintained at all times.

### **Procedure**

1. Client (CG/PWD) communication
  - a. All communication ‘touches’ between PN and CG/PWD will be captured in the [name of program] intake platform during the ongoing navigation. The mode of communication ‘touches’ include phone calls, emails, face-to-face, faxes, social media, texts, Canada posts, research, etc.
  - b. The following criteria will be captured on the intake platform for each ‘touch’ with the CG/PWD during ongoing navigation: date, the goal associated with the ‘touch’, the mode of communication, the audience, the amount of time in minutes spent on it, the task associated with the ‘touch’ and notes. If the ‘touch’ involved referring the CG/PWD to a specific program or service, this will also be recorded with the ‘touch’.
  - c. Communication follow-up with CG/PWD will be initiated by PN within a timeframe of at least 2 weeks unless another communication date has been set.
2. Care provider communication
  - a. Consent for communication with indicated care provider will be signed by CG/PWD and sent to care provider by PN (see Appendix H).
  - b. All communication ‘touches’ between PN and any care provider, community organization, or third party will be captured in the [name of program] intake platform during the ongoing navigation. The type of communication ‘touches’ include phone calls, emails, face-to-face, faxes, social media, texts, Canada posts, etc.
  - c. The following criteria will be captured on the intake platform for each ‘touch’ with any care provider, community organization, or third party during ongoing navigation: date, the goal associated with the ‘touch’, the type, amount of time in minutes spent on it, the task associated with the ‘touch’ and notes.

3. Navigation tasks may be assigned to a student by any [name of program] PN.
4. Consultation on cases among [name of program] PNs and PFAC members is encouraged on a regular basis.
5. Meetings with CG/PWD/ACG or care providers may be virtual or face-to-face for ongoing case navigation under PN discretion.
6. New resource information collected for ongoing navigation will be crosschecked with the [name of program] Online Database and entered by PN or trainee.
7. Break in communication
  - a. In the event that a PN cannot reach a CG/PWD after 3 emails and 2 phone calls or a period of 2 months, the disenrollment procedure will begin (using PN discretion)
8. New goals
  - a. If new goals are identified before the resolution of assessment goals and are unrelated to assessment goals, a new goal assessment will be conducted and documented during ongoing navigation
9. Resolution of goals
  - a. When the goals set in the assessment have been met or the case can no longer move forward, the disenrollment procedure will begin.
    - Note: If the goals are not met due to a gap in services refer to [insert gap policy]
  - b. If new goals are identified at resolution outside of those captured during assessment and are unrelated to current goals, a goal assessment will be conducted and documented in the platform database to continue ongoing navigation

## *Disenrollment: Person with Dementia/Caregiver*

### **Policy**

1. Standard of disenrollment for all caregiver (CG) and persons with dementia (PWD) cases
2. All cases will be disenrolled once the goals identified at intake have been met and/or no further action can be taken.
3. CG/PWD may be disenrolled at any point in the navigation process.
4. Confidentiality will be maintained at all times.

### **Procedure**

1. The PN will disenroll the CG/PWD by phone if the intake was completed by phone.
2. CG/PWD/ACG will be informed by the PN that at any point they can reopen their case with new goals.
3. The PN will collect new goal ratings at disenrollment and collect ratings for individual goals by using the following rating system.
  - 3.1. -2 = Worse
  - 3.2. -1 = No change in goal
  - 3.3. 0 = Goal was met
  - 3.4. +1 = Exceeded goal expectation
  - 3.5. +2 = Greatly exceeded goal expectation
4. Research data collection
  - 4.1. CG/PWD/ACG will be reminded by the PN of the [name of program] research data collection to be completed by the Research Team.
  - 4.2. The satisfaction survey will be sent out within 2 weeks post discharge.
  - 4.3. The interview will be conducted within 2-4 weeks post discharge, or immediately post intervention, whichever comes first.
  - 4.4. The follow-up survey will be sent out 3 months post-intervention.
5. CG/PWD/ACG cases will be marked as closed in the [name of program] intake platform by the PN.
6. Should a case be disenrolled due to a break in communication, the disenrollment date will be the last contact with CG/PWD/ACG.

7. The PN will follow-up with the CG/PWD/ACG post intervention for feedback on quality and appropriateness of the intervention for program improvement.
  - 7.1. If the intervention occurs before disenrollment, the follow-up date will be the same as the disenrollment date.
  - 7.2. If the intervention occurs after disenrollment, the PN will follow-up with the CG/PWD/ACG at an appropriate time. Once the follow-up is complete.
  
