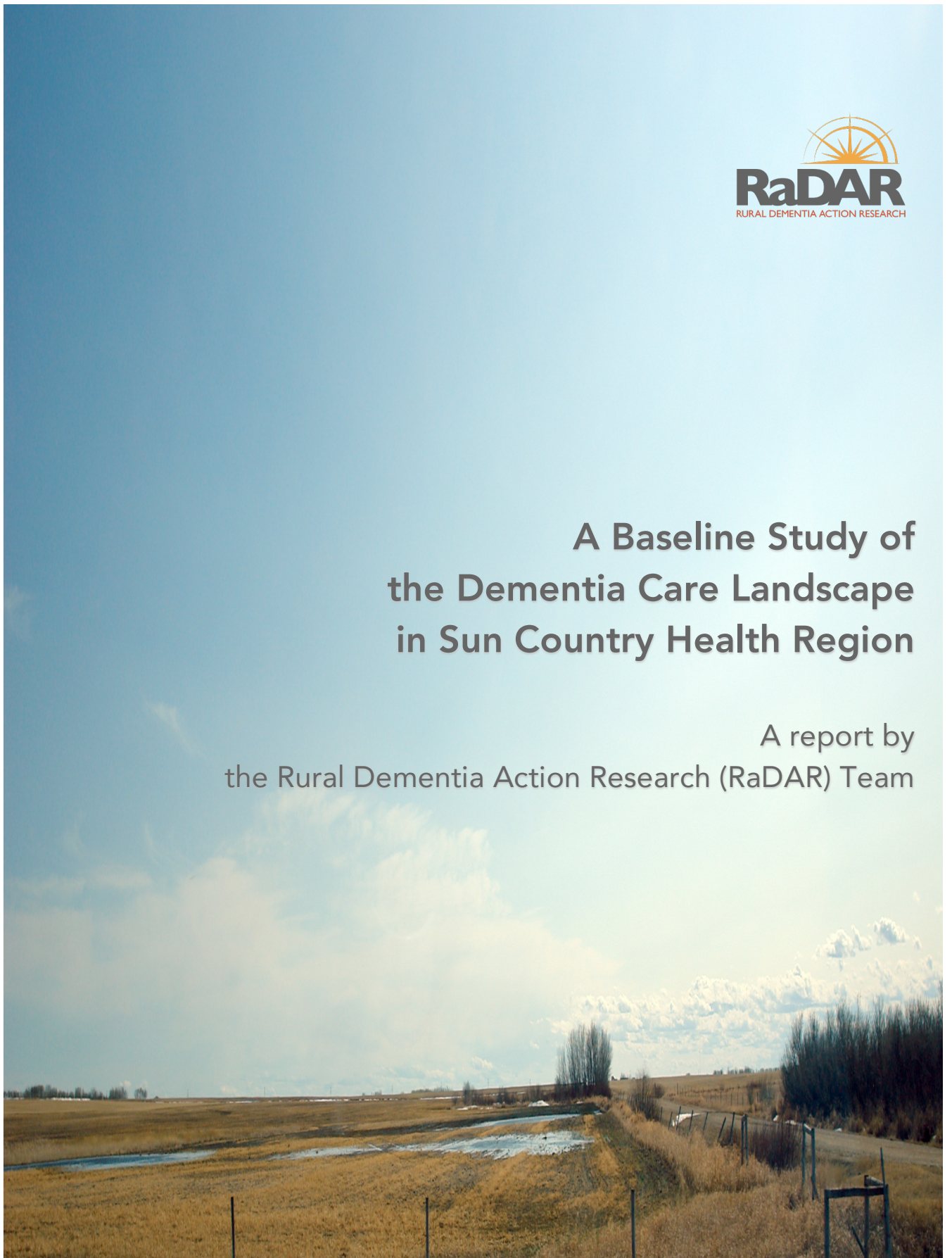**RaDAR**
RURAL DEMENTIA ACTION RESEARCH

A Baseline Study of
the Dementia Care Landscape
in Sun Country Health Region

A report by
the Rural Dementia Action Research (RaDAR) Team

Contents

Background

New models of primary health care (PHC) to address the many challenges of dementia diagnosis and treatment have been tested in Canada and elsewhere. The most effective and comprehensive models have several main elements in common, which we have integrated into the Rural PHC Dementia Model (Figure 1).

Figure 1. Rural Primary Health Care (PHC) Dementia Model

Care co-ordination	Decision support tools	Specialist to provider support
- Multidisciplinary team - Ongoing care management for patients with dementia - Regular follow-up for patients with dementia - Education/support for patients with dementia and caregivers	- Standard tools, guidelines, protocols - Access to IT resources	- Access to dementia specialists - Formal dementia education for all providers

elements based on Aminzadeh et al. (2012)

Some elements of the Rural PHC Dementia Model already exist in primary health care teams throughout Saskatchewan, including Sun Country Health Region. Other elements will be introduced as part of a 5-year study (2014-2019) undertaken by the Rural Dementia Action Research (RaDAR) Team.

Phase 1 of a 5-year RaDAR study involved a baseline assessment of dementia care best practice gaps and strengths across Sun Country Health Region, with a particular focus on primary health care teams. **This report presents the findings of the baseline assessment.**

Summary

Thirty-two (N = 32) one-on-one telephone interviews were conducted with primary health care team members, decision-makers, and patients/caregivers in Sun Country Health Region in 2015.

The majority of PHC team members agreed that *care co-ordination* elements of the **Rural PHC Dementia Model** were present in their team for patients with dementia (68-89%) and were less likely to agree that they had access to *decision support tools* (47-63%) and *specialist-to-provider support* (16-21%).

In terms of **assessment best practices**, the large majority of team members (84-100%) indicated that the assessment of patients with suspected dementia by their team involved collecting collateral information, conducting a complete medical history, and administering a formal cognitive assessment and depression assessment. The majority (68%) reported that their team completed a physical exam and referred for comprehensive bloodwork. Team members were less likely (42-53%) to report that patients were typically referred to a specialist when warranted (e.g., suspicion of early onset dementia).

The large majority of team members (84%) reported that they personally regularly administer **standardized testing** such as the MMSE to individuals with suspected dementia, and the majority (74%) regularly administer the clock drawing test and activities of daily living instrument. Team members were less likely (32-58%) to personally regularly administer the MoCA, trail making test, instrumental activities of daily living and geriatric depression scale.

The large majority of team members (79-89%) reported following **management best practices** in terms of referring patients for Home Care Assessment, giving advice about safety issues, prescribing anti-dementia medications, making patients aware of changes in medication management and driving capacity (as part of planning for the future), providing information on community services to patients, and asking caregivers about how they were managing. The majority of respondents (58-74%) also indicated that their team discussed non-pharmacologic management options and medicolegal issues with patients, assessed patients for behavioural and psychological issues, made patients aware of changes in functioning independence, notified SGI about patients' medical condition with respect to driving ability, referred patients to the Alzheimer Society First Link, and gave advice to caregivers regarding respite care. Respondents were less likely to report that their team flagged patient records to indicate a dementia diagnosis (16%) and no respondents reported providing or referring caregiver training (psychosocial management).

Only a small minority of family physicians and nurse practitioners (11%) agreed that **specialist access** was adequate for patients with dementia or suspected dementia. A minority reported that they always (44%) or sometimes (33%) refer patients to neurologists; a further 33% sometimes refer to other specialists.

Good team communication and the relative lack of anonymity in small communities (which allowed changes in patient behaviour to be noticed relatively quickly) were the

most frequent **PHC team strengths** cited by team members in terms of assessing patients with suspected dementia. Good team communication was also noted as a top strength in diagnosing and managing patients. Team members noted that patient/family resistance to assessment and low access to specialists were the most frequent **PHC team challenges** in assessment and diagnosis. Inadequate local community resources were cited as the most frequent challenge in managing patients with dementia (e.g., day programs and respite).

Overall, in terms of **PHC team effectiveness** regarding dementia care, 79% of PHC team members agreed that their team effectively assesses patients, 63% agreed that their team effectively diagnoses, and 63% agreed that their team effectively manages patients with suspected dementia.

Health human resources in terms of strong leadership and staff, capable physicians and nurse practitioners, and good team communication, were cited as top **health region strengths** in dementia care by decision-makers. Decision-makers noted that difficulty establishing a dementia diagnosis was the top **health region challenge** in dementia care.

Regarding **PHC team and community strengths** from the viewpoint of patients/caregivers, they described care received from their PHC teams as personal, attentive, and informative. Communities were described as inclusive and helpful from the time respondents or their family members first start experiencing symptoms or are diagnosed with dementia.

Study limitations

It must be noted that family physicians from PHC teams were under-represented in this study. Furthermore, the small sample sizes of each of the three groups (PHC team members, decision-makers, and patients/caregivers) may not be representative of their respective populations in Sun Country Health Region. These **limitations** are factors that limit the generalizability of the study findings to the health region as a whole.

Background

Dementia refers to a clinical syndrome of deterioration in cognition that negatively affects daily functioning, and is not an outcome of delirium or another condition (i.e., medical, neurological, or psychiatric) [Chertkow et al. 2013]. Alzheimer's disease is the most common cause of dementia (50-75%), followed by vascular dementia (20-30%), frontotemporal dementia (5-10%), and dementia with Lewy bodies (<5%) [Alzheimer's Disease International (ADI) 2014].

An estimated 46.8 people currently live with dementia worldwide, and an estimated 9.9 million develop dementia each year [ADI 2015]. Those living with dementia in Canada will likely exceed 1.1 million within the next 20 years, according to the national Rising Tide report [Dudgeon 2010]. In Saskatchewan, 13,200 individuals were identified as currently living dementia (dementia prevalence) through contact with the health care system (hospital, physician, prescription drug, long-term care) [Kosteniuk et al. 2015]. However, this figure is likely an underestimate of true prevalence since dementia is significantly underdiagnosed in the health care systems of many countries [Bradford et al. 2009].

Since 2008, 39 clinical guideline groups worldwide have proposed recommendations for the diagnosis and treatment of dementia [Ngo and Holroyd-Leduc, 2015], including the 4th Canadian Consensus Conference Guideline Working Group [Gauthier et al. 2012]. Regardless of guidelines, diagnosing and managing dementia can be complex and time-consuming. Without a diagnosis, it can be challenging for individuals with dementia and their families to readily access the necessary services and resources.

New models of primary health care to address the many challenges of dementia diagnosis and treatment have been tested in Canada [Lee et al. 2010, Moore et al. 2012] and elsewhere [Austrom et al 2006, Banerjee et al. 2007, Stellefson et al. 2013, Callahan et al. 2014]. The most effective and comprehensive models have several main elements in common [Aminzadeh et al. 2012]. The elements most relevant to rural primary health care are summarized in **Figure 1**, within the three domains of *care co-ordination*, *decision support tools*, and *specialist-to-provider support*.

Some elements of the Rural PHC Dementia Model already exist in primary health care teams throughout Saskatchewan, including Sun Country Health Region – these features are notable strengths of PHC teams.

Figure 1. Rural Primary Health Care (PHC) Dementia Model		
Care co-ordination	Decision support tools	Specialist to provider support
- Multidisciplinary team - Ongoing care management for patients with dementia - Regular follow-up for patients with dementia - Education/support for patients with dementia and caregivers	- Standard tools, guidelines, protocols - Access to IT resources	- Access to dementia specialists - Formal dementia education for all providers
elements based on Aminzadeh et al. (2012)		

For instance, multidisciplinary team care is a key feature of primary health care [Saskatchewan Ministry of Health 2012], as is access to information technology (IT) resources such as electronic medical records. Standardized care is also provided to patients with certain chronic conditions under the provincial Chronic Disease Management Quality Improvement Program (CDM-QIP), which in turn facilitates ongoing care management and regular follow-up care [SMA CDM-QIP 2015].

However, several elements of the Rural PHC Dementia Model will be new to Saskatchewan primary health care, and will be introduced as part of a 5-year study (2014-2019) undertaken by the Rural Dementia Action Research (RaDAR) Team. Based at the University of Saskatchewan and led by Dr. Debra Morgan, RaDAR is part of a collaboration of 370+ researchers across Canada known as the Canadian Consortium on Neurodegeneration on Aging (CCNA). More information about RaDAR's initiative in Sun Country Health Region can be found on the CCNA [http://goo.gl/8TStR6] and RaDAR website [http://goo.gl/emrxjA].

Phase 1 of a 5-year RaDAR study focused at the regional level with a baseline assessment of dementia care best practice gaps and strengths across Sun Country Health Region. After establishing the regional Dementia Steering Group in 2013 (which meets every 3 months), the RaDAR team conducted a baseline assessment of dementia care best practice gaps and strengths focused on the 8 primary health care (PHC) teams in the health region at the time of the assessment in 2015. The methods

of the baseline assessment are outlined in **Box 1**. **This report presents the findings of the baseline assessment.**

Phase 2 began with an active collaboration between RaDAR and the Kipling PHC team in 2015 to operationalize the Rural PHC Dementia Model and essentially develop, adapt, and implement best practices in dementia care to fit the local context of the PHC team and community. Additional PHC teams will be invited to collaborate with RaDAR to adapt and refine the model, and a process evaluation will be conducted with each team to identify the barriers and solutions to implementing best practices in rural dementia care. By the end of the 5-year study, we will conduct a follow-up assessment to determine whether a change occurred between baseline and follow-up in best practice gaps and strengths in dementia care across the Sun Country Health Region.

Box 1. Methods

Baseline Assessment of Best Practice Gaps and Strengths

Three distinct groups were sampled as part of the baseline assessment: primary health care team members, regional decision-makers, and patients/caregivers. Data collection took place by one-on-one telephone interview with each respondent.

Data collection

1. Primary Health Care (PHC) Teams

    Data collection took place May to September, 2015. In April, 2015, an email invitation was sent to the regional managers of the health care professionals serving the 8 primary health care (PHC) teams in Sun Country Health Region. The regional managers forwarded the email invitation to all family physicians, nurse practitioners, occupational therapists, and home care nurses associated with the 8 PHC teams in the region (total of 31 health care professionals). The email invitation included a request to contact the study coordinator to arrange a telephone interview.

    Given that this initial invitation generated a low response, the regional managers provided the coordinator with the work email addresses and telephone numbers of potential respondents for follow-up contact. The study coordinator subsequently directly contacted all potential respondents who had not already responded. Once the dates of telephone interviews had been arranged, the coordinator emailed a consent form for the respondent to review before the interview.

2. Regional decision-makers

    Data collection took place February to May, 2015. In January, 2015, a consent form and invitation were sent to all members of the Sun Country Dementia Steering Group and PHC facilitators. Respondents were asked to contact the study coordinator to arrange a telephone interview. A study reminder was emailed to all non-respondents in February, 2015.

3. Patients and caregivers

    Data collection took place March to June, 2015. In January, 2015, an email invitation was sent to the nurse practitioners serving the 8 primary health care (PHC) teams in Sun Country Health Region. Each nurse was requested to pass along research packages to no more than 10 patients or caregivers. Each research package contained a consent form and an invitation to contact the study coordinator to arrange a telephone interview. An honorarium in the form of a $35 Visa gift card was offered to respondents.

