

Webinar Discussion Series - Community Dementia Care and Support:

Innovations supporting people living with dementia and care partners closer to home

March 9, 2021, Webinar Discussion Summary

Mar 9, 2021, Webinar Synopsis:

This webinar provided an overview of the [Community Dementia Care and Support webinar discussion series](#). Participants discussed the innovation **Primary Care Dementia Assessment & Treatment Algorithm (PC DATA)**.

The moderators for the session were Mimi Lowi-Young (Chair of the Board of Directors: AGE-WELL Network Centre of Excellence INC.) and Mary Beth Wighton (Chair & Co-founder: Ontario Dementia Advisory Group (ODAG) and Dementia Advocacy Canada (DAC); Member - Federal Ministerial Advisory Board on Dementia), who provided insights throughout the session, including these two quotes:

“In 2012 I was diagnosed with Probable Frontotemporal Dementia. That experience left me scarred and frankly angry. As I began to speak with other people living with dementia, we each talked about the terrible experience of being diagnosed with a lack of compassion and access to immediate supports. The person with dementia must be seen as someone with rights who still has much to contribute to society. This would mean providing individualized, responsible, flexible, social and personal care services.”

- Mary Beth Wighton

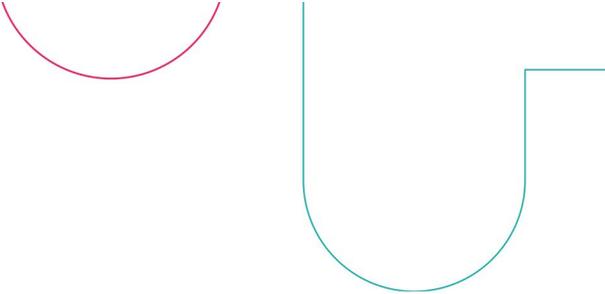
“There are technological solutions that have been designed that can and should support effective and timely diagnosis of dementia. These innovative solutions should be fully tested so they can then spread and scaled to benefit many more individuals.”

- Mimi Lowi-Young

Feb 10, 2021, Discussion Highlights:

(A) Presentation 1: PC DATA

- Based on the Canadian Consensus Conference Guidelines on Diagnosis and Treatment of Dementia (CCCDTD)
 - created in 1999, updated in 2001, 2007, 2012 and 2019
- Dementia Education for Primary Care
 - Patients with dementia assessed and managed by their primary care physicians
 - All clinicians care for patients with dementia have to acquire the core knowledge and skills

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- A multifaceted education program should be implemented to promote adoption of the CCCDTD recommendations
 - Dementia education and dementia care managers are key mechanisms to improve the quality of dementia in primary care
 - Primary Care – Dementia Assessment and Treatment Algorithm Project (PCDATA)
 - Funded by Canadian Institutes of Health Research (CIHR)
 - Develop knowledge tools to facilitate assessment and management of Alzheimer’s disease and related dementias by Primary Care Providers (PCP) based on best evidence
 - Transfer these knowledge tools into a variety of primary care settings in Ontario (Saskatchewan, Online)
 - Development of PCDATA Tools
 - Literature review to identify key components of dementia management for primary care physicians
 - Literature review of patient and caregiver healthcare experience to identify current gaps in care
 - Focus groups (5) with people living with dementia and caregivers to understand the local context
 - Pilot testing of tools with PCPs
 - PCDATA Tools
 - Three Algorithms developed to assist PCP in evaluation and management of Dementia
 - Evaluation (Module 1 – 45 minutes)
 - Initial Management of Dementia (Module 2 – 30 minutes)
 - Ongoing Assessment and Monitoring (Module 3)
 - Brief visit flow cheat sheets to assist patient assessment
 - Hardcopy manual, electronic copies and website developed for tools
 - Incorporated existing tools in assessment (e.g. AD8, MoCA)
 - To learn more about PC DATA visit their [website](#).

(B) Discussion and Participation: Questions, Answers, and Comments/Suggestions.

Participants were invited to ask questions and engage in a discussion. Below is the list of questions asked and the responses.

Q: Does the course include information about primary care/diagnosis/support for diverse populations (i.e. different cultural considerations, language, people with disabilities, etc.)?

A: Currently the information is only available in English and therefore one of our first priorities is to secure resources to translate the course to French. We will be looking at incorporating overarching principles regarding working with diverse communities as well as inclusion and equity throughout the course material as well as creating some specific modules on these topics.

Q: Can the online PC-DATA training be accessed by all healthcare providers or targeted to physicians?

A: There is a fee for accessing the online modules, but it is available for everyone to access.

Q: Have you investigated partnering with primary care to disseminate this tool?

A: We have been partnering with rural primary health care teams to operate memory clinics and these teams use the PC DATA flow sheets which are integrated into the EMR. We were trying to meet the need of low touch broad based education. We have team members from the primary health memory clinics who have taken the modules.

Q: Is the course being promoted by the various provincial Colleges of Physicians?

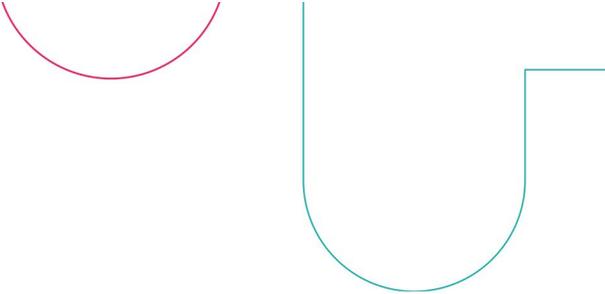
A: The initial project was promoted by the Ontario College of Family Physicians. We are working with them and the Alzheimer Society of Canada to partner on the needs assessment they are conducting with family physicians. We are always interested in partnering with primary care organization and professional colleges.

Q: Could you comment on the role of dementia care managers? Are there Canadian regions where families have access to dementia care managers?

A: Quebec had some care management nurses as part of their strategy. Unfortunately, the care management model has not taken off in Canada as much as it has in the U.S. for example. In some cases, there are existing services that fulfil those roles, for example some Alzheimer societies might work directly with primary care and help with the coordination of services. In some areas these processes might be managed by home care service organizations. This type of service is not consistent across the country.

Q: How have people living with dementia been involved in the training?

A: People living with dementia were part of the group that was providing input into the training materials but are not directly involved in the training. In future modules, it would be lovely to have learnings that were provided from the experience of the person living with dementia and incorporating that experience into the materials. This is an area we would like to strengthen in the future if there are opportunities to do so.



Q: Are measures being taken to ensure that the information does not become too focussed on "medical" interventions and also includes available community and social supports?

A: The most effective treatments we have for dementia are people and services. The first step after the disclosure of diagnosis in our training materials is to facilitate a referral to First Link© and other supports and services that might be helpful for the individual who was just diagnosed with dementia and taking into consideration their specific circumstances when making these referrals. Examples of these supports and services could be recreational programs, home care services, activity programs, etc. We would like to build the training for it to provide specific recommendations and contacts for supports in your area based on where you are located.