

Planning for the Rising Tide: New Models of Rural Primary Healthcare for Persons with Dementia

Community-Based Primary Healthcare Team Grant
Planning Session, October 17, 2011

REPORT



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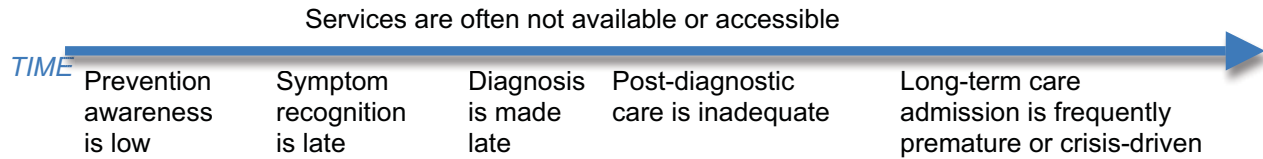
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KEY MESSAGES

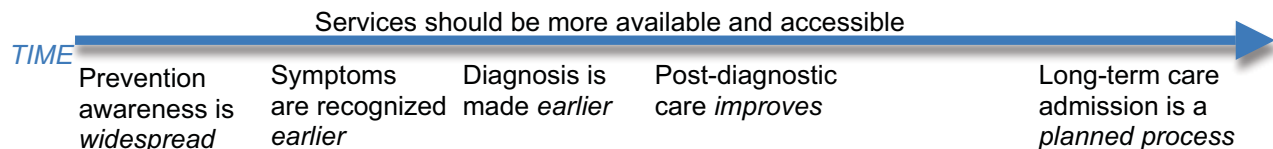
The current picture of healthcare services for rural people with mild cognitive impairment and dementia and their caregivers, according to Planning Session participants:



Gaps in healthcare

- ✦ Symptoms of mild cognitive impairment (MCI) and dementia are challenging to recognize early in the disease for families and healthcare professionals, and may be attributed to normal aging. Some people feel that a diagnosis of dementia carries a stigma.
- ✦ Families typically seek help when they have reached a crisis point. As a result, diagnosis is frequently delayed.
- ✦ Post-diagnostic care services are not consistent across the province and can be difficult to access, such as primary care and home care services.
- ✦ Long-term care admission is frequently either premature or crisis-driven. Individuals with dementia and their caregivers do not receive the range of services they need in order remain as independent as possible and to stay in their own homes for as long as possible.

The way healthcare services should look for rural people with mild cognitive impairment and dementia and their caregivers, according to Planning Session participants:



Improve healthcare by:

- ✦ Improving early recognition of mild cognitive impairment (MCI) and dementia symptoms among the public and healthcare professionals.
- ✦ Improving access to early diagnosis of MCI and dementia among the rural and remote population.
- ✦ Improving post-diagnostic care for rural and remote people with MCI and dementia and support to their caregivers throughout the continuum of care.
- ✦ Supporting caregivers to allow people with dementia to stay in their homes longer, reduce caregiver distress, and delay admission to long-term care.

Key recommendations by participants:

- ✦ Develop dementia care facilitators to provide case management and system navigation
- ✦ Offer education and training to improve the knowledge base of healthcare professionals
- ✦ Establish guidelines to improve prevention, early detection, and diagnosis
- ✦ Introduce care pathways for primary healthcare professionals
- ✦ Support a provincial and national strategy for dementia
- ✦ Lobby provincial government to recognize dementia as a chronic disease

ACKNOWLEDGEMENTS

The Community-Based Primary Healthcare (CBPHC) Innovation Team Grant Planning Session was made possible by support from:

- ✦ The Canadian Institutes of Health Research
- ✦ Saskatchewan Health Research Foundation
- ✦ University of Saskatchewan
- ✦ Canadian Centre for Health and Safety in Agriculture

We would also like to thank the Planning Session participants, who gave so generously of their time to take part in this project.

1. EXECUTIVE SUMMARY

Team Objectives

Our team's objectives are to develop and implement an interdisciplinary and cross-jurisdictional (national and international) program of research to improve the delivery of healthcare to persons with mild cognitive impairment (MCI) and dementia and their caregivers in rural and remote primary healthcare settings.

Background

Our team has been working together since 2003 to deliver services, in person and by telehealth, to persons with dementia in rural and remote (northern) Saskatchewan through the Rural and Remote Memory Clinic in Saskatoon and related projects (e.g. telehealth support group for caregivers). With Dr. Debra Morgan as Principal Investigator, the team was originally funded in 2003 by Canadian Institutes of Health Research (CIHR) as a "New Emerging Team (NET)." Saskatchewan Health has continued to fund the Rural and Remote Memory Clinic's services since the research demonstration project ended in 2009. Since then, the NET team has continued its momentum with research funding from CIHR and the Saskatchewan Health Research Foundation, with guidance from a 27-member Decision-Maker Advisory Council. Other funding organizations have also provided support for research, trainees, and research-related travel.

The Rural and Remote Memory Clinic in Saskatoon provides diagnostic support, management, and follow-up for rural and remote patients presenting with atypical and complex cases of dementia and mild cognitive impairment. However, the clinic also receives referrals for relatively uncomplicated patients, indicating that family physicians are not sufficiently prepared to meet the current need for diagnosing and managing patients with Alzheimer's disease and other dementias. In addition, our team's research over the last several years points to a significant need for new ways to deliver care to people with mild cognitive impairment and dementia, as well as to their caregivers.

The impetus for the October 17th Planning Session was supported by a call from CIHR for Planning Grant applications of \$25,000, to enable researchers and stakeholders to meet face-to-face and develop plans for a full Community-Based Primary Healthcare (CBPHC) Innovation Team Grant. CIHR plans to fund a number of CBPHC Innovation Teams in the area of primary healthcare for a minimum of five years, with the possibility of extension to ten years.

Planning Session Objectives

We had three specific objectives for the October 17th Planning Session:

- bring together researchers, stakeholders, family caregivers, and international experts to identify important issues in primary healthcare for people with MCI and dementia and their caregivers living in rural and remote areas
- identify innovative and feasible service delivery models to improve primary healthcare for people with MCI and dementia and their caregivers living in rural and remote areas
- establish relationships with stakeholders who are interested in working with our team to implement future intervention projects in Rural Dementia Care

Method

The one-day Planning Session was held at the Sheraton Cavalier Hotel in Saskatoon on October 17, 2011. A number of stakeholder groups were invited to the Planning Session, including family physicians and Nurse Practitioners; health region directors of primary healthcare, chronic disease

management, long-term care, and Home Care; and selected past participants of the Annual Knowledge Network in Rural and Remote Dementia Care Summit, including family caregivers of Rural and Remote Memory Clinic patients. Prior to the Planning Session, we mailed a binder of meeting documents by post to each participant.

The Planning Session included brief presentations in the morning by Dr. Debra Morgan (Team Principal Investigator), Dr. William Albritton (Dean of College of Medicine, U of S), and Sheila Achilles (Director, Primary Health Care and Chronic Disease Management, Saskatoon Health Region). A session of focus groups and a facilitated panel discussion followed. During the afternoon session, our Team's international collaborators, Dr. Sridhar Vaitheswaran (Consultant Old Age Psychiatrist, Scotland) and Alan Murdoch (Dementia Services Development Manager, Scotland), presented their program of telepsychiatry in dementia service delivery in the remote Shetland Islands in Scotland. This presentation was followed by a second session of focus groups, a facilitated panel discussion, and a self-administered survey of Planning Session participants that identified challenges and solutions to implementing interventions.

Planning Session participants were asked to discuss the following five questions during the morning and afternoon session of the focus groups:

Thinking of people with dementia and their caregivers in rural and remote areas:

- *What are the gaps in primary healthcare (i.e., pressing issues or challenges)?*
- *What are the reasons for these gaps?*
- *How can these gaps be resolved?*
- *What objectives should be kept in mind when designing services to provide primary healthcare to this group?*
- *What would an ideal model of rural primary healthcare look like? Which specific interventions should be included in this model?*

Ethics approval was obtained from the University of Saskatchewan Behavioural Research Ethics Board (BEH# 11-192) to collect focus group and survey data during the Planning Session.

Results

The Planning Session was attended by 53 stakeholders and 13 co-investigators, collaborators, and research assistants. Stakeholders included health region directors, family physicians, nurse practitioners, family caregivers, the Alzheimer Society of Saskatchewan, Health Quality Council, and health region employees.

Participants identified the following gaps in primary healthcare for people with dementia and their caregivers in rural and remote areas:

- Symptoms of MCI and dementia are challenging to recognize early in the disease for families and healthcare professionals, and may be attributed to normal aging. Some people feel that a diagnosis of dementia carries a stigma.
- Families typically seek help when they have reached a crisis point. As a result, diagnosis is frequently delayed.
- Post-diagnostic services are not consistent across the province and can be difficult to access, such as primary care and home care services.
- Long-term care admission is frequently either premature or crisis-driven. Individuals with dementia and their caregivers do not receive the range of services they need in order remain as independent as possible and to stay in their own homes for as long as possible.

The following reasons for gaps in primary healthcare for people with dementia and their caregivers in rural and remote areas were singled out by participants:

- Insufficient education for healthcare professionals and the general public resulting in inadequate public awareness and stigma
- Rural isolation and a need for travel to access diagnostic and supportive management services in cities
- Human resource shortages
- Rigid health region boundaries, and services that are inconsistent across health regions
- Inadequate public funding for services and costs to rural patients and families to access private services

According to participants, the objectives that should be kept in mind when designing services to provide primary healthcare to persons with dementia and their caregivers include:

- Improving early recognition of MCI and dementia symptoms among the public and healthcare professionals
- Improving access to early diagnosis of MCI and dementia among rural and remote populations
- Improving post-diagnostic care for rural and remote people with MCI and dementia and support to their caregivers throughout the continuum of care
- Supporting caregivers to allow people with MCI and dementia to remain functionally independent, in order to stay in their homes longer, reduce caregiver distress, and delay admission to long-term care

The specific interventions that should be included in rural primary healthcare for persons with dementia and their caregivers, as identified by participants:

- Develop dementia care facilitators to provide case management and system navigation
- Offer education and training to improve the knowledge base of healthcare professionals
- Establish guidelines to improve prevention, early detection, and diagnosis
- Introduce care pathways for primary healthcare professionals
- Support a provincial and national strategy for dementia
- Lobby provincial government to recognize dementia as a chronic disease

Next Steps

Based on the results of this Planning Session and subsequent meetings, our team intends to develop innovative ways to improve the delivery of healthcare to persons with mild cognitive impairment and dementia and their caregivers in rural and remote settings. Our team intends to:

- ✦ Consult with individual stakeholders to identify primary healthcare interventions that build on existing resources (e.g., Alzheimer Society of Saskatchewan)
- ✦ Lobby the provincial government to provide funding for pilot interventions
- ✦ Work with health regions to further develop feasible and effective primary healthcare interventions
- ✦ Conduct a baseline provincial (and regional level) study to determine current rates of healthcare and social service use, identify gaps in care and support services, and target potential areas for quality improvement
- ✦ Develop a CBPHC Innovation Team Grant proposal to submit to CIHR in Fall of 2012

2. TEAM MEMBERS



Debra Morgan

Canadian Centre for Health and Safety in Agriculture (CCHSA)
University of Saskatchewan

Debra Morgan is a Professor at the Canadian Centre for Health and Safety in Agriculture, University of Saskatchewan, where she holds a College of Medicine-funded chair in Rural Health Delivery and a CIHR-SHRF Applied Chair in Health Services & Policy Research (2009-2014) titled “Healthcare Delivery Across the Continuum for Rural and Remote Seniors with Dementia”. Her research program focuses on rural and remote dementia care and has two main themes: community-based care (e.g., early assessment/diagnosis, barriers to use of services, home care) and institution-based care (e.g., organizational factors affecting front-line caregivers, influence of organizational context on use of best practices). She was the principal investigator of a New Emerging Team (NET) funded by the Canadian Institutes of Health Research and provincial partners (2003-2009) titled “Strategies to Improve the Care of Persons with Dementia in Rural Areas”.



Julie Kosteniuk

Canadian Centre for Health and Safety in Agriculture (CCHSA)
University of Saskatchewan

Julie Kosteniuk is a postdoctoral fellow in the Canadian Centre for Health and Safety in Agriculture, and is a member of the Rural and Remote Memory Clinic team. She received her PhD in Psychiatry from the University of Saskatchewan, with a focus on family physicians’ diagnosis and management of patients with depression and anxiety. Julie has held training fellowships with PHARE (Public Health and the Agricultural Rural Ecosystem) and TUTOR-PHC (Transdisciplinary Training and Understanding on Research – Primary Health Care).



Margaret Crossley

Department of Psychology
University of Saskatchewan

Margaret Crossley is a Professor and the Director of Clinical Psychology Training in the Department of Psychology at the University of Saskatchewan. She teaches in the areas of clinical and experimental neuropsychology, psychogerontology, and psychopathology. Crossley is a co-investigator with Debra Morgan (P.I.) and the New Emerging Team (NET) on Aging (now the Knowledge Network in Rural and Remote Dementia Care) and, together with Megan O'Connell, coordinates the neuropsychological assessment team at the Rural and Remote Memory Clinic. In collaboration with her graduate students and colleagues, she researches cognitive indicators of normal aging and early stage dementia, and develops and evaluates interventions designed to improve quality of life for rural and remote patients and their family caregivers, including telehealth delivered support groups, and culturally appropriate procedures for the assessment and diagnosis of cognitive impairment and dementia in Aboriginal seniors.



Andrew Kirk

Neurology Division, Department of Medicine
University of Saskatchewan

Dr. Andrew Kirk is Professor and Head of Neurology at the University of Saskatchewan where he has worked since 1991. He is Past-President of the Canadian Neurological Society and the Canadian Neurological Sciences Federation. Dr. Kirk was a co-investigator on the CIHR New Emerging Team grant on rural dementia care and has been the Neurologist with the Rural and Remote Memory Clinic since 2004.



Megan O'Connell

Department of Psychology
University of Saskatchewan

Megan E. O'Connell is an Assistant Professor in clinical psychology at the University of Saskatchewan, and she is a member of the neuropsychological assessment team at the Rural and Remote Memory Clinic. Megan's research interests include issues relevant to dementia differential diagnosis and interventions for those with dementia and their caregivers. Megan has been working with Margaret Crossley and their caregiver collaborators to develop and evaluate the use of telehealth videoconferencing to deliver a support group for spouses of persons diagnosed with atypical dementias, such as the frontotemporal variants. Megan is PI on a recently awarded a grant to build the Videotherapy Analysis Lab (ViTAL) where the focus of her program of research is use of videoconferencing (via telehealth or the internet) to deliver interventions to rural families of persons diagnosed with dementia.



Norma Stewart

College of Nursing
University of Saskatchewan

Dr. Norma Stewart is a Professor in the College of Nursing at the University of Saskatchewan and her research interests are in dementia care and rural health services. Her academic background is in Psychiatric Nursing (University of California) and Psychology (University of British Columbia). She has supervised or served on thesis committees for over 50 Master's and PhD students in Nursing, Psychology, and other Health Science disciplines. Currently, she is conducting a study of sons as caregivers for a parent with dementia in a rural context. She works closely with Dr. Debra Morgan on studies related to her Chair mandate (Rural Health Delivery; Health Services & Policy) and the Saskatchewan site of the CIHR-funded Translating Research for Elder Care (TREC) project, led by Dr. Carole Estabrooks at the University of Alberta.



Dorothy Forbes

Faculty of Nursing
University of Alberta

Dr. Dorothy A. Forbes, RN, PhD is Associate Professor, Faculty of Nursing, University of Alberta. Her program of research focuses on supporting persons with dementia and their care partners in rural and urban Canada. Currently, Dr. Forbes is conducting an exploration of rural home care providers, persons with dementia and their family and friend caregivers' co-creation of evidence-informed decision making related to dementia care. She also conducts Cochrane Reviews on interventions that manage the symptoms of dementia and is examining the influence of gender on social support among home care clients using interRAI data. Dr. Forbes is a co-investigator on several projects: the evaluation of the CHSRF EXTRA program (Malcolm Anderson, PI); enhancing

rehabilitation across sectors through better use of health information (Paul Stolee, PI); the effects and costs of a nurse-led interprofessional mental health promotion intervention for depressed older adults using home support services (Maureen Markle-Reid, PI); and knowledge to action processes in SHRTN collaborative communities of practice (James Conklin, PI). Dr. Forbes held a CIHR New Investigator award from 2003-2008 and was President of the Canadian Association for Nursing Research from 2003-2007. She is currently a member of the management committee of the Canadian Dementia and Knowledge Translation Network, and Adjunct Professor, College of Graduate Studies and Research, University of Saskatchewan.