8. Case time data collection
  - 8.1. The intake platform will calculate the total number of touches and time spent on emails, phone calls and research after disenrollment.
  
9. Contact after disenrollment
  - 9.1. Should a CG/PWD/ACG make contact after disenrollment due to break in communication to resume functional goals, the case will resume as previous case number
  - 9.2. Should a CG/PWD/ACG make contact after disenrollment due to break in communication to determine new functional goals, a new case will be opened.

## Care Provider Intake

### **Policy**

1. Standard of intake for all care providers (CP) that call the program.
2. Completed in the [name of program] intake platform.
3. Care providers may be any health/social professional or community worker involved in the care of the person with dementia (PWD).
4. Confidentiality will be maintained at all times.

### **Procedure**

1. CP contact is initiated by phone, email, fax, or social media to any Patient Navigator (PN).
  - The PN must make two attempts to contact the CP to complete the intake. If the CP does not respond, the case will remain unopened until the CP calls back.
2. The research consent (*if applicable*) and the intake assessment is completed by the intaking PN.
3. Intake data will be stored by CP case number in the NaviCare/SoinsNavi intake platform.
4. Consent
  - 4.1. Recorded consent to use case file data and participate in the research (survey and interview, *if applicable*) is obtained before intake assessment data is collected.
  - 4.2. A CP unwilling to consent to the [name of program] research will not participate in the [name of program] service (*if applicable*).
  - 4.3. A record will be kept of any CP that has not consented to research (*if applicable*).
  - 4.4. If CP is calling for a specific family, CP is asked whether the family is aware that they are calling us. If the family is not aware, CP cannot participate in the [name of program] service for that specific family.
5. Assessment
  - 5.1. Collection of the intake variables.
  - 5.2. Description of goals as indicated by the CP are collected, but no goal ratings are necessary for CPs.
6. Case will be assigned to one of [name of program] PNs based on current caseload.
  - 6.1 The PN that completes the phone enrolment will add said case to their caseload.

7. Once intake assessment has been completed, an initial 'welcome' e-mail will be sent by PN within one business day.
8. Returning CP
  - 8.1. The cases of a returning CP will be numbered with a new numeric code and this will be linked to all their old case files.

## *Active Navigation: Care Provider*

### **Policy**

1. Standard of active navigation for all care providers (CP) that call the program.
2. Collection of data to be stored on the [name of program] intake platform.
3. Collection of data can be performed by any [name of program] Patient Navigator (PN).
4. All communication and research time will be tracked for evaluation (*if applicable*).
5. Confidentiality will be maintained at all times.

### **Procedure**

1. CP communication
  - 1.1. All communication ‘touches’ between PN and CP will be captured in the [name of program] platform database during the ongoing navigation. The type of communication ‘touches’ include phone calls, emails, face-to-face, faxes, social media, texts, Canada posts, research, etc.
  - 1.2. Communication follow-up with CP will be initiated by PN within a timeframe of at least 2 weeks unless another communication date has been set.
2. Other CP communication
  - 2.1. All communication ‘touches’ between PN and any other CP, community organization or third party will be captured in the [name of program] intake platform during the active navigation. The type of communication ‘touches’ include phone calls, emails, face-to-face, faxes, social media, texts, Canada posts, etc.
3. Consultation on case navigation among [name of program] PNs and Patient and Family Advisory Council is encouraged on a regular basis.
4. Meetings with CG/PWD/ACG or care providers may be virtual or face-to-face for ongoing case navigation under PN discretion.
5. New resource information collected for ongoing navigation will be crosschecked with the [name of program] Online Database and entered by PN.
6. Break in communication
  - 6.1. In the event that a PN cannot reach a CP after 3 emails and 2 phone calls or a period of 2 months, the disenrollment procedure will begin.

7. New goals
  - 7.1. If new goals are identified before the resolution of assessment goals and are unrelated to assessment goals, a new goal will be documented in the platform database during ongoing navigation, but goal ratings are not necessary for CPs.
  
8. Resolution of goals
  - 8.1. When the goals set in the assessment have been met or the case can no longer move forward, the disenrollment procedure will begin.
  - 8.2. If new goals are identified at resolution outside of those captured during assessment and are unrelated to current goals, a goal assessment will be conducted and documented in the platform database to continue ongoing navigation

## *Disenrollment: Care Provider*

### **Policy**

1. Standard of disenrollment for all care provider (CP) cases.
2. All cases will be disenrolled once the goals identified at intake have been met and/or no further action can be taken.
3. CPs may be disenrolled at any point in the navigation process.
4. Confidentiality will be maintained at all times.

