# People, Partners & Possibilities

Transforming dementia care in the community

Alzheimer Society
ONTARIO

Ontario College of Family Physicians

# Pre-Symposium Survey

## Synthesis of Feedback

June 2014

The Symposium is made possible with the support of

MERCK

OACCAC Ontario Association of Community Care Access Centres / ACASCO Association des Centres d'accès aux soins communautaires de l'Ontario

Ontario Health Quality Ontario / Qualité des services de santé Ontario

Ontario Brain Institute / Institut ontarien du cerveau

Ontario Society of Occupational Therapists

OMA Ontario Medical Association

RNAO Registered Nurses' Association of Ontario / L'Association des infirmières et infirmiers autorisés de l'Ontario

Speaking out for nursing. Speaking out for health.

# Contents

Thank you to the people and organisations who contributed to making this Symposium possible, particularly the planning committee for their contributions and wise counsel; the individuals who gave their time to participate in the survey, and to system45, the Ontario College of Family Physicians and the Alzheimer Society of Ontario who put together the Pre-Symposium Synthesis of Feedback report you are reading.

# Introduction, Background and Context

## The Symposium

The Alzheimer Society of Ontario and the Ontario College of Family Physicians are co-hosting a stakeholder symposium June 13 and 14, 2014. The purpose of the symposium is to bring together thought leaders and service providers to discuss and determine opportunities to:

***Increase the capacity of primary care to respond effectively to the needs of community-dwelling people living with dementia and their care partners***

Participants invited to the symposium include primary care physicians, geriatric care specialists, allied health care providers, government agencies, leaders in education, associations, researchers, community agencies and people living with dementia, either with a diagnosis or as a care partner.

The specific objectives of the symposium are to:

- Identify the needs of people living with dementia and their care partners
- Identify provider challenges
- Develop actionable solutions and strategies
- Build momentum

## The Surveys

As an input to the symposium, the following two surveys were administered in late March and early April 2014:

### A survey for people living with dementia and their care partners

Survey feedback was collected through an online survey and face-to-face meetings. Survey responses were received from 16 respondents.

The following survey questions were asked:

- Question 1: “What must the health-care system start, stop or continue doing to better meet the needs of people with dementia and their caregivers?”
- Question 2: “What programs, tools or other supports have you found useful along your journey?”

### A survey for service providers and other health professionals

Survey results were collected through an online survey. Survey responses were received from 46 respondents.

The following questions were asked:

- Question 1: “What challenges are limiting primary care’s ability to respond effectively to the needs of community-dwelling people with dementia and their caregivers?”
- Question 2: What programs, tools or other supports have you provided or are aware of that have helped meet the needs of these patients and their caregivers?

## Overview of Survey Feedback

This document contains a synthesis of the responses received from both surveys. The responses are organized by topic and theme. For each topic, a statement of the theme is provided and a sample of corresponding survey responses (shown in italics) is included.

Comments noted with a "(LE)" at the beginning indicate that the feedback was provided by a person with lived experience (with dementia or a care partner).

The feedback was categorized in the following topics:

- Disease identification, assessment and diagnosis
- Meeting holistic needs of person and family
- Time, funding and resources
- System navigation and coordination
- Training and education
- Disease-related sensitivities and complexities
- Community supports and resources

## Using the Notes Text Box

Each of the pages of the document contains a notes box. Please use this space to capture any notes or ideas that may come to mind as you review the material. If you are participating in the symposium, these notes or ideas may be a useful reference for the participant-led agenda setting and discussion portions of the session.

- **Content tagged with a green exclamation point is particularly relevant to the symposium.** ❗

- ***Prompting Questions listed in blue font and italicized are offered for pre-symposium reflection.***

## Definitions of Acronyms

- CCAC = Community Care Access Centre
- CG = Caregiver
- CHC = Community Health Centre
- FHT = Family Health Team
- GP = General Practitioner
- MD = Medical Doctor
- NP = Nurse Practitioner
- OT = Occupational Therapist
- PSW = Personal Support Worker
- PWD = Person with Dementia
- RN = Registered Nurse
- RPN = Registered Practical Nurse

