

Summary

- There are 15,000 people living with dementia (PLWD) in New Brunswick. This population, their care partners (CPs), and their health and social care providers (HSCPs) experience challenges through the dementia diagnostic process and with the delivery of post-diagnostic support.
- The Forward with Dementia (FWD) project aimed to design, deliver, and evaluate an awareness campaign that improved these identified problem areas. Specifically, they aimed to:
 - Improve HSCPs' communication of dementia diagnoses and their provision of support during the first year following diagnoses, and
 - Increase the knowledge and use of existing services and supports for PLWD and their CPs.
- 148 stakeholders (130 women, 17 men, 1 unspecified) participated to evaluate the FWD project.

HSPF Focus Area

Project Start & End Date

Organization/Agency

Location

Principal Investigator(s)

Developing innovative care pathways

January 1, 2020 – September 30, 2023

University of New Brunswick Saint John

Province-wide

[Dr. Shelley Doucet](#), [Dr. Alison Luke](#), and [Dr. Pam Jarrett](#)

Indicator	Impact / Outcome / Result	Quote
Experiences with the diagnostic process and post-diagnostic support	<p>In focus groups, PLWD and CPs expressed the need for diagnostic information that is individualized and coupled with practical support strategies.</p> <ul style="list-style-type: none"> • They felt that compassionate care, support (e.g., network, navigating the system), and education were facilitators. • Access to care (e.g., waitlists, geography), continuity of care, stigma, and caregiver burnout were barriers. 	<p><i>"I do have difficulty telling people that [I have dementia]. That's a really hard thing for me. People, they don't know what to do and they treat you differently and I don't like that."</i> – PLWD</p>
	<p>Surveys showed that CPs had a wide variation in their ease of finding information on services and supports.</p>	<p><i>"I don't see any real major support coming from the system per se. The public system, even private system support is very difficult to secure. So, it means added responsibility for families."</i> – CP</p>
	<p>HSCPs shared in focus groups that a team approach (e.g., shared responsibilities, memory clinics), supporting patients "where they're at" (e.g., providing a plan, patient and care partner education), and relationships (e.g., provider-patient relationship, family perspectives) were facilitators in the diagnostic process.</p> <ul style="list-style-type: none"> • Perceived barriers included differential diagnosis (e.g., polypharmacy, lack of context), access to care (e.g., lack of providers, late-stage referrals), and discomfort (e.g., hesitancy, stigma). • In surveys, HSCPs were least satisfied with available resources to support the diagnostic process ($M = 3.07, SD = 1.14$) and linkage to post-diagnostic support/services ($M = 3.00, SD = 1.14$). 	<p><i>"I would say, you know, education of patient and caregivers is the most... important part of it... There can be a lot of misunderstanding and misconceptions... about the disease."</i> – HSCP</p> <p><i>"I think another really pragmatic challenge, particularly in New Brunswick, is people who don't have primary care providers."</i> – HSCP</p>

Indicator	Impact / Outcome / Result	Quote
Knowledge, attitudes, and healthcare practices	In response to surveys, 89% of PLWD found the FWD website moderately to extremely helpful, and they somewhat agreed that the FWD campaign helped them learn how to live well with dementia ($M = 3.67, SD = 1.03$).	"If I had had this information early on, I would have gone right on." – CP
	82% of CPs who responded to surveys found the FWD website moderately to extremely helpful, and they generally agreed that the FWD campaign helped them better understand dementia ($M = 4.00, SD = 0.85$).	
	HSCPs reported in surveys that the website and webinar information were helpful ($M = 4.00, SD = 0.58$ and $M = 3.82, SD = 0.87$, respectively), and 94% plan to use FWD in their practice .	"Very informative [webinar] and it was nice to hear from a person living with dementia, I appreciate new ideas that I can use with my clients", and "I found it very informative." – HSCP

Methods and Comparison

- 129 stakeholders (109 women, 20 men) – including 8 PLWD, 54 CPs, 42 HSCPs, and 25 stakeholders in other roles – responded to a needs assessment survey, which guided FWD awareness campaign development.
- 18 PLWD, 48 CPs, 42 HSCPs, and 20 stakeholders in other/multiple roles responded to surveys, which assessed the campaign's impact on participants' knowledge of, attitudes toward, and behaviours related to the dementia diagnostic process and delivery of post-diagnostic support. Focus groups and interviews were held with 1 PLWD, 2 CPs, 11 HSCPs, and 6 other stakeholders to gather website feedback.

Conclusions and Lessons Learned

- Overall, participants felt that the information provided on the websites and at the webinars was helpful. The campaign helped CPs better understand dementia and nearly all HSCPs planned to use what they learned through FWD in their healthcare practice.
- Connecting with older adults virtually emphasized the need for accessible technology training and the willingness of older adults to learn new skills and engage in project initiatives.
- The information and tools available on the website appear to be most helpful for people who have recently been diagnosed, or who have a family member/friend who was recently diagnosed.

Recommendations

- Although the virtual information was useful, the project team feels that older adults might benefit from a dementia diagnosis and support advisor within the health and social care system.
- The project team along with international partners have tested the FWD awareness campaign in five countries and have developed recommendations that are detailed in the FWD Playbook.

Next Steps

- The Canadian team (Principal Investigators at UNB, Waterloo, and McGill) have agreed to collaboratively continue supporting the maintenance of the websites following the funding period.
- Additional funding was awarded by the Public Health Agency of Canada's Dementia Strategic Fund: Awareness Raising Initiatives. The extension of the FWD initiative called "Addressing stigma and supporting living well for persons living with dementia and care partners: The Forward with Dementia initiative" will be led by Dr. Carrie McAiney and staff members at the Research Institute for Aging.
- In partnership with the Alzheimer Society, an additional HSP project called "Navigating dementia NB" has strengthened the team's relationship with the partnered First Link Coordinators.

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Financial contribution from



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