### **Procedure**

1. The PN will disenroll the CP by phone if the intake was completed by phone.
2. CP will be informed by the PN that at any point they can reopen their case with new goals.
3. CP will be reminded by the PN of the [name of program] satisfaction survey to be sent by the Research Team.
4. CP cases will be marked as closed in the [name of program] intake platform by PN.
5. Should a case be disenrolled due to a break in communication, the disenrollment date will begin at last contact with CP.
6. Case time data collection
  - 6.1. The intake platform will calculate the total number of touches and time spent on emails, phone calls and research after disenrollment.
7. Contact after disenrollment
  - 7.1. Should a CP make contact after disenrollment due to break in communication to resume functional goals, previous case number will remain
  - 7.2. Should a CP make contact after disenrollment due to a break in communication to determine new functional goals, a new case will be opened.

## *Tracking Significant Gaps & Barriers*

### **Policy**

1. Standard of documentation of gaps and barriers identified by caregiver, people with dementia, and/or care provider.
2. A significant gap or barrier (SGB) is defined as a system gap that causes a disruption or barrier to the care of a person with dementia.
3. Documented in the intake platform.

### **Procedure**

1. SGBs are documented as they arise within a case by any Patient Navigator (PN) assigned to that case.
2. SGBs will be documented by date in the intake platform.
3. Collection
  - 3.1. Case numbers associated with SGBs will be documented to track SGB frequency.
  - 3.2. The organization of SGBs will be in order of their identification date, separated by the Policy Brief number and date to which they belong
4. Reporting
  - 4.1. After a determined amount of time, SGBs will be presented in the form of a policy brief for the Department of Health.
5. Filing
  - 5.1. Once the SGB has been reported to the Department of Health, it will be filed, and the preparation of a new Policy Brief will begin.

## *Program Outreach*

### **Policy**

1. Standard of capturing information on outreach communication to track activity and determine whether the activity has been effective in increasing calls to the program.
2. Completed in the [location of document].

### **Procedure**

1. Background
  - 1.1 All outreach communication must be recorded in the 'Master Outreach Plan' excel. This includes initial communication, drop-ins, cold calls, meetings, presentations and follow-ups.
  - 1.2 The colours of the excel will change automatically based on which tasks have been completed.
    - a) Red: No significant meeting has been completed; however, an initial communication, drop-in or cold call may have been completed.
    - b) Yellow: A significant meeting has been completed, but no follow-up.
    - c) Green: A significant meeting and follow-up have been completed.
2. Entering Information
  - 2.1 The excel is separated according to location and one for organizations covering the entire province. When communicating with an organization, the information should be added to the appropriate tab, ensuring that the organization has not previously been entered.
  - 2.2 The following are the columns that should be completed for an entry.
    - a) Organization
      - Indicate the organization or the name of the geriatrician, primary care provider, etc.
    - b) Type of Service
      - Select from the dropdown:
        - i. Education
        - ii. Health
        - iii. Social
    - c) Population/Group
      - Select from the dropdown (examples):
        - i. Community Health

- ii. Community and Wellness Centre
- iii. In-home Support
- iv. Government of NB – SD (Social Development)
- v. Hospitals
- vi. Non-profit
- vii. Primary Health Care
- viii. Geriatrician
- ix. Long-term Care Facility
- x. Group Home
- xi. Other

*Note:* Should a specific population/group continue to appear, and it is not listed here, this can be added to the dropdown by adding it on the ‘Drop-Downs’ tab at the end of the excel.

d) Priority Populations

- Does the organization fall under one of our priority populations? Select the appropriate response:
  - i. Francophone
  - ii. LGBTQ2+
  - iii. Indigenous
  - iv. Newcomer
  - v. N/A

e) Contact (Position)

- Include any relevant contacts that you have been communicating with for this organization and their position within the organization.

f) Contact Information

- If possible, include their phone number and/or email.

g) City

- Include the location of the organization’s office within the appropriate zone.

h) Initial Communication (to set up a meeting)

- Include the date of your initial communication with them (phone or email) in order to try and set up a meeting.
- Include your name in brackets.

i) Drop-in/Cold Call

- If the drop-in/cold call did not lead to a meeting where significant information was exchanged, indicate whether it was a drop-in or cold call, the date and your name.
- If the drop-in/cold call led you to an impromptu meeting where detailed information about [name of program] was provided, refer to the ‘Meeting’ column (J).