**Notes**:

# The Feedback

## Disease Identification, Assessment and Diagnosis

- There are challenges with early identification, recognition and diagnosis
    - *At times it seems primary care struggles to support patients with early identification and resource information*
    - *There is a reluctance/inability of GPs to appropriately diagnose individuals with dementia, especially in rural areas*
    - *There is a reluctance to address concerns from clients about memory issues or give a diagnosis*
- Accessing a specialized assessment can be a challenge
    - *(LE) The wait for a geriatric assessment is 6-8 months in our area, and there are no follow-up calls for appointments*
    - *(LE) People under 65 years old cannot get access to a geriatric assessment*
    - *It is difficult to get quick access to a cognitive assessment without a physician referral*
    - *Access to Interdisciplinary Assessment Teams is a challenge*

## Meeting Holistic Needs of Person and Family

- There is a need to respond to the role of care partners
    - *(LE) Care partner's own needs often go unaddressed in the presence of the physician – care partners do not want to feel like they are a complainer at a visit for the PWD*
    - *(LE) The health system must recognize the needs of the dyad – both the PWD and the care partner*

***Why do you think the inputs or needs of care partners are not well responded to in primary care settings?***

- Knowledge of available resources is a barrier
    - *There is a lack of knowledge/awareness of community resources to provide support to PWD and caregivers*
    - *Resources are scattered, are often hidden, and are not well known to all providers*
    - *Unsure about the services that are available, particularly in rural areas*

**Notes**:

***Why do you think primary care providers are not better informed about community resources for people living with dementia and their care partners?***

## Provider Time, Funding and Resources

- Health providers lack the time and remuneration needed for dementia patients and their caregivers
    - *There is a lack of time for activities such as needs assessments, house calls, focussing on non-medical issues and time with caregivers*
    - *There is insufficient counselling time required for disclosure of diagnosis, ongoing management and addressing of future planning*
    - *The workload/workflow of primary care limits their ability to provide outreach services*
    - *Compensation is inadequate for the time required to provide appropriate care for these persons and their caregivers*
    - *There is limited willingness to spend time on the assessment, and too much dependence on specialist support*
    - *The government does not see dementia as a priority so there is no 'incentivization', especially from government, to support caregiver or doctor involvement*
- There is a need for additional health human resources
    - *There is a lack of family physicians in our area*
    - *There is inadequate urgent access to dementia specialists*
    - *Greater access to support services is needed, especially consultants in times of crisis*
    - *There is a lack of Advanced Nurse Practitioners trained in dementia care*

***What do you think are the barriers to building the number of or increasing access to primary care providers with training/expertise in dementia care?***

- Additional funding is needed for research and support for medication costs
    - *(LE) More funds should be provided for research for a cure for Alzheimer's and Dementia*
    - *(LE) Aricept is the only medicine covered by OHIP*

## System Navigation and Coordination

- There is a disconnect and lack of coordination between health-care providers and organizations
    - *It is difficult to deploy the needed resources as they are uncoordinated and uneven in accessibility*
    - *Only 20% of primary care is structured like a FHT, the rest is not really a 'system of care'*
    - *Often recommendations from memory clinics are sent to the primary care provider and are not followed-up*
    - *There are challenges bringing a multidisciplinary team together to properly assess and plan for care*
    - *There are communication barriers between care providers*
    - *There are silos of service rather than seamless service with realistic overlaps (hospital, primary care, community)*
    - *Health system services are fragmented, for example, cutbacks to outpatient services or limited number of CCAC visits*
    - *Different referral data requirements can make it more challenging for primary care to refer*
    - *There are too many repetitive and similar forms*
    - *There is a lack of recognition or diagnosis of dementia as part of chronic disease management (CDM)*

***What else do you think gets in the way of health-care/service providers working in a more coordinated way?***

- There is a lack of system navigation across care providers
    - *Case management support of multiple complex health problems over multiple providers is needed*
    - *There is no follow-up to see if recommendations are followed through, if they worked, if person has confidence and has conviction to implement recommendations*
    - *There is inadequate regional system navigation and referral tools that both MDs and persons with dementia / family can use*
- The role of primary care is not well-defined
    - *There are variable definitions of 'primary care' – it could mean individual family physicians, or publicly funded groups such as*

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*CHCs/FHTs or the activities of clinical micro-systems at a sub-LHIN level – thus roles, accountability and access to funding are not clear*