Vanina Dal Bello-Haas
School of Rehabilitation Science
McMaster University

Vanina Dal Bello-Haas is Associate Professor and Assistant Dean, Physiotherapy in the School of Rehabilitation Sciences, McMaster University. She is also adjunct Associate Professor, School of Physical Therapy, University of Saskatchewan, and until very recently she was the consultant Physical Therapist in the Rural and Remote Memory Clinic. Vanina's research interests include understanding the interplay among impairments, activity limitations and participation restrictions in community dwelling people with dementia, fall risk in people with early-stage dementia, and community-based interventions for people with neurodegenerative diseases, including dementia. Vanina and Co-investigators Dr. Megan O'Connell, Dr. Debra Morgan and Dr. Margaret Crossley (NET members) have examined the feasibility of offering exercise via telehealth to individuals with early-dementia, and she and NET member Dr. Jenny Basran are involved in interdisciplinary research regarding use of technology to enhance data transfer of clinically important information about near-falls and falls in community dwelling seniors.



Anthea Innes
School of Health and Social Care
Bournemouth University, Bournemouth, England

Dr Anthea Innes is Professor of Health and Social Care Research at the School of Health and Social Care at Bournemouth University. Dr. Innes has specialised in the field of dementia studies since 1995. Dr Innes' current research includes a focus on diagnosis and post-diagnostic support for people with dementia and their carers in Scotland. This includes a Knowledge Transfer Project in the Highland region of Scotland, the geographical area in Scotland considered to be most remote and rural. Other research interests include: design and technology; care environments; frontline care staff; and the experiences of people with dementia.



John Keady
School of Nursing, Midwifery, and Social Work
University of Manchester, Manchester, England

Dr. John Keady is Professor of Older People's Mental Health Nursing, a joint appointment between The University of Manchester and the Greater Manchester West Mental Health NHS Foundation Trust. John is founding and Co-Editor of the journal: 'Dementia: The International Journal of Social Research and Practice', and a member of five active European/International Networks. John is a trained mental health nurse and founding and co-editor of the Sage journal 'Dementia: the international journal of social research and practice'. He has a long standing interest in the dementia care, covering practice, research and educational developments, and his

PhD on the subjective experience of living with dementia commenced in the early 1990s when he was a community mental health nurse in dementia care.



Sridhar Vaitheswaran

NHS Grampian
Royal Cornhill Hospital, Aberdeen, Scotland

Dr. Vaitheswaran is a Consultant Old Age Psychiatrist and Clinical Director for Old Age Psychiatry Directorate in NHS Grampian, Scotland. His interests are in remote and rural dementia care delivery, and he is currently providing clinical support to developing such a service in Shetland Islands. He is also leading a liaison Old Age Psychiatry team that is providing input to a busy University general hospital in Aberdeen, Scotland.



Alan Murdoch

NHS Shetland
Lerwick, Shetland, Scotland

Alan Murdoch is a Dementia Services Development Manager. After qualifying as a Registered Mental Nurse in Glasgow in 1983 Alan initially worked in acute inpatient wards before moving to a post as a Community Psychiatric Nurse in 1985. Alan worked in Glasgow as a CPN until 1990 when he moved to Shetland as a Senior CPN and gradually helped to develop the Community Mental Health Team, taking over as manager of this team in 1999. Alan has always maintained an interest in working with people with dementia and in September 2009 was invited to take on a new challenge to set up a local Memory Assessment Service. He was also tasked with developing systems to provide support and education for non-specialist staff working with people with dementia and their carers. Later this year Alan will be moving into a new role of Alzheimer Scotland Dementia Nurse Consultant working within NHS Shetland. This role carries additional responsibilities relating to improving the management of people with dementia in Acute Hospitals and residential care settings.

3. BACKGROUND

3.1 Objectives of the Planning Session

We had three specific objectives for the October 17th Planning Session:

- bring together international experts, stakeholders, and family caregivers to identify important issues in primary healthcare for people with dementia and their caregivers living in rural and remote areas
- identify innovative and feasible service delivery models to improve primary healthcare for people with dementia and their caregivers living in rural and remote areas
- establish relationships with stakeholders who are interested in working with our Team on future intervention projects in Rural Dementia Care

On the day following the Planning Session (October 18th), the team co-investigators met to accomplish two goals:

- review the outcomes from the Planning Session
- lay the groundwork for the CBPHC Innovation Team Grant application to propose a comprehensive program of intervention research focused on collaborative community-based models of primary healthcare for people with mild cognitive impairment and dementia in rural and remote areas.

3.2 Background

Dementia is a term for symptoms that are the outcome of disorders that damage brain cells and results in memory loss and severe decline in language skills, object recognition, motor abilities, and sound judgment (1). Dementia has been termed an ‘epidemic’ that is forecast to nearly double in the next 20 years in global prevalence from 35.6 million people to 65.7 million (2). Mild cognitive impairment (MCI) is a condition that can be detected on cognitive tests but may not interfere with daily life. People with MCI have problems with memory, language, or another essential cognitive function, which may develop or may not develop into Alzheimer's disease or other dementias (1).

Canadian primary healthcare professionals face growing numbers of individuals presenting with symptoms of mild cognitive impairment (MCI) and dementia. Some 500,000 Canadians currently have Alzheimer's disease or a related dementia. The number of people with dementia is estimated to increase 103,000 each year (one new case every 5 minutes) for the next 30 years (3). By 2038, 1.1 million Canadians are expected to have dementia, and many more will exhibit the mild cognitive impairments that are characteristic of the prodromal phases of these chronic brain-based disorders. In the face of this expected epidemic, experts recommend that Canada introduce major policy changes to mitigate substantial short and long-term impacts (4, 5).

Early diagnosis of MCI and dementia benefits patients and their caregivers, since underdiagnosis is associated with insufficient support and services (6). Appropriate and effective prevention strategies can be implemented. Symptom progression can be slowed and patient and caregiver quality of life improved by recognizing the disease early and providing active disease management (7). Early recognition of MCI and dementia allows individuals and families to plan

for the future (8-13), access support services and groups (8-10, 12, 13), access new medications and treatments (8-10), and participate in research (8, 10). Early diagnosis also provides families the opportunity to implement changes that improve individuals' physical safety and decrease their stress and fears (13).

Other countries have developed national policies to support care for people with dementia and their caregivers, including Australia, France, South Korea, Scotland, and England (6). In addition to improving long-term care services and community support, these countries are focusing on increasing capacity among primary care professionals to diagnose and treat dementia in its early stages. For instance, a key recommendation from the government of England's 2009 report *Living Well With Dementia: A National Dementia Strategy* was that new specialist services be created to receive referrals from primary care for patients with symptoms of dementia (14). Subsequently, England's Department of Health established quality dementia care outcomes, including good quality early diagnosis and intervention for all (15). Further, the Scottish government has established dementia diagnosis targets based on estimates of the population likely to have dementia, requiring general practitioners to diagnose dementia in nearly 40,000 people across Scotland by 2011 (16). In contrast, Canada lacks a national dementia strategy, and policies vary across the provinces: no single department in any of the provinces takes sole responsibility for dementia policy (3).

Rural and remote residents with MCI and dementia and their caregivers face considerable geographic challenges accessing necessary services located mainly in larger cities (17). These challenges typically are intensified by age, behavioural symptoms, and coincident health problems. At 15%, Saskatchewan is ahead of other provinces in terms of seniors' share of the population and this is even higher in rural communities (17%); the majority of seniors in Saskatchewan (58%) live in rural areas, compared with only 42% in urban areas (18). The 2009 Saskatchewan Ministry of Health's *Patient First Review* noted that rural and remote Saskatchewan communities in particular, and the senior population as a whole, were at a disadvantage with respect to healthcare service delivery, and recommended a "comprehensive and innovative strategy for rural and remote service delivery that improves access to primary health, diagnostic, and specialist services" [19, p. 8].

Family physicians are typically the first point of contact with the healthcare system, yet the capacity for dementia care among this group of healthcare providers is not optimal. Recently published Canadian studies indicate that family physicians exhibit high levels of uncertainty in providing dementia care (20) and specialist referral rates among dementia patients are high (21). A recent Canadian study of family physicians' attitudes regarding caregivers of elderly patients found that a significant majority (94%) of physicians believed that they met caregivers' needs, yet 82% experienced stress in managing those needs and 75% thought they were not adequately remunerated for their stress in caring for caregivers (22). A retrospective chart review study conducted by Pimlott et al. found that family physicians in three Canadian cities exhibited poor to good compliance with the 1999 Second Canadian Consensus Conference on Dementia (CCCD) guidelines, in that few Physicians recommended the optimal tests, referred caregivers for support and referred patients for driver assessment (21). Pimlott et al. also found that fewer than half of physicians were aware of the 1999 guidelines, and physicians indicated that the guidelines did not reflect the realities of dementia care in their practice (23).

International research suggests that some barriers faced by dementia care providers are specific to rural and remote settings, such as travel, time, and cost. For instance, a study of rural general practitioners in Ireland found that GPs reported difficulty accessing CT and MRI scans, and perceived that stigma, in addition to their familiarity with patients, hindered dementia diagnosis (24). A U.S. study of rural primary healthcare providers also found that specialist services were difficult to access locally due to limited availability and consequent wait times, and difficult to access in urban centres due to travel (25). Primary healthcare providers further indicated a lack of support for home patient care, including nursing, day-care, and respite care (26). In addition, rural primary healthcare providers tend to be generalists with heavier workloads than their urban counterparts. Rural family physicians in Saskatchewan face challenges particular to practicing in rural locales in contrast to their urban colleagues. These challenges include fee-for-service remuneration incongruent with the on-call demands and hospital-based work requirements of rural practice, limited accessibility to information and staff during emergencies, and inaccessibility to specialists (27).

The 2004 *A Strategy for Alzheimer Disease and Related Dementias in Saskatchewan* report from the Saskatchewan Ministry of Health and the Alzheimer Society of Saskatchewan recommended that the province address the diagnosis and treatment of Alzheimer Disease and related dementias in primary care, as one of seven suggested strategic issues (28). The report called for adherence to diagnosis and treatment guidelines, creation of guidelines for referral from Physicians to specialists for purposes of diagnosis, easy access to education and support information for healthcare providers, and the need for healthcare providers other than family physicians such as primary healthcare teams, occupational therapists, and nurse practitioners, to make assessments leading to the diagnosis of dementia. However there has been limited implementation of the Strategy's recommendations, perhaps due to a lack of committed resources, health policies, and clear strategies for operationalizing the recommendations.

Improving capacity for rural dementia care requires new roles for primary healthcare professionals, new approaches to collaborating with specialists across the full spectrum of care (i.e., prevention, assessment, diagnosis, management, and referral), and helping both individuals and their family caregivers navigate the healthcare system. Primary Healthcare teams can improve access to timely assessment, diagnosis, and treatment for patients with suspected dementia (5). It has been suggested that if the scope of practice of nurse practitioners, pharmacists, dietitians, and physiotherapists were to be expanded, this could relieve the burden of care upon family physicians (29). Within Canada, it has also been suggested that Alzheimer's nurse care navigators roles be established, and that such nurses co-operate with family physicians in the full spectrum of care, from assessment to management and referral (4).

There is clearly a need for dementia care initiatives that take into account the context of rural healthcare professionals (e.g., barriers regarding geographic distance, shortages of healthcare providers, and stigma of seeking dementia care). With Canada's aging population, more people with MCI and dementia symptoms will be visiting the offices of family physicians and primary healthcare teams. Canada's primary healthcare professionals must have the basic skills to diagnose, treat, and support people with MCI and dementia and we must develop innovative models of care to meet the increasing demand for MCI and dementia services.

4. PREPARATORY MATERIAL

Prior to the October 17th Planning Session, we mailed a binder of meeting documents by post to each participant. The binder included:

- a welcome letter from the principal investigator (Dr. Morgan)
- CIHR announcement of the CBPHC Team Grant competition
- our team's CIHR Planning Grant application to host the October 17th Planning Session
- Planning Session objectives, participant contact information, presentations, and consent forms to participate in research
- 6 key journal publications on dementia care research
- two original research reports written by our team as background material for the Planning Session

5. INVITED PARTICIPANTS

We mailed invitations to the Planning Session by post to members of a number of stakeholder groups. First, we invited all family physicians practicing in Saskatchewan outside of Saskatoon and Regina (N=402) (30). We also emailed invitations to all health region directors of primary healthcare, chronic disease management, long-term care, and Home Care, using a current list provided by a Saskatchewan Health staff member. As well, the Saskatchewan Registered Nurses Association (SRNA) emailed an invitation on our behalf to all 122 Saskatchewan RN(NP)s on their listserve (31). Selected past participants of the Annual Knowledge Network in Rural and Remote Dementia Care Summit were also invited, including family caregivers of Rural and Remote Memory Clinic patients.

After the invitations were sent, additional stakeholders learned of the Planning Session and contacted our Team to register for the Planning Session. Appendix A lists the participants of the October 17th Planning Session.



6. AGENDA

The agenda for the day began at 8 am and ended at 4:30 pm (Appendix B). We developed the



agenda so as to conduct one session of focus groups followed by a panel discussion in the morning and a session of focus groups followed by a second panel discussion and a self-administered survey in the afternoon. A member of the team (Allison Cammer) facilitated the panel discussions and provided a summary of the morning's events prior to the afternoon session.

The morning presentations prior to the first focus group session were intended to situate our common objectives within Saskatchewan's rural primary healthcare context. The morning presentations (Appendix C) included:



- Debra Morgan (Principal Investigator, U of S): *Welcome and overview of CBPHC Team Grant*
- William Albritton (Dean, College of Medicine, U of S)
- Sheila Achilles (Director, Primary Health Care and Chronic Disease Management, Saskatoon Health Region): *Primary Health Care: Client-Centred, Community Design, Team Delivered*

After the morning presentations, attendees joined one of five pre-assigned focus groups to discuss three questions:

Thinking of people with dementia and their caregivers in rural and remote areas:

- *What are the gaps in primary healthcare (i.e., pressing issues or challenges)?*
- *What are the reasons for these gaps?*
- *How can these gaps be resolved?*

The focus group discussions were followed by a facilitated panel discussion. The panel was comprised of one member from each of the five groups tasked with providing feedback to the larger group, followed by an open discussion with all of the participants.



The afternoon session began with a summary of the morning's events, followed by a presentation by our Team's international collaborators (Appendix D). Since the afternoon's focus group discussions concentrated on interventions and the objectives of such interventions, we anticipated that our collaborators' presentation would offer some insight into the innovations possible in rural dementia care provision in other countries:

Sridhar Vaitheswaran (*right*, Consultant Old Age Psychiatrist, NHS Grampian, Scotland, UK) and Alan Murdoch (*below*, Dementia Services Development Manager, NHS Shetland, Scotland, UK): *Use of Tele-psychiatry in Dementia Service delivery in Shetland*



Following the afternoon presentation by the team's international collaborators, the focus groups reconvened to discuss two questions:

Thinking of people with dementia and their caregivers in rural and remote areas:

- *What objectives should be kept in mind when designing services to provide primary healthcare to this group?*
- *What would an ideal model of rural primary healthcare look like? Which specific interventions should be included in this model?*

A second facilitated panel feedback and discussion followed the focus groups, followed by a brief self-administered survey of meeting participants. Dr. Morgan closed the program with a presentation and group discussion of research priorities, ideas for building capacity, maintaining ongoing contact, and project involvement.

7. DATA COLLECTION

Ethics approval was sought and obtained from the University of Saskatchewan Behavioural Research Ethics Board (BEH# 11-192) to collect data during the Planning Session:

- Focus group audio-recording transcripts
- Focus group whiteboards
- Self-administered survey

7.1 Focus Groups



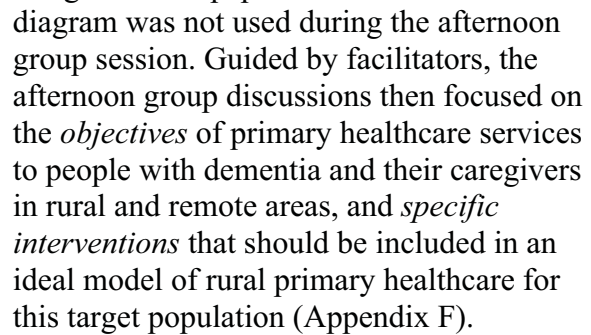
Prior to the Planning Session, Team members used the participant list to create five groups of approximately 12 persons each. Each group included two or more family physicians, at least one nurse practitioner, family caregiver, and member from the Alzheimer Society of Saskatchewan, and several health region representatives. The focus group facilitators were Team co-investigators, with the exception of one focus group led by a Team research manager.