- j) Meeting (To discuss [name of program])
- This is a significant meeting or presentation where all necessary details of the program were shared.
  - This could be a set meeting or presentation based on Initial Communication, or an impromptu meeting from a Drop-in or Cold Call.
  - Information that should be included in this column is:
    - i. Number of communication (e.g., 1, 2 or 3): Is this the first, second or third significant meeting?
    - ii. Indicate the type of communication: Was this a presentation, meeting, drop-in, phone conversation, etc.?
    - iii. The date of the communication.
    - iv. Who was present from [name of program] at the meeting?

- k) Communication Date (1)
- Any significant communication in the 'Meeting' column should be indicated by a number.
  - Only the date for the first (1) significant communication should be indicated in this column. This allows researchers to easily find meetings based on dates.

- l) Communication Date (2)
- Only the date for the second (2) communication should be indicated in this column.

- m) Communication Date (3)
- Only the date for the third (3) communication should be indicated in this column.

*Note:* Should a fourth communication be completed with the same group, a new column would need to be added called 'Communication Date (4).'

- n) Follow-up
- Any follow-up completed after a significant communication ('Meeting') should be recorded here.
  - Follow-ups can be by email, phone, or in-person.

- o) Brochures (Date (#))
- Indicate the number of English and French brochures given to the organization and the date they were given.

- p) Posters (Date (#))
- Indicate the number of posters given to the organization and the date they were given.

- q) Notes
- Any other notes that may be useful.

## Marketing

Marketing of the navigation program increases its visibility to the target population and aids in the outreach of community programs. Your marketing strategy will depend on your navigation program. For example, if your navigation program is located outside of the healthcare system, in the community, then you will need to advertise and conduct outreach to raise awareness of those in the healthcare system. If your program is based in the healthcare system, you will need a marketing strategy that targets the necessary community organizations. Recommended marketing tools include, but are not limited to:

- Website
- Social media (e.g., Facebook, Twitter, etc.)
- Connections articles highlighting people with dementia, caregivers, and health and social care providers involved in caring for people with dementia
- Community program guide
- Promotional video
- Business cards
- Brochures

## Program Evaluation and Research

To continue improving, evaluation of the patient navigation program may be an ongoing process. If your team has capacity, this can be done in house. Otherwise, you may want to consider bringing in a consultant who can help you with this. To participate in research, clients are required to provide consent. The evaluation plan may include measuring a number of short, medium, and long-term outcomes, such as increased knowledge of resources and services; increased ability to participate in activities at home and community; reduced stress for caregivers; and improved quality of life. Metrics are tools that can be used to help evaluate a navigation program. You may be interested in evaluating the quality of care, user experiences, health outcomes, and cost-effectiveness of care for persons with dementia. The key metrics may include those that are most likely to be impacted by patient navigation and may take into consideration the cultural, educational, familial, financial, and other socio-demographic considerations of the population in which the patient navigation intervention is being studied. As such, keeping track of activities at the following data collection points may be helpful:

- Client referral source
- Reason(s) for call
- Diagnosis/no diagnosis
- Number of touches
- Time spent on phone, in videoconference, in person meetings with clients
- Time spent contacting care providers for client cases
- Time spent on researching programs, service, resources
- Time spent with follow-ups
- Date of intake
- Date of closing
- Total calls/emails/faxes/in person visits per month

The evaluation and research documents include:

- Patient and/or caregiver research consent forms
- Care provider research consent forms
- People with dementia and caregivers research welcome email
- Care provider research welcome email
- Caregiver interview guide
- Care provider interview guide
- Caregiver online survey
- Care provider online survey

*Patient and/or Caregiver Research Consent Form*

**TELEPHONE CONSENT TO PARTICIPATE IN [NAME OF PROGRAM]**

TITLE:

PRINCIPAL INVESTIGATORS:

---

I would like to start by informing you that this conversation is being recorded.