  - *Not all settings are embracing the full scope of practice of primary care nurses (RN, RPN and NP) and other primary care providers*
  - *Programs that do not recognize the role of family physicians as expert coordinators, navigators for their patients; it is rare for patients with dementia to have a single diagnosis of dementia; comprehensive approaches to the care of the elderly are needed*

## Training and Education for Care Providers

- Many care providers do not have the necessary knowledge, training and expertise
  - *Many physicians lack the knowledge/understanding of dementia and how to communicate diagnosis effectively*
  - *There is inadequate teaching in concepts other than diagnosis or drugs – concepts of care, communication, planning*
  - *(LE) General practitioners need skills and understanding to address role and concerns of the care partner*
  - *Solo physicians do not have capacity for continuing education*
  - *Providers do not have the language skills or cultural competencies required to serve the diverse population (i.e., they do not understand the delusions, etc.)*
  - *There is a lack of uptake of evidence-based practice (i.e. clinical practice guidelines)*
  - *There is a lack of knowledge of behavioural symptoms*
  - *There is a lack of knowledge about dementias and how to link patients with community resources*
  - *There are not many trained to assess early dementia*
  - *There is a lack of patient, caregiver, and family education*

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## Disease-Related Sensitivities and Complexities

- There are societal stigmas related to the disease
    - *(LE) A campaign to normalize dementia would be helpful – the mental illness industry has had success in this vein and that might be a model*
    - *Stigma associated with the dreaded term "Alzheimer's", thus limiting people from seeking help*
- There are difficulties getting consent from patients and families and communicating about difficult and sensitive issues
    - *(LE) Getting consent from PWD is often a barrier to support*
    - *There is an opportunity to expand the knowledge of the cultural implications and interpretations of dementia*
    - *There can be discomfort sharing information about how dementia progresses with patients and caregivers*
    - *Family/patient resistance to accepting help before reaching a crisis level is a challenge*
    - *Dealing with driving issues is a challenge: it is time consuming and difficult for primary care*

***How do cultural differences impact primary care?***

***Why do you think primary care providers have discomfort discussing topics like progression of dementia and driving with patients?***

## Community Supports and Resources

Many survey respondents with lived experience and health-care providers shared challenges and ideas for better supporting the needs of people with dementia living in the community and their care partners through community supports and resources. Though these are out of the scope of what can be addressed in the Primary Care setting they provide important information about system improvements. A summary of these responses can be found in *Appendix A*.

# Appendices

## APPENDIX A - Community Supports and Resources (from surveys)

- There is a need for additional homecare resources as well as community supports and day programs
    - *(LE) There are currently wait lists for support programs, respite and day programs*
    - *(LE) More meetings with persons with the same conditions are needed*
    - *(LE) Dementia is being identified earlier, but many who are under the age of 65 cannot find support programs or get access to services that are considered 'seniors' services*
    - *(LE) Medication errors are a concern – there should be a service available to administer medication, through public health or CCAC*
    - *There is a lack of PSW service for brief daily visits for people who do not require showering or dressing assistance*
    - *24 hour home care is needed*
    - *(LE) Even subsidized day programs are too expensive for many*
- There is a need for continued Alzheimer Society supports and programs
    - *(LE) More personal visits for persons with dementia from the Alzheimer Society are needed*
    - *(LE) Provide more funds to the Alzheimer Society to have more programs available to people with Dementia*
- There is a need for additional caregiver supports and respite programs
    - *(LE) More home care and home support is needed for caregivers*
    - *(LE) There is a six month wait for respite companion programs*
    - *(LE) Provide respite programs with trained people who also assist in transitioning to those programs – there is no use having day programs if person refuses to go so help is needed to get people there*
    - *(LE) Financial assistance should be provided for caregivers at home who have had to leave work to look after loved ones*
    - *The processes for accessing residential respite care are cumbersome*
- There are opportunities to improve the role of the CCAC
    - *(LE) The CCAC is constantly in flux – regarding eligibility criteria, etc. – no set guidelines and fluctuations in rules make things difficult for both people and professions*
    - *(LE) It is hard to get the CCAC to appreciate the care needs of people with cognitive impairment – and for the CCAC to understand the implications of refusal of service*
    - *(LE) The level of service that you receive from the CCAC depends on the particular case manager that you get*