    Eligible patients were aged 45 or older, lived either in the community or in long-term care, received a diagnosis of dementia while a patient of one of the 8 PHC teams in Sun Country Health Region, and was cognitively capable of taking part in a telephone interview conducted in English. Caregivers were eligible for the study if they were able to take part in an interview conducted in English, and were a spouse, child, relative, or friend of an individual (in either the community or in long-term care) who received a diagnosis of

dementia while a patient of one of the 8 PHC teams in Sun Country Health Region. Nurse practitioners asked permission from interested patients and caregivers to transmit their name and contact information to the study coordinator, and the coordinator then contacted interested patients and caregivers directly. A caregiver recruitment poster was also posted in the clinics of the 8 PHC teams.

Questionnaire development

Three separate questionnaires were developed for this baseline study, and are available upon request from the RaDAR lead (debra.morgan@usask.ca).

The PHC team questionnaire consisted of the following sections related specifically to patients with dementia unless otherwise specified: 1) respondent demographics and professional position, 2) strengths and gaps in dementia care, 3) elements of the Rural PHC Dementia Model, 4) assessment, 5) diagnosis, 6) management, 7) referral, and 8) continuing education. The development of the PHC team questionnaire was informed by relevant literature regarding best practices in dementia care [Glasser and Miller 1998, Aminzadeh et al. 2012, BC Guidelines 2014, Moore et al. 2014, Murphy et al. 2014, Ngo and Holroyd-Leduc 2014, Parmar et al. 2014]. Pilot testing of the survey questionnaire took place in Kelsey Trail Health Region, conducted by Kathleen Kulyk in the College of Nursing, University of Saskatchewan.

The regional decision-maker questionnaire included questions regarding respondent demographics and professional position, as well as the following issues related to individuals with dementia and their families: strengths and gaps in current care pathways, information and education, accessibility, care co-ordination, population orientation, comprehensiveness, and quality of care. Development of the questionnaire was informed by a previous environmental scan of dementia-related services across Saskatchewan [Morgan et al. 2015 HHCSQ].

The patient/caregiver questionnaire focused on patients' and caregivers' experiences during the processes of assessment, diagnosis, and management, and the strengths of the patients' primary care providers and communities [Glasser and Miller 1998; Murphy et al. 2014; Singh et al. 2014].

Ethical approval

This study received approval from the Behavioural Research Ethics Board of the University of Saskatchewan (BEH #14-435; pilot study BEH #14-474).

Response rates
- PHC team members – 19 of 31 eligible individuals completed a telephone interview (61% response rate)
- Regional decision-makers – 9 of 11 eligible individuals completed a telephone interview (82% response rate)
- 4 patients/caregivers – the rate of patient/caregiver reponse was not calculated due to the recruitment method (purposive sampling and clinic poster)

Respondent characteristics

Characteristics of the interview participants (Primary Health Care team members) are presented in **Table 1**. Eight PHC teams in Sun Country Health Region are represented in this baseline study, with two members each taking part from four teams (Carnduff, Lampan/Estevan, Maryfield, Weyburn), three members from one team (Carlyle), and four members each from two teams (Bengough/Radville and Kipling). Three of the Bengough/Radville PHC team members were also members of the Coronach PHC team.

The majority of respondents had practiced with their current PHC team for less than 5 years (58%; $n = 11$), and attained their highest level of education within the last 14 years (53%; $n = 10$). Most respondents indicated that their role encompasses most aspects of dementia care, with the exception of medication prescription (42%; $n = 8$) and diagnosis (42%; $n = 8$). Most respondents indicated that their teams hold regular team meetings (74%; $n = 14$).

Table 1. PHC Team member characteristics (N = 19)

	n (%)
Location of Primary Health Care (PHC) Team member	
Bengough/Radville	4 (21)
Carlyle	3 (16)
Carnduff	2 (11)
Kipling	4 (21)
Lampman/Estevan	2 (11)
Maryfield	2 (11)
Weyburn	2 (11)
Position on PHC Team	
Family Physician	3 (16)
Nurse Practitioner	6 (32)
Occupational Therapist	5 (26)
Home Care Nurse	5 (26)

Table 1. PHC Team member characteristics (N = 19)

	n
Years practiced with current PHC team (mean, SD)	
Fewer than 2	6 (32)
2-4	5 (26)
5 or more	8 (42)
Years since attaining highest level of education (mean, SD)	
Fewer than 5	6 (32)
5-14	4 (21)
15 or more	9 (47)
Role responsibilities	
Prescribing medication for dementia	8 (42)
Case finding and screening	14 (74)
Assessment	17 (89)
Diagnosis	8 (42)
Care Planning	18 (95)
Implementation and management of care plan	17 (89)
Proactive monitoring of patients	16 (84)
Review	18 (95)
PHC team holds regular team meetings	
Yes	14 (74)
No	4 (21)
No reply	1 (5)

Rural PHC Dementia Model

Primary health care (PHC) team members were asked whether the elements of the Rural PHC Dementia Model (**Figure 1**) could be found in their particular PHC team with respect to patients with dementia (5-point response scale from 'agree' to 'disagree').

As shown in **Figure 2**, the element of multidisciplinary team care for patients with dementia can be found in their PHC team according to 89% (*n* = 17), ongoing care management for patients with dementia by 85% (*n* = 16), and regular follow-up for patients with dementia by 68 percent (*n* = 13).

According to **Figure 3**, 21% (*n* = 4) agreed that access to formal dementia training for health care professionals and other clinic staff is an element of their PHC team. A further 16% (*n* = 3) agreed that access to dementia specialists is an element of their team, and 63% (*n* = 12) agreed that access to IT resources (e.g. EMR, decision support tools) is also an element of their PHC team.

As seen in **Figure 4**, the use of standard tools, protocols or guidelines to support consistent care for dementia was reported to be an element of their PHC team by 47% (*n* = 9), personal access to EMR by 53%, and support for patients with dementia or caregivers in collaboration with community agencies also by 53 percent (*n* = 10).

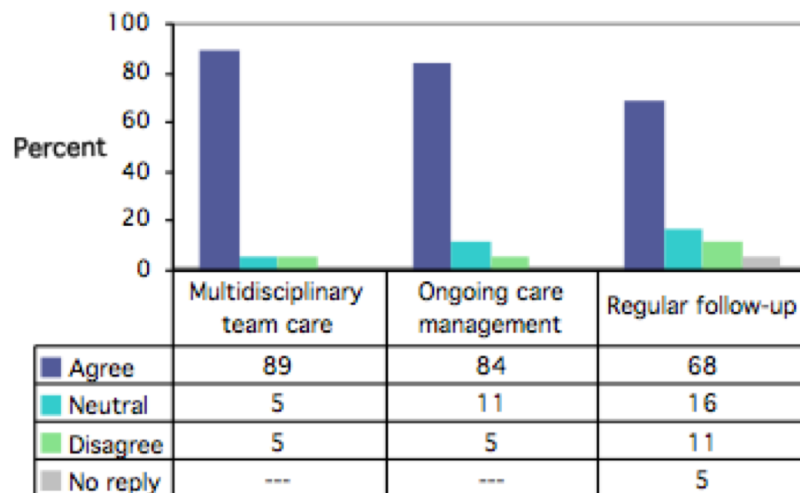|	Multidisciplinary team care	Ongoing care management	Regular follow-up
Agree	89	84	68
Neutral	5	11	16
Disagree	5	5	11
No reply	---	---	5

Figure 2. PHC team: multidisciplinary team care, ongoing care management, and regular follow-up (N = 19)

	Access to training	Access to specialists	Access to IT resources
Agree	21	16	63
Neutral	37	21	16
Disagree	37	47	21
No reply	5	5	---

Figure 3. PHC team: access to training, specialists, and IT resources (N = 19)

	Use of standard tools, protocols, or guidelines	Personal access to EMR	Support from community agencies
Agree	47	53	53
Neutral	21	---	32
Disagree	26	47	11
No reply	5	11	5

Figure 4. PHC team: use of standard tools, personal access to EMR, support from community agencies (N = 19)

Assessment

Team awareness of changes in patient cognition or behaviour

PHC team members reported on the main ways that they typically first become aware of changes in cognition or behaviour in patients that cause them to suspect dementia. The three main 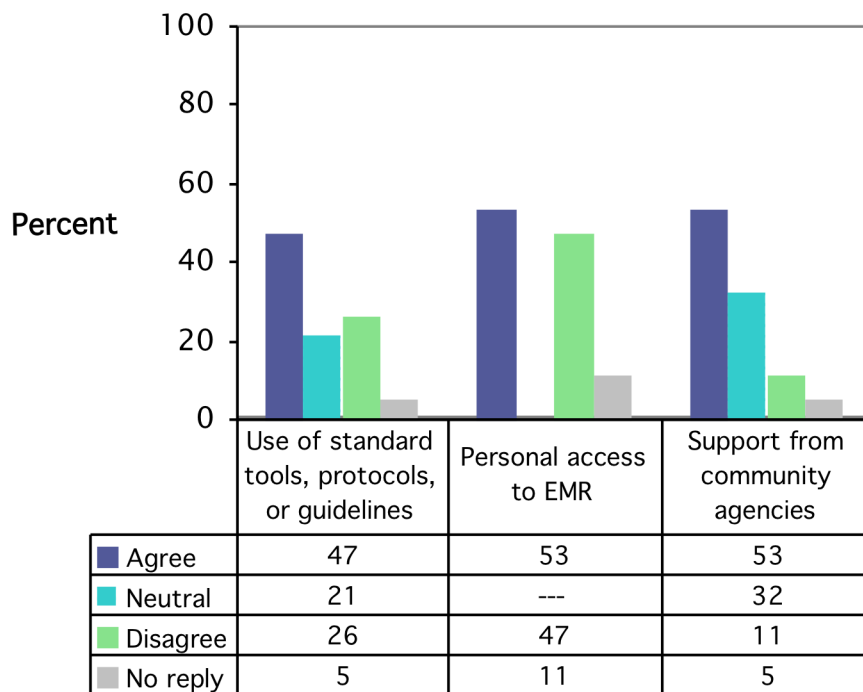sources were family members, patient visits, and referrals from other team members (some respondents provided multiple responses):

- contact by family members (42%; $n = 8$)
- routine patient visits for other reasons (37%; $n = 7$)
- referrals from other PHC team members (37%; $n = 7$)

A small minority of respondents ($n = 2$) also indicated that they first become aware of possible dementia in patients through contact from community members.

> "It would either be through my visits to them or it would be through the family, family would consult me and say, 'have you noticed that Mom and Dad do this or this? This is what we're noticing.' Sometimes it's referral from the doctor or the nurse practitioner." (PHC07)

> "Usually at routine visits, noting that patients, as I call it, talk a lot about nothing; so … their demeanor, as well as their language." (PHC16)

> "…something that we started doing in our vascular clinic, so we do a lower-leg assessment of anybody over the age of, I think it's 70, we get them to draw a clock and if the clock is wrong, then we think hmm…" (PHC05)

> "Usually they come with a family member; one patient came with his wife, he's denying the symptoms and his wife is insisting that he's losing his way and forgetting his keys and those issues. And another came, and the daughter was so worried about her Mom, actually, so usually the family member is the one who brings the patient." (PHC10)

> "It is often their family members contacting us and in the small communities it's us being stopped in the street and 'you guys need to see Mrs. So and So'." (PHC19)

Team communication about changes in patient cognition and behaviour

Two main avenues of communication between PHC team members regarding changes in patient cognition and behaviour were reported by respondents (some respondents provided multiple responses):

- Electronic medical record (42%; *n* = 8)
- Personal conversation by telephone or face-to-face (32%; *n* = 6)

    "We're a really small team so we see each other fairly frequently, so it's usually like verbally discussing problems with the patient." (PHC17)

    "Partly through the medical record, electronic medical record, which I mean, that's how everything's communicated between some of us and, like I say, the Home Care nurse is here in the building. Those two days that she works every week, I mean there's never a week that she and I aren't discussing some patient. So just in an informal meeting." (PHC03)

    "It would have probably been all of them [all of the ways], face to face, EMR, it would have been on the referral forms, hard copy." (PHC13)

Assessment best practices

Respondents were asked (yes/no) whether the assessment of patients with suspected dementia conducted by their PHC team generally involved the best practices listed in **Table 2**. These best practices were derived from the relevant literature, as noted in **Box 1**. Respondents were asked to keep the last few patients of their team in mind for these questions, if this tactic proved helpful.

Table 2. Assessment Best Practices (N = 19)

Best Practice	Yes n (%)	No n (%)	Unsure n (%)	n/a* n (%)
Was a complete medical history conducted?	16 (84)	1 (5)	2 (11)	--
Was a physical exam conducted?	13 (68)	3 (16)	3 (16)	--
Was collateral information obtained from family and caregivers to assist with assessment, for instance, information on basic activities of daily living and instrumental activities of daily living?	19 (100)	--	--	--
Was a formal cognitive assessment conducted using a standardized test for individuals with suspected cognitive impairment?	19 (100)	--	--	--
Were patients assessed for co-morbid depression using a validated tool?	16 (84)	1 (5)	2 (11)	--
Were patients referred for comprehensive bloodwork?	13 (68)	1 (5)	5 (26)	--
Were the following causes of cognitive impairment ruled out?				
• Delirium	18 (95)	1 (5)	--	--
• Alcohol dependence	15 (79)	3 (16)	1 (5)	--
• Co-morbid diseases	18 (95)	--	--	1 (5)
• Adverse drug effects or polypharmacy	15 (79)	2 (11)	--	2 (11)
Was a standardized scale for staging dementia used (e.g., Global Deterioration Scale, Clinical Dementia Rating Scale)?	1 (5)	5 (26)	13 (68)	
Are patients typically referred to a specialist for assessment, in the following cases?				
• Early onset (before age 65)	9 (47)	3 (16)	6 (32)	1 (5)
• Rapidly progressive	10 (53)	--	8 (42)	1 (5)
• Diagnostic uncertainty or atypical features	10 (53)	2 (11)	3 (16)	4 (21)
• Management issues that are difficult to resolve	8 (42)	3 (16)	2 (11)	6 (32)
• Risk of harm to self or others	10 (53)	2 (11)	1 (5)	6 (32)

* 'n/a' refers to instances where respondents were not asked these questions

All respondents reported that collateral information was obtained from family/caregivers (100%; *n* = 19) and a formal cognitive assessment was conducted (100%; *n* = 19).

A large majority of respondents noted that a complete medical history was conducted (84%; n = 16), patients were assessed for co-morbid depression (84%; *n* = 16), and other causes of cognitive impairment were ruled out (e.g., delirium according to 95%; *n* = 18).

The majority of respondents also indicated that a physical exam was conducted (68%; n = 13), and patients were referred for comprehensive bloodwork (68%; *n* = 13).

However, respondents were less likely to agree that patients were typically referred to a specialist for assessment when warranted (e.g., suspicion of early onset or rapidly progressive dementia), with 42-53% reporting that their team referred patients to specialists in these instances.