**INTRODUCTION**

As part of providing patient navigation services, we maintain an electronic record for every [name of program] client using a secure online research database. Included in this database is the patient's Medicare number. Medicare numbers will be collected for the explicit purpose of linking them to administrative data. Please note that this data, once linked, will be deidentified. Information is collected primarily to provide navigational services, but also to gather information on how well the program is working; to inform changes in policy and practice; and for research. No identifiable client information is reported. For the purposes of ongoing research, **the research team is seeking your consent to include a copy of your information in our research database, and to be contacted for future research.**

**VOLUNTARY PARTICIPATION**

Your participation in this research as a client of [name of program] is voluntary. You are free to refuse to participate or discontinue your participation at any time without explanation. However, where this is a research centre, if you choose not to participate, or if you discontinue your participation, you will also be withdrawn from [name of program]'s patient navigation services as we require access to our client data for program evaluation and research.

**WHAT IS INCLUDED IN THE RESEARCH DATABASE?**

The research database will include information that you provide during the intake process and during any follow-up with the patient navigator until your file is closed.

**HOW WILL YOUR INFORMATION BE PROTECTED?**

All of your information will be kept strictly confidential by using a code (Client ID) to identify you, which only authorized personnel will have access. The code that links your name with your data will be kept in separate, password-protected folders in [electronically or in an office as applicable to your organization]. Your privacy will be protected at all times. Any information used to disseminate research findings will not include any identifiable information. As findings become available, they can be found on our [name of program] website.

**FUTURE ACCESS AND USE**

Any research conducted with data from this research database must be approved by the Research Ethics Board before the research begins.

Your information will be accessible by:

- The [name of program] research team who have been approved to access your records as part of the program.
- Members of the Research Ethics Board for the purposes of ensuring the proper monitoring

of the research database.

- You, as you maintain the right to view your personal information and ask to have appropriate corrections made.

### **QUESTIONS AND CONTACT INFORMATION**

If you have any questions about this research database or your involvement in the research, please contact the lead investigators [Name and contact information].

*Do you have any questions?*

*By consenting to this research, you are indicating that you fully understand the information I have shared and agree to participate in this study.*

**Do you consent to include a copy of your information in our research database, and to be contacted for future research?**

Yes

No

Name of Participant

\_\_\_\_\_  
Name

\_\_\_\_\_  
Date

**I confirm that I have explained the nature and purpose of the [Program] research project and I have answered all questions.**

\_\_\_\_\_  
Name of Person  
Obtaining Consent

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

This research has been reviewed and approved by the Research Ethics Board. If you have any questions or concerns about this study, you may contact [Name and contact information].

## *Care Provider Research Consent Form*

### **Care Provider Research Consent**

[Name of program] is a research centre and we collect data to help with the evaluation of our program and improve the care of people with dementia in [location]. For the purposes of ongoing research, the research team is seeking your consent to include a copy of your information in our research database, and to be contacted for future research.

The research team is seeking your consent to use the data collected during the intake process and during any follow-up with the patient navigator until your file is closed. You may also be contacted to participate in futures research. For this particular evaluation study, you may be invited to participate in an interview, as well as to complete a satisfaction survey (sent out within 2 weeks after you finish working with [name of program]).

*Research Welcome Email: People with Dementia and Caregivers*

Client,

It was a pleasure speaking with you earlier! I have attached a copy of the research consent for your own records. If you could also fill out the attached “authorization for release of information” form so that I can get started by reaching out to [CARE PROVIDER], that would be great!

To better ensure that clients continue to receive quality care, our research team is currently engaging in an evaluation of the program. As mentioned in the consent form, you may be contacted to participate in future research. For this study, you may be invited to participate in an interview, as well as to complete a satisfaction survey (sent out within 2 weeks after you finish working with [name of program]), and a follow-up survey (sent out after you have received the resources and services organized by [name of program]). While we greatly appreciate your input, your participation is voluntary.

Please do not hesitate to reach out with any questions or concerns, and I look forward to working with you!

Sincerely,  
PN

*Research Welcome Email: Care Provider*

Care provider,

It was a pleasure speaking with you earlier!

To better ensure that families continue to receive quality care, our research team is currently engaging in an evaluation of the program. As mentioned earlier, you may be contacted to participate in future research. For this study, you may be invited to participate in an interview, as well as to complete a satisfaction survey (sent out within 2 weeks after you finish working with [name of program]). While we greatly appreciate your input, your participation is voluntary.

Please do not hesitate to reach out with any questions or concerns, and I look forward to working with you!