- It can be difficult receiving services from different (unknown) people in a person's home
    - *(LE) Often with PSWs, different people are coming in on different days – it's like a stranger is coming in the house, which is hard for PWD*
    - *Patients and their caregivers have concerns about "outsiders" coming into their homes*
- There is a lack of supportive / affordable housing
    - *Supportive housing options for those with dementia are lacking*
    - *There is a lack of affordable housing with access to a variety of affordable supports while living with family in dignity*
- There is a lack of transportation supports
    - *(LE) Transportation is a barrier to utilization – taxi trips are commonly $30 each way and parking at hospitals is $8*
    - *(LE) Transportation is a particularly difficult issue for PWD who are living alone*
    - *Transportation to programs is lacking*
- Improved access to appropriate long-term care homes is needed
    - *(LE) More nursing homes are needed just for people with Alzheimer's*
    - *There is a lack of timely access to long-term care beds*
    - *More assisted living homes would help transition from home to long-term care; these are available in larger centers but not locally*
    - *(LE) Additional funding is needed for more support workers in long-term care homes*
- Many care providers do not have the necessary knowledge, training and expertise
    - *(LE) More education for front-line workers in hospitals and LTCHs*
    - *(LE) Educate hospital personnel to understand dementia. Not just a seminar, but a true education on how to manage people with dementia, how to speak to them, how much they will not understand about what is going on; make sure people with dementia in hospitals are monitored more closely as they are unable to ask for help*
    - *(LE) Agencies do not know how to deal with responsive behaviours – people with responsive behaviours can lose home care services*

# APPENDIX B - Links to Research-Based Evidence and Comments from Reviewers

## Links to Research-Based Evidence

There has been much research conducted looking at the experience of primary care for both health-care providers and those with lived experience (persons with dementia and their care partners). Two particularly relevant pieces of research reviewed existing literature to identify themes within the primary care setting related to dementia.

- **Prorok JC, Horgan S, Seitz DP. Health care experiences of people with dementia and their caregivers: a meta-ethnographic analysis of qualitative studies. *CMAJ* 2013; 185(14): e669-680.**
- **Aminzadeh, F, Molnar, F., Dalziel, W.B., Ayotte, D. A review of barriers and enablers to diagnosis and management of persons with dementia in primary care. *Canadian Geriatrics Journal;* 2012; 15(3): 85-94.**

*These articles can be found on the Alzheimer Knowledge Exchange (AKE) Resource Centre at: www.akeresourcecentre.org/primarycare.*

Two of the authors of these articles, Dr. Frank Molnar and Jeanette Prorok, were asked to review the synthesis of data collected through the pre-symposium survey conducted for *People, Partners and Possibilities: Transforming Dementia Care in the Community.* They provided comment on how these results compared to their own findings and indicated many of the survey response themes reflect the themes within their research. Their responses can be found on pages 11-13 of this document.

## Reviewer Comments - Jeanette Prorok

***Author***: *Prorok JC, Horgan S, Seitz DP. Health care experiences of people with dementia and their caregivers: a meta-ethnographic analysis of qualitative studies. CMAJ 2013; 185(14): e669-680.*

In April 2014, the Alzheimer Society of Ontario together with the Ontario College of Family Physicians administered a survey to people with dementia and their care partners and health-care providers. Feedback provided by persons with dementia and their caregivers (those with Lived Experience) align with the themes and health service implications identified within a conceptual framework developed by Prorok et al. in a recent meta-ethnographic analysis of qualitative studies examining the healthcare experiences of persons with dementia and their caregivers. The framework proposes four stages of the healthcare experience: seeking information and understanding; identifying the problem; role transition; and living with change.

In the first stage, persons with dementia and their caregivers are commonly met with lengthy waits for assessment and a prolonged path to diagnosis. Similar experiences were echoed by those with lived experience within the theme of disease identification, assessment and diagnosis in the survey. Timely diagnosis is critical, as it can aid in management and long term planning for the dementia journey. In some instances, delays in obtaining a diagnosis may be as a result of a person with lived experience. Campaigns to normalize dementia were suggested by survey respondents, in addition to sensitivity to cultural norms which may discourage people from seeking help.

The health service implications of the second stage of the framework include building capacity for healthcare providers to evaluate cognition. This theme was largely prevalent in survey results. Both system those with lived experience and system providers stressed the need for improved knowledge and understanding. One person with lived experience deemed system provider training in dementia to be “essential”. Beyond the diagnostic stage, increased dementia training was also suggested for frontline hospital and long term care personnel.