After participants broke into five focus groups for the initial morning session, the facilitators asked group members to read and consider signing a form consenting to participate in the group (Appendix E). The facilitators then asked for three volunteers: a whiteboard writer, a whiteboard notetaker,



and a volunteer to fill in a Continuum of Care diagram with group feedback. Guided by their facilitators, the groups discussed three questions concerning people with dementia and their caregivers in rural and remote areas: *gaps in primary healthcare, reasons for these gaps, and possible ways to resolve these gaps* (Appendix F). After lunch, participants once again broke into the same five focus groups as in the morning session.

diagram was not used during the afternoon group session. Guided by facilitators, the afternoon group discussions then focused on the *objectives* of primary healthcare services to people with dementia and their caregivers in rural and remote areas, and *specific interventions* that should be included in an ideal model of rural primary healthcare for this target population (Appendix F).



A survey consent form (Appendix G) and survey (Appendix H) were distributed to all attendees just prior to the end of the Planning Session. The self-administered survey covered two of the same topics as the focus group discussions (i.e., most important issues in primary healthcare and preferred primary healthcare interventions) and asked participants to identify some challenges to implementing primary healthcare interventions and possible solutions to these challenges. Participants were also asked whether they would be willing to provide a letter of support to the team, and whether they agree to be involved in a primary healthcare intervention in dementia care.

Of 53 attendees who participated in the morning session focus groups, 49 attendees subsequently participated in the afternoon focus groups, and 45 participants completed a self-administered survey (excluding 13 co-investigators, collaborators, and research assistants). In addition to health region directors (22%), family physicians (18%), nurse practitioners (15%), and family caregivers (9%), respondents came from diverse groups such as the Alzheimer Society, Home Care, Client Care Co-ordination, Institutional and Emergency Care, RxFiles, and the Health Quality Council.

Participant role	n	%
Family caregiver	4	9
Health region director	10	22
Family physician	8	18
Nurse practitioner	7	15
Other specify	16	36
Total	45	100.0

9. RESULTS

The following results are based on data from the Planning Session focus groups and the self-administered survey completed by participants at day's end (Appendices I and J). The focus group data includes whiteboard notes made by a volunteer from each focus group (Appendix I), as well as transcripts based on audio-recordings of the focus group discussions.

Participants were asked to discuss the following questions during their focus group sessions:

Thinking of people with dementia and their caregivers in rural and remote areas:

- *What are the gaps in primary healthcare (i.e., pressing issues or challenges)?*
- *What are the reasons for these gaps?*
- *How can these gaps be resolved?*
- *What objectives should be kept in mind when designing services to provide primary healthcare to this group?*
- *What would an ideal model of rural primary healthcare look like? Which specific interventions should be included in this model?*

The self-administered survey that was circulated at the end of the Planning Session day asked participants to reflect on some of the same questions that they had discussed during their focus groups, as well as additional topics:

- *In your health region or community, what might be the challenges to implementing the interventions?*
- *What might be some solutions to these challenges?*

In the following sections, we present our analysis of the data organized according to the preceding seven questions.

9.1 Gaps in Primary Healthcare (i.e., pressing issues or challenges)

Participants identified gaps in primary healthcare for people with dementia and their caregivers in rural and remote communities associated with three key issues: services (at the diagnostic and post-diagnostic stages), knowledge, and healthcare professionals.

Gaps in Services (diagnostic)

Participants suggested that people with dementia and their caregivers in rural and remote communities face considerable challenges obtaining a diagnosis in the early stages of the disease due to gaps in services. Participants identified substantial gaps in accessibility, availability, and timeliness of diagnostic services. It was noted that during the time spent trying to obtain a formal diagnosis, treatment is likely not being provided and families are not accessing necessary social and healthcare services.

Gaps in services (diagnostic) included:

- ✦ early identification of dementia
- ✦ in-home assessment
- ✦ diagnosis of dementia

“...lots of families struggle; they talk about length of time to get a diagnosis, lack of willingness to get a diagnosis or getting a general diagnosis of dementia which leaves the family in a situation where half are saying well, there’s nothing wrong with Mom because she doesn’t have a diagnosis so then they don’t seek services and treatment and support and the other half saying well definitely there is something wrong. And I think it stems right back to lack of recognition of warning signs.” (Focus Group 4)

“Well I think that one of the big gaps in rural and remote Saskatchewan is access to expert care, expert services as far as diagnosis, early diagnosis.” (Focus Group 3)

“... lots of people will say I was told I was too young and so it couldn’t possibly be Alzheimer’s disease so you know it does affect people under the age of 65 and I don’t know that we really look for it under that age.” (Focus Group 4)

“... there may be family physicians and internationally trained family physicians who that’s not part of their training on aging and mental health issues and those types of things (they) don’t recognize them and acknowledge the changes that are happening. So just even some of the challenges of getting a diagnosis is when the family member does identify that there are signs and wanting to figure out what’s going on, getting that diagnosis is extremely challenging.” (Focus Group 5)

“...we really don’t have good screening tools in very early dementia. I’ve had several patients where there’s something not quite right, you know a lot of times they’ve got a bit of a weight loss or whatever, and yet they pass the MMSE with flying colours and then three years later well it’s obvious that it’s probably the early stages of Alzheimer’s or some sort of dementia. Had we an effective screening tool to identify these people, get the families involved early, so that three years later they’re not coming down from the city, saying what happened to my mother? You know, we came down a year ago and she was fine...” (Focus Group 4)

Gaps in Services (post-diagnostic)

Participants singled out many post-diagnostic services that are largely unavailable or inaccessible to people in rural and remote communities, and expressed a significant need for accessible, culturally appropriate, and timely services for people with dementia and their caregivers. Gaps in post-diagnostic services were evident throughout the continuum of care. For instance, in the middle stages of the disease, people with dementia and their caregivers in many rural and remote communities do not have access to the type of care and support that would help individuals remain in their homes longer, such as day care, respite care, and in-home care. As the disease progresses and individuals require long-term care, they may need to settle into care homes away from their family and friends outside of their home communities. Participants indicated that post-diagnostic service gaps impact individuals' quality of life and unnecessarily increase the level of caregiver stress.

Gaps in services (post-diagnostic) included:

- ✦ qualifying for treatment
- ✦ interventions and treatment (e.g., physical therapy and exercise therapy)
- ✦ management of competency issues
- ✦ co-ordinated care
- ✦ post-diagnostic support throughout continuum of disease
- ✦ transitions through stages
- ✦ individualized patient and caregiver care
- ✦ community-based support for people with dementia and family/caregiver
- ✦ support for family/caregiver (e.g., counselling, support groups, travel, and respite)
- ✦ family/caregiver support of people with dementia
- ✦ Home Care, particularly 'soft' services (e.g., homemaking, respite, transportation, etc.)
- ✦ telehealth
- ✦ emergency care
- ✦ respite and day care
- ✦ in-home care
- ✦ personal care homes
- ✦ long-term care, specifically beds and assisted living
- ✦ palliative care

"...when you have one person that is ... capable of being a carer, we don't support those people so they don't burn out and I think what I have seen in my travels around rural Saskatchewan is what I call the 'crash and burn' phenomena and there's no support in place and the caregiver finally has to just dump this partner, because they just can't do it anymore. And then the transition into long-term care is so nasty for all concerned. It's nasty for the facility, it's nasty for the residents, and it's really nasty for the person who has had to do that so there's no preparation and transitioning into long-term care is really, not very smooth in a lot of cases." (Focus Group 2)

"...the best place for a demented person is in familiar surroundings like in his home, but we have got no support from Home Care where we are, absolutely none." (Focus Group 2)

"...we're talking about (someone) who wants to run to town to pick up groceries but can no longer trust her husband in the vehicle with her. That may be two or three hours but then she needs to find someone to come into the home and she has to do that privately and how hard is that to do in a farming community where we're spread for miles. I mean, personal experience, yes, you sometimes have a family member who can come and sit, but not always and not always is that family member able to cope with their parent. What do I do when he decides he's going to go outside in his underwear in the winter? They don't have the tools to deal with that." (Focus Group 2)

“So typically in rural you start having health problems and you go into the hospital and you’re either going to go back home or into low-income housing. There’s nothing else in between, generally speaking...alternative housing, I think is a big issue here as well.” (Focus Group 2)

“...there’s a problem here, too, because most of the seniors, whether they be wherever in the province, don’t have any coverage for travel or they don’t have coverage for medications because they get enough pension they just shove them out of that group. Social Services is not willing or unwilling to assess them based on their needs, so even if you had Joe Blow in Small Town, Saskatchewan, how the hell does he get down to Saskatoon, or Regina, to get interventions?” (Focus Group 5)

“... even if they get a placement, they’ll be told there’s a bed waiting say, at such a distance away. The whole family lives here, and the availability of the bed...is so far away. Now they are going to go into another environment where there’s a new family doctor, new care, no family visiting them on a regular basis. There’s a big difference if the family was in the same city or town, without having to go to another place which is so many kilometres away. Where is the compassion? Where is the continuity of care? (Focus Group 3)

“I think actual physical access, however we do it, I think that’s a huge gap in our rural (areas) and that’s easy to say because every study shows it. We are not getting people in, we are not seeing the consistency right across the continuum ... we’ve got stats through our whole Home Care system where when ... they get to a certain level of dementia, we are not supporting them at home...so I think across the continuum we are not getting appropriate access to what is out there for people and be it medication, be it support, group support.” (Focus Group 4)

“... most people want to stay in their homes, but we do very little to support informal caregivers and I mean the stress that they have, what we expect them to manage, the knowledge that they get after the diagnosis. Often, they’re just told, your family member has Alzheimer Disease or dementia, and they’re sent home. So they don’t understand the diagnosis, they don’t know how that disease will progress, they don’t understand how there’s going to be changes in their family member, their behaviour. And in a lot of ways we’re expecting them to keep the person at home but we’re not giving them the skills to help them to stay at home ... we have this big crisis looming, so we’re expecting family caregivers to do the job of informal caregiving. They may or may not be there, so I would say supporting informal caregivers is essential for us being able to provide dementia care services into the future.” (Focus Group 4)

“...one thing we see a lot of is you have early dementia and people function not too bad for a little while, in their own home, and then there’s this gap, kind of in the middle of early and more progressed dementia where they really don’t qualify for a care home, but they really are unable to stay at home and caregivers get maxed out and burnt out just trying to follow them around and make sure they don’t light the stove on fire.” (Focus Group 1)

“...funding for staffing in long-term care is very poor. It’s not uncommon to have one RN (registered nurse) to 50 residents and you might have an LPN.” (Focus Group 3)

“I think there’s a gap in younger people, so if you’re diagnosed with frontal temporal dementia, you could be in your mid forties or early fifties ... and then a lot of the services are geared towards helping elderly senior caregivers, so if you’re still working and you’re having to care for a spouse and children, it’s a very different set of needs that they have and often they feel like the services that are available aren’t meeting their needs. So I think we really need to think about how we support younger people and younger caregivers who are affected and probably more specifically the frontal temporal dementias.” (Focus Group 4)

Knowledge

Participants indicated that it is particularly important to improve the knowledge levels of the general public, families and caregivers, and healthcare professionals. Improving public awareness of dementia and openly discussing the disease will help to lessen the stigma surrounding the disease and prompt more families to seek necessary treatment and resources. Healthcare professionals must receive further education in order to recognize symptoms, properly treat patients with dementia, and support caregivers as patients progress in the disease.

Gaps in knowledge included:

- ♦ a lack of public awareness (leading to stigma)
- ♦ healthcare professionals require additional knowledge
- ♦ families and caregivers require relevant information
- ♦ needs include knowledge of patient disease progression, medications, non-pharmacotherapy options, standards for treatment and support, support programs, and so forth

“...you have to lift that stigma; you have to lift that veil so ... people recognize that it’s okay when Mrs. Brown forgets things, you know that we recognize that, you don’t have to ignore it. You don’t have to pretend it’s not happening because there’s a stigma associated with it. Because sometimes that’s what happens to people too; they don’t know how to react so they just pretend it’s not happening.” (Focus Group 4)

“I think there’s a gap in the area of education. I know that events for physicians occur periodically, but it’s almost like it has to be a very specialized kind of experience; you’ve got to book your weekend, you’ve got to travel too and there’s a gap in terms of education and evolving knowledge being delivered to the front line staff, the people who work in home care and in the hospital.” (Focus Group 5)

“...as a nurse practitioner, there are a couple of classes of drugs that I cannot prescribe and any of the research that you do those are the medications that you need to have, and then when I talk to a family physician to get that, if they’re not knowledgeable about the dementia or the medications, then it’s a difficult time for me to say, but you know that’s what they (need)...” (Focus Group 1)

“Often we hear families that are affected by dementia saying we don’t know what kinds of resources are available and how to access those resources and ... sometimes families don’t access help until there’s a crisis...” (Focus Group 3)

“...it’s the awareness of the caregivers, family members who know the patient and I know that they’re heading down that road. They don’t know where to go to access the service, they don’t know what services there are available, they suffer in silence and... Everyone in the community like the people in the Co-op recognize that there’s something going on, there’s something wrong with him ... that stigma that’s attached ... proud and never want anyone to know about this. Now how do those people, you know, where to go and access the care in a little town? There’s Home Care, there’s maybe a day program, but what kind of services are there? What kind of supports are there for them to go and get the help that they need?” (Focus Group 5)

Healthcare Professionals

Participants noted that older people in some rural and remote communities do not have a regular family Physician and oftentimes must travel much further than people in the city to receive primary healthcare. Other healthcare professionals are also in short supply, such as occupational therapists and continuing care consultants, while specialists such as geriatricians and geriatric psychiatrists typically practice only in cities. Compared to patients in larger centres, patients and their caregivers in rural and remote communities must travel further, and more often, to access both primary and speciality care.

Gaps in healthcare professionals included:

- ✦ primary healthcare providers (e.g., family physicians and nurse practitioners)
- ✦ continuing care consultants and behavioural management consultants
- ✦ multidisciplinary/interdisciplinary team approach to care
- ✦ Home Care providers
- ✦ specialists such as geriatricians and geriatric psychiatrists

“I mean, we’re faced with that all the time, we’ve got little towns where you’ve got huge populations of elders but there’s no health care provider in that town.” (Focus Group 2)

“...for rural people in our region the biggest gap would be access to primary care because ... we’re losing our physicians; we do have nurse practitioners in those primary care centres but we’re getting to a point where we’re bigger in one, we move a nurse practitioner over to another one and now we’ve left these people with nothing, you know, it’s really very difficult for access to that type of initial diagnosis and care.” (Focus Group 1)

“...often if someone comes from healthcare region X, I’m not even sure what the resources are there so sometimes I’ll say you know you need an occupational therapist and they will laugh and say there’s no occupational therapist in our health region.” (Focus Group 3)

“...at one point, there was one doctor in Kamsack to serve a huge area; there was a lot of people that couldn’t get care because they couldn’t get in. There were no emergency services; emergency services in Yorkton were available, but who’s going to take Grandma who’s acting a little off to emergency in Yorkton to sit for eight hours before she sees someone and says oh, it’s just a bladder infection, go home. Like that whole system of care is not available a lot of times in rural Saskatchewan, you know? We’ve got hospitals that are closing; we have nobody in to do even a clinical practice in some of these communities to do the assessment. Is it dementia: Is it delirium?” (Focus Group 2)

“...in rural Saskatchewan over this past summer we’ve had just a lack of physicians out in our area that lots of times memos are going out that there’s no doctors in Kindersley for this, no doctor coverage in Biggar for this month, so ... I know even my parents they’re physically lacking a family physician, someone that knows them and someone that can get them to and from the specialist and be their (provider) across the continuum of care.” (Focus Group 5)

“From the little town perspective here, we have physicians that come in from the city on a weekly basis on Wednesday afternoon (it’s) supposed to be so and so, or supposed to be except that often changes, so you get your parent to go to the family physician, a family physician, it may not be their family physician because you can’t always see the same one in a small town and they don’t know what to tell you. Yeah, he’s getting old. Well, there’s more than that.” (Focus Group 5)

9.2 Reasons for gaps in Primary Healthcare

Participants identified reasons for the gaps in rural dementia care at five levels, including services, system (health region and province), knowledge (on the part of healthcare professionals and the public), healthcare professionals, and patients/caregivers.