"…not everyone always knows their role. I find that tricky and then communicating like once you have your information, then what? You know, who do you all communicate that with and what's the best way to communicate that with? We don't have things like that ironed out at all." (PHC02)

"I just wish we had better access to you know, behavioural assessments you know. We've actually gone out of province, but I mean that doesn't work very well 'cause they don't really want us out of province, but as far as this part of the world, I don't really know where you'd go for a true say geriatric behavioural assessment. [Where have you sent patients?] Brandon. But there's such a wait list again for that too." (PHC11)

"Oftentimes things are happening for a long time in a person's home before, and we might pick it up on the visit they have here, but for 20 minutes things might seem quite fine and if spouses or other caregivers aren't mentioning it or saying anything, sometimes I'm not sure how early we do kind of get in there to do any kind of intervention." (PHC03)

"I use lots of tools to help make the diagnosis or determine that's what is happening. The problem is after the fact, there's not much in society on the whole and here we don't always have a lot to offer, especially in the rural

setting...We don't have the resources as a society on the whole to help look after people, to help until they get to a point where they need institutionalizing and at that point it's very difficult because of the way things are set up. So a person's loved one might be sent maybe a hundred, 150 km away and typically, the partner or spouse may be in an advanced stage at that time, and can't easily go see them. Very traumatic for everybody." (PHC09)

Team strengths in assessment

PHC team members were asked to describe the mains strengths of their team in assessing patients with dementia. Team communication and the relative lack of anonymity in small communities were the two most frequent strengths cited by respondents (some respondents provided multiple responses):

- Good team communication (26%; *n* = 5)
- Changes in patients' behavior are noticed quickly in their small communities (21%; *n* = 4)
- Team members frequently discuss patients with one another (16%; *n* = 3)
- Availability of local post-diagnosis resources (16%; *n* = 3)
- Multidisciplinary nature of the team (11%; *n* = 2)
- Team-based approach to patient care (11%; *n* = 2)

Other strengths included the involvement of Home Care in arranging services to allow patients to remain in their home (5%; *n* = 1), access to local Alzheimer Society First Link coordinators (5%; *n* = 1), idea-sharing and respect amongst the team (5%; *n* = 1), attention to detail, use of RAI home care assessments (5%; *n* = 1), specialized training of some team members (*n* = 1), the fact that some team members visit patients in the home (5%; *n* = 1), and understanding the 'rural' context of patients (5%; *n* = 1).

"I would say that we're all very close and so it's easy to email, phone call, run into each other on the street kind of thing. I'd say that people stick on the radar a little bit easier and they don't fall through the cracks as much." (PHC13)

"I think we have pretty good access to First Link for patients and families who require or want more education, more counselling on dementia and I think Home Care is really good at following up and putting services in place for people who are still able to live at home and not necessarily ready for long-term care yet." (PHC08)

"The strength of our team is that they're going to be able to hit one-stop shopping. Meaning like there's OT, Home Care, physio, like there's everything, so if they need it, they're going to get it. If they're not eating well, then they're going to see the dietician on the team, if we have questions about the drugs, then we call the pharmacist up and she can see the medications we're doing and what we're doing and make suggestions…" (PHC15)

"I think we're great team players. We have a good working relationship between all entities. And we understand rural, I guess is the other thing 'cause we have some challenges being rural." (PHC11)

"The strengths of our team are that we are small enough that we can have face-to- face mini conferences and we can get fairly quick action and we live in a small community so we know people. We have a lot of background info just by being part of the community. People trust us." (PHC07)

Team challenges in assessment

PHC team members were asked to describe the top 2 or 3 challenges faced by their team in assessing patients with dementia. Resistance to the assessment process on the part of patients and family members topped the challenges, followed by low access to specialists (some respondents provided multiple responses):

- Patient/family resistance to assessment (42%; $n = 8$)
- Low access to specialists (26%; $n = 5$)
- Long wait times for MRI or CT scan (11%; $n = 2$)
- Family members living at a distance (11%; $n = 2$)
- Family conflict (11%; $n = 2$)
- Inadequate local caregiver support (11%; $n = 2$)
- Inadequate communication between team members (11%; $n = 2$)

Other challenges included a lack of proper assessment tools for patients in early stages (5%; $n = 1$), the need for a protocol for conducting assessments (5%; $n = 1$), difficulties interpreting assessments (5%; $n = 1$), knowing when to start patients on medication (5%; $n = 1$), a lack of readily available respite and long-term care space

(5%; *n* = 1), time constraints (5%; *n* = 1), and the absence of case conference between patient, family, and health care providers (5%; *n* = 1).

"There is no two-way communication, unless I try to reach out to them. I talk to the GP, then I talk to the family members, there's no way to communicate at the same place. So that makes it harder to provide accurate assessment." (PHC01)

"Family dynamics. I think so often about people who are living at home and starting to get sick. And the daughter who lives in the same community notices and the daughter's getting burnt out because Mom is needing all this care. And Mom is getting sicker and the brother who lives in Calgary or the sister who lives in Edmonton just don't see eye to eye." (PHC18)

"Sometimes when I see clients that are a little bit earlier on, our assessments might not be as sensitive as they maybe could be, so they'll kind of get through the assessment and there won't be a lot that shows up in the assessment. So I guess properly assessing those people that are earlier on and making sure that we review them regularly so that we can get them diagnosed earlier. So that is a challenge." (PHC14)

"It's sometimes difficult because there is always denial or coping mechanisms that are going along with the dementia. So getting that consent to start some screening is difficult. I think that's about the biggest one and then just how to approach in a respectful and diplomatic manner with the patient is difficult at times." (PHC04)

"Sometimes to get early recognition can be challenging because nobody wants to admit that's what's happening. Either there might be fear if it's the person themselves or from a spouse or partner's situation; they don't want to know that that's actually what's happening. So it could be delayed diagnosis because it's not brought forth in early stages." (PHC09)

Team effectiveness in assessment

As shown in **Figure 5**, a large majority of PHC team members agreed that their team effectively assesses patients with suspected dementia (79%; *n* = 15) [5-point response scale]. A small minority disagreed (11%; *n* = 2) or were neutral (11%; *n* = 2) regarding the issue of effective assessment of patients with suspected dementia.
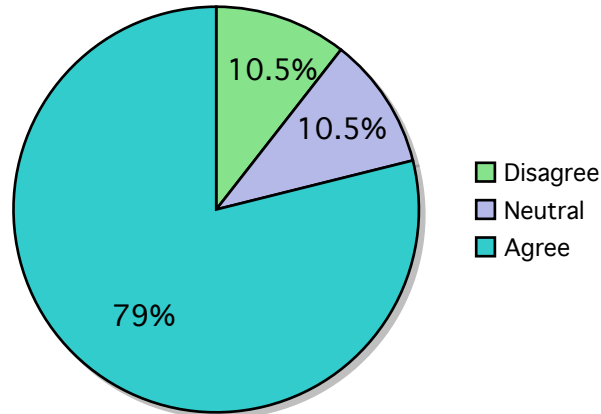

Figure 5. As a whole, my PHC team effectively assesses patients with suspected dementia (N = 19)

Diagnosis

Standardized testing

Team members were asked about the frequency with which they administer 8 different standardized tests to individuals with suspected dementia (**Table 3**) [5-point response scale]. A large majority indicated that they regularly administer the MMSE to individuals with suspected dementia (84%; n = 16). The majority administer the clock drawing test (74%; n = 14), and the activities of daily living test (74%; n = 14). Team members were less likely to regularly administer the MoCA (58%; n = 11), trail making test (47%; n = 9), instrumental activities of daily living (37%; n = 7) and geriatric depression scale (32%; n = 6). Most PHC team members rarely/never administer the Mini-Cog (74%; n = 14).

Table 3. Administration of standardized testing (N = 19)

Standardized tests	Often/ Occasionally n (%)	Rarely/ Never n (%)	Do not know the test n (%)	No reply n (%)
Mini Mental State Examination (MMSE)	16 (84)	3 (16)	0	0
Activities of Daily Living	14 (74)	3 (16)	2 (11)	0
Clock Drawing Test	14 (74)	5 (26)	0	0
Montreal Cognitive Assessment (MoCA)	11 (58)	8 (42)	0	0
Trail Making Test	9 (47)	9 (53)	1	0
Instrumental Activities of Daily Living	7 (37)	7 (37)	2 (11)	3 (16)
Geriatric Depression Scale	6 (32)	13 (68)	0	0
Mini-Cog	0	14 (74)	5 (26)	0

Team communication and documentation of diagnoses

Respondents were asked to describe the frequency with which they communicate and document dementia diagnoses (5-point response scale). As seen in **Figure 6**, the majority of respondents (74%; n = 14) indicated that dementia diagnoses are 'always/frequently' documented in patients' charts or electronic medical records.

Once patients are diagnosed, that diagnosis is 'always/frequently' conveyed to patients according to the majority of respondents (68%; *n* = 13) and a family member is 'always/frequently' present during diagnosis according to the majority (63%; *n* = 12).

When asked whether their PHC team effectively communicates dementia diagnoses to patients and the rest of the PHC team, the majority agreed in both instances (68%; *n* = 13) as per **Figure 7**.
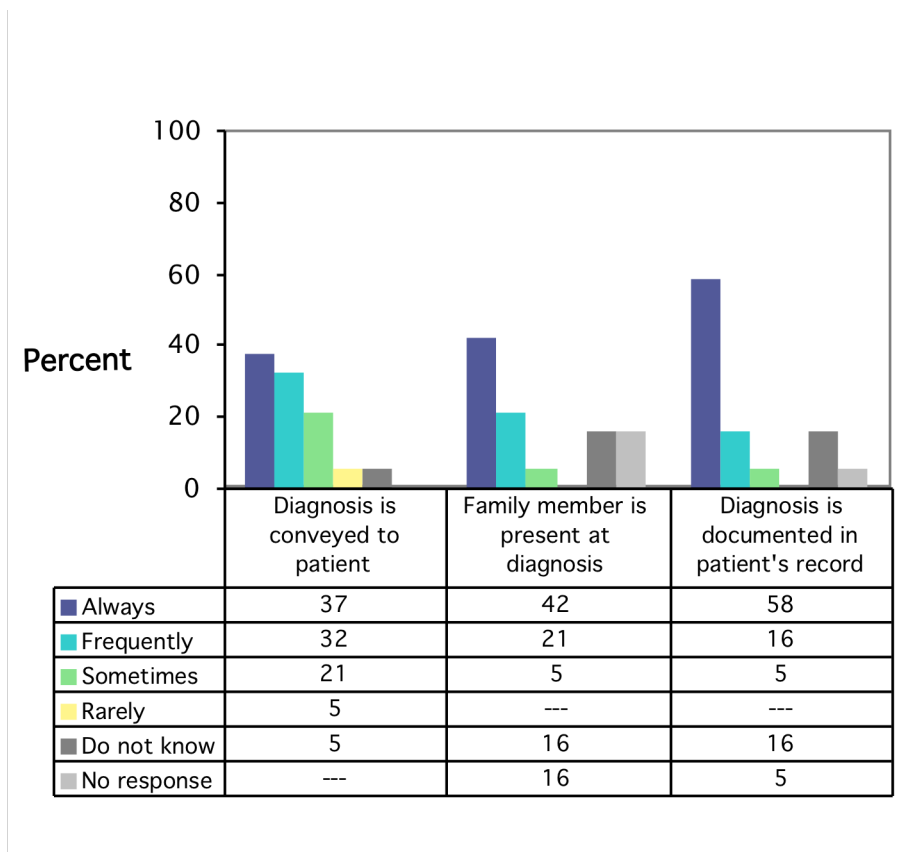
Percent

	Diagnosis is conveyed to patient	Family member is present at diagnosis	Diagnosis is documented in patient's record
■ Always	37	42	58
■ Frequently	32	21	16
■ Sometimes	21	5	5
■ Rarely	5	---	---
■ Do not know	5	16	16
■ No response	---	16	5

Figure 6. Documentation of diagnosis and frequency of diagnosis
communication (N = 19)

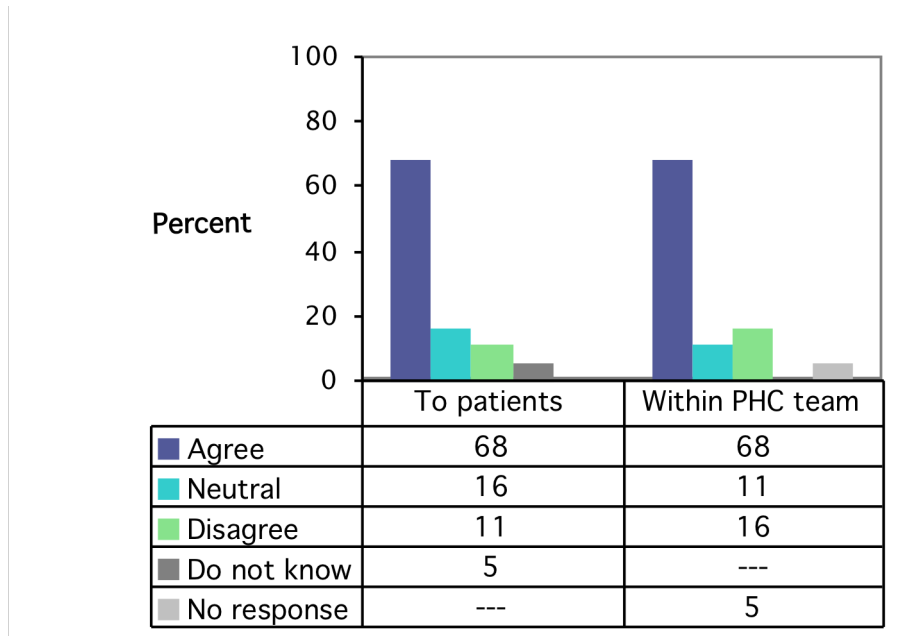|	To patients	Within PHC team
■ Agree	68	68
■ Neutral	16	11
■ Disagree	11	16
■ Do not know	5	---
■ No response	---	5

Figure 7. Communication of dementia diagnoses is effective (N = 19)

Once a PHC team member, or specialist outside of the PHC team, informs patients of their diagnosis, this information is then communicated to the rest of the PHC team primarily in the following ways (some respondents provided multiple responses):

- Electronic medical record (EMR) (47%; *n* = 9)
- Personal conversations by telephone or face-to-face (37%; *n* = 7)

One respondent noted that they may not become aware of a patient's diagnosis until the patient has been admitted to hospital or accesses home care services.

"Well, it could be on the EMR...I think it would probably be more one on one. We don't do a lot of case reviews until it seems like it's a crisis and all of a sudden everybody pulls together and decides we need to talk about this." (PHC14)

"Myself, it would be the electronic medical record and again for between myself and other members of the team, if it's a referral, then it's communicated on the referral form. If it is a Home Care nurse for example, it's going to be informal communication. There's a number of ways there." (PHC03)

"Usually through the EMR, most communication is through the EMR. Or using the fax definitely, because not every part of the team gets access to the EMR. I think Home Care or Social worker don't get access to our EMR." (PHC10)

Team strengths in diagnosis

PHC team members were asked to describe the main strengths of their team in diagnosing patients with dementia. Similar to strengths identified in the assessment process, team communication was the top strength observed by respondents. Additional main strengths were related to the small size of the communities and the PHC teams, and family involvement in the diagnosis process. Two respondents reported that their teams did not have strengths in terms of the diagnosis process (some respondents provided multiple responses):

- Good team communication (21%; $n = 4$)
- Changes in patients' behavior are noticed quickly in small communities (11%; $n = 2$)
- Small size of team allows for regular communication between team members (11%; $n = 2$)
- Good family involvement (11%; $n = 2$)
- No strengths (11%; $n = 2$)

Other strengths noted by respondents included access to the Alzheimer Society (5%; n = 1), access to facilities (5%; $n = 1$), and the dementia expertise of particular team members (5%; $n = 1$).