The role transition stage identified in the framework states that both persons with dementia and caregivers require support in their new roles. This was also identified by survey respondents, as one person with lived experience commented that care partners own needs often go unaddressed, and another stressed the need for the system to recognize the needs of the person with dementia and caregiver dyad. Several actionable suggestions, aimed at improving support, are provided by those with lived experience in the survey results.

The fourth stage proposed in the healthcare experiences framework is living with change. As persons with dementia and caregivers move forward, they must learn to make continuous lifestyle adjustments to allow for home and community living. Those with lived experience have identified several challenges with respect to this stage. For example, one respondent shares that there is no use in having day programs if the person refuses to attend. They expressed the need for help in getting the person with dementia to attend. Several respondents cited logistical issues such as transportation to and from programs or appointments. Financial constraints may also limit the resources and supports accessed by people with lived experience. One of the health service implications associated with the living with change stage is focusing on current and foreseeable care needs. Those with lived experience have expressed challenges accessing community supports and services that are congruent to their care needs and goals. Several of the comments from people with lived experience support this point, citing specific examples such as the need for age-appropriate programs as well as disease or stage-specific programs. Foreseeable care needs often times include the need for long term care. Many expressed that improved access to appropriate long-term care homes is needed.

The conceptual framework provides general themes and health service implications for each of the proposed stages of the healthcare experience. Though there are several similarities between the framework and survey results, the feedback used to generate the survey themes provides specific suggestions by people with lived experience to meet the needs and challenges encountered in everyday life on the dementia journey. This feedback is valuable and necessary in order to make system improvements which will significantly and positively impact the quality of life of people with dementia and care partners.

## Reviewer Comments - Dr. Frank Molnar

***Author**: Aminzadeh, F, Molnar, F, Dalziel, WB, Ayotte, D. A review of barriers and enablers to diagnosis and management of persons with dementia in primary care. Canadian Geriatrics Journal; 2012; 15(3): 85-94.*

The People, Partners and Possibilities: Transforming Dementia Care in the Community pre-symposium survey results affirmed many of the findings from our review of the literature related to barriers and enablers to diagnosis and management of persons with dementia in primary care.

Related to challenges with early identification, recognition and diagnosis and the reluctance to address concerns from clients about memory issues or give a diagnosis, there is evidence that many Primary Care Physicians (PCP) have difficulty recognizing the early symptoms of dementia and/or tend to overlook their importance. For instance, many PCPs express low confidence in making a diagnosis of dementia particularly in the early stages of the disease, feel that their training has been insufficient to prepare them for this task, and express a strong desire for a specialist consultation. There is evidence that many PCP view the diagnosis and management of dementia disorders as being more complex than other chronic conditions, both biologically and psychosocially. Across studies, between one-third to three-quarters of PCP question their ability to address various aspects of dementia diagnosis, such as recognizing the significance of early symptoms, identifying dementia sub-types, and making an accurate diagnosis.

However, many PCP remain unaware of the existing Clinical Practice Guidelines (CPG), are unfamiliar with the specific content, and question the credibility, applicability, and feasibility of the recommendations. Given the multifaceted nature of the obstacles to the use of CPG, combined strategies are needed to overcome them. The following approaches are worth considering: a) adopting multiple and more active dissemination strategies; b) making the guidelines available in user-friendly, concise, and varied formats; c) including PCP in the development process; d) seeking input of PWD/ caregivers to capture their perspectives and experiences; e) minimizing the influence of pharmaceutical companies' funding which can undermine the objectivity and credibility of the guidelines; f) conducting more targeted research to better inform guideline recommendations; g) making attempts to "synchronize" related guidelines to minimize "guideline fatigue"; h) implementing strategies to support their local adaptation; and i) using information technology, including electronic decision supports and health records, with integrated reminders for guideline implementation.

Survey respondents also noted that it is difficult to get quick access to specialized cognitive assessment without a physician referral, however, Canadian and international research point to the high rates of referrals of suspected cases of dementia from PCP to medical specialists. These referrals are not always preceded by adequate diagnostic investigations and/ or deemed appropriate by the specialists.