Services

Service level reasons for gaps in primary healthcare gaps included:

- ◆ screening and assessment tools are not consistent with healthcare coverage
- ◆ long-term care bed shortages due to ‘bed blocking’
- ◆ not all communities have telehealth sites
- ◆ process to access services is not straightforward
- ◆ navigation of the healthcare system is difficult, and patients and caregivers are unaware of existing resources

“...I have a (patient who is a) school teacher, well, soon as she did the exam she’s got it memorized, you know, so it doesn’t matter what you change that to, she knows that test is coming every three months, she’s got it on her calendar; it’s in the agenda, she does her studying.” (Focus Group 4)

Regarding the process to get EDS (Exception Drug Status) coverage: “You’ve got to beat somebody to death with a stick on the other end, sometimes, and some of them (seniors) just barely make it, like they’re taking money off their food budget to buy medications which sometimes aren’t covered. That’s for regular stuff, without considering above and beyond.” (Focus Group 5)

“... a global lack of personnel and resources to be able to provide appropriate care at those levels of dementia for respite, right?” (Focus Group 2)

“We used to be able to offer a caregiver, send someone into your home for three or four hours respite, rather than it’s very difficult to move a dementia person to a day program, like how are you going to get him there if he doesn’t want to come, but if I could send someone in there, the same person all the time to be that sitter for the afternoon, so that consistent caregiver, that, we just don’t have the bodies, so whether it’s day care in the home or respite during the day or during the night...” (Focus Group 5)

“The hours are limited and plus what we can do is (limited) have more staff that we could get them, help them with their grocery lists, help them shop appropriately, but that kind of funding isn’t there ...” (Focus Group 5)

“... the lack of appropriate long term care facilities as an example. You may have the beds, but they may not be the appropriate beds for people with dementia or your staff may not be appropriately trained in a long term care facility so there’s two kind of measures going on.” (Focus Group 2)

System (Health Region and Province)

System level reasons for gaps in primary healthcare included:

- ♦ Home Care funding has decreased, particularly for 'soft' services (e.g., homemaking)
- ♦ alternative methods of transportation are not offered to rural residents
- ♦ across health regions, services are inconsistent, a common language does not exist, and there is unnecessary bureaucracy
- ♦ we do not have a provincial strategy for dementia and dementia is not a provincial priority

"... sometimes that balance between whether a person can manage in their home well or be institutionalized is based on those softer services. You can't live in your home if you can't clean your windows, you know, all that kind of stuff. You can't grocery shop and so how much of it falls to your family and I think that sometimes in rural Saskatchewan, I'm sure it happens in the city a lot, too, but the people choose to be institutionalized because they don't want that onus thrust upon their families." (Focus Group 5)

"I think it's just a way in which they're funding because ... because each health region gets their own pocket of funding from Health to do with, to deliver the service. It doesn't promote inter region collaboration." (Focus Group 5)

"...it's still the economics, uh, I think is what we're talking about for the system, economics. So in rural, a lot of your time is spent on travel, as opposed, versus being able to actually deliver hands on care." (Focus Group 2)

"...the challenge that we find trying to help people navigate the system is there's however many different health regions, there's that many different ways of dealing with it and what might be available in RQHR isn't available in Prairie North or is available in Prairie North so you're throwing at a dart board when you're trying to help families navigate the system." (Focus Group 5)

Knowledge

Knowledge level reasons for gaps in primary healthcare gaps included:

- ♦ lack of continuing medical education opportunities
- ♦ lack of public education
- ♦ stigma of dementia

"We talk about stroke; we talk about early signs of heart attack, but we really don't talk about dementia. My parents for two years were wandering around in the community, doing odd things. I didn't know about it until they were placed. Oh, yeah, your Mom used to come in and she used to ... Well, if somebody would have told me that sooner, I would have been able to help them sooner, maybe kept them in their homes." (Focus Group 2)

"There's also the embarrassment too, and I'm thinking, rural communities you know I don't want anybody to know to know there's something wrong with my Dad or my husband and therefore I'm not going anywhere." (Focus Group 3)

"...sometimes there's the sense that there's not much you can do for people with Alzheimer's disease or other dementias so why give them the label of Alzheimer's disease? So that's another sort of gap in getting a diagnosis is the feeling that because there aren't effective treatments, what's the point of giving somebody this label that then has all these other difficulties associated with it?" (Focus Group 4)

Healthcare Professionals

Healthcare professional reasons for gaps in primary healthcare included:

- ♦ human resource shortages due to isolation, burnout, difficulty attracting healthcare providers, funding, and trend to urban medicine
- ♦ professional territorialism
- ♦ healthcare professionals have inadequate training to use telehealth

“...one of our family physicians in the rural said I love hunting and fishing and so for him that’s one of the reasons why he’s out in the rural areas, ‘cause he’s very close to it. A lot of them if they want to be, not on call, not phoned in the night, you know, all of those kind of things, they want to be in the bigger practices...” (Focus Group 1)

“...retaining rural practitioners whether it’s family physicians or geriatric psychiatrists or like that because there’s just not enough or people won’t stay and then once a better job comes along, they leave Melfort Saskatchewan and then go to Saskatoon or Regina or the States and you just can’t get that consistency of care because there’s not enough follow through and enough folks there to be able to provide those services.” (Focus Group 3)

“...it’s tough for us to get a doctor in Yorkton and we’re 15,000 or 20,000, but how do we get one in Kamsack that is 5,000 or 2,000?” (Focus Group 1)

Patients/Caregivers

Patient/caregiver reasons for gaps in primary healthcare included:

- ♦ some patients and caregivers may have unrealistic expectations of drug therapy
- ♦ some patients and caregivers do not drive or do not drive in large cities and therefore cannot drive to appointments or to access services
- ♦ some patients do not live in the same community as their families and caregivers
- ♦ population of older people has increased and the number of caregivers has decreased

“...it’s only recently that people from our area have become generally comfortable driving in the city, there’s been a big change in ten years. Historically people would not drive into the city or rarely would. So you take someone that is you know, in their 50s, 60s, 70s, who is having difficulty of memory plus you add onto that the culture of living in a small town versus being in the city and trying to negotiate it.” (Focus Group 5)

“We had the unfortunate circumstances (of) an elderly woman who ... everybody knew was having a few issues, so the community kind of supported her but one son lives in Florida, one son lives in Calgary and it wasn’t until at 40 below weather, she’s out knocking on the door of her neighbour’s house which, fortunately, for some reason miraculously opened and she got in and of course when the other elderly woman woke up in the morning, there’s this woman sitting on her couch.” (Focus Group 2)

“...a lot of these seniors live on the family farm with children who don’t want to farm and the parents have broken the ground and so they don’t want to give it up so they live way out in the boonies, miles from anywhere, even miles from a family physician. They’re elderly; they can’t drive, or what I’ve seen, too, is that they have family members that will drive them, but they say the trip is too far, too long, I can’t go that way. Some people they hire, I know, somebody had to pay \$100.00 to somebody to drive them from Yorkton to Regina. I mean that’s a lot of money for a trip for these elderly people on limited income ...” (Focus Group 3)

9.3 Resolving gaps in Primary Healthcare

Participants suggested ways to resolve the gaps in rural dementia care by focusing on factors associated with services, system (health region and province), knowledge (on the part of healthcare professionals and the public), and healthcare professionals.

Services

Resolve primary healthcare gaps by focusing on services, such as:

- ♦ introduce trained dementia care providers (e.g., care co-ordinators, case managers, and care navigators) to offer individualized case management
- ♦ offer early referral to services
- ♦ establish immediate assessment team
- ♦ offer patient- and family-centred care
- ♦ establish collaborative care
- ♦ offer travelling primary healthcare services
- ♦ provide access to Geriatric Assessment Unit for patients with multiple conditions
- ♦ improve crisis management and follow-up
- ♦ establish contact persons in each town/area
- ♦ expand circle of care to include non-traditional community partners
- ♦ broaden Home Care services
- ♦ expand Rural and Remote Memory Clinic
- ♦ increase number of long-term care beds
- ♦ improve access to services and efficiency of services
- ♦ expand videoconferencing (e-health) and remote technology

“... the lack of appropriate long term care facilities as an example. You may have the beds, but they may not be the appropriate beds for people with dementia or your staff may not be appropriately trained in a long term care facility so there’s two kind of measures going on.” (Focus Group 2)

“...we’ve got palliative care coordinators within each region managing all the care, managing palliative care clients, could we not have a dementia care coordinator for each region?” (Focus Group 3)

“I think the key to that is you need people in the community who are interacting on a regular basis with individuals who are developing these problems. You need to have workers, people who have a knowledge base, so that they can pick up on things when they’re going off track, because ... really the treatment is how you adjust as the person evolves in their condition so it’s almost week by week, month by month adjustments that have to be made by the family. So a large part of the time is spent in the family, so there needs to be someone within that interaction with that family, be it the nurse practitioner, the family physician. Usually it’s special care aide or the home care worker. They have to have the knowledge that they need in order to support the family to make those changes, those adjustments.” (Focus Group 5)

“...the reality ... in this province is there’s not going to be a doctor in every community, then why are we not using other health care professionals, like nurse practitioners, Home Care nurses, who can then communicate with physicians? Why are we not trained to assess a patient and get ongoing care and report to the physicians?” (Focus Group 5)

“...we developed that mobile health bus in the city of Saskatoon, so the primary health centre actually goes into the inner city neighbourhoods to convenient locations so people can actually walk for health care. Do you think the mobile health bus would fit in let’s say, Swift Current, where you’ve got large tracts of land before you get to the next community. Would bringing the health centres to those smaller remote communities be better? I know it’s kind of like the library, right?” (Focus Group 2)

“...maybe for care of dementia in their own home, maybe what we need is devices to support that, so security devices so people don’t wander out without knowledge ... the installation of switch off for stoves and things like that ...” (Focus Group 2)

“ ... in Shetland (Scotland), a lot of young people who, as part of their education they’re encouraged to volunteer ... try to match them up with people that are interested and to promote the image of young people go in and adopting a granny. That’s a way forward.” (Focus Group 4)

“One of the things we’ve done in our community to our provider team ... we have a list of people who are willing to sit with dementia patients living in their homes to allow the caregivers, the 24-hour caregivers a break...A volunteer program, some people insist on being paid, and we do fundraising to do that, but I mean those are resources that should be provided ... what we see is they’re often those types of resources that are created informally within the smaller rural communities, out of necessity but aren’t necessarily available within the cities.” (Focus Group 5)

“The one thing my parents need more than anything else is a case worker, a specific person that will know where things are for them, that will go to appointments with them if necessary, if they’re going to meet, for example, with neurologist team or whatever on Telehealth, they need that person to know what is going on, so that they can then act on that and that they can remind my parents if I am not there...”(Focus Group 5)

“...That’s what we need for dementia is someone coming to Wynyard to see 15 dementia people in that, or ten or whatever they want to do in a day, to provide that education for the families and for the health care providers ... that’s one ... of my solutions, to keeping people in their home but you can’t expect people to drive from Wynyard to Regina or Saskatoon, ‘cause they won’t go. It’s too far; ‘I’m fine’, but they will come to a clinic or that nurse can go to their house or whatever.” (Focus Group 4)

System (Health Region and Province)

Resolve primary healthcare gaps by focusing on the system, such as:

- ♦ offer alternative housing
- ♦ subsidize services, offer tax rebate for purchasing services, and provide employment benefits for caregivers
- ♦ use existing MDS data to allocate service funding
- ♦ strengthen communities to care for one another
- ♦ make regional boundaries more permeable
- ♦ establish a provincial or federal dementia strategy
- ♦ recognize dementia as a chronic disease

“... the onus should not be on families. When you compare the cost of maintaining someone who is relatively capable in their own home to institutionalization, I mean the differential is astronomical. What are we doing?” (Focus Group 5)

“So we’re actually kicking ourselves in the foot because if we had that pool of money put out to provide services to keep people at home, we’d have more money than we have now, because now it’s so fragmented and so diverse based on every province. We’ve no federal intervention at all.” (Focus Group 5)

“...I’ve had seniors who have moved ... they realize that the old farm home is not good for them anymore and if you can get them in while they’re still, well maybe mild so that they’re, now, this is my new home, it’s smaller, I still have a little garden to putter in out back, but somebody will come here and help me. Then I think from there, you can add more services in that smaller area than having the nurse trek 20 miles north to a place where there may not be running water, you know? (Focus Group 2)

“...there are some other things the government could do to help support informal caregivers (like) enhance the tax benefits, maybe ... provide flexibility for employers, able to give caregivers time off work to provide care.”(Focus Group 4)

“...there also needs to be a sense of community welcoming someone in the community ... ‘cause small towns, and I feel like I can say this because I grew up in one, but sometimes you’re not one of us so you’re not necessarily welcome...my husband and I lived in northern Alberta for a period of time and ...well, we’re not there anymore so I guess, obviously we didn’t feel, you know, part of that community either, so there was that two, those two different things going on for us as, you know, needing that privacy of not having people asking me for your blood results or your lab results at the grocery store but also feeling that need to be part of the community and that quality of life too, so... (Focus Group 1)

“I think about families in Saskatoon where to get a pretty decent long-term personal care home is \$3,000/month and if you’re on a fixed income, how do you afford that? And so then we get people stuck in acute care walk-in beds, so you know, maybe that’s one thing that needs to be looked at is personal care homes in rural settings.” (Focus Group 3)

Knowledge

Resolve primary healthcare gaps by focusing on improving knowledge about dementia, such as:

- ✦ increase education to family physicians
- ✦ offer continuing education to nurse practitioners
- ✦ establish care pathways (i.e., standards of care and algorithms)
- ✦ teach risk reduction strategies
- ✦ increase education to families
- ✦ improve caregiver support
- ✦ remove stigma of dementia

“I think that really goes back to the early diagnosis part too. If you diagnose this person before they start to have these major problems, and get them on the medications, then you have certainly a better chance of maintaining them there as opposed to when they’re already having social issues and functional issues at home and then they expect this pill that’s going to reverse that. It’s not going to happen.” (Focus Group 4)

“I think if there was some sort of provincial directory of services, that would be quite helpful. People might read it and say oh, there’s this ... that’s what we need.” (Focus Group 3)

“The family physician needs the training to be able to say okay, this looks like it’s on the dementia scale somewhere... they need to be able to say, here’s the package of information that you probably will need to deal with your parent or whoever it is at this point in time.” (Focus Group 5)

“...if you can educate the public about dementia first of all, and here’s some preventive stuff as well, people then have less stigma about it when they have the diagnosis and they’re more bound to talk to their neighbours and talk to their family to say ‘okay, I’ve got this, I’m going to have to go on with this’ and as the disease progresses. Especially in a small community, they’ll rally around and they’ll know that Jimmy down the road there ... and they’ll see them get out and they’ll keep an eye on them, as you say, they’ll go out and they’ll buy the lard, then the next day they’ll take it back again.” (Focus Group 4)

“One of the programs that we implemented at the Alzheimer’s society is called First Link, which is a direct referral program where physicians, specialists, health care professionals, social workers, who are working with a person with a dementia or their family members can be directly referred to the Alzheimer society, because what we find is often health professions will say, why don’t you give the Alzheimer society a call, but there’s a barrier there and most people don’t call and ask for help and so with the direct referral, it’s then passed onto us and we give the family or whoever is listed as the contact, we give them a call and make contact with them...” (Focus Group 3)

Healthcare Professionals

Resolve primary healthcare gaps by focusing on healthcare professionals, such as:

- ✦ encourage healthcare provider students to work in rural areas
- ✦ recruit and retain rural healthcare providers and offer recruitment and retention packages
- ✦ prevent healthcare provider burnout by encouraging the public to respect healthcare professionals’ privacy

“...Let’s motivate that as part of the family medicine, rotation from the pre-graduated student, the student may have some rotation with well defined doctors in rural areas for them to practise rural medicine, to live with doctor there...” (Focus Group 1)

“... I think we need to expose people going into all realms of medicine, of all the different areas of what a primary health team looks like and how they function in rural Saskatchewan. I’ve had the privilege of having two first year med students hang out with the nurse practitioner and they were aghast. You do all this?! You do all this here? Well, yeah.” (Focus Group 2)

9.4 Possible interventions in Primary Healthcare

Participants put forward numerous creative and feasible interventions in the areas of prevention and screening, diagnosis and management, services, system (health region and province), and knowledge (on the part of healthcare professionals and the public).