"Well, again, like I said, we're small and I think we see each other and we talk on a regular basis so any concerns we can talk about it fairly quickly and make a plan right away. There's no wasted time that way." (PHC17)

"…the strength here would be because we do know these people so we would be more apt to notice a difference even in our half hour session with them than what we would if we didn't know them. Also in a small place, you can look at these as bad things or good things but I mean other people in town will sometimes come in and say, 'I'm kind of worried about so and so, like I'm not sure they knew where they were the other day when they were out walking', or whatever." (PHC03)

"We work together and we communicate well together, so that shared expertise and knowledge helps along with having the family, the person with dementia and their family involved in the care directly, so the team approach." (PHC09)

Team challenges in diagnosis

Similar to challenges associated with assessing patients, PHC team members described the top diagnosis challenges as low access to specialists and patient/family resistance to the process (some respondents provided multiple responses):

- Low access to specialists (32%; *n* = 6)
- Patient/family resistance to seeking help, further testing, and/or diagnosis (26%; *n* = 5)
- Long wait times for MRI or CT scan (16%; *n* = 3)
- Difficulty of obtaining a good patient history (11%; *n* = 2)
- Implications for patients (e.g., losing driver's license) (11%; *n* = 2)
- Diagnostic uncertainty (e.g., difficulty of differential diagnosis) (11%; *n* = 2)
- Diagnostic inaccuracy regarding specific cause of dementia (11%; *n* = 2)
- Lack of proper assessment/diagnosis tools (e.g., an algorithm) (11%; *n* = 2)

Other challenges included family members living at a distance (5%; *n* = 1), dispersion of PHC team members across two or more communities (5%; *n* = 1), and a need for better communication between team members (5%; *n* = 1).

"I think that we as providers aren't always comfortable saying, 'okay, this is Alzheimer's' without the help of other people or criteria that helps us come to this diagnosis" (PHC05)

"…if there are no family members around … what I realize is there's someone about two hours or three hours (away) and is giving us the history. And I'll say, 'When last did you see this person?' 'Oh, well may a couple of months.' And it's very hard to accept that kind of history and, so that's a big challenge." (PHC12)

"That's probably the biggest thing I think, is people coming to acceptance, whether that be their family or support person, there is a problem and they

need help and often – sometimes – they come too late. They're already way too stressed and suffering some sort of burnout from caring for them 'cause I think maybe there's a bit of stigma still attached." (PHC19)

"Taking away their driver's license. 'Cause around here, it tends to have been the man who is the driver. Then them having to give up the farm 'cause they can no longer drive, so those would be the big, big things." (PHC15)

"Access to specialists would be one. I think people are, I think practitioners are always a little bit leery to give that diagnosis when they're unsure, so the specialist and then I think you know, a guide, that's where I see the algorithm as handy to kind of give like a pathway of what to rule out, like the whole differential diagnosis end of things. I'd say that's probably where I'd see the problems." (PHC14)

"Sometimes to get all the team together, it's time because again we're rural. So for example (provider name) is 45 minutes from here and she serves a huge region, so she comes when she can but we may only see her twice a month, so – because she has such a huge region and she's not employed full-time hours so – and I do, most of the time, get her involved to help with the diagnosis." (PHC11)

"In the diagnosis, probably waiting for a neurological consult because sometimes that takes a long time to get. And that's probably the biggest one, the time it takes if the patient is going to have a CT or MRI, the time, the waiting time because it takes so long to get that done. …it can take up to, a neurologic consult, probably three to six months and then MRI or CT, I guess it depends on if the neurological physician thinks that the CT or MRI should be done urgently then it's done fairly quickly; if not, if they feel it's just to make sure, then it's another six months after that." (PHC17)

"…I think that both patients and families sometimes really cover for a long time, so they might not be open to telling you the little things that are kind of happening that might be, not quite the usual – so that might be a challenge, especially in early diagnosis like I say, we see people for half an hour or whatever, but we might not be getting the information from patient and family about what things are happening at home." (PHC03)

Team effectiveness in diagnosis

As shown in **Figure 8**, the majority of PHC team members (63%; *n* = 12) agreed that their team effectively diagnoses individuals with dementia. A further 21% disagreed with this statement, and 16% were neutral/did not reply.
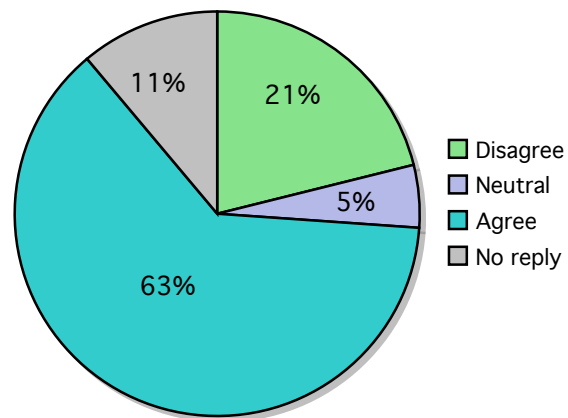

Figure 8. As a whole, my PHC team diagnoses individuals with dementia (N = 19)

Management

Respondents were asked (yes/no) whether the management of patients with dementia by their PHC team generally involved the best practices listed in **Table 4**, keeping in mind the last few patients of their team if it proved helpful. These best practices were derived from the relevant literature (see **Box 1**), except where noted with an asterisk.

Table 4. Management best practices (N = 19)

Best Practice	Yes n (%)	No n (%)	Unsure n (%)	n/a n (%)	No reply n (%)
Were patients' records "flagged" to indicate they had been diagnosed with dementia? *	3 (16)	11 (58)	4 (21)	0	1 (6)
Were patients prescribed anti-dementia medications, for instance, cholinesterase inhibitors such as Aricept, as appropriate?	16 (84)	1 (6)	1 (6)	0	1 (6)
Were non-pharmacologic management options discussed with patients, for instance exercise and recreation?	13 (68)	4 (21)	1 (6)	0	1 (6)
Were patients referred for Home Care assessment? *	17 (89)	1 (6)	0	0	1 (6)
Were patients made aware of changes in driving capacity as dementia progresses, as part of managing for the future?	15 (79)	0	1 (6)	1 (6)	2
Were patients made aware of the changes in functioning independence as dementia progresses, as part of managing for the future? *	13 (68)	2 (11)	1 (6)	0	3 (16)
Were patients made aware of the changes in medication management as dementia progresses, as part of managing for the future? *	16 (84)	0	0	0	3 (16)
Was advice given about patient safety issues, e.g., wandering and household safety?	17 (89)	0	1 (6)	0	1 (6)
Was Saskatchewan Government Insurance notified about patient's medical condition re:	11(58)	3 (16)	3 (16)	1 (6)	1 (6)

Table 4. Management best practices (N = 19)

Best Practice	Yes n (%)	No n (%)	Unsure n (%)	n/a n (%)	No reply n (%)
driving ability? *					
Were caregivers given advice re: respite care?	14 (74)	3 (16)	1 (6)	0	1 (6)
Were patients provided information on community services?	15 (79)	2 (11)	1 (6)	0	1 (6)
Were patients referred to Alzheimer Society First Link? *	14 (74)	3 (16)	1 (6)	0	1 (6)
Were patients assessed for behavioural and psychological issues?	11 (58)	1 (6)	4 (21)	0	3 (16)
Were medicolegal issues discussed (personal directives, power of attorney, capacity assessment)?	13 (68)	1 (6)	4 (21)	0	1 (6)
Were caregivers asked about how they were managing?	17 (89)	0	1 (6)	0	1 (6)
Were caregivers of patients provided, or referred for, caregiver training (psychosocial management) outside of the PHC team?	0	9 (47)	1 (6)	0	9 (47)

* Question suggested by a member of the Sun Country Health Region Dementia Working Group or the RaDAR Team

Management best practices

Respondents were asked (yes/no) whether the post-diagnosis management of patients with dementia followed by their PHC team generally involved the practices listed in **Table 4**.

A large majority of respondents reported that their team referred patients for Home Care Assessment (89%; n = 17), gave advice about safety issues (89%), asked caregivers about how they were managing (89%; n = 17), prescribed anti-dementia medications (84%; n = 16), made patients aware of changes in medication management (84%; n = 16) and driving capacity (79%) as part of planning for the future, and provided information on community services to patients (79%; n = 15).

The majority of respondents also indicated that their team gave advice to caregivers regarding respite care (74%; *n* = 14), referred patients to the Alzheimer Society First Link (74%; *n* = 14), discussed non-pharmacologic management options with patients (68%; *n* = 13), made patients aware of changes in functioning independence (68%) as part of planning for the future, discussed medicolegal issues (68%; *n* = 13), assessed patients for behavioural and psychological issues (58% *n* = 11), and notified SGI about patients' medical condition with respect to driving ability (58%; *n* = 11).

Respondents were less likely to report that their team flagged patient records to indicate a dementia diagnosis (16%; *n* = 3) and no respondents reported providing or referring caregiver training (psychosocial management).

> "I don't think people get a firm diagnosis all that often… I think it's just one of those things you might get some type of diagnosis and then it's just kind of like, 'okay, let's just wait until they can't manage anymore,' and then – you know. There's definitely lots of steps along the way where there could be opportunity for more interaction with the team and education and such." (PHC14)

> "When we first recognize that something's going on, we try and, if I can use the word, 'gently' involve the family member and so that he can get used to the idea that the spouse will be needing more care than can be given at home. At all times the spouse is welcome to come to us as caregivers to share their thoughts, share their concerns, that kind of thing." (PHC16)

> "…we can talk to people about respite, we can talk to people about Home Care; we may find out that that can't be given because there isn't enough Home Care workers in this area at this time to be able to give this much respite, or to be able to do – so people don't always get what they need, sometimes because of lack of human resources or because of lack of funds for the existing resources or whatever." (PHC03)

Team communication and documentation of patient management

Respondents reported that information regarding the management of patients with dementia is communicated within the team primarily by personal communication and the electronic medical record (some respondents provided multiple responses):

- Personal conversations by telephone or face-to-face (53%; *n* = 10)
- Electronic medical record (EMR) (47%; *n* = 9)
- Team meetings (11%; *n* = 2)
- Chart (11%; *n* = 2)

Other means of communication noted by respondents included sharing care plans (5%; *n* = 1), shared documentation (5%; *n* = 1), email (5%; *n* = 1), referral (5%; *n* = 1), and Procure (5%; *n* = 1).

> "Well, there's always got to be a chart but there's probably a lot of the other stuff – like it would for sure be in the EMR but then there'd probably be phone calls, emails, that kind of stuff to hand off to the next person if there's an action needed." (PHC13)

> "It's provided in the EMR; otherwise if it involves a certain other person in the team, then either via direct conversation, referring them to the EMR for the care plan, or a one-to-one discussion." (PHC04)

As shown in **Figure 9**, a minority (37%; *n* = 7) reported that their PHC teams hold case discussion meetings for each patient with dementia. A small minority (11%; *n* = 2) indicated that their PHC teams use flow sheets based on clinical practice guidelines to manage the ongoing care of patients with dementia.

> "Probably not a formal (case) discussion; it's more on a one-to-one or whoever-needs-to-know basis." (PHC17)

> "We used to do like a case conference but not specifically with regards to dementia. And we've actually stopped doing it for a while now." (PHC12)

> "We have case conferences when we're starting to see a crisis." (PHC19)

> "… we would very much like that (flow sheets) and I think it's kind of too bad that in the E-Viewer and EMRs and stuff, we do have, we have those flow sheets for other chronic diseases and for things like that. So it would be very nice if something like that was incorporated, and I find flow sheets very helpful. They do just clue you in to make sure that you're not missing things when you have a patient visit." (PHC03)
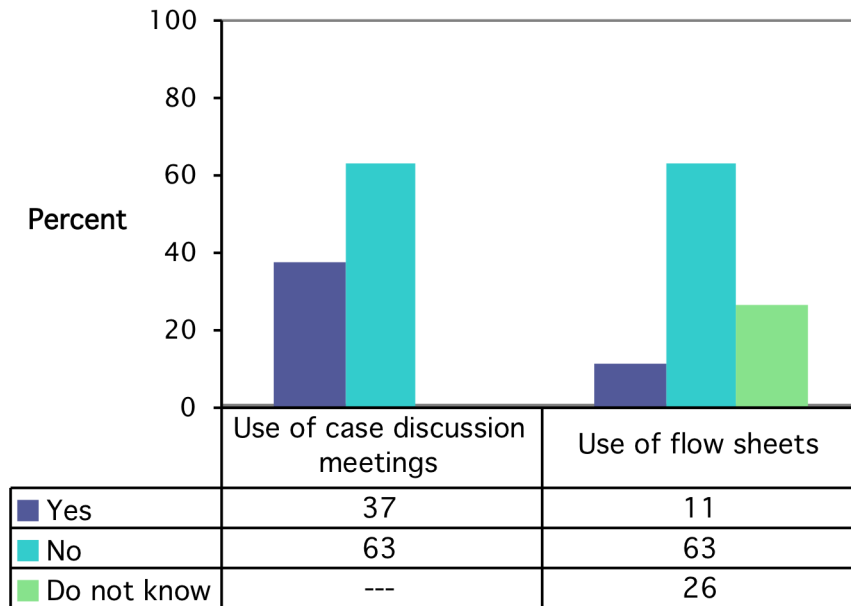
	Use of case discussion meetings	Use of flow sheets
■ Yes	37	11
■ No	63	63
■ Do not know	---	26

Figure 9. Use of case discussion meetings and flow sheets   for patient management within PHC teams (N = 19)

Specialist referral

Table 5 indicates that neurologists were the first choice among family physicians and nurse practitioners when referring to a specialist for assessment, diagnosis, or management of patients with dementia (5-point response scale). Of the 9 family physicians and nurse practitioners eligible to respond to this question, 44% (n = 4/9) reported 'always' referring patients to neurologists. A further 33% (n = 3/9) 'sometimes' refer to neurologists, 22% (n = 2/9) to the Rural and Remote Memory Clinic, and 33% (n = 3/9) to other specialists.

As shown in **Figure 10**, only a small minority of respondents agreed (11%; n = 1/9) when asked whether access to specialist support for patients with dementia is adequate (5-point response scale).

Table 5. Frequency of specialist referral (*n* = 9 family physicians and nurse practitioners)

Specialist	Always/ Often n (%)	Sometimes n (%)	Rarely/ Never n (%)	Do not know n (%)
Neurologist	4 (44)	3 (33)	1 (11)	1 (11)
Neuropsychologist	0	0	5 (56)	4 (44)
Rural and Remote Memory Clinic	0	2 (22)	6 (67)	1 (11)
Other*	0	3 (33)	6 (67)	0

*Includes psychiatrist (*n* = 3), psychologist for depression consult (*n* = 1), and unspecified (*n* = 2)

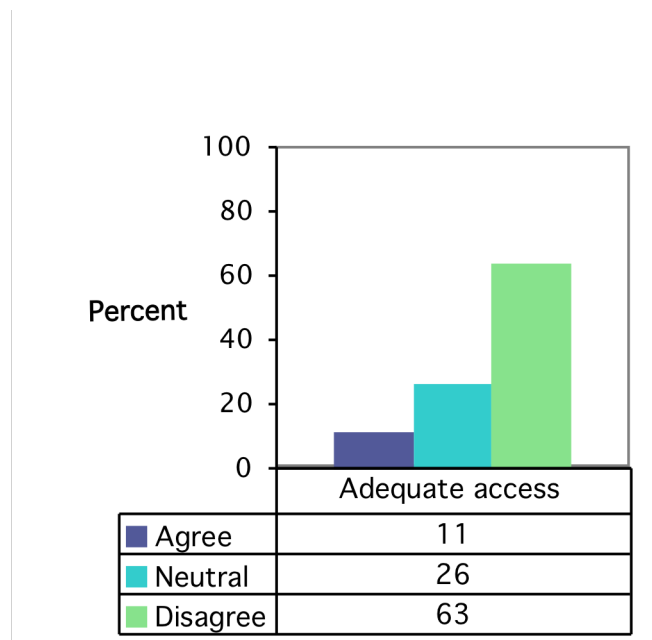|	Adequate access
Agree	11
Neutral	26
Disagree	63

Figure 10. Access to specialist support (N = 19)

Barriers to approaching the issue of driving

Asked to describe the barriers to approaching the issue of driving with patients and families, patient/family resistance and lack of alternative transportation topped the barriers (some respondents provided multiple responses):

- Patient/family resistance (i.e., denial, hostility) (42%; *n* = 8)
- Lack of alternative transportation (37%; *n* = 7)
- Patient independence (21%; *n* = 4)
- Patient-provider relationship (16%; *n* = 3)

One respondent also noted the difficulties faced by patients required to travel to Regina for driver testing (5%; *n* = 1).