As described by survey respondents with lived experience, several review papers and surveys/ qualitative studies of family caregivers reveal some level of dissatisfaction with the manner of disclosure, the transference of critical information, post-diagnosis guidance, and follow up psychosocial support provided by PCP.. Moreover, there is evidence that many PCP have great difficulty managing the broader quality of life and psychosocial needs of persons with dementia/caregivers after a dementia diagnosis is made. Some PCP express greater confidence in their diagnostic competence compared to their communication and management skills, especially with regard to support needs. In a number of Canadian and international studies, many PCP readily admit that they are insufficiently informed about the available support services for people with dementia/ caregivers. This has been identified as a major obstacle to a more comprehensive approach to primary dementia care. This reflects a narrow paradigm that is largely constrained by the traditional bio-medical definitions of "treatment".

The realities of primary care can constrain the ability of PCP to provide quality care to PWD/caregivers. For instance, insufficient time, which many PCP identify as being the single most important barrier to optimal dementia care, is closely linked to the inadequate payment models adopted in most health-care systems in Western nations. The reactive, time-limited care systems that reward brief medical encounters present significant barriers to timely dementia diagnosis and optimal management. However, there is a growing recognition that the current state of affairs, in which practice is skewed towards brief office based assessments with referral to specialists for diagnosis and early management, and blanket referrals to community organizations that may or may not be appropriate and that are not linked in time or place to the primary care practices, is not effective and/or sustainable.

Under the theme of system navigation and coordination the research also corroborates participant responses. A recent innovation in this field is the creation of interdisciplinary memory clinics within primary care settings. The emerging evidence point to the potential benefits of these programs in building capacity within primary care, while improving the efficacy of the use of specialist expertise. The common features of these more intensive interventions are that they incorporate a combination of the following key strategies: a) the use of multidisciplinary teams of clinicians with relevant expertise (as opposed to the traditional models of primary medical care in which PCP take the full responsibility for patient care); b) on-going care management, typically coordinated by a nurse working closely with the PWD/caregiver, attending PCP, and other care providers; c) the provision of formal dementia training for PCP (and other clinic staff), including access to an advanced practice geriatric nurse and/or a medical specialist for educational detailing and consultation; d) the use of standard tools, protocols, and guidelines to ensure active case finding and consistent care processes; e) access to various types of information technology resources (e.g., electronic patient records, medical record prompts, decision support tools, and Internet-based care management systems); f) the provision of education and support for PWD/caregivers in collaboration with community agencies, such as local Alzheimer Societies; and finally, g) regular patient follow-ups to monitor care processes and outcomes.

Survey results identified that many care providers do not have the necessary knowledge, training and expertise and that there is inadequate teaching in concepts other than diagnosis or drugs such as concepts of care, communication, and planning. According to the research, some PCP express greater confidence in their diagnostic competence compared to their communication and management skills, especially with regard to the support needs of people with dementia/caregivers. This has been identified as a major obstacle to a more comprehensive approach to primary dementia care.

Traditional passive strategies (e.g., lecture style educational meetings, guidelines and other printed materials, and passive media), especially if used alone, have generally proved to be less effective compared to the combined intervention strategies utilizing more interactive approaches (e.g., audit and feedback, small group interactive scenario–discussion workshops, educational outreach visits, and decision support systems). Using interactive approaches, case studies have been successfully used in multidisciplinary working groups.. Among other dementia knowledge transfer approaches that have received some research interest is the on-site outreach academic detailing (by other physicians and/ or interdisciplinary clinicians). The goal is to provide more contextualized dementia training to PCP, facilitate the adaptation of guidelines, and/or promote the use of local resources. The positive outcomes reported so far include: a) increased referral to local community agencies; b) self-reported positive effects on knowledge, confidence, skills, and motivation to work with PWD; and c) improved adherence to guidelines. The main barriers were perceived time constraints and the reluctance of some PCP to receive education from non-physician clinicians. Furthermore, a variety of computer-based learning methods (e.g., computer-assisted learning packages, computer decision-support systems, and computer-based audit and feedback tools) have been developed and tested. Such products have the advantages of low cost and adaptability for individual learning and practice styles. However, emerging international research on their feasibility and effectiveness for dementia training in various primary care settings reveals continued pragmatic challenges (e.g., lack of access, time and skills in using them) and only modest results so far.