Sincerely,  
PN

## *Interview Guide for Caregivers*

### **Introduction**

Hello, my name is (insert). I am the researcher conducting the study called “An Evaluation of [name of program]”

I would like to thank you for agreeing to participate in this interview. Before we start, I would like to review the consent form with you. If you have any questions, please do not hesitate to ask.  
*(Go through the form and answer questions)*

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

- 1) Can you share with me your experiences with [name of program]?
  - a) **Probe:** What brought you to contact the program?
  
- 2) Can you describe what you found to be most helpful, or not helpful, when working with the PN?
  - a) **Probe:** Did the PN listen and understand your needs?
  - b) **Probe:** Did the PN answer your questions/address your concerns?
  - c) **Probe:** Did you feel the PN was knowledgeable about programs and services?
  
- 3) Did you learn about any services and programs in the province or elsewhere that you had not heard of, or had not considered using?
  - a) **Probe:** What services or resources did the PN connect you with?
  - b) **Probe:** Have you accessed/used any of the services or resources? If yes, can you describe your experience using these services or resources?
  
- 4) Can you describe how the program assisted, or did not assist, the person you care for, and/or family in overcoming barriers to obtaining care? For example, think about financial, language, transportation, and/or the health system.
  - a) **Probe:** Prior to calling the program, were you able to access services and programs in a timely manner? Has this changed since your interaction with the PN? If so, how?
  - b) **Probe:** Do you feel that working with the [program name] affect the time between receiving a diagnosis and accessing services or treatments? If so, please explain.
  
- 5) In your situation, what might you have done without the PN?

- 6) Has your experience with the [name of program]'s PN changed your ability to navigate the system? Please explain.
- 7) In what ways did the PN affect your ability to support the person with dementia in your life? (ask for examples)
  - a) **Probe:** In what ways did the services provided through [program name] affect the amount of time required to care for the person with dementia in your life?
- 8) Has your personal ability to participate in parts of your life changed since you received support from [name of program]? For example, your relationships, employment/unpaid work, your health, and well-being, spiritual or leisure activities.
- 9) Has your ability/the ability of the person with dementia in your life to participate in parts of their life changed since receiving support from [name of program]?
- 10) In what ways did the services provided through [name of program] affect communication between you and your care team? Among members of your care team? Can you elaborate please?

**Note:** *May need to explain care team. This could involve care providers through the healthcare system as well as through social service, not-for-profit organizations, or private organizations.*
- 11) In what ways did the services provided through [name of program] affect the integration and/or coordination of a person with dementia's care?

**Note:** *May need to explain integration and/or coordination of care. Integration is how well all the various parts of the system(s) are working together. Coordination of care involves organizing care activities and sharing information among all the participants concerned with a person with dementia's care to achieve safer and more effective care. Care coordination is any activity that helps ensure that the person with dementia's needs and preferences for services and information sharing across people, functions, and sites are met over time.*
- 12) What are potential areas where the program can make improvements to support care providers and families around navigation and coordination of care for people with dementia?
- 13) Is there anything else you would like to add to regarding your experiences with [name of program]?

**Conclusion**

This concludes the interview. Once again, I would like to thank you for your time and participation in this study. The results of the study will be available on the [name of program] website once the project has been completed.

## *Interview Guide for Care Providers*

Questions will be semi-structured and will explore the following outcomes: satisfaction, knowledge, and experience with coordination, integration, and continuity of care.

### **Introduction**

Hello, my name is (insert). I am a researcher conducting the study called “An Evaluation of [name of program]”

I would like to thank you for agreeing to participate in this interview. Before we start, I would like to review the consent form with you. If you have any questions, please do not hesitate to ask. *(Go through the form and answer questions)*

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

### **Satisfaction**

1. Please describe your experience with the program [name of program].
2. Have you received any services directly from the program’s patient navigator?
  - a. If yes, proceed to question 3
  - b. If no, proceed to question 11
3. Overall, how satisfied were you with [name of program] [e.g., the services offered by the patient navigator (PN)]?
4. Were you satisfied with the PN’s ability to listen and understand issues related to the needs of people with dementia and their caregivers under your care?
5. What was your experience like with the PN in terms of their ability able to answer your questions?
6. Did the PN direct you to any services or resources? Were the resources helpful or useful for you? Why or why not? Please explain
7. In general, how helpful was the PN?
  - a. **Probe:** Was the PN able to assist you in supporting people with dementia and their caregivers?
  - b. **Probe:** Do you feel that the PN was knowledgeable about the services available in your area?