"… there is no bus, there is no taxi, there's no train in this area…we don't have bus services when clients want to go outside the town to join some activity. I'm very aware that if the client is not able to drive anymore that means their life is so limited and their function… So I'm very concerned about the risks of the limitation but in the meantime I don't want to put the public in danger or the client themselves. So sometimes a family member lives in Regina or Saskatoon, they're no longer able to come down when they want to go on their weekly basis and their spouse, they have health concerns so they're not ready to provide the driving… I have so many things to take into consideration …it's a very sensitive issue." (PHC01)

"… a lot of times people's last sort of bit of control, right, to be on their own, it's their last bit of independence, that's the word I'm looking for and when that's taken away, a lot of people feel that it's their last bit of independence." (PHC18)

"Well, sometimes we've had people refuse to do assessments, so I guess that tells you quite a bit there and just our other modes of transportation in rural Saskatchewan are not – there's not a whole lot available for people so losing their license is a big deal." (PHC14)

"Well, you don't want them to get mad at you. And you're the one who's trying to help them so if you build up a wall between you and them, then everything else can lose its effectiveness, too." (PHC07)

"It's a huge issue, especially in rural areas, because you can't get anywhere without a car. It's not like you can take a taxi… we don't even have a bus in (town name) that goes to the city…and even for these people to get from their house downtown for coffee, which is a very therapeutic thing, you know, go to the centre for coffee with your friends…some of them might not be able to walk the five or six blocks so I mean, it's huge, huge if they don't have a vehicle." (PHC03)

Team strengths in management

When asked to describe the main strengths of their PHC team in managing patients with dementia, respondents proposed four distinct team features: team communication, good problem solving, multidisciplinarity, and empathy for patients. Respondents also recognized the availability of community resources as a team strength (some respondents provided multiple responses):

- Good team communication (32%; *n* = 6)
- Good problem solving abilities (11%; *n* = 2)
- Multidisciplinary nature of the team (11%; *n* = 2)
- Empathy and dignity for patients (11%; *n* = 2)
- Available community resources, e.g., respite care, day program (11%; *n* = 2)

Other strengths noted by respondents included good documentation (5%; *n* = 1), flexibility of particular team members' time (5%; *n* = 1), the dementia expertise of particular team members (5%; *n* = 1), and the small size of their team allowing for regular communication between team members (5%; *n* = 1).

"I think there is support if people are able to access them, like I think Home Care is really looking strongly at providing more effective respite services and there is some day programming and there is the First Link people. So there is something out there, but they're not necessarily utilized." (PHC14)

"I think the team members themselves, that we have as many team members that we do or professions involved." (PHC02)

"I think they're committed; I think they really do want the best for everyone and I think, like I said, I think we communicate well and we do our best to problem solve." (PHC11)

Team challenges in management

The leading challenge reported by PHC team members in terms of managing patients with dementia was the inadequacy of local community resources such as day programs for patients with dementia and timely access to respite. Inadequate levels of communication (with team members and patients/caregivers), inadequate local caregiver support, and patient/family resistance to care were also cited as notable challenges to patient management (some respondents provided multiple responses):

- Inadequate local community resources, e.g., respite care (32%; *n* = 6)
- Inadequate communication among all team members (16%; *n* = 3)
- Inadequate communication among patient/family and all team members (11%; *n* = 2)
- Inadequate local caregiver support, e.g., Alzheimer support group (11%; *n* = 2)
- Patient/family resistance to care (11%; *n* = 2)
- A need for dementia education 11%; *n* = 2)

Additional challenges included a need for decision support tools (5%; *n* = 1), the dispersion of PHC team members across two or more communities (5%; *n* = 1), the difficulty of supporting patients/families in LTC transition decisions, and managing behavioural issues (5%; *n* = 1).

"We're big on the algorithm (so it) would really be nice to have an algorithm saying okay, if they're showing this and this it's probably this, or this is what you have to do." (PHC05)

"… and just the communication between all of the members and patients and family. It definitely would be great to have case managers involved that could bring people together for education issues and all that sort of stuff." (PHC14)

"The ruralness. It's hard to have a small amount of staff spread out over a large area to physically get to everybody…We're spread over a couple facilities… we

all kind of float around…" (PHC13)

"Often when the issue is brought forth and it's been the same behavior difficulty going on for some time and they've gotten to a point, there's been a certain amount of escalation going on, so everybody's looking for some help right now or immediately and that's difficult." (PHC09)

"Acceptance by the patient and family of the diagnosis is probably the most important one. Once a patient or family have accepted the diagnosis and Home Care gets involved and looking at when it is time to go into the lodge that's usually the easy part. The difficult part is actually getting to the stage where patient and family accept the diagnosis." (PHC16)

"I guess it would be probably be the lack of yes, the lack of community, formal community support. Like I say, it's funny 'cause you look at these and you see both sides. I mean small communities are very supportive so in a lot of ways people get maybe more support than they do in cities. But as far as formal, where certain caregivers can be there at a certain time or whatever, those kind of things are kind of a challenge, probably." (PHC03)

"Probably lack of support systems – official. I mean in a small community it's really like neighbours and everybody just pitches in and tries to help and stuff like that, right? … like to have say, an Alzheimer support group would be really nice sometimes because you get specific information, specific support, right? People who understand. We don't have that within our community and I don't even know where the closest one would be, but I can see that that would be a real benefit but I just don't know that we have it. … and nobody with a loved one with Alzheimer's can go to meetings like that two hours away." (PHC07)

Team effectiveness in management

As shown in **Figure 11**, a majority of PHC team members agreed that their team effectively manages patients with suspected dementia (63%; *n* = 12). A small minority were neutral (21%; *n* = 4) or disagreed (11%; *n* = 2) that their PHC team effectively manages patients with diagnosed dementia.
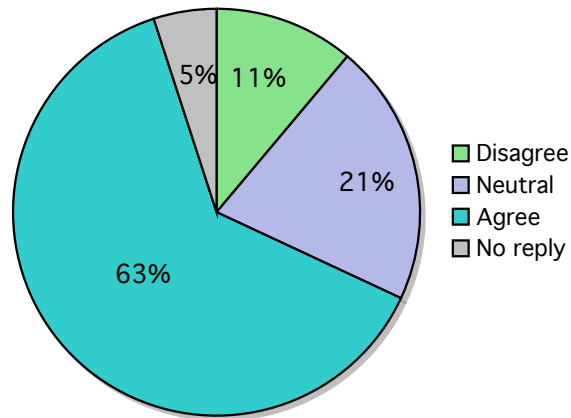

Figure 11. As a whole, my PHC team effectively manages patients following a diagnosis of dementia (N = 19)

What is most necessary to improve dementia care?

When asked 'what do you think is most needed to improve dementia care' based on their experience working in their community, PHC team members most often pointed to the need to introduce standardized processes, improve local capacity for dementia diagnosis and management, and improve specialist access (some respondents provided multiple responses):

- Implement standardized processes for diagnosis and management (16%; *n* = 3)
- Improve capacity for local diagnosis and management of patients without specialist referral (16%; *n* = 3)
- Improve specialist access (16%; *n* = 3)
- Diagnose earlier (11%; *n* = 2)

- Increase the local availability of caregiver support groups, e.g., teleconference options (11%; *n* = 2)
- Increase the local availability of First Link coordinators in rural areas (11%; *n* = 2)

Respondents also described the need to increase the use of telehealth, e.g., for specialist visits and behavior clinics (5%; *n* = 1), increase public awareness and education about dementia (5%; *n* = 1), improve education about dementia among health care professionals (5%; *n* = 1), and establish a resource person for behavioural management (5%; *n* = 1).

"I would say we need to early diagnose so that the family is aware and they can start to take steps for safety for that person as they deteriorate, so us to be able to early diagnose them. It's not that it's going to get much better just because we diagnose them, but then we can have things in place for them to help with their safety, etc. etc." (PHC05)

"I think just changing the way people think about aging, it's not the healthy part, or it's not that every person gets old and has dementia. It's a disease, so I think a lot of public education or teaching the public about it. That early help is easier to get. I think that's big and I think education too for health care providers." (PHC18)

"Well, I'm excited by this whole pathway idea to give us a tool by which to work with. So it would be interesting to see how much we can do because it's really difficult for us to control what happens as far as waiting lists in the city and that sort of thing, but if we can do more within our own team for people, then that would be great." (PHC14)

"I'd like to see a resource person for behavioural management. (Okay. And anything else?) I think that's our biggest need. I think they're managed reasonably well otherwise, but often we come up with behaviours say, in our housing – we have an enriched housing facility here so they're provided with meals and laundry. And we get early dementia people in there frequently and then what happens is they deteriorate and then they become, their behaviours become an issue. And often we kind of feel at wits' end. How are we going to cope with this person until they qualify for long-term care? Because it seems like that whole 'whether a person qualifies for long-term care or not' can be quite a long time." (PHC07)

"I think you mentioned something like the Alzheimer's Society. I don't think there's anything here. I know it's a small community. I don't know if that's possible, something to educate people and to get them involved as a group, not necessarily the patient with Alzheimer's but also the caregivers. Because going to Regina is okay but might not be easy for majority. I think the social aspect is, I mean we need more, I think, as a society (and) as a community we need more social support, instead of referring all the social things to (name of city) (which) could be tough and not feasible." (PHC12)

Respondent characteristics

The characteristics of decision-makers participating in an interview are listed in **Table 6.**

The respondents included regional managers and directors (n = 4), primary health care facilitators (n = 3), and other decision-makers (n = 2). Role responsibilities are listed below.

Table 6. Decision maker characteristics (N = 9)

	n
Professional role	
Regional Manager/Director	4
Primary Health Care Facilitators	3
Other	2
Role responsibilities	
Coordinate programs	3
Team building	3
Community development	2
Improve collaborative practice	2
Staff supervision/management	2
Support PHC teams	2
Track PHC team measures	2
Other*	7

*Includes clinical practice redesign, clinical service, facilitating improvement initiatives, improving access for patients, screening of long-term care residents, overseeing PHC sites, and patient counselling

Strengths and Challenges

Strengths in regional dementia care

Top strengths in dementia care across their health region noted by decision-makers focused on health human resources in Sun Country, namely strong leadership and staff, capable physicians and nurse practitioners, and good team communication (some respondents provided multiple responses):

- Leadership and staff willing to test and implement promising new initiatives ($n = 2$)
- Physicians and nurse practitioners able to assess and diagnose dementia ($n = 2$)
- Good team communication between physician, nurse practitioners, and other health care providers ($n = 2$)
- Effective home care programs ($n = 2$)

Other strengths included a team-based approach to patient care ($n = 1$), strong commitment to client care ($n = 1$), good familiarity with patients due to the relatively small size of the health region ($n = 1$), reasonable wait times to see a primary health care provider ($n = 1$), comprehensive care in primary care clinics ($n = 1$), strong information technology tools ($n = 1$), implementation of Gentle Persuasive Approach ($n = 1$), access to a behavioural consultant ($n = 1$), and effective long-term care programs ($n = 1$).

> "I would say the main strength is we have willing leadership, our managers are always willing when there's a new initiative and they think it's worthy to be implemented; there's always this push and willingness to do it and to do it right and I also notice that the staff are always willing." (DM01)

> "I would say that one of the strengths of our region is a really strong commitment to individual client care. I really find our staff cares about Mrs. Smith, you know, and that is a good thing. We do know our clients, seeing it's a small region. I do believe we have some excellent teamwork." (DM03)

> "I think our biggest strength in our primary health care teams is the real push towards collaborative practice or team-based care and the understanding that not one professional is the expert, and that it needs to be a team approach and

utilizing everyone's skills and roles and strengths to be able to treat that one person." (DM05)

"I think one of our biggest strengths is that we have a really strong group of people that are passionate about dementia care and want to make it a priority. …and it's not just in one pocket you know, it's not just in one small community or one specific profession that has passion about it. It transcends professions; it transcends communities, so I feel very optimistic that change will occur, positive change will occur." (DM08)

Challenges in regional dementia care

Difficulty establishing a dementia diagnosis was cited as the top challenge across their health region by decision-makers. Other challenges involved inconsistent and under-use of best practice tools and guidelines for diagnosis and managing patients with dementia, and a need for support for individuals with dementia across the health system (some respondents provided multiple responses):

- Difficulty in establishing dementia diagnoses ($n = 4$)
- Under-use of standardized tools and best practice guidelines for dementia diagnosis and management ($n = 2$)
- Health system support for individuals with dementia ($n = 2$)
- Travelling to Regina and Saskatoon for services ($n = 2$)
- Among health care providers, low awareness of dementia-related programs and services ($n = 2$)
- Among the public, low awareness of dementia-related programs and services ($n = 2$)

Other challenges included low public awareness of dementia and dementia prevention ($n = 1$), stigma ($n = 1$), inadequate local caregiver support ($n = 1$), ensuring that patients have consistent care providers ($n = 1$), being able to live with dementia in one's home community ($n = 1$), long wait times for long-term care admission ($n = 1$), and low availability of long-term care beds in one's home community ($n = 1$).

"Travel. I'm not sure what the wait times are to access, to get into long-term care once they need that. That could very well be a problem and I know that sometimes when patients are needing or do get into long-term care, that there

aren't beds necessarily available in their home communities, that they have to go to other communities. So that might be an issue, especially for families." (DM02)

"…we are not understanding dementia adequately and what we can do about it and so that moves into the education…I think that dementia, we've got to take it out of the realm of stigma into – 'hey, here's something and here's something we can help you do with it.'" (DM03)

"I think there are opportunities to educate our care providers on pathways and services even internally within our region. I think there's also that same opportunity to educate the patients, to get them the right care that they need at the right time." (DM04)

"Consistent use of tools and best practice guidelines, I think is a challenge. There's so many tools out there and I don't think that people fully understand which are the best ones to use… they don't feel that at a system level that maybe they're being allowed to use the best practice guidelines and the best tools as well." (DM05)

Information and Education

Decision-makers were asked whether there is adequate information and education available to individuals with dementia and their families, considering the Sun Country Health Region as a whole (yes/no).