Prevention and screening

Possible prevention and screening interventions:

- ✦ increase prevention services
- ✦ offer community-based screening and early diagnosis every 2-3 years in a blitz
- ✦ offer presentations on dementia and Alzheimer's Disease at seniors groups, church groups, economic development groups
- ✦ incorporate dementia screening into routine check-ups and Wellness clinics
- ✦ offer primary healthcare programs for early access to information and resources

Diagnosis

Possible interventions at the diagnostic stage:

- ✦ offer better diagnostic services
- ✦ offer travelling CT scan bus for diagnosis and other travelling services for communities

Management

Possible management interventions:

- ✦ offer financial assistance for medications
- ✦ improve follow-up treatment and management
- ✦ address co-morbidity
- ✦ offer multidisciplinary interventions and follow-up
- ✦ improve respite services
- ✦ improve Home Care services
- ✦ increase access to telehealth and videoconferencing
- ✦ offer recreational services
- ✦ improve behaviour management services
- ✦ improve support for family/caregiver

Services

Possible interventions targeting services:

- ✦ dementia care co-ordinator/navigator/case manager to be “go-to” person and offer one-on-one care
- ✦ develop multidisciplinary outreach teams
- ✦ ensure equal access to all healthcare professionals
- ✦ increase number of healthcare professionals providing dementia care (i.e., specialists, family physicians, and Nurse Practitioners)
- ✦ develop multi- and interdisciplinary teams and Primary Healthcare teams with embedded case management

- ✦ make Memory Clinics accessible in rural areas
- ✦ offer collaborative care that includes Society programs and services
- ✦ establish local specialists
- ✦ increase human resources
- ✦ improve accessibility, availability, appropriateness, and timeliness of services
- ✦ co-ordinate services across regions and province

System (Health Region and Province)

Possible interventions at the system level:

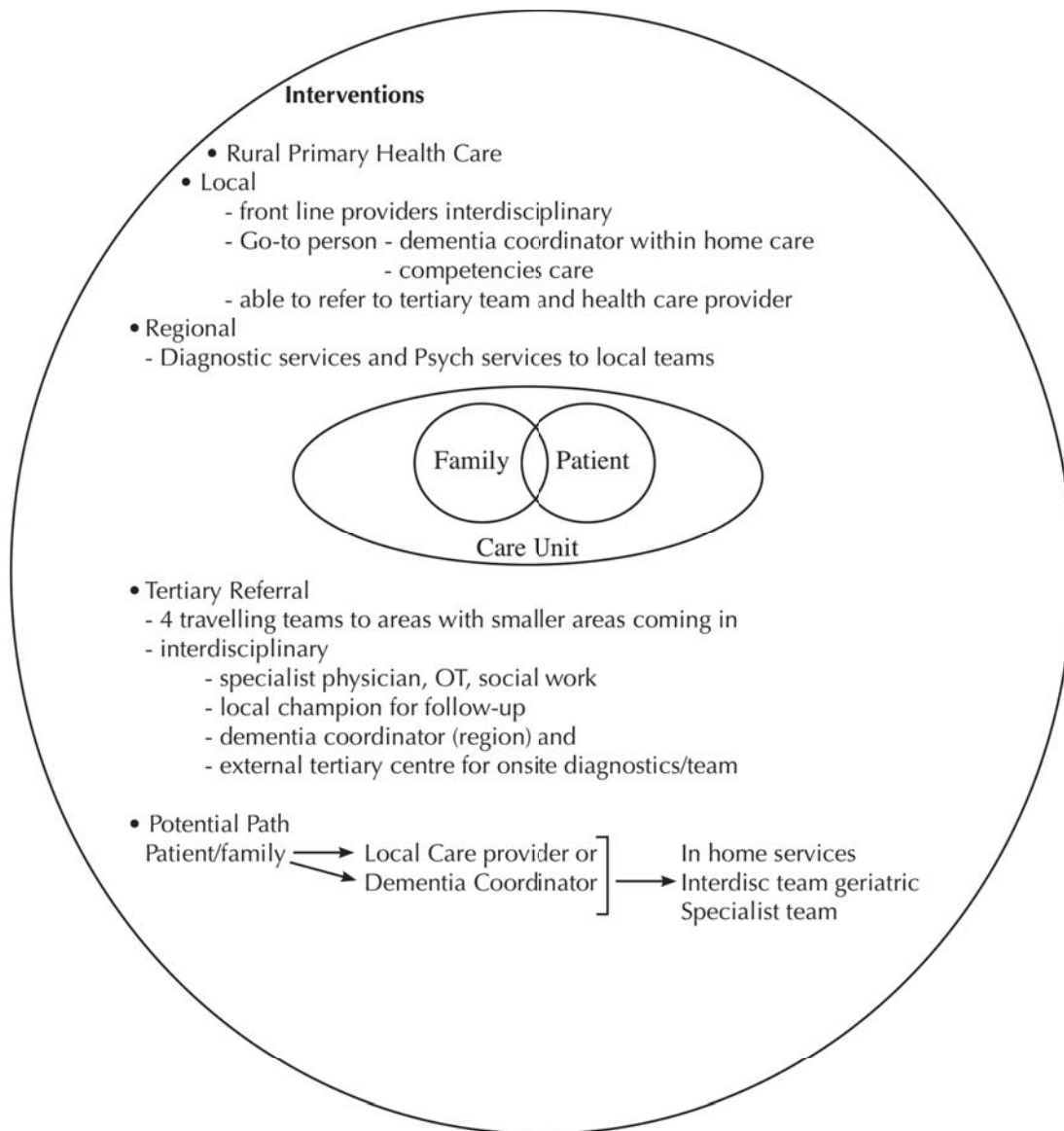
- ✦ offer more resources in rural areas
- ✦ make transportation easy and affordable
- ✦ increase surveillance of disease rates
- ✦ offer regional service directory
- ✦ improve government funding
- ✦ develop a provincial/national strategy for dementia
- ✦ recognize dementia and Alzheimer's Disease as a chronic disease

Knowledge

Possible interventions to improve knowledge:

- ✦ increase public awareness
- ✦ increase education for healthcare professionals
- ✦ increase professional evaluation of healthcare professionals
- ✦ train dementia care co-ordinators and chronic disease management program providers
- ✦ establish standards/algorithms of care
- ✦ offer education to family/caregivers regarding disease progression
- ✦ offer education to people with dementia (interactive and written)

MODEL OF CARE SUGGESTED BY FOCUS GROUP 1



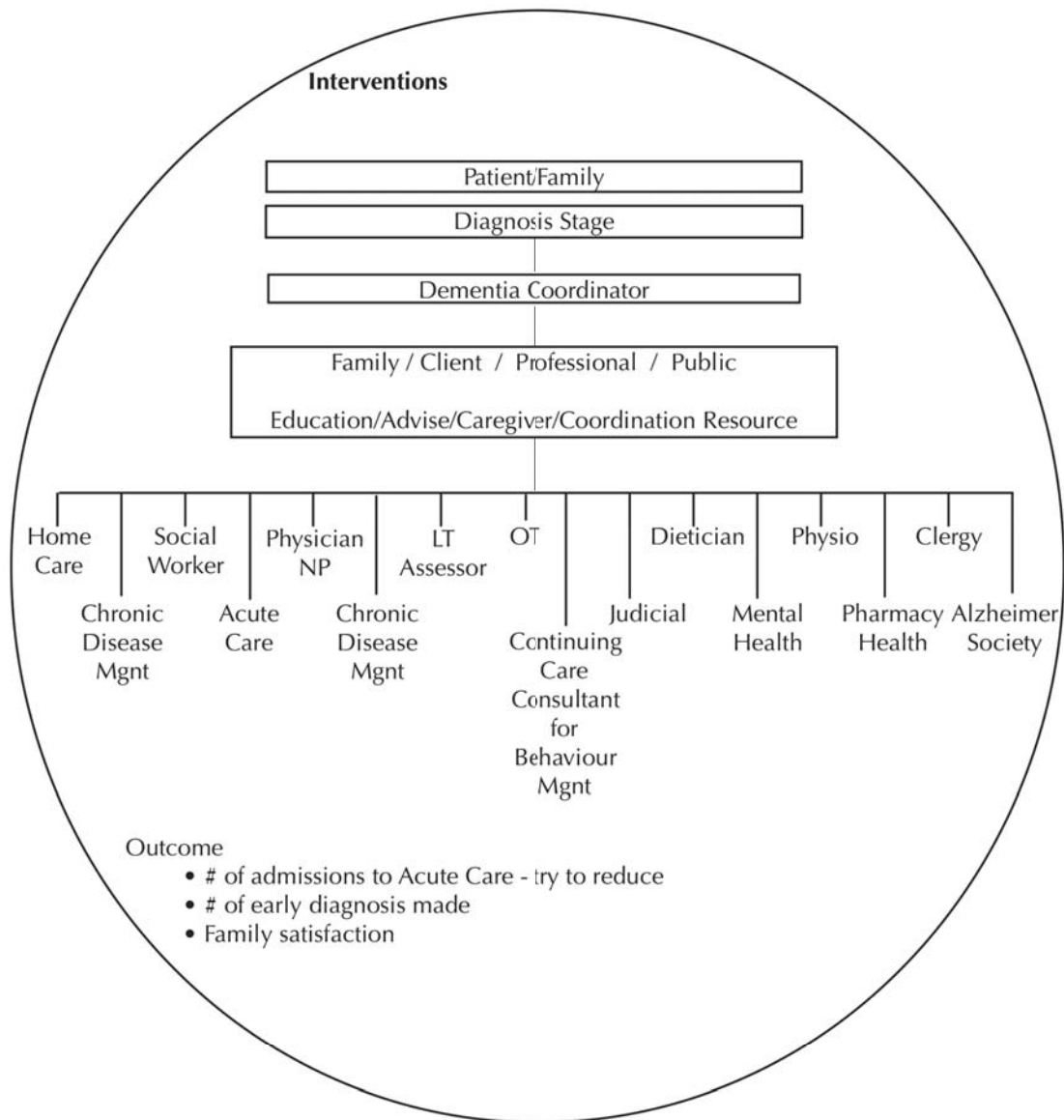
MODEL OF CARE SUGGESTED BY FOCUS GROUP 2



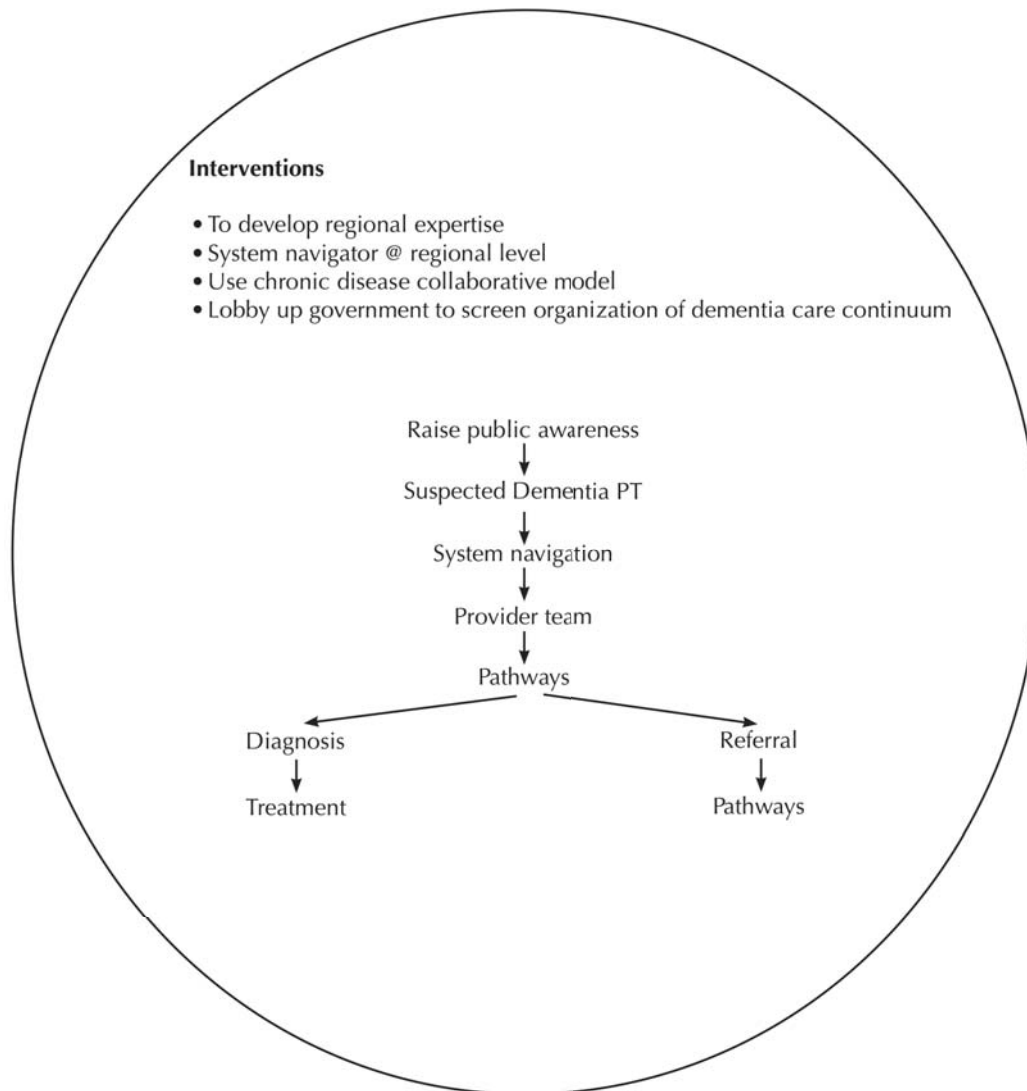
Interventions

- Support groups
- Case management (to assist with and establish CPs)
- Care pathways? - standards of current services - response to needs of community
- Electronic health records that travel with patient
- Hospice care (philosophy not a building)
- Telehealth - technology

MODEL OF CARE SUGGESTED BY FOCUS GROUP 3



MODEL OF CARE SUGGESTED BY FOCUS GROUP 4



MODEL OF CARE SUGGESTED BY FOCUS GROUP 5

Interventions

- Case manager/system navigator/dementia care coordinator
- Team care pathways - info: who, what, when
- Dementia bus
 - public awareness
 - initial screening and referral
- Dementia screening as part of annual medical/check-up
- Increase interprofessional diagnostic teams (in each region)
- Comprehensive training and education programs (entry level and ongoing)
- Expanding roles of existing programs/services (ie Wellness Clinic)
- Consistent services/languages across province
- Develop appropriate screening tool that most HCPs can utilize
- Dementia - Chronic Disease management strategy
- Lobby for funding
- Referral to Alzheimer's Society and First Link Program
- Technology - expansion
- Review/revamp home care program, respite programs (day, short-term)
 - jurisdictions, responsibilities

9.5 Objectives of interventions in Primary Healthcare

Participants indicated that the objectives of interventions to improve primary healthcare services should focus on factors related to prevention and screening, diagnosis and management, services, system (health region and province), and knowledge (on the part of healthcare professionals and the public).

Prevention and screening

Objectives of prevention and screening interventions:

- ♦ provide prevention and early intervention

Diagnosis

Objectives of interventions at the diagnostic stage:

- ♦ ethical competency assessment
- ♦ improve diagnostic services

Management

Objectives of management interventions:

- ♦ improve post-diagnostic services
- ♦ provide patient- and family-centred dementia care
- ♦ provide holistic care
- ♦ provide multi- or interdisciplinary care
- ♦ provide quality of care for patient and family
- ♦ provide culturally appropriate care
- ♦ provide continuity of care
- ♦ provide co-ordinated care
- ♦ keep people with dementia in community
- ♦ compulsory standardized SGI assessment (Drive Able program from AB)

Services

Objectives of interventions targeting services:

- ♦ honor Canada's Health Act – accessible, portable, universal services
- ♦ make patient and caregiver services affordable/free
- ♦ offer services that travel to rural residents
- ♦ improve communication between healthcare providers
- ♦ provide system navigation

System (Health Region and Province)

Objectives of interventions at the system level:

- ♦ reduce long-term cost burden for dementia care
- ♦ keep costs down
- ♦ integrate existing services into care
- ♦ develop medical records that travel with patients
- ♦ create patient advocate for patient care

- ♦ reduce regional boundaries
- ♦ recognize dementia and Alzheimer's disease as a chronic disease
- ♦ recognize dementia as a healthcare priority
- ♦ increase funding

Knowledge

Objectives of interventions to improve knowledge:

- ♦ improve public awareness, especially among baby boomers, about warning signs and early diagnosis (e.g., "Facing dementia" booklet for patients and "Coping with dementia" booklet for caregivers from Scottish healthcare system)
- ♦ reduce stigma
- ♦ offer continuing education for healthcare professionals
- ♦ offer accurate and up-to-date information to families and professionals
- ♦ develop standards of care and algorithms

9.6 Challenges to implementing interventions in Primary Healthcare

Participants cited challenges to implementing interventions to improve primary healthcare services at the level of services, system (health region and province), knowledge (on the part of healthcare professionals and the public), healthcare professionals, and patients/caregivers.