8. How helpful was the information provided to you from the PN to your ability to assist people with dementia and their caregivers?
9. Would you seek support from [program name] again?
10. Would you refer people with dementia in your care to use the program? Explain why or why not.
11. Have you used the [name of program] website? How satisfied were you with the contents of the website? Please explain.

### **Knowledge**

1. If you received any services directly from the PN with [name of program], did you learn about new programs or services for people with dementia and their caregivers?
2. In what ways did the PN affect your ability to support and coordinate care for families in your care?
3. In what ways does the education offered through [name of program] services assist and support care providers and families in the [area of program delivery]? Please explain.

### **Experience with coordination, integration, and continuity of care**

1. In what ways did the services provided through the program and the PN affect the time you spend caring for families in your practice?
2. How does the presence of the program and support of the PN affect communication between care team members and families?
3. Referring to families who are in your care and have used [name of program], in what ways do you feel the program and PN affect their ability to navigate the system when caring for a person with dementia?
4. In what ways has the program changed your rates of referrals to specialists, programs, and services for families? Have you either witnessed a change or heard about it from your patients/families in your care?
5. Overall, do you think the program has affected collaboration, coordination, integration, and navigation of the system for both care providers and families?

### **General Overall Concluding Questions**

1. To what extent have services from [name of program] affected your practice?
2. What are potential areas where the program can make improvements to support care providers and families around navigation and coordination of care for people with dementia.

3. Is there anything else you would like to add to regarding your experiences with the patient navigation program?

**Background questions**

1. Where do you work?
2. Are you employed through the public, private sector, or not-for-profit sector?
3. What is your current position?
4. What setting do you work in?
5. Do you have direct experience with the patient navigation program or has your involvement been through one or more of your clients/patients?

**Conclusion**

This concludes the interview. The results of the study will be available on the program's website once the project has been completed. Once again, I would like to thank you for your time and participation in this study.

## *Caregiver Online Satisfaction Survey*

### **Introductory message:**

Please help us improve our program by answering some questions about the services you have received at [name of program]. We are interested in your honest opinions, whether they are positive or negative. Please answer all of the questions. We also welcome your comments and suggestions.

Thank you very much, we appreciate your help.

Sincerely,

1. How would you rate the quality of service you received?
  - Poor
  - Fair
  - Good
  - Excellent
2. Did you get the kind of service you wanted?
  - No, definitely not
  - No, not really
  - Yes, generally
  - Yes, definitely
3. To what extent has our program met your needs?
  - None of my needs have been met
  - Only a few of my needs have been met
  - Most of my needs have been met
  - Almost all of my needs have been met
4. If a friend needed similar help, would you recommend our program to them?
  - No, definitely not
  - No, I don't think so
  - Yes, I think so
  - Yes, definitely
5. How satisfied are you with the amount of help you received?
  - Quite Dissatisfied
  - Indifferent or mildly dissatisfied
  - Mostly Satisfied
  - Very Satisfied
6. Have the services you received helped you to deal more effectively with your concerns?
  - Yes, they helped a great deal

- Yes, they helped somewhat
- No, they really didn't help
- No, they seemed to make things worse

7. In an overall, general sense, how satisfied are you with the services you received?

- Quite Dissatisfied
- Indifferent or mildly dissatisfied
- Mostly Satisfied
- Very Satisfied

8. If you were to seek help again, would you come back to our program?

- No, definitely not
- No, I don't think so
- Yes, I think so
- Yes, definitely

9. How did you primarily interact with the patient navigator?

- Phone
- E-mail
- In-person
- Other (please specify)

10. How satisfied were you with the method of communication that you indicated above?

- Dissatisfied
- Indifferent or mildly dissatisfied
- Mostly Satisfied
- Very Satisfied

Comments:

11. How satisfied are you with the frequency of contact with the Patient Navigator?

- Too little contact
- The right amount of contact
- Too much contact

Comments:

12. How satisfied are you with the Patient Navigator in the following areas:

	Quite Dissatisfied	Indifferent or mildly dissatisfied	Mostly Satisfied	Very Satisfied
Ability to understand the reason for your call	0	0	0	0
Ability to listen to your concerns	0	0	0	0

13. Based on the list below, how satisfied are you with the Patient Navigator's ability to help you meet your identified goals? (select "NA" for any goals that do not apply to your situation)