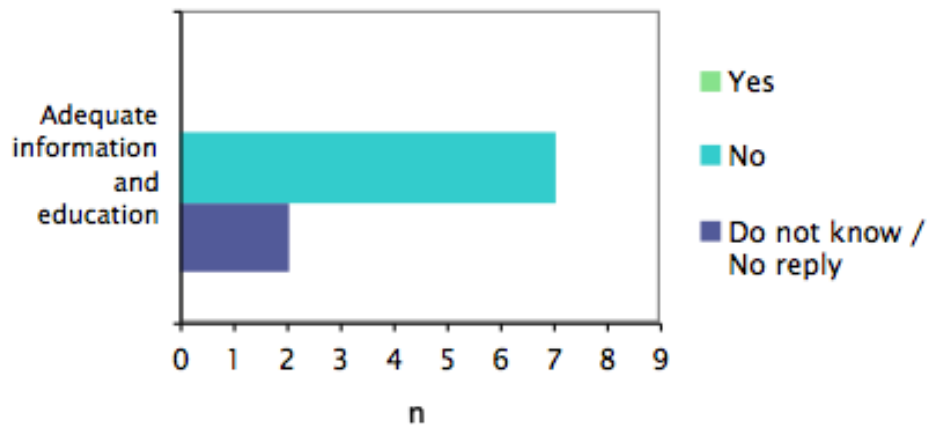As shown in **Figure 12**, no respondent reported the information and education available to be adequate.

Figure 12. Adequacy of information and education available to individuals
with dementia and their families (N = 9)

Public awareness about "what to do or where to go" if dementia is suspected

"People may - their first line may be to go to their primary health care provider, so whether their physician or nurse practitioner, but as far as where to go after that or even what support can be provided I don't think people are aware. …it seems like when they're not aware of what those symptoms are or what they should be looking for, then it almost becomes too late by the time they do seek help." (DM04)

"But then I find that people who have been given a diagnosis it just seems to be so much easier – I don't know if it's easier but they can make plans and they can kind of know what's coming. Whereas a lot of people that get into long-term care, they've never been diagnosed, so it's pretty obvious by that point they have dementia but nobody's really told them that." (DM09)

Public education to reduce the stigma of dementia

"In Sun Country Health Region I haven't seen or I'm not aware of any awareness - if I'm allowed to use it that way - around dementia because I think the only group that might be involved in dementia care would be the Alzheimer Society. So in Sun Country, we don't have awareness around that yet." (DM01)

"I don't know if it's adequate. The stigma's still there. I really can give a plug to the Alzheimer's Society for their efforts and I give a real plug to our Home Care who treat dementia as a part of chronic illness, but as an overall people are still very – there's still a real stigma out in our communities about when dementia might be suspected." (DM03)

Knowledge among health care professionals

"…I think one of the main deficiencies, and it's really nobody's fault, is the fact that when there isn't a cure, we all conspire to try and ignore the situation and that's right at the family level and it moves up through our professions and this is not new. This is something we've done forever, like cancer, diabetes went through this and I think it's just a matter of, if people can see there's things we can do, we will all start embracing a better and better utilization of the knowledge that's out there." (DM03)

 "I don't think we have people, I don't think our practitioners are diagnosing. I think it's like there's a 'suspicion of' or 'may have', but I don't think we have the diagnosis. And part of that would be because they don't know what to do with them, where to get services, what services are there." (DM07)

Possible variations in adequacy of information and education across PHC teams

"I know in (name of city), there is a lot more support than when I look at our outlying sites, for example, (name of town), or even the opposite way if we go towards the (name of towns) area, the overall supports aren't there the same as people who are in the bigger centres. …the urban areas have better access to services like First Link whereas rural areas there's not as good access even to your primary care provider, let alone to the extra programs." (DM04)

"I think the (PHC) teams are excellent… Are we picking it up consistently across the region? Possibly not. It may be the standards are getting very good and we're trying to get a good format, but is it getting across this huge area? No, not yet." (DM03)

Accessibility

Accessibility of health care services

Respondents were asked whether health care services (e.g., primary health care, home care, telehealth, long-term care) are accessible specifically to individuals with dementia and their families (yes/no). Decision-makers were asked to consider the Sun Country Health Region as a whole in their responses.

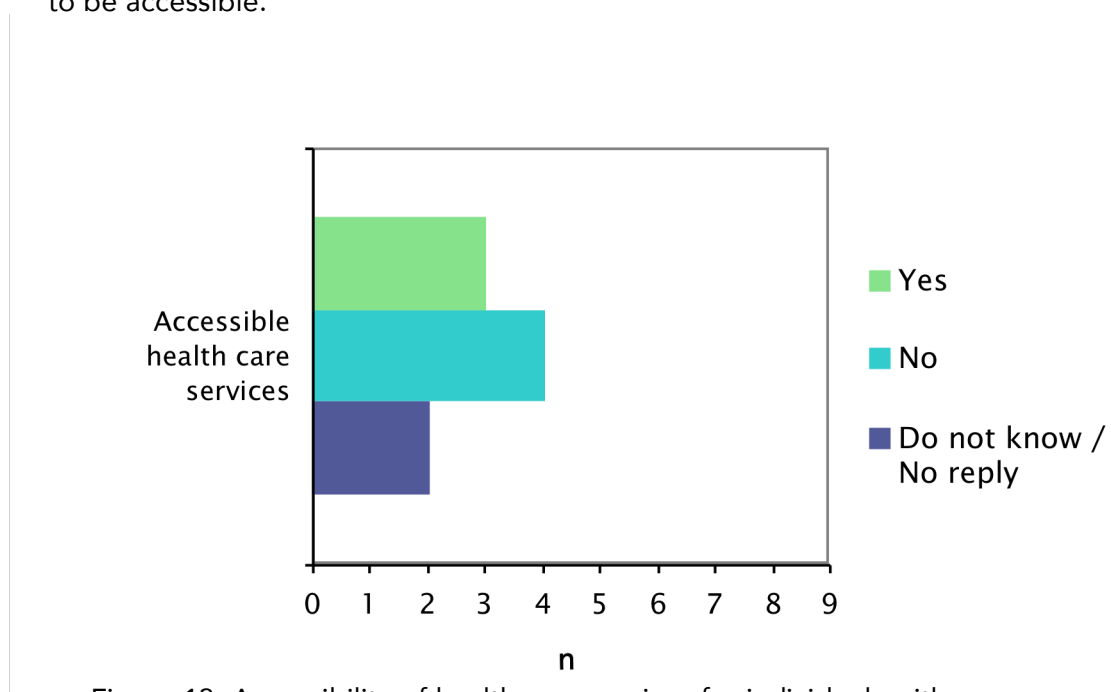**Figure 13** shows that less than half of the respondents overall reported services to be accessible.

Figure 13. Accessibility of health care services for individuals with dementia and their families (N = 9)

Geographic accessibility

"Definitely, geography plays a role in individuals accessing services…So if you're living rural, you're very limited on what can be offered to you. Driving becomes an issue, getting to the appointment is a barrier as well. Telehealth is definitely a potential solution but there are still many practitioners that don't feel comfortable using it, so it's not perfect." (DM08)

"Potentially yes. We are spread out. We do have clinics in all, basically, all our communities but it could be probably an issue for maybe elderly people if they live in a smaller community that they have to travel to the neighbouring community if they don't have family. Yeah it could be an issue and I do feel that if even if they do have family that it's still a lot of work and a burden for them for sure if they have maybe full-time jobs and things." (DM02)

Language, culture, and other accessibility factors (e.g., awareness)

"I would say no because most of this work that's been done around dementia, people don't seem to know about it, people are not aware of it, so people don't know we even offer if there are some things we do offer, and so I won't say people know to access the services." (DM01)

Possible variations in accessibility of health care services across PHC teams

"I think our teams are very consistent in looking at the services and the care and the quality of care that they provide to their patients. I think when we look at the system as a whole is where we see a little bit more of a breakdown 'cause as far as our (PHC) sites, I think our sites are doing a fair job in managing and making those appropriate referrals." (DM04)

"What I mean is there is no standard, how do I say it, standard care or like standard template that everybody has to follow when it comes to dementia, so people will look for information and try to adjust or adapt it to their teams on the way to work for it." (DM01)

"This is one thing where we're all pretty rural. (Names of cities) don't have much, you know, for the kind of services… we can give more Home Care in more populated areas, but I don't think that speaks to the dementia issue specifically." (DM03)

Care coordination

Considering the Sun Country Health Region as a whole, respondents were asked whether health care services for individuals with dementia and their families (e.g., primary health care, home care, telehealth, long-term care) are coordinated (yes/no). Coordination was defined as the "care delivered by different health care professionals is connected and coherent" (Haggerty et al. 2007).

Figure 14 indicates that fewer than half of respondents reported services overall to be coordinated.
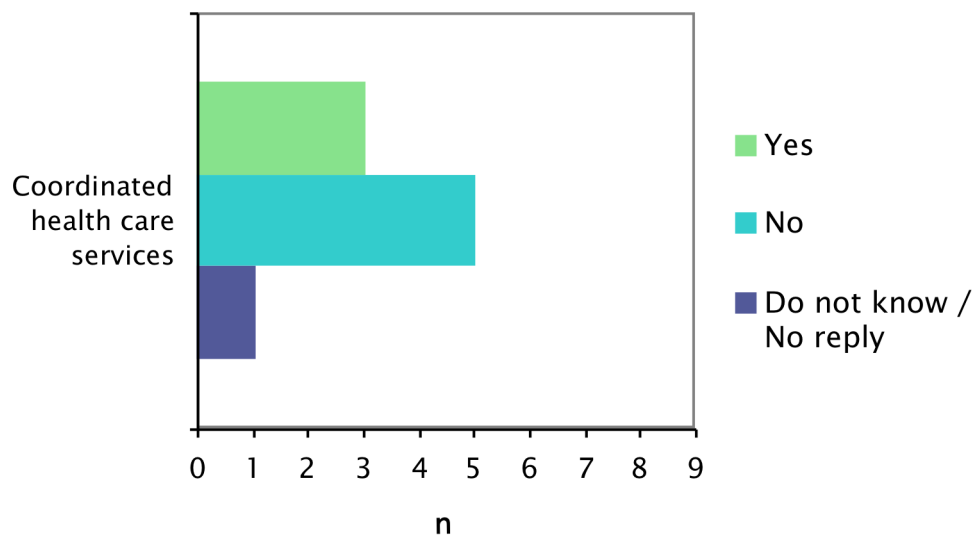

Figure 14. Coordination of health care services for individuals with dementia and their families (N = 9)

Access to the health history of patients with dementia

"Yes, and I think it's getting better and better with implementation of the electronic medical records and even their older system with their paper charts, I do think that they have (access to health history), especially if that patient has been living in the community for some time..." (DM02)

"We can have. We have the capacity. But with the physicians, you know, we have to make that connection, (it is) absolutely crucial." (DM03)

"It's getting better with the use of the electronic medical records, but it all depends on their past charts and where they've seen physicians in the past and whether they're on the same medical records or if they're on different ones. It's not always consistent or easily accessed." (DM05)

Coordination among health care professionals

"…I definitely see that we're working on developing better communication, but I think that there's still a lot of room to improve on that." (DM08)

"Yes, I think that they are connected somewhat. I think that there's always improvements that can be made and that, but I do think that our primary health care providers are aware of the Allied Health Professionals such as Home Care and that they do communicate with them when needed. So I'd say that they are connected for sure." (DM02)

Coordination between community agencies and health care professionals

"I think it also depends on the site. We've really tried to promote some of the other services that are available, for example First Link, with the Alzheimer Society, however, in some of our more rural communities that person is based out of Weyburn, so I think sometimes it gets lost with geography. So it's not consistent, no." (DM05)

"When we're looking at sharing information with outside like with community agencies, it gets more complicated, I think, with privacy with what you can share and what you can't share, all releases, and what have you." (DM08)

Transition from community to long-term care for individuals with dementia

"...unless you have a good understanding of the health care system and the process and the pathways, they're very confusing and conflicting, especially if you're moving a dementia patient from a bed in one facility while they're waiting to get into a bed in their home facility. And then you're looking at family having to travel and add excess change and in dementia patients, lots of change for them is not good. They need that consistency. So I don't think it's seamless." (DM04)

Possible variations in coordination of health care services across PHC teams

"That can be because of the players, but it is also because not all the electronic systems are in place…. so it can be like a really keen group that absolutely becomes a team and or it can also be you're a wonderful team but you're having a real hard time getting all the data to each other." (DM03)

"It would vary that way, definitely 'cause we have some large teams, some small teams, some teams that are not even together yet, so definitely, it would vary with every clinic and then the area as well…because we have some pretty small clinics in small towns and so the teams tend to be made up of individuals from other communities too." (DM06)

Community Fit

Community fit of services

Respondents were asked whether the nature and level of services available for individuals with dementia and their families fit the needs of these individuals, i.e., community fit (yes/no), considering the Sun Country Health Region as a whole.

Figure 15 shows that 1 in 9 respondents reported a fit between services available and the needs of individuals with dementia and their families.
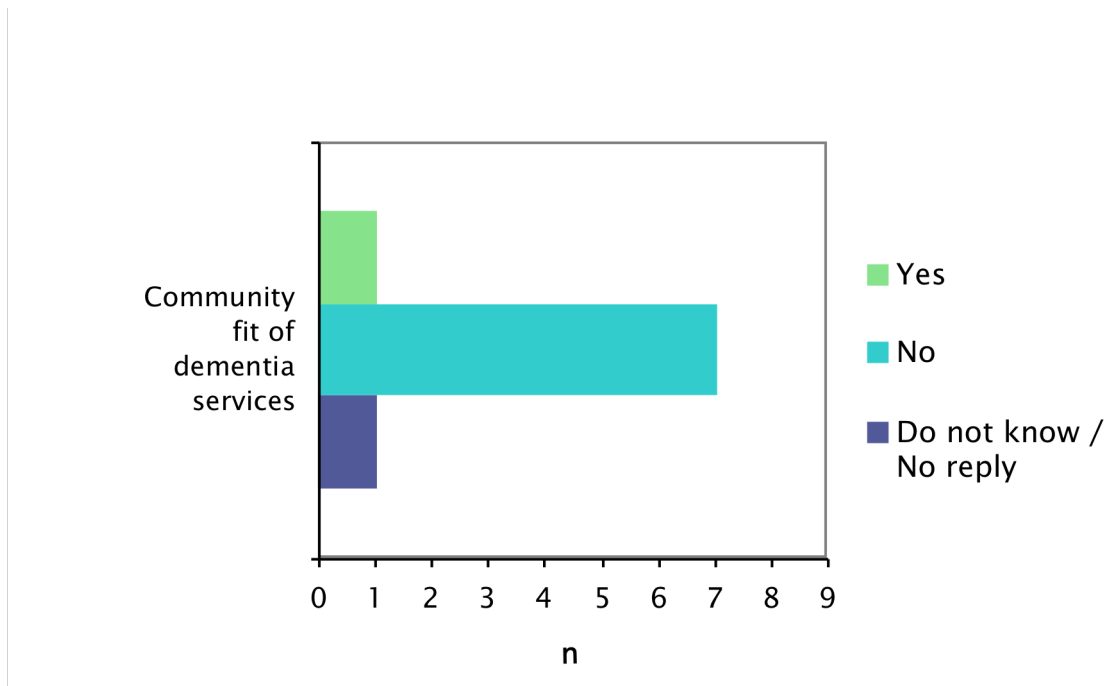
Figure 15. Community fit of health care services for individuals with
dementia and their families (N = 9)

Primary health care

"...we have I see a lot of people who are floundering without diagnosis, so
they're not really sure what they're dealing with and then even when they do
have the diagnosis, the support is, it feels disjointed and it feels we could, we
should be doing so much better." (DM08)

Home care

"I would say home care will meet the needs of people with dementia more than
others (primary health care, home care, long-term care) because they tend to
see them more often and I think they provide these services more often to
these people compared to the other." (DM01)

"...now people want to stay in their own communities, so we're dealing with...
much more difficult behaviour. So that's kind of at the other end of the
spectrum. Until they get into long-term care, usually they get some home-
making service, maybe a little bit of respite through Home Care but Home Care
services are limited. Usually the Home Care Health aides are scheduled for like
15 minutes or a half hour, an hour would be stretching it, so there isn't, in that

scheme of things, there isn't a lot of assistance, in my mind, for these people."
(DM09)

Long-term care

"…a lot of times we can't look at a problem if we don't know it's there and if you look at the demand, how many people are in long-term care beds and the ratio of physicians, I think that there's a missing piece in prevention as far as going in to look at that because the acute care crisis takes priority. So unless they have family or that caregiver who's advocating for the consistent care, I can see it being very easy for somebody who without those pressing needs, to get preventive care." (DM04)

Other care

"When I look at the support of what caregivers have to provide to their loved ones, especially while they're still in the home and then the toll that that takes on them emotionally … I don't see consistent support for caregivers across the region and I think that is so important because dementia takes such a toll on the caregiver." (DM04)

Possible variations in community fit of services across PHC teams

"…everybody's just doing it the way they think it should run so that is a problem we are having now." (DM01)

"…I can't speak to it specifically, but I'm sure that they (variations across the PHC teams) do exist because different staff are going to have different comfort levels and different confidence levels." (DM05)

Comprehensiveness

Comprehensiveness of health care services

Considering the Sun Country Health Region as a whole, decision-makers were asked whether health care services for individuals with dementia and their families are comprehensive (yes/no). Services included primary health care, home care, telehealth, and long-term care.