Services

Challenges to implementing interventions, associated with services:

- ✦ lack of a team approach prevents continuity of care
- ✦ cost of services
- ✦ shortage of resources
- ✦ shortage of structures (e.g., respite, mental health group homes, etc.)
- ✦ determining existing resources
- ✦ tests of evidence-based practice to improve dementia care

System (Health Region and Province)

Challenges to implementing interventions, associated with the system:

- ✦ lack of funding
- ✦ determining best way to deliver specialized care (i.e., telehealth, mobile health, or providing transportation)
- ✦ health regions are large
- ✦ lack of collaboration among regions and Ministry of Health
- ✦ lack of leadership within health region
- ✦ provincial government is focused on acute care rather than primary care and home care
- ✦ elderly care and dementia care are not priorities of the Ministry of Health or the provincial government
- ✦ lack of provincial dementia strategy
- ✦ culture change to encourage funding of research

Knowledge

Challenges to implementing interventions, associated with knowledge:

- ✦ education delivery must be appropriate and accessible to healthcare professionals
- ✦ education for healthcare professionals must be mandatory
- ✦ healthcare professionals must be educated about the importance of early diagnosis
- ✦ current knowledge about guidelines for dementia care is inadequate
- ✦ lack of standard documentation
- ✦ false belief that a diagnosis is not beneficial and there is nothing that can be done
- ✦ lack of public awareness
- ✦ stigma of dementia
- ✦ technology is fragmented
- ✦ developing standards of care

Healthcare Professionals

Challenges to implementing interventions, associated with healthcare professionals:

- ✦ travel and weather challenges
- ✦ shortage of rural human resources
- ✦ shortage of rural healthcare professionals trained in dementia care
- ✦ some communities do not have a family Physician or Nurse Practitioner
- ✦ some health regions do not have a specialist
- ✦ recruitment and retention of rural healthcare professionals (e.g., specialists, long-term care staff, home care, Occupational Therapists, family physicians, and Nurse Practitioners)
- ✦ healthcare professionals have many responsibilities
- ✦ some healthcare professionals do not want to work overtime or extra hours
- ✦ philosophical orientation of some family physicians and Nurse Practitioners must change to increase interaction with patients and families

Patients/Caregivers

Challenges to implementing interventions, associated with patients/caregivers:

- ✦ geographic and weather challenges
- ✦ lack of recognition of the important role of family and caregivers in patient's care team
- ✦ patient's family does not reside in the same community
- ✦ patients and families wait for a crisis before accessing primary care
- ✦ isolation
- ✦ lack of community transit and taxis
- ✦ dearth of programming to delay long-term care admission
- ✦ lack of a coordinated continuum of care
- ✦ patients do not accept services
- ✦ privacy concerns
- ✦ tax rebates for caregivers who leave the workforce

9.7 Solutions to challenges to implementing interventions in Primary Healthcare

Participants put forward a number of solutions to address challenges to improving primary healthcare services at the level of services, system (health region and province), knowledge (on the part of healthcare professionals and the public), healthcare professionals, and patients/caregivers.

Services

Solutions to address challenges to implementing interventions, associated with services:

- ✦ introduce dementia case worker
- ✦ fund dementia case worker with Saskatchewan Union of Nurses (SUN) Partnership funds
- ✦ systematic team approach rather than crisis management approach
- ✦ improve access to specialists via telehealth
- ✦ use existing resources (Occupational Therapy, Chronic Disease Nurse Practitioners, Home Care Wellness Clinics, Visiting programs via churches)
- ✦ increase number of telehealth sites
- ✦ centralize Primary Healthcare teams into hub and spoke service model

System (Health Region and Province)

Solutions to address challenges to implementing interventions, associated with the system:

- ✦ establish a dementia care collaborative similar to Health Quality Council chronic disease management collaborative
- ✦ national or provincial elderly and dementia strategy
- ✦ Ministry of Health must recognize dementia as a chronic disease
- ✦ lobby provincial government to establish dementia as a healthcare priority
- ✦ align dementia care with provincial government Primary Healthcare redesign
- ✦ lobby government to support patients to stay in their home
- ✦ lobby government to establish infrastructure of coordinated services
- ✦ restructure current programs
- ✦ establish provincial programs
- ✦ conduct government review of Home Care scope of services and dementia care
- ✦ conduct pilot projects
- ✦ offer community funding
- ✦ expand Alzheimer Society of Saskatchewan's First Link program
- ✦ incorporate respite care into existing structures
- ✦ subsidize services from private agencies for patients and caregivers
- ✦ increase funding for community-based services (e.g., Home Care, respite-in-home)
- ✦ encourage corporate sponsorship
- ✦ encourage culture change
- ✦ integrate existing services
- ✦ discourage competition for rural healthcare professionals amongst health regions

Knowledge

Solutions to address challenges to implementing interventions, associated with knowledge:

- ✦ make education accessible
- ✦ improve public awareness and education about dementia
- ✦ if public awareness increases, then public will be more likely to demand services
- ✦ promote early diagnosis
- ✦ remove stigma by normalizing dementia
- ✦ improve awareness about the high costs of undiagnosed dementia
- ✦ educate decision-makers about dementia
- ✦ provide education for healthcare professionals
- ✦ provide education for students and residents
- ✦ provide Geriatric Nurse Practitioner training
- ✦ mandatory in-service for healthcare professionals
- ✦ establish provincial standards for documentation
- ✦ Ministry of Health should develop standards of care/algorithms of care/care pathways

Healthcare Professionals

Solutions to address challenges to implementing interventions, associated with healthcare professionals:

- ✦ implement aggressive rural healthcare professional recruitment and retention strategies

Patients/Caregivers

Solutions to address challenges to implementing interventions, associated with patients/caregivers:

- ✦ provide financial support for caregivers
- ✦ reduce travel burden
- ✦ provide mobile services
- ✦ improve rural transportation systems
- ✦ work with caregivers to plan for adverse patient events
- ✦ offer screening programs by primary healthcare professionals

9.8 Support for Team's next steps

We asked participants of the Planning Session whether they would be willing to provide a letter of support for the CBPHC Team Grant application to the Canadian Institutes for Health Research (CIHR), and 31 participants (69%) responded positively.

Participants were also asked whether they would be willing to be involved in a Primary Healthcare intervention in dementia care, and 28 (62%) attendees agreed to be involved.

10. CBPHC INNOVATION TEAM'S NEXT STEPS

Based on the results of this Planning Session and subsequent meetings, our team intends to develop ways to improve the delivery of healthcare to persons with mild cognitive impairment and dementia and their caregivers in rural and remote primary healthcare settings. Our team intends to:

- ♦ Consult with individual stakeholders to identify primary healthcare interventions that build on existing resources (e.g., Alzheimer Society of Saskatchewan)
- ♦ Lobby the provincial government to provide funding for pilot interventions
- ♦ Work with health regions to further develop feasible and effective primary healthcare interventions
- ♦ Conduct a baseline provincial (and regional level) study to determine current rates of healthcare and social service use, identify gaps in care and support services, and target potential areas for quality improvement
- ♦ Develop a CBPHC Innovation Team Grant proposal to submit to CIHR in Fall of 2012

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Appendix A: Participant List

Participant	Position	Affiliation or Health Region
Team members in attendance		
Debra Morgan	Principal Investigator	U of S
Julie Kosteniuk	Co-investigator	U of S
Andrew Kirk	Co-investigator	U of S
Megan O’Connell	Co-investigator	U of S
Margaret Crossley	Co-investigator	U of S
Norma Stewart	Co-investigator	U of S
Vanina Dal Bello-Haas	Co-investigator	McMaster University, Hamilton, Ontario
Sridhar Vaitheswaran	Collaborator	Royal Cornhill Hospital, Aberdeen, Scotland
Alan Murdoch	Collaborator	Lerwick, Shetland, Scotland
Sheena Walls-Ingram	Research Manager	U of S
Allison Cammer	Professional Research Associate	U of S
Freda Elash	Research Assistant	U of S
Duane Minish	Research Assistant	U of S
Invited Guests		
William Albritton	Dean of Medicine	U of S
Anne Neufeld	Director of Strategic Development Health Research and Innovation	U of S and Saskatoon Health Region
Lesley McBain	Assistant Professor	First Nations University
Tanya Verrall	Senior Researcher	Health Quality Council
Evangeline Patkau	First Link Coordinator	Alzheimer Society of Saskatchewan
Joanne Bracken	CEO	Alzheimer Society of Saskatchewan

Participant	Position	Affiliation or Health Region
Joanne Michael	Program Services Manager	Alzheimer Society of Saskatchewan
Trina Hodgson	First Link Coordinator	Alzheimer Society of Saskatchewan
Ignacio Barretto	Family Physician	Cypress
Siva Balasingam	Family Physician	Cypress
Daniel Glaeske	Family Physician	Five Hills
Cathy Ringrose	Nurse Practitioner	Heartland
Francisco Lang	Family Physician	Heartland
Faye Hofer	Director of Primary Health Care	Heartland
Ruth Miller	Director of Continuing Care	Heartland
Nicole Gerein	Client Care Coordinator	Heartland
Jan McMillen	Nurse Practitioner	Keewatin Yatthe
Stephen Britton	Family Physician	Keewatin Yatthe
Pat Olson	Nurse Practitioner	Kelsey Trail
Valerie Kimball	Nurse Practitioner	Kelsey Trail
Larry Sandomirsky	Family Physician	Kelsey Trail
Pamela McKay	Vice President of Institutional and Emergency Care	Kelsey Trail
Michelle Hrychuk	Regional Telehealth Coordinator	Kelsey Trail
Del Doucette	Nurse Practitioner	Kelsey Trail
Kobus Steenkamp	Family Physician	Prairie North
Bev Greenwood	Continuing Care Consultant	Prairie North
Joan Zimmer	Director, Continuing Care Services	Prairie North
Heather Dyck	Family Caregiver	Prince Albert Parkland
John Rye	Family Physician	Prince Albert Parkland
Vipul Parekh	Family Physician	Prince Albert Parkland
Bev Dougan	Community Team Manager	Prince Albert Parkland

Participant	Position	Affiliation or Health Region
Carol Gregoryk	Vice President of Integrated Services	Prince Albert Parkland
Darlene Batty	Director of Long-term Care	Prince Albert Parkland
Tammy Robinson	Registered Psychiatric Nurse	Prince Albert Parkland
Fran Neuls	Director of Clinical Services for Rural Facilities	Regina Qu'Appelle
Gretta Lynn Ell	Executive Director, Family Medicine/Continuing Care/Program Development, Rural Restorative and Continuing Care	Regina Qu'Appelle
Karen Earnshaw	Executive Director of Rural Services	Regina Qu'Appelle
Lori Tulloch	Director of Home Care	Regina Qu'Appelle
Tamara McDermit	Home Care Manager - Rural	Regina Qu'Appelle
Chester Beddome	Family Caregiver	Saskatoon
Dale de Tremaudan	Family Caregiver	Saskatoon
Lynda Smallwood	Nurse Practitioner	Saskatoon
Mark Tarry	Nurse Practitioner	Saskatoon
Julia Bareham	RxFiles, Academic Detailer	Saskatoon
David Gibson	Director, Continuing Care and Seniors Health	Saskatoon
Sheila Achilles	Director, Primary Health Care and Chronic Disease Management	Saskatoon
Helena Peters	Client/Patient Access Services, Rural Coordinator	Saskatoon
Tracy Danylyshen-Laycock	Behavioural Consultant	Saskatoon
Marnell Cornish	Nurse Manager, Long-term Care	Sun Country
Pat Kessler	Director of Home Care	Sun Country
Edna Parrott	Family Caregiver	Sunrise
Dawna Abrahamson	Nurse Practitioner	Sunrise
Nola Walsh	Director of Home Care	Sunrise

Appendix B: Agenda

MONDAY OCTOBER 17, 2011

7:30 – 8:30 **Registration**

8:00 – 8:30 **Full Buffet Breakfast**

8:30 – 9:00 **Dr. Debra Morgan**, Professor, U of S
Welcome and overview of CBPHC Team Grant

9:00 – 9:15 **Sheila Achilles**, Director, Primary Health Care and Chronic Disease
Management, Saskatoon Health Region
Primary Health Care: Client-Centered, Community Designed, Team Delivered

9:15 – 9:30 **Dr. William Albritton**, Dean, College of Medicine, U of S
Presentation

9:30 – 9:45 **Small groups** (allotted time to move into small groups)

9:45 – 10:45 **Focus group discussion**
Identifying gaps in Primary Healthcare

10:45 – 11:00 **Break**

11:00 – 12:00 **Panel**
Small group feedback and discussion

12:00 – 12:50 **Lunch**

12:50 – 1:00 **Allison Cammer**, Professional Research Associate, U of S
Summary of Morning Session

1:00 – 1:30 **Dr. Vaitheswaran and Alan Murdoch**, Scotland, UK
Use of Tele-psychiatry in Dementia Service delivery in Shetland Islands

2:00 – 2:45 **Small group discussion**
Developing interventions to address gaps in Primary Healthcare

2:45 – 3:30	Panel <i>Small group feedback and discussion</i>
3:30 – 3:45	Survey
3:45 – 4:00	Dr. Debra Morgan <i>CBPHC Team Grant and Next Steps</i>
4:00 – 4:30	Open discussion
4:30 – 4:35	Wrap-up


Appendix C: Morning Presentations

**Planning for the Rising Tide:
New Models of Rural Primary Healthcare for
Persons with Dementia**

**Planning Meeting for a CIHR Team Grant
in Community-Based Primary Healthcare**
Oct 17th, 2011, Saskatoon, SK

Goals of this Planning Meeting


1. **Planning for an initial 5-year program of research focusing on *community-based primary healthcare* for individuals with dementia and their caregivers.**
2. **This consultation is about the needs, gaps, and opportunities in rural primary healthcare for dementia**
 - What are the research priorities?
 - What are the gaps in rural CBPHC for dementia?
 - What models or interventions can best address these gaps?
 - What objectives should these interventions target?
3. **Outcomes of this consultation are valuable research outputs in their own right**



Dr. Anthea Innes

- Senior Lecturer, University of Stirling, Scotland
- Specialized in dementia studies since 1995
 - Focus on diagnosis and post-diagnostic support for people with dementia and their carers in rural and remote Scotland
- Manages undergraduate and post-graduate training programmes, Dementia Services Development Centre
- Keynote, Summit 2009, Saskatoon

Lerwick, Shetlands





Inverness






Dr. Sridhar Vaitheswaran

- Consultant in Old Age Psychiatry and Clinical Director for Old Age Psychiatry Directorate in NHS (National Health Services) Grampian, Aberdeen
- Interest in remote and rural dementia care delivery
- Provides clinical services in Shetland Islands

Alan Murdoch

- Dementia Services Development Manager, NHS Shetland, Lerwick, Shetland Islands
- Registered Mental Health Nurse (Glasgow 1983)
- Community Psychiatric Nurse since 1985
- Manager of Community Mental Health Team since 1999
- New role later this year: Alzheimer Scotland Dementia Nurse Consultant (includes acute and long-term care)

Shetland Islands, January 2011






Dr. John Keady

- Professor of Older People's Mental Health Nursing, School of Nursing, Midwifery, & Social Work, University of Manchester (2006)
- Trained as mental health nurse in Essex
- PhD examined social construction of dementia as experienced by people with dementia and their families
- Long-standing interest in dementia care, including primary care, roles of physicians and nurses, educational interventions.
- Founder and Co-Editor of "Dementia: The International Journal of Social Research and Practice" (SAGE journal)
- Keynote, Summit 2010, Saskatoon



Dr. William Albritton

- Dean, College of Medicine & Professor, Dept of Pediatrics
- Interest in evaluation of healthcare delivery systems for the underserved, especially in rural areas
- Interest in issues related to medical education (admissions policies, curricula, social accountability, professionalism)



Sheila Achilles

- Director, Primary Health and Chronic Disease Management, Saskatoon Health Region (2003)
- MN thesis: understanding the dissemination of information within a primary health interdisciplinary team environment
- Worked with SK Ministry of Health for last year as Co-Project Lead for Primary Health Care re-design



Participants

- Rural services
- Primary healthcare & chronic disease
- Long-term care sector
- Home care sector
- Health Region Administration
- Nurse Practitioners
- Family Physicians
- Family members
- Ministry of Health
- Researcher Team members, students
- Alzheimer Society of Saskatchewan
- Telehealth Saskatchewan, Health Quality Council, Rx Files
- Who did I miss?



Summit 2010

Dementia

- Dementia is a syndrome due to disease of the brain, characterized by progressive and typically irreversible loss of intellectual abilities, including memory, learning, orientation, language, comprehension, and judgment
- Dementia syndrome is linked to a large number of underlying brain pathologies
- Alzheimer Disease (AD) is the most common form
- Other subtypes include frontal-temporal (with variants), Lewy Body, vascular, mixed

World Alzheimer Report 2009



Rising Tide Report 2010 Alzheimer Society of Canada

In **Canada** in the next 30 years: numbers will double

- incidence will rise to 257,000 cases per year
- prevalence will reach 1.1 million

In **Saskatchewan** in the next 30 years:

- incidence will increase from 4,000 to 8,000 new cases/yr
- prevalence will increase from 17,000 to 28,000



Why focus on dementia care in rural areas?