	Quite Dissatisfied	Indifferent or mildly dissatisfied	Mostly Satisfied	Very Satisfied	N/A
Funding	0	0	0	0	0
Care Coordination	0	0	0	0	0
Respite	0	0	0	0	0
In-home care	0	0	0	0	0
Mental health support for the person with dementia	0	0	0	0	0
Peer support or psychological services for the person with dementia	0	0	0	0	0
Educational materials for the person with dementia	0	0	0	0	0
Equipment	0	0	0	0	0
Other	0	0	0	0	0

If "other" please describe what goal you worked on:

14. If you had not been able to contact [Name of Program], who would you have contacted for assistance?

15. Do you have any final comments you would like to share about your experiences with [Name of Program]?

## *Care Provider Online Satisfaction Survey*

Please help us improve our program by answering some questions about the services you have received at [name of program]. We are interested in your honest opinions, whether they are positive or negative. Please answer all of the questions. We also welcome your comments and suggestions.

Thank you very much, we appreciate your help.  
Sincerely,

1. How would you rate the quality of service you received?
  - Poor
  - Fair
  - Good
  - Excellent
  
2. Did you get the kind of service you wanted?
  - No, definitely not
  - No, not really
  - Yes, generally
  - Yes, definitely
  
3. To what extent has our program met your needs?
  - None of my needs have been met
  - Only a few of my needs have been met
  - Most of my needs have been met
  - Almost all of my needs have been met
  
4. If a colleague needed similar help, would you recommend our program to them?
  - No, definitely not
  - No, I don't think so
  - Yes, I think so
  - Yes, definitely
  
5. How satisfied are you with the amount of help you received?
  - Quite Dissatisfied
  - Indifferent or mildly dissatisfied
  - Mostly Satisfied
  - Very Satisfied
  
6. Have the services you received helped you to deal more effectively with your concerns?
  - Yes, they helped a great deal
  - Yes, they helped somewhat
  - No, they really didn't help

- No, they seemed to make things worse

7. In an overall, general sense, how satisfied are you with the services you received?

- Quite Dissatisfied
- Indifferent or mildly dissatisfied
- Mostly Satisfied
- Very Satisfied

8. If you were to seek help again, would you come back to our program?

- No, definitely not
- No, I don't think so
- Yes, I think so
- Yes, definitely

9. How did you primarily interact with the patient navigator?

- Phone
- E-mail
- In-person
- Other (please specify)

10. How satisfied were you with the method of communication that you indicated above?

- Dissatisfied
- Indifferent or mildly dissatisfied
- Mostly Satisfied
- Very Satisfied

Comments:

11. How satisfied are you with the frequency of contact with the Patient Navigator?

- Too little contact
- The right amount of contact
- Too much contact

Comments:

12. How satisfied are you with the Patient Navigator in the following areas:

	Quite Dissatisfied	Indifferent or mildly dissatisfied	Mostly Satisfied	Very Satisfied
Ability to understand the reason for your call	0	0	0	0
Ability to listen to your concerns	0	0	0	0

13. Based on the list below, how satisfied are you with the Patient Navigator's ability to help you meet your identified goals? (select "NA" for any goals that do not apply to your situation)

	Quite Dissatisfied	Indifferent or mildly dissatisfied	Mostly Satisfied	Very Satisfied	N/A
Funding	0	0	0	0	0
Care Coordination	0	0	0	0	0
Respite	0	0	0	0	0
In-home care	0	0	0	0	0
Mental health support for the person with dementia	0	0	0	0	0
Peer support or psychological services for the person with dementia	0	0	0	0	0
Educational materials for the person with dementia	0	0	0	0	0
Equipment	0	0	0	0	0
Other	0	0	0	0	0

If "other" please describe what goal you worked on:

14. Rate what impact, if any, [name of program] has had on the following:

	Decreased greatly	Decreased slightly	Stayed the same	Increased slightly	Increased greatly
My awareness/understanding of the [name of program] program	0	0	0	0	0
My understanding/knowledge of resources and services available to help my clients	0	0	0	0	0
My understanding of how to best support and coordinate care for clients	0	0	0	0	0
My ability to obtain the resources and/or services my clients needed	0	0	0	0	0
The coordination of care and/or services for my client (e.g., appointments with other care providers, additional resources, etc.)	0	0	0	0	0
The communication between me and others providing services for my client (e.g. not-for-profit groups, clinics, etc...)	0	0	0	0	0

15. Please comment on coordination, integration and/or continuity of care specific to your experiences with [name of program].

16. Do you have any final comments you would like to share about your experiences with [name of program]?