Figure 16 shows that 2 respondents reported that the health care services available to individuals with dementia and their families are comprehensive.
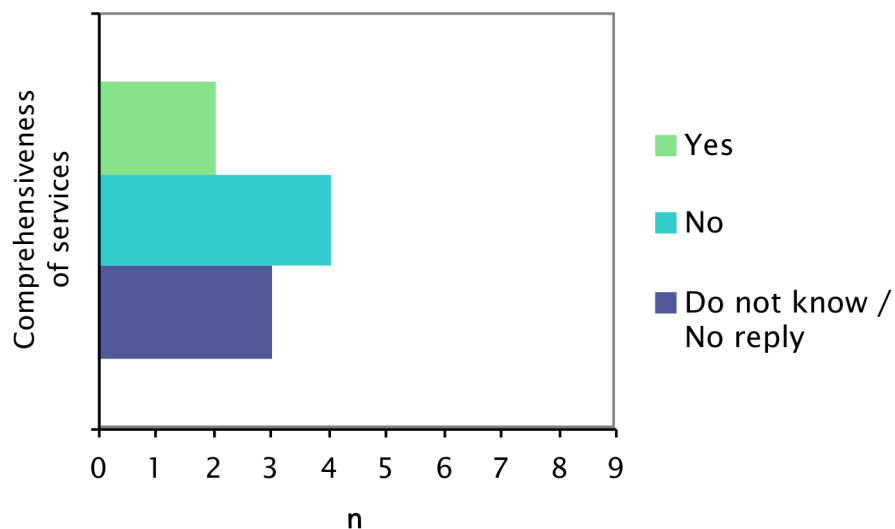

Figure 16. Comprehensiveness of health care services for individuals with dementia and their families (N = 9)

Timely referral to appropriate health and social services

"There are cases certainly where things happen appropriately at the right time. We're just not at a place where that's our consistent practice yet." (DM08)

"…that's becoming a little bit better especially in some of the primary health sites, and then they might get Home Care for a very short period of time if the family members will contact them or will use the service. It's all just very kind of disjointed." (DM09)

Dementia viewed as a chronic disease

> "I've heard varying views on that, but I would say the majority do believe it (dementia) is (viewed as a chronic disease)." (DM05)

> "I think it's a culture that is starting to become more accepted; I certainly think that more people are thinking that way than even, I want to say even a year ago. I am hearing that language a little bit more often. I don't know if it's a pervasive belief yet though." (DM08)

Possible variations in comprehensiveness of services across PHC teams

> "…I do believe that they are able to give care from the start of diagnosing to all the way through, yes." (DM02)

> "I think you'll get some interesting and you'll see variations if they come out, which I think there are." (DM03)

Quality of Care

Quality of care in health care services

Respondents were asked whether there is quality of care in health care services (primary health care, home care, telehealth, and long-term care) provided to individuals with dementia and their families (yes/no). Quaity of care examples provided to respondents included: individuals with suspected dementia receive timely diagnosis, and standardized diagnostic criteria for clinical guidelines are followed for diagnosis and management. Decision-makers were asked to consider the Sun Country Health Region as a whole.

Figure 17 shows that 2 respondents agreed that there is quality of care in health care services provided to individuals with dementia and their families.
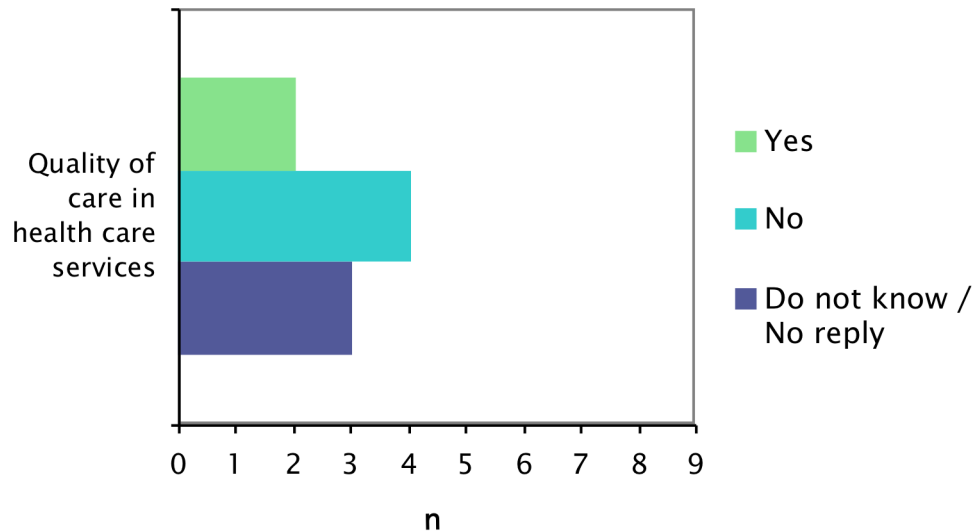
Figure 17. Quality of care in health care services provided to individuals with dementia and their families (N = 9)

Timely diagnosis

"No, I don't think that we have anything that's standardized as far as that goes yet, and timely diagnosis, not on any sort of consistency, I don't think at this point. That's a sad statement, but no I don't think we have that yet." (DM08)

"I think a lot of it goes back to diagnosis. I think if we had clear cut, we could tell, we can give people the information and say these are the things that you need to consider and give them more of a clear idea of what they're dealing with, I think we would see better, better uptake of services. Whether we could handle, whether we have the people resources to handle that uptake, that's the question." (DM09)

Use of standardized criteria for diagnosis and management

"It's not a standard across any of our sites and it certainly wouldn't be in the physician clinics that aren't part of primary health care either." (DM07)

"We don't have like standard clinical guidelines to use for dementia, we don't have like standard follow-up and management strategies, we don't have those." (DM01)

Safety monitoring of individuals with dementia living at home

"Not necessarily. Because oftentimes they hide it from us so we don't even know and other times you're out in (name of place) Saskatchewan, how do we monitor it? We do not have some of the systems in place that might be valuable." (DM03)

"I think our quality of care is really good but I think it again comes back to that patient and what they're willing to hear and act on as far as early intervention. Our doctors are empowered to do as much as they can within their scope." (DM04)

Possible variations in quality of care across PHC teams

"I would say that it varies… team to team, practitioner to practitioner, I think." (DM05)

"I think the variations here would not be I just think that it's a pervasive thing. It's not this one might do this or that one might do that, but I don't see any, none of us are doing say the electronic monitoring at all, so we're consistently not doing that. So I would say… I don't see any pockets of 'Wow! We're really doing a great job here.'" (DM03)

Results – Patients and Caregivers

Respondent characteristics

Table 7. Respondent characteristics (N = 5)

	n
Relationship to Patient	
Adult child	3
Spouse	1
Patient	1
Gender	
Female	5
Male	0
Marital Status	
Married/Common-law	4
Widowed	0
Divorced/Single	1
Age group	
<65 years	2
65-85	3
>85 years	0

Three separate telephone interviews were conducted with 4 caregivers, including one interview with two caregivers at the same time. One interview was also conducted with a patient.

Characteristics of the interview respondents are provided **in Table 7**. Respondents included three adult children, a spouse, and a patient. All respondents were under the age of 85 years.

Nature of problem

The nature of the problem that caused the most concern before their family members received their diagnosis ranged from loss of interest to depression-like symptoms, faulty reasoning, and memory loss.

> "Probably the main thing is just her loss, her loss of interest in doing things that she loved to do before. We thought it was like a depression because she had had a hysterectomy and she just never really came back to being herself." (PTCG01)

> "Well she had a small stroke in September of last year. Before that, we noticed she wasn't quite the same Mom, you know, like she would say funny things like, 'oh, I think you'd better move the hose because the sun is going to wreck it', you know, the water hose. And I said 'but Mom, the hose has always been there', and I thought, 'gee, that's funny'. So we noticed a few things several months, maybe three quarters of a year before that." (PTCG04)

Specific diagnosis

When asked about the specific diagnosis they were told by their PHC team, specialist, or other health care provider, all of the respondents indicated that a specific diagnosis was not conveyed to them.

> "This is what I had written: her memory is impaired. She's getting some sort of dementia, probably Alzheimer's." (PTCGT01)

> "There wasn't any specific diagnosis; just that it was a form of dementia." (PTCG03)

> "No, not really, just that she (had) dementia, you know, that type of thing. I don't think they said Alzheimer's because she knows everybody, and I don't know with Alzheimer's, do you know people (when you have Alzheimer's)?" (PTCG04)

"No. Just that she put me on the drug. I think s/he probably knew that I knew, you know what I mean? Don't know how to say that, but I knew what was wrong with me, even if s/he didn't tell me." (PTCG05)

Diagnosis process

With the exception of a gait assessment experienced by one patient, none of the respondents reported that any unexpected activities took place during the diagnosis process. Likewise, other than their family member not receiving a specialist referral, none of the respondents reported expecting certain activities that did not take place.

"I don't know if we really had any expectations. As I said, we thought it was a depression, a hormonal imbalance or something." (PTCG01)

"Well, I maybe thought there would have been a referral to a specialist but it didn't surprise me that there really wasn't because you know – things were going quite well, actually, and still are." (PTCG03)

The respondents were mainly satisfied with the communication from the PHC team during the diagnosis process. When asked whether there were specific services or resources that they needed but did not receive from the PHC team during the diagnosis process, most indicated that they received everything necessary. However, one respondent reported that a referral for caregiver support would have been useful.

"See I don't know what resources Dad has ever been offered, but to me I would like to see more of a referral to like Alzheimer support. So we know more about the disease, I guess." (PTCG01)

Overall, the respondents reported being satisfied with the diagnosis process experienced with the patient's PHC team.

When asked whether they thought the diagnosis process might have proceeded differently if they had lived in Regina or Saskatoon, one respondent noted that their family member might have been referred to a specialist. Other respondents reported that the diagnosis process was likely no different between their community and Regina/Saskatoon.

"Well, it likely would have (gone differently). There probably would have been a referral to a specialist, but to refer us at our age to something that may not supply any help or anything, getting to the city is a headache for us 'cause we don't drive in the city. So you know, if the services were supplied in, well, even if it could have gone to Weyburn or you know, not into Regina. We find going into Regina a real headache." (PTCG03)

Management

Management process

Aside from the nature of activities provided to long-term care residents, none of the respondents reported experiencing any unexpected activities during the management process, or expecting certain activities that did not take place.

"...she's moved in there (long-term care) and everything seems to be flowing quite well and they're looking after her good, and the activity people keep them busy with little quizzes and I guess I didn't expect that, but I guess that's what they do. And there are some that don't have dementia and they all kind of sit around the table and answer questions and it's hard. I said, 'oh, you need to be a university graduate, some of those questions. I was stumped!'" (PTCG01)

The respondents reported general satisfaction with communication from the PHC team during the management process. When asked whether there were any specific services or resources they needed and did not receive from the PHC team during the management process, one respondent indicated that their family member did not receive day care and meals on wheels from Home Care.

"We're wishing there was more Home Care available, but because they live on the farm still, we can understand that Meals on Wheels isn't an option and things like that. Like Day Care – if someone could go and stay with Mom so Dad could go off for a day and do whatever, and I don't know if that would be available in town either, but...like Meals on Wheels kind of thing, I guess, at least once a day would be ideal. The one thing that Dad is starting to notice the most is that Mom won't eat. If we go and make the meal and are there, she eats, but when it's just the two of them, he can't get her to eat and he's finding that really frustrating." (PTCG01)

Generally, the respondents reported receiving the services and resources necessary from their family member's community during the management process. In particular, one respondent noted the value of wheelchair accessibility in their community.

> "She is able to get out with the wheelchair to several places, into the restaurant; she's going to the museum and any place that's got a ramp… she wouldn't be able to go, you know, and she was so used to going and being out and about, so yes, it's really good to have ramps, that's for sure." (PTCG04)

Overall, the respondents were satisfied with the management process experienced with the patient's PHC team.

Similar to responses to the question of whether they believed the diagnosis process might have proceeded differently had they lived in Regina or Saskatoon, one respondent noted their family member may have been referred to a specialist for management had they lived in Regina or Saskatoon. Other respondents reported that there were likely no differences in the management process between their community and Regina/Saskatoon.

> "Like I said, he probably would have been referred to a specialist to give a more complete – I know they can't diagnose Alzheimer's – but he probably would have had a more complete assessment if he'd been in the city." (PTCG03)

> "I sure thought my little village, they just all came together and maybe that's because I shared the information too, like with my two neighbours. I just thought they should know in case I do something really foolish, but they're very supportive now, so maybe that helped." (PTCG05)

Strengths of PHC Teams

The positive aspects of the care received by patients since they were first diagnosed with dementia, as described by respondents, reflected the personal and attentive nature of the PHC teams:

- Patients are treated like individuals
- Patients and families are personally known
- PHC team is caring and informative
- Questions of patient and family are answered
- The same PHC provider is available when needed (continuity of care)

"They sent her for extra assessment with the fainting spell or whatever you know, like even – she's not a young person, she's not a healthy person, they're still treating her as an individual, like (name of PHC provider) is just exceptional with personal relationships and so (name of PHC provider) has been really good with all of us…. There's probably a lot of positives from being in a small community and a doctor's available when you need it, I mean the same doctor. You don't have to take whoever you can get in to." (PTCG01)

"They answered all my questions, no matter what I asked, and sometimes (PHC provider) looks up some information if s/he's not sure, but I know that's one thing as far as, you know, anything I need to know, or s/he'll even tell me stuff that I haven't suspected and that really helps when you know where you're at. And now I have to write a lot of it down, so sometimes s/he just gives me printouts of stuff s/he has so that helps too." (PTCG05)

Strengths of Communities

Likewise, respondents described their family members' communities as inclusive and helpful since they or their family members first started experiencing symptoms or were diagnosed with dementia:

- Community tries to be inclusive
- Neighbors stop to visit

- Patient/family carried on with usual activities
- Feel relaxed, able to ask for help or a ride

"The community's actually been very good, you know, they'll stop and visit with him and even though he might ask them the same question over again three times, well, they're very good, actually." (PTCG03)

"Just that I would never hesitate to call anybody and that's very positive when you're, you know, afraid of what might happen. I just find that I live in a very nice community … I'm relaxed. I'm not afraid you know, to talk to people if I have to or if say if I ever needed a ride to go to (name of town) say I had a bad spell or something." (PTCG05)

Summary

Led by Dr. Debra Morgan, the Rural Dementia Action Research (RaDAR) team is part of the Canadian Consortium on Neurodegeneration on Aging (CCNA), a collaboration of 370+ researchers across Canada.