- age is the main risk factor for dementia
- seniors are over-represented in rural areas
 - 15% of population of cities
 - 22% of towns and villages (SK Trends Monitor, 2007)
- ... but less access to specialized dementia care services in rural and remote areas
- low population density creates challenges in delivering community-based primary healthcare and specialist services

New Emerging Team (2003-2009) Canadian Institutes of Health Research



- "Strategies to Improve the Care of Persons with Dementia in Rural and Remote Areas"
 - Interdisciplinary research
 - Interprofessional training
 - Capacity development

The Rural & Remote Memory Clinic Team



Nursing
Neurology
Neuropsychology
Physical Therapy
Neuroradiology
Geriatric Medicine
Sociology
Internal Medicine
Geography

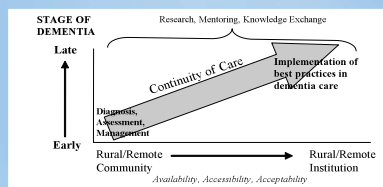
Debra Morgan, Andrew Kirk, Margaret Crossley, Vanina Dal Bello-Haas, Sheri Harder, Jenny Basran, Norma Stewart, Carl D'Arcy, Dorothy Forbes, Jay Biem, Lesley McBain, Megan O'Connell

Applied Chair in Health Services & Policy Research (2009-2014)

- "Healthcare Delivery Across the Continuum for Rural and Remote Seniors with Dementia"
- An integrated program of:
 - Research
 - Mentoring and education
 - Knowledge translation and exchange (KTE)
- Funding partners: CIHR, SHRF



Conceptual Framework Guiding the New Emerging Team and Applied Chair Research Program



"Knowledge Exchange"

Involves interaction between decision makers and researchers and results in *mutual learning* through:

- **planning**
- **producing**
- **disseminating, and**
- **applying research in decision-making**
- **is integrated** throughout the research process

Reference: Canadian Health Services Research Foundation

Why use **integrated** knowledge translation and exchange (KTE)?

- Decision makers identify emerging issues, needs, and priorities
- Collaboration leads to:
 - increased quality and relevance of the research
 - more feasible recommendations
 - better uptake
- Researchers and knowledge users learn about each others' worlds

Reference: CIHR

Knowledge Network in Rural and Remote Dementia Care

Summit 1 (Nov 2008)



Summit 2 (Oct 2009)



Summit 3 (Oct 2010)



Summit 4 (Oct 27-28, 2011)

CIHR Roadmap Signature Initiative in Community-Based Primary Healthcare (CBPHC)

- New program launched by CIHR (Institute of Health Services & Policy Research) spring 2011
- "PHC has evolved beyond its origins in family medicine to encompass a broad range of preventative and healthcare services provided by a range of healthcare providers in diverse community settings. We use the term *community-based* primary healthcare to emphasize this evolution" (CIHR 2011).

Community-Based Primary Healthcare (CBPHC) Initiative funding announcement

- CBPHC includes:
 - health promotion and disease prevention,
 - diagnosis, treatment, & management of chronic and episodic illness
 - rehabilitation support, end-of-life care, and care coordination
- These services can take place in a wide range of community settings, including:
 - people's homes, long-term care facilities, hospices, community health centres, walk-in clinics, and physician's offices, and can be delivered by a number of different healthcare professionals"

CBPHC Funding Tools

1. **CBPHC Planning Grants (awarded Oct 2011)**
 - Support researchers to come together to build active collaborations and to understand the existing CBPHC research landscape, including needs and priorities, before embarking on a full CBPHC Team Grant application
2. **CBPHC Team Grants (deadline Jan 31, 2012)**
 - Support **interdisciplinary, cross-jurisdictional** teams of researchers

Objectives of the CBPHC Initiative

1. **Research**
 - develop high-quality research evidence
2. **Capacity**
 - build new CBPHC capacity
 - Developing skills, knowledge, & resources of individuals and organizations involved in health research
3. **Knowledge Translation & Exchange:**
 - increase consideration research evidence by decision-makers in policy-making, clinical, and community settings

CBPHC Priority Areas

1. **Better Systems: Chronic Disease Prevention and Management**
 - How do we best prevent, treat, manage, and coordinate care for individuals with chronic illness?
 - How can CBPHC providers and systems better coordinate and integrate care to ensure smooth transitions across the continuum of care?
2. **Access to Appropriate Community-Based Primary Healthcare for Vulnerable Populations**
 - What approaches are effective in improving access and outcomes in high risk groups (e.g., Northern, rural and remote; First Nations, Inuit and Métis; persons with mental illness; frail elderly)?
 - What models of care work best for provision of safe, effective, accessible, and culturally-appropriate CBPHC?

CBPHC Team Grants (8 will be funded in Canada)

- **Key criteria:**
 - Multi-disciplinary
 - Cross jurisdictional (cross provincial/territorial, and/or international)
 - Inclusive of decision-makers and/or healthcare providers
- **Advice:**
 - Think big (innovative models and action-oriented research)
 - Focus on your area of expertise within CBPHC
 - Position team for programmatic research (not discreet one-off projects)
- **Programmatic research involves:**
 - A series of multiple research projects that are conceptually linked and implemented over several years
 - Based on an analysis of gaps in current knowledge
 - An interdisciplinary group of researchers and knowledge-users engaged in the program's development and implementation

Why study rural PHC now?

- *National Dementia Strategies* in numerous countries highlight the need for early diagnosis & intervention, better services, coordinated care, support for patients and families, and a trained workforce
- Saskatchewan 2004: *Alzheimer Society of Saskatchewan Strategy*
- Saskatchewan 2009: *Patient First Review*
- Alzheimer Society of Canada 2010: *Rising Tide Report*
- World Alzheimer Report 2011: *The Benefits of Early Diagnosis and Intervention*
- Saskatchewan Health 2011: *Primary healthcare redesign*
- Our own research program over the last 9 years
 - has identified gaps in PHC for individuals with dementia, their families, and healthcare providers

Patient First Review Commission (2009)

Recommendations include:

- Patient and family-centred health system for Saskatchewan
- Equitable care
 - Develop a **comprehensive and innovative strategy for rural and remote service delivery** that improves access to primary health, diagnostic, and specialist services for rural and remote residents
- Comprehensive care
 - Develop and implement a province-wide chronic disease management **strategy that ensures patients receive evidence-based care, wherever they live**, and connects patients with multidisciplinary health care teams
- Coordinated care
- Functional e-health care

Issues in dementia diagnosis & management

- Canadian Consensus Guidelines on the Diagnosis & Treatment of Dementia (2006) state that "most patients with dementia can be assessed and managed adequately by their primary care physicians"
- However, research indicates that:
 - dementia is underdiagnosed
 - many primary care physicians are uncomfortable with diagnosis and management of dementia
 - adherence to guidelines is not always optimal
 - specialist referral rates are high
 - primary care providers face barriers in providing care to patients with dementia and their caregivers
 - Given the complexity of diagnosis and management, collaborative, team-based models are recommended

Dementia Care in Rural and Remote Settings:

Two Systematic Reviews published in *Maturitas* journal in 2010*

- Paper 1: Formal or paid care
- Paper 1: Informal/family caregiving
- Identified needs for research:
 - intervention studies; cross-country comparisons
 - use of technology for staff development, service delivery
 - how to provide integrated, coordinated care across all stages of the dementia trajectory
 - what is the impact of rurality on informal caregiving experiences, and the needs of family caregivers.
- Identified needs for service delivery:
 - opportunities for basic and continuing dementia-specific training for formal caregivers
 - range of rural dementia care models adapted to local needs

*Both reviews are included in the meeting binder, Tab 10

Background research for this meeting*

1. **Primary healthcare for people with dementia & their caregivers in rural and remote areas: Perspectives of health region directors** (Kosteniuk & Morgan)
 - Interviews with 10 PHC and Chronic Disease directors representing eight health regions in Saskatchewan
 - Gaps identified at patient/caregiver, healthcare professional, and health region levels
2. **A systematic review of primary care-based dementia case management models** (Kosteniuk & Morgan)
 - 266 abstracts screened; 64 articles assessed for eligibility
 - 18 studies included in final synthesis
 - Only 1 study mentioned rural location

*documents are in your binder, Tab 11

Agenda overview

- Presentations:
 - Sheila Achilles
 - Dr. William Albritton
- Small group discussion
- **Break**
- Report back on small groups
- **LUNCH**
- Summary of AM Session
- Presentations: International collaborators
 - Dr. Vaitheswaran and Alan Murdoch
 - Dr. John Keady
- Small group discussion and feedback
- Survey
- Next steps
- Wrap-up



- Sheila's slides start here

Dr. William Albritton

- Dean, College of Medicine & Professor, Dept of Pediatrics
- Interest in evaluation of healthcare delivery systems for the underserved, especially in rural areas
- Interest in issues related to medical education (admissions policies, curricula, social accountability, professionalism)



Small Group Discussion - AM

- Your group number is on your nametag
 - Groups will stay the same in AM and PM
- East Room (here)
 - Groups 1 and 2
- Downstairs:
 - Group 3: Canadian Room
 - Group 4: Board Room
 - Group 5: Cavalier Room

Small Group Discussion - AM

Thinking of people with dementia and their caregivers in rural and remote areas:

1. What are the gaps in primary healthcare* (i.e. pressing issues or challenges)?
2. What are the reasons for these gaps?
3. How can these gaps be resolved?

Each Group

- Continuum of Care poster:
 - Identify where on the continuum the gaps are (volunteer 1)
- Gaps, reasons, strategies
 - Whiteboard chart (volunteer 2)
 - Copy whiteboard onto form to report back (volunteer 3)
- Facilitator
 - Assigned
- Recording of the discussion:
 - Consent form



Small Group Discussion - PM

Thinking of people with dementia and their caregivers in rural and remote areas:

- What objectives should be kept in mind when designing services to provide primary healthcare to this group? (at the level of patient, caregiver, healthcare professionals, health region, etc.).
- What would an ideal model of rural primary healthcare look like? Which specific interventions should be included in this model?

Small Group Discussion - PM

- Identify interventions/elements in an ideal model
 - 2nd Whiteboard (volunteer 1)
 - Copy whiteboard onto form to report back (volunteer 2)
- The AM continuum of care poster and whiteboard are available to refer to

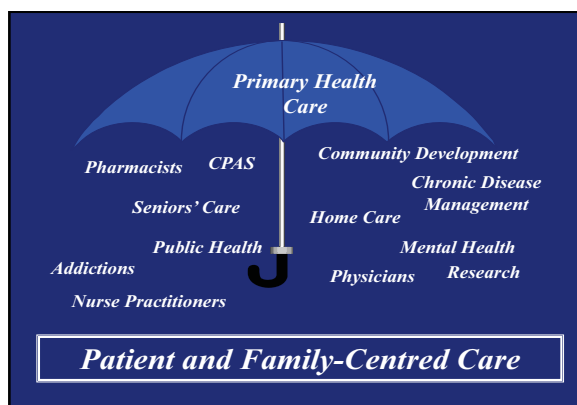


Primary Health Care: Client-Center, Community Designed, Team Delivered

October 17, 2011

Sheila Achilles
Director

Primary Health & Chronic Disease Management



Saskatchewan Health Region

What is Primary Health Care? (Extracts from ALMA-ATA 1978)

Primary health care is essential health care ... made universally accessible to individuals and families in the community through their full participation and at a cost that the community and of contact of individuals, the family and community with the health system country can afford to maintain at every stage of their development...It is the first level bringing health care as close as possible to where people live and work...

Saskatchewan Health Region

What is Primary Health Care?

- Primary health care is a system that expands on primary care by ensuring:
 - a holistic approach to health;
 - a continuum of services;
 - a range of health providers;
 - involvement of the public;
 - a recognition that health is influenced by many factors outside the traditional system.
- Primary Care, a part of primary health care, is the care that addresses a particular problem or everyday health need. It is care provided at the first level of contact with the health system.

Saskatchewan Health Region

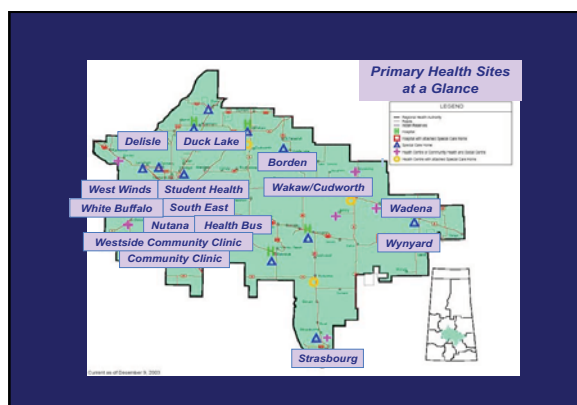
What is Primary Health Care?

- Five Key Principles of Primary Health Care include:
 - Accessibility to services that are geographically, financially, culturally and functionally available to the whole community.
 - Population Health Promotion, including education and promotion of basic human needs.
 - Community Participation in individual health and health services.
 - Intersectoral Collaboration beyond boundaries typically thought of as health.
 - Appropriate Resources including sound research, teams of health workers, and communication and information technology.

Saskatchewan Health Region

From Co-location to Integration

- Co-location of services is a positive step toward improved accessibility "one stop shopping"
- An intermediate step toward a vision of integration
- Team members & and community work as a team to create a seamless, unified and whole system



Saskatchewan Health Region

Duck Lake

- Interagency Primary Health Team with focus on youth in school (Nurse Practitioner, Addiction Worker, Public Health Nurse, Community School Liaison Worker, Principals, Town Administrator, Physician)
- Nurse Practitioner located in school
- Linked to Rosthern Physician Clinic
- Working with community; established Day Care
- Obesity; Dental Health; Teen Pregnancy

Team Building



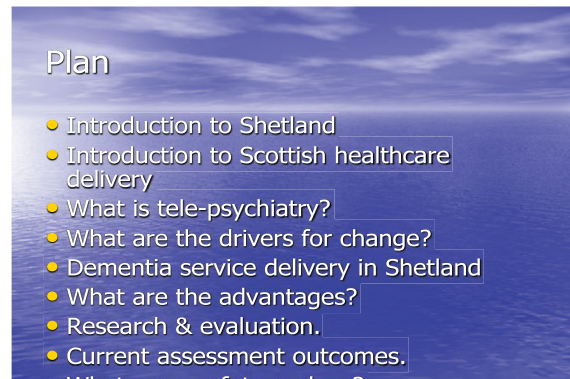
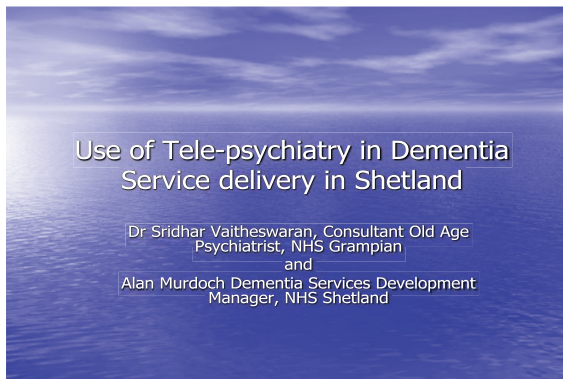


Common CDM Program Pillars

<i>Exercise</i>	<i>Disease-Specific Management</i>	<i>Patient Self-Management Skills</i>
<ul style="list-style-type: none">• Community-based exercise and rehabilitation programs providing personalized exercise prescription• Education sessions• Group and social support	<ul style="list-style-type: none">• Inter-professional team working closely with individuals, their family, Family Physicians and Specialists• Evidence-based optimal care delivery	<ul style="list-style-type: none">• Individualized plan of action for patients• Peer-led support classes through the LiveWell with Chronic Conditions Program• Enhanced self-management skills



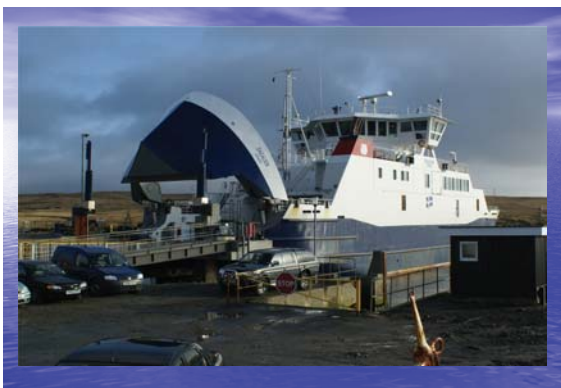
Appendix D: Afternoon Presentations





Shetland demographics

- 16 inhabited islands in group of over 100
- 21,950 population (2007 mid-year)
- 3,640 people aged 65 and over
- 2,175 more individuals aged 65+, an increase of 9.9% by 2030
- 4,562 decline in the working age population, a 20.9% decline in same period
- Over a third of population live within 8 miles of the capital Lerwick
- Low unemployment
- Low crime rate
- Regarded in 'unofficial 2008 newspaper survey' as 'one of best places to reside in UK'
- As close to Bergen in Norway as Aberdeen





Shetland

- Norwegian province until 15th century
- Sheep farming, fishing, aquaculture and tourism
- Sullom Voe terminal opened in 1978 and is the largest oil export harbour in the UK
- Oil revenue has impacted on community
- Community used to 'quality'
- High expectations of 'public and voluntary sector services'.