Phase 1 of a 5-year RaDAR study involved a baseline assessment of dementia care best practice gaps and strengths across Sun Country Health Region, focused on primary health care teams. **This report presents the findings of the baseline assessment.**

Thirty-two (N = 32) one-on-one telephone interviews were conducted with primary health care team members, decision-makers, and patients/caregivers in Sun Country Health Region in 2015.

Primary Health Care (PHC) Teams

Nineteen (19) PHC team members representing 8 teams took part in one-on-one telephone interviews.

Rural PHC Dementia Model

- The majority of PHC team members agreed that *care co-ordination* elements were present in their team for patients with dementia (68-89%) and were less likely to agree that they had access to *decision support tools*

Figure 1. Rural Primary Health Care (PHC) Dementia Model

Care co-ordination	Decision support tools	Specialist to provider support
- Multidisciplinary team - Ongoing care management for patients with dementia - Regular follow-up for patients with dementia - Education/support for patients with dementia and caregivers	- Standard tools, guidelines, protocols - Access to IT resources	- Access to dementia specialists - Formal dementia education for all providers

elements based on Aminzadeh et al. (2012)

(47-63%) and *specialist-to-provider support* (16-21%).

Assessment

- **Changes in patient cognition or behaviour** – PHC team members reported becoming aware of changes in cognition or behaviour in patients that might signal possible dementia, through family members, patient visits, and referrals from other team members. Electronic medical records and personal conversations were the main avenues of communication between team members.

- **Assessment best practices** – The large majority of team members (84-100%) indicated that the assessment of patients with suspected dementia by their team involved collecting collateral information, conducting a complete medical history, and administering a formal cognitive assessment and depression assessment. The majority (68%) reported that their team completed a physical exam and referred for comprehensive bloodwork. Team members were less likely (42-53%) to report that patients were typically referred to a specialist when warranted (e.g., suspicion of early onset dementia).

- **Team strengths and challenges** – Good team communication and the relative lack of anonymity in small communities (which allowed changes in patient behaviour to be noticed relatively quickly) were the most frequent strengths cited by team members in terms of assessing patients with dementia. Team members noted that patient/family resistance to assessment and low access to specialists the most frequent challenges.

- **Team effectiveness** – Overall, 79% of PHC team members agreed that their team effectively assesses patients with suspected dementia, 11% disagreed, and 11% were neutral.

Diagnosis

- **Standardized testing** – The large majority of team members (84%) reported that they personally regularly administer the MMSE to individuals with suspected dementia, and the majority (74%) regularly administer the clock drawing test and activities of daily living instrument. Team members were less likely (32-58%) to personally regularly administer the MoCA, trail making test, instrumental activities of daily living and geriatric depression scale.

- **Team communication and documentation** – The majority of team members indicated that a diagnosis of dementia was 'always/frequently' conveyed to patients (68%), documented in patient records (74%), and effectively communicated to patients as well as to the rest of their team (68% for both

items). Electronic medical records and personal conversations were the main avenues of communicating a patient's dementia diagnosis amongst team members.

- **Team strengths and challenges** – Similar to strengths in assessment, good team communication was cited as the top strength in terms of diagnosing patients with dementia according to team members. Patient/family resistance and low access to specialists were cited as the most frequent diagnosis challenges, similar to assessment challenges.
- **Team effectiveness** – Overall, 63% of PHC team members agreed that their team effectively diagnoses individuals with dementia, 21% disagreed, and 16% were neutral/did not reply.

Management

- **Management best practices** – The large majority of team members (79-89%) reported that their team referred patients for Home Care Assessment, gave advice about safety issues, prescribed anti-dementia medications, made patients aware of changes in medication management and driving capacity (as part of planning for the future), provided information on community services to patients, and asked caregivers about how they were managing. The majority of respondents (58-74%) also indicated that their team discussed non-pharmacologic management options and medicolegal issues with patients, assessed patients for behavioural and psychological issues, made patients aware of changes in functioning independence, notified SGI about patients' medical condition with respect to driving ability, referred patients to the Alzheimer Society First Link, and gave advice to caregivers regarding respite care. Respondents were less likely to report that their team flagged patient records to indicate a dementia diagnosis (16%) and no respondents reported providing or referring caregiver training (psychosocial management).
- **Team communication and documentation** – Similar to team communication regarding diagnosing patients with dementia, most respondents indicated that team communication about patient management took place primarily by electronic medical records and personal conversation. A minority (37%) reported that their teams hold case discussion meetings for each patient with dementia and a small minority (11%) indicated that their teams use flow sheets based on clinical practice guidelines for managing patients with dementia.
- **Specialist referral** – Only a small minority of family physicians and nurse practitioners (11%) agreed that specialist access was adequate for patients

with dementia or suspected dementia. A minority reported that they always (44%) or sometimes (33%) refer patients to neurologists; a further 33% sometimes refer to other specialists.

- **Barriers to approaching the issue of driving** – PHC team members described the top barriers as patient/family resistance and lack of alternative transportation; others included patient independence and patient-provider relationship.
- **Team strengths and challenges** – Good team communication was the most frequent strength cited by team members in terms of managing patients with dementia. Team members noted that inadequate local community resources was the most frequent challenge in managing patients with dementia (e.g., day programs and respite).
- **Team effectiveness** – Overall, 63% of team members agreed that their team effectively manages patients with suspected dementia, 11% disagreed, 21% were neutral, and 5% did not reply.

Health Region Decision-makers

Nine (9) health region decision-makers took part in one-on-one telephone interviews.

- **Health region strengths and challenges** – Health human resources in terms of strong leadership and staff, capable physicians and nurse practitioners, and good team communication, were cited as top regional strengths in dementia care. Decision-makers noted that difficulty establishing a dementia diagnosis was the top regional challenge in dementia care.
- **Information and Education** – When asked whether there was adequate information and education available to individuals with dementia and their families across the health region, none of the decision-makers (0 of 9) agreed.
- **Accessibility** – A minority of decision-makers (3 of 9) agreed that health care services across the health region are accessible when specifically considering individuals with dementia and their families. Health care services were defined as primary health care, home care, long-term care, and telehealth; accessibility was defined in terms of geography, language, culture, and other factors.
- **Care coordination** – A minority of decision-makers (3 of 9) agreed that health care services for individuals with dementia and their families across the health region are coordinated. Coordinated care was defined as connected and coherent care delivered by different health care professionals; health care

services were defined as primary health care, home care, long-term care, and telehealth.

- **Community fit** – A small minority of decision-makers (1 of 9) agreed that the nature and level of services across the health region available for individuals with dementia and their families fit the needs of these individuals. Services were defined as those provided by primary health care professionals, specialists, home care services, day care, and other community-based services.
- **Comprehensiveness** – A small minority of decision-makers (2 of 9) agreed that health care services for individuals with dementia and their families across the health region are comprehensive (e.g., health care professionals are able to provide diagnosis and management, there is timely referral to health and social services). Health care services were defined as primary health care, home care, long-term care, and telehealth.
- **Quality of care** – A small minority of decision-makers (2 of 9) agreed that there is quality of care in health care services provided to individuals with dementia across the health region (e.g., individuals with possible dementia receive timely diagnosis, standardized diagnostic criteria or clinical guidelines are followed for diagnosis and management). Health care services were defined as primary health care, home care, long-term care, and telehealth.

Patients and Caregivers

Five (5) caregivers and patients participated in one-on-one telephone interviews (in one instance, 2 caregivers took part in the same interview).

- **Nature of the problem and specific diagnoses** – The nature of the problem that caused the most concern before their family members received their diagnosis ranged from loss of interest to depression-like symptoms, faulty reasoning, and memory loss. All of the respondents indicated that a specific diagnosis was not conveyed to them.
- **Diagnosis process** – The respondents were mainly satisfied with the communication from the PHC team during the diagnosis process and the diagnosis process overall. While most respondents reported that they received everything necessary from the PHC team during the diagnosis process, one respondent indicated that a referral for caregiver support would have been useful. While most respondents reported that the diagnosis process was likely no different between their community and Regina/Saskatoon, one respondent

noted that their family member might have received a specialist referral had they lived in Regina/Saskatoon.

- **Management** – The respondents were generally satisfied with communication from the PHC team during the management process and the management process overall. While most reported receiving the services and resources necessary from the PHC team and community during the management process, one respondent indicated that their family member did not receive day care and meals on wheels from Home Care and one respondent noted the value of wheelchair accessibility in their community. Similar to the question of whether the diagnosis process might have proceeded differently if they had lived in Regina or Saskatoon, one respondent noted their family member may have been referred to a specialist for management had they lived in Regina or Saskatoon.
- **PHC team and community strengths** – Respondents described the care received by patients from their PHC teams as personal, attentive, and informative. Communities were described as inclusive and helpful since respondents or their family members first started experiencing symptoms or were diagnosed with dementia.

Study limitations

It must be noted that family physicians from PHC teams were under-represented in this study. Furthermore, the small sample sizes of each of the three groups (PHC team members, decision-makers, and patients/caregivers) may not be representative of their respective populations in Sun Country Health Region. These limitations may limit the generalizability of the study findings to the health region as a whole.

References

Alzheimer's Disease International. *World Alzheimer Report 2014: Dementia and Risk Reduction.* Available at: http://www.alz.co.uk/research/world-report-2014.

Alzheimer's Disease International. *World Alzheimer Report 2015: The Global Impact of Dementia.* Available at: http://www.alz.co.uk/research/world-report-2015.

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

Austrom M, Hartwell C, Moore P, Perkins A, Damush T, Unverzagt F, Boustani M, Hendrie H, Callahan C. An integrated model of comprehensive care for people with Alzheimer's disease and their caregivers in a primary care setting. *Dementia.* 2006; 5(3): 339-352.

Banerjee S, Willis R, Matthews D, Contell F, Chan J, Murray J. Improving the quality of care for mild to moderate dementia: an evaluation of the Croydon Memory Service Model. *International Journal of Geriatric Psychiatry.* 2007; 22(8): 782-788.

British Columbia Ministry of Health Guidelines and Protocols Advisory Committee. 2014. C*ognitive Impairment: Recognition, Diagnosis and Management in Primary Care.* Accessible at http://www2.gov.bc.ca/gov/topic.page?id=45355C78707542F5BB248E74C17CE623.

Bradford A, Kunik M, Schulz P, Williams S, Singh H. Missed and delayed diagnosis of dementia in primary care: prevalence and contributing factors. *Alzheimer Disease and Associated Disorders.* 2009; 23(4): 306-314. doi:10.1097/WAD.0b013e3181a6bebc.

Callahan C, Sachs G, LaMantia M, Unroe K, Arling G, Boustani M. Redesigning systems of care for older adults with AD. *Health Affairs.* 2014; 33: 626-32.

Chertkow H, Feldman H, Jacova C, Massoud F. Definitions of dementia and predementia states in Alzheimer's disease and vascular cognitive impairment: consensus from the Canadian conference on diagnosis of dementia. *Alzheimer's Research & Therapy.* 2013; 5, Suppl 1, S2. doi:10.1186/alzrt198.

Dudgeon S. *Rising Tide: The Impact of Dementia on Canadian Society.* 2010. Toronto, Ontario: Alzheimer Society.

Gauthier S, Patterson C, Chertkow H, Gordon M, Herrmann N, Rockwood K, Rosa-Neto P, Soucy JP on behalf of the CCCDTD4 participants. Recommendations of 4th Canadian Consensus Conference on Diagnosis &Treatment of Dementia. Canadian Geriatrics Journal. 2012;15: 120-26.

Glasser M, Miller B. Caregiver and physician perspectives of medical encounters involving dementia patients. *American Journal of Alzheimer's Disease and Other Dementias.* 1998; 13: 70.

Haggerty J, Burge F, Gass D, Lévesque J, Beaulieu M, Pineault R, Santor D. Operational definitions of attributes of primary health care: consensus among Canadian experts. *Annals of Family Medicine*. 2007; 5: 336–44.

Kosteniuk J.G., Morgan D.G, O'Connell M.E., Kirk A., Crossley M., Teare G.F. et al. Incidence and prevalence of dementia in linked administrative health data in Saskatchewan, Canada: a retrospective cohort study. *BMC Geriatrics*. 2015; 15: 73. doi:10.1186/s12877-015-0075-3.

Lee L, Hillier L, Stolee P, Heckman G, Gagnon M, McAiney C, Harvey D. Enhancing dementia care: a primary care-based memory clinic. *Journal of the American Geriatrics Society*. 2010; 58: 2197-2204.

Morgan D, Kosteniuk J, Stewart N, O'Connell M, Kirk A, Crossley M, Dal Bello-Haas V, Forbes D, Innes A. Availability and primary health care orientation of dementia-related services in rural Saskatchewan, Canada. *Home Health Care Services Quarterly*. 2015; 34(3): 137-158.

Moore A, Patterson C, Lee L, Vedel I, Bergman H. Fourth Canadian Consensus Conference on the Diagnosis and Treatment of Dementia: Recommendations for family physicians. *Canadian Family Physician*. 2014; 60: 433-438.

Murphy K, O'Connor D, Browing C, French S, Michie S, Francis J, Russell G, Workman B, Flicker L, Eccles M, Green S. Understanding diagnosis and management of dementia and guideline implementation in general practice: a qualitative study using the theoretical domains framework. *Implementation Science*. 2014; 9:31.

Ngo J, Holroyd-Leduc J. Systematic review of recent dementia practice guidelines. *Age and Ageing*. 2015; 44(1): 25-33.

Parmar J, Dobbs B, McKay R, Kirwan C, Cooper T, Marin A, Gupta N. Diagnosis and management of dementia in primary care. *Canadian Family Physician*. 2014; 60: 457-465.

Saskatchewan Ministry of Health. *Patient Centred, Community Designed, Team Delivered*. 2012. Available at: https://www.saskatchewan.ca/~/media/files/health/additional%20reports/other%20ministry%20plans%20and%20reports/primary%20health%20care.pdf.

Singh I, Varanasi A, Williamson K. Assessment and management of dementia in the general hospital setting. *Reviews in Clinical Gerontology*. 2014; 24(3): 205-218.

Saskatchewan Ministry of Health. *Chronic Disease Management Quality Improvement Program: Information for Providers*. 2014. Available at: http://www.ehealthsask.ca/services/Pages/cdm.aspx.

Stellefson M, Dipnarine K, Stopka C. The Chronic Care Model and diabetes management in US primary care settings: A systematic review. *Preventing Chronic Disease Public Health Research, Practice, and Policy*. 2013; 10: 120180. DOI: http://dx.doi.org/10.5888/pcd10.120180.