Community Mental Health Services

- Adult Team – 1 Consultant Psychiatrist, 3.5 CPNs, 1 Specialist Social Worker.
- Substance Misuse Team – 1 CPN Team Leader, 1.5 CPNs.
- CAMHs Team – 1 CPN Team Leader, 1 Link Worker, sessions of Associate Psychologist time, Consultant Psychiatrist (visiting), Psychologist (visiting)
- Memory Assessment Service – 1 Manager/ Specialist Nurse, 0.1 Consultant Old Age Psychiatrist (Grampian based).

Additional Services

Shetland Islands Council (SIC) provide a range of services including:

- Supported accommodation and outreach support.
- Generic Care Centres
- Specialist Dementia Care Centre

All SIC and NHS mental health services managed by a joint post of Service Manager, Mental Health.



Scottish Healthcare Delivery

- Public funded
- Free of cost at the point of delivery
- Primary care provided by GPs
- Secondary care in community & hospital settings by specialist teams
- Social care provided by local authorities

What is tele-psychiatry?

- Provision of psychiatric services from a distance using tele-communication technologies

Tele-psychiatry: Current applications

- NHS Grampian Mental Health Services
 - Management
 - Educational
 - Clinical
 - Eating Disorders Service
 - Orkney Mental Health Services
 - Dementia Service for Shetland

Videoconference Equipment

- There are 19 videoconference suites at various NHS locations around Shetland
- Systems in use are Tandberg Classic or Tandberg MXP
- Cisco TelePresence Movi

Drivers for Change

- Until January 2010
 - No clear pathway
 - GPs, General Physicians
 - Patients with relatives travel to Aberdeen for specialist assessment
 - Overnight admission in hospital
 - Accommodation for relatives

Drivers for Change

- Delivering for mental health (2006)
 - Emphasis on equality, non-discrimination, social inclusion & availability of services to everyone in Scotland
 - Commitment 8: "ensure that people are managed and cared for more effectively in the community and avoid inappropriate admissions"

Drivers for Change

- Dementia identified as a national priority in 2008
- HEAT targets for dementia
 - From April 2008 each NHS Board is required to deliver agreed improvements in the early diagnosis and management of patients with a dementia by March 2011
- Integrated Care Pathway (ICP) for dementia

Drivers for Change

- Delivering for Remote and Rural Health Care (2008)
 - "patients should receive the same standards of care for common procedures irrespective of where they live"
 - Provision of telehealth identified as one of the themes
 - Obligate networks recommended
 - eHealth principles: specialist advice from distance, avoidance of travel, ability to transfer digital data

Drivers for Change

- Scotland's National Dementia Strategy (2010)
 - "developing and implementing standards of care for dementia, drawing on the Charter of Rights produced by the Scottish Parliament's Cross Party Group on Dementia"
 - "improving staff skills and knowledge in both health and social care settings"
 - "providing integrated support for local change, including through implementation of the dementia care pathway standards and through better information about the impact of services and the outcomes they achieve"

Drivers for Change

- Scotland's National Dementia Strategy (2010)
 - "continuing to increase the number of people with dementia who have a diagnosis to enable them to have better access to information and support"
 - "ensuring that people receiving care in all settings get access to treatment and support that is appropriate, with a particular focus on reducing the inappropriate use of psychoactive medication"
 - "continuing to support dementia research in Scotland"

Drivers for Change

- Scotland's National Dementia Strategy (2010)
 - In taking this work forward there will be a particular focus on two key change areas -
 - "following diagnosis, by providing excellent support and information to people with dementia and their carers"
 - "in general hospital settings, by improving the response to dementia, including through alternatives to admission and better planning for discharge"

Drivers for Change

- Standards of Care for Dementia in Scotland (2011)
 - Key Themes –
 - a person with dementia has the right to:
 - "a diagnosis"
 - "to be regarded as a unique individual and to be treated with dignity and respect"
 - "access a range of treatment, care and supports"
 - "be as independent as possible and be included in my community"
 - "have carers who are well supported and educated about dementia"
 - "end of life care that respects my wishes"

Drivers for Change

- Standards of Care for Dementia in Scotland (2011)
 - Because the standards are based on outcomes for people with dementia there is no one measurement that can be used across all the standards. Each standard has been given at least one way it can be measured but in many cases there will be more than one.
 - Monitoring will be by way of internal and external reporting

Obligate Managed Clinical Network

- Established 2008 to improve collaboration and working relationships between Orkney, Shetland and Grampian Mental Health Services.
- Main aim is to improve communication and to improve patient pathways of care and promote better use of shared resources

What is happening now?

- 1 WTE Dementia Development Services Manager (*Mr. Alan Murdoch- based in Lerwick*)
- 1 session Consultant Old Age Psychiatrist (*Me, based in Aberdeen*)
- Weekly VC session lasting 2 hours
- E-mails, other correspondences, coming to Saskatoon!

Referral process

- GPs refer to the DSDM
- Referrals discussed at the weekly VC session
- Decision made to accept the referral
- If more information is needed GPs are requested to provide this
- A plan regarding assessment process is made

Assessment

- The initial assessments are always by the DSDM
- Home visits/clinic assessments
- Corroborative information from appropriate sources
- Mental health assessment including cognitive function screening

Assessment

- The assessments are discussed at the weekly VC session
- Based on the information decision for further investigations made
 - E.g. CT Head
- VC assessments for some
 - Always accompanied by a relative
 - DSDM always present to facilitate

Diagnosis

- Discussed first at the weekly VC meetings
- In majority of the cases, DSDM communicates with the person with dementia, family & GP
- In some cases diagnosis is discussed with the person with dementia & family via VC by Consultant
- Information provided to the person with dementia & family

Treatment

- Acetylcholine esterase inhibitors/ Memantine discussed with the person with dementia & family, if appropriate
- If accepted GPs are requested to prescribe
- Review of response by DSDM in 6 months
- Discharge back to primary care

Follow-up consultation

- Give person with dementia 'Facing dementia' book
- Give carer 'Coping with dementia' book
- Discuss advance planning, power of attorney
- Discuss driving – Driver & Vehicle Licensing Agency notification
- Medication
- Advice on coping mechanisms
- Signposting to sources of support & local services, including benefits & welfare rights
- Follow-up & onward referral if required

Service user experiences

"It came as a shock to me to be diagnosed with the onset of Alzheimer's Disease...my ability to come to terms and accept my circumstances is due to the videolink with Dr Sridhar and also the support of local Dementia Service Development Manager, Alan Murdoch"

Mr. G. Person with dementia

Carer Experience

"as a wife and carer, I would like to say how impressed I have been with the help we have been given since my husband was diagnosed with early onset of Alzheimer's Disease. We were lucky to be able to attend a new clinic recently opened in Lerwick where everything was explained to us so well"

Mrs. M. Carer

Advantages

- Improves equity of access to specialist dementia service across geographically isolated region
- Shifts the balance of care
- Enhances skills & knowledge among work force
- Reduces professional isolation & staff burn-out for those working in isolated areas
- Saves time for people with dementia & their carers
- Reduces carbon foot-print

Evaluation

- Partnership with Dementia Services Development Services, Stirling who have carried out an independent evaluation of the service
- Guidance from the Scottish Centre for Telehealth

Evaluation

- Service design & delivery
 - Use of telepsychiatry model
 - Economic evaluation – potential savings
- Training plan for staff in using the model
- Transfer of data across sites
- Feasibility of using this model in other regions

Significant issues

- No inpatient facility on-island. Main admission hospital Royal Cornhill in Aberdeen
- 220 mile air ambulance journey
- Access to specialist mental health assessments and treatments limited
- Many older residents have never been off the islands
- Attitudes towards diagnosis of dementia
- Hidden numbers of people with dementia

Significant issues

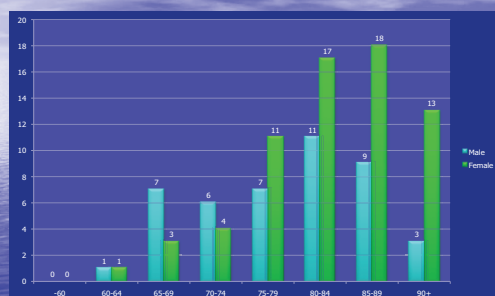
- Commencement of AChEI by GP
- Limited PD support
- No neuro-psychology support in Shetland
- No access to specialist Allied Health Professionals (AHPs)
- No local access to Geriatricians
- Insufficient access to Specialist Dementia Care Units including emergency respite

Current Referral Data

111 referrals, February 2010- September 2011

Age	Male	Female
<60	0	0
60-64	1	1
65-69	7	3
70-74	6	4
75-79	7	11
80-84	11	17
85-89	9	18
90+	3	13
Total	44	67

Referrals



Outcomes of referrals

Referred	Diagnosed	Advice	Awaiting Assessment	Awaiting Further Assessment
111	80	16	10	5

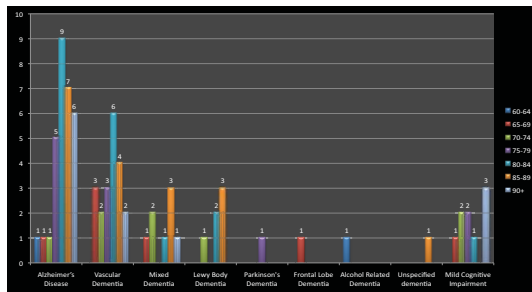
Outcomes



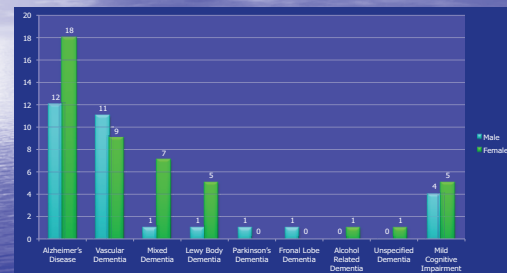
Diagnosis

Diagnosis	60-64	65-69	70-74	75-79	80-84	85-89	90+
Alzheimer's Disease	1 M	1 M	1 M	2 M 3 F	5 M 4 F	1 M 6 F	1 M 5 F
Vascular Dementia		3 M	1 M 1 F	2 M 1 F	2 M 4 F	3 M 1 F	2 F
Mixed Dementia		1 F	1 M 1 F		1 F	3 F	1 F
Lewy Body Dementia			1 M		2 F	3 F	
Parkinson's Dementia				1 M			
Frontal Lobe Dementia		1 M					
Alcohol Related Dementia	1 F						
Unspecified Dementia						1 M	
Mild Cognitive Impairment		1 M	2 M	2 F	1 F		1 M 2 F
Depression					1 F	1 F	
Personality Disorder		1 F					
Total	2	8	8	11	20	19	12

Diagnosis by age



Diagnosis by sex



Evaluation of telehealth in Shetland and Grampian

- Funders: Millar-McKenzie Trust and NoSPG (£25k)
- Team: Innes, McCabe (Stirling) Murdoch (NHS Shetland) and Vaitheswaran (NHS Grampian)
- May – Dec 2011

Evaluation of telehealth in Shetland and Grampian

- 2 fieldwork areas: Shetland (complete) and Grampian (pending Nov 2011)
- Interviews completed with:
 - 4 people with dementia and their carers who have used telehealth
 - 6 people with dementia and their carers who have not used telehealth
 - 1 member of staff
- Structured questionnaires - 10 people with dementia and their carers

Rurality

- All interviewees lived within 15 miles of Lerwick, the main town in Shetland
- All but one of the people with dementia were born in Shetland
- All but two couples had other family members living with ten miles
- All currently had someone who could drive them to appointments, two people with dementia were still driving themselves, but there were clear problems for some carers having to take time off work to provide transport/support

Rurality

- Bus services were not seen as particularly useful.
- Most participants had experience of home visits as part of the memory service and this was the preferred option over travelling to the clinic or travelling outwith the Shetland Islands for treatment. This final option was time consuming for carers and could be stressful for everyone, although all participants had experience of this in the past.
 - 'I'd rather he come to me as me go to them'* (person with dementia, 02)

Using the videoconference facility (service user views)

Those who had used the VC facility found the experience a bit daunting at first but fairly quickly settled into things.

'We got quite taken with it because we didn't know who he was or what he looked like...and all of a sudden this face appeared and he was talking' (carer, 07)

'I didn't feel uncomfortable with it or anything like that, I just answered what I could' (person with dementia, 02)

Using the videoconference facility (service user views)

Those who had not used the VC facility were split between those who didn't see a problem and one or two who didn't feel it was something they would like.

'I can't see that it would make much difference...speaking to a man on a screen or sitting there on the couch...I mean, not going to get up and punch him' (person with dementia, 04)

Questionnaire responses from those who had used the VC facility

Topic	Overall score (maximum 4)	Overall rating (poor/fair/ good/excellent)
Voice quality of VC	2.25	Fair
Visual quality of VC	2.75	Good
Personal comfort during use of VC	2.5	Fair/good
How well staff answered questions about equipment	3	Good
Ease of getting to the clinic	3.75	Excellent
Length of time spent at VC appointment	2.5	Fair/Good
Overall experience using VC	2.75	Good
Thoroughness, skillfulness and carefulness of team	3.25	Good

Views of the service manager

- Use of VC is developing as the memory service and skills of team members develop.
- VC used more for staff meetings and supervision and less for direct assessment of people with dementia.
- Memory service manager now has confidence and skills to undertake assessments and deliver diagnosis with support through VC from consultant.
- Assessments more often take place at home as better for all involved.
 - *'It takes longer to go to their own home, but I think they're more comfortable, they're more relaxed, they've performed better in their own home, you get a truer picture.'* (service manager)

Views of the memory service

The service provides valuable support for people with dementia and their carers, many describing a very positive relationship with the service manager:

- *'He's never been great at remembering people's names and so on, but I don't think there's any danger of him forgetting [the service manager's]'* (carer, 01)
- *'We just speak as friends, we've become very good friends with [service manager]... we think the service is splendid'* (carer, 07)

Views of the memory service

Participants also reported clear outcomes from the service such as:

- Prescription of new medication
- Getting a clear diagnosis and information about their condition
- Improvements in mood and stress levels for people with dementia and carers

'Granny just went from being really upset the whole time...to just being back to normal... she's just back to the same old, same old granny' (carer, 06, discussing effect of memory service and new medication)

Future Plans

- Education (CPD) for GPs, hospital doctors, nurses, care workers
- Working in partnership with Alzheimer Scotland to further develop services
- Develop a fully integrated service for people with dementia and their carers
 - ICPs
 - Protocols



Thank you!



Appendix E: Consent to Participate in Focus Groups

CONSENT TO PARTICIPATE IN PLANNING SESSION SMALL GROUP DISCUSSIONS

You are invited to participate in a research study entitled *Dementia Care Models in Saskatchewan Rural and Urban Primary Healthcare*.

Researchers: The study researchers from the University of Saskatchewan are Drs. Debra Morgan, Julie Kosteniuk, Megan O'Connell, Margaret Crossley, Andrew Kirk, Carl D'Arcy, and Norma Stewart. The researchers also include Drs. Anthea Innes from the University of Stirling, John Keady from the University of Manchester, Vanina Dal Bello-Haas from McMaster University, and Dorothy Forbes from the University of Alberta.

Purpose and Procedure: We hope that this study will improve our understanding of community resources and primary healthcare models for rural patients with dementia and chronic diseases. The two small group discussions will each take 45-60 minutes.

Potential Benefit: The potential benefit of participating in these small group discussions is an increase in our knowledge regarding primary healthcare models for rural patients with dementia and chronic diseases. This benefit is not necessarily guaranteed.

Potential Risks: There are no known risks to you associated with participating in these small group discussions.

Storage of Data: Transcripts from the small group discussions constitute the data for this research study. This data will be stored in the office of Dr. Debra Morgan (Room 3614, Wing 3E), in the Canadian Centre for Health and Safety in Agriculture, Royal University Hospital for a period of five years upon completion of the study. No participants' names will appear in any publication of results. If you withdraw from the study at any time, any data that you have contributed will be destroyed at your request.

Confidentiality:

1. Focus Groups: The small group discussions will be audio-recorded and the audio-recordings will be subsequently transcribed. The researchers will undertake to safeguard the confidentiality of the discussion, but cannot guarantee that other members of the group will do so. Please respect the confidentiality of the other members of the group by not disclosing the contents of this discussion outside the group, and be aware that others may not respect your confidentiality. The transcripts and audio-recordings will be kept strictly confidential. Direct quotations from participants' answers will be used when reporting study results; however, any information that may identify a participant or a participant's community will be removed to guarantee anonymity.

Right to Withdraw: Your participation is voluntary, and you can answer only those questions that you are comfortable with. There is no guarantee that you will personally benefit from your involvement. The information that is shared will be held in strict confidence and discussed only with the research team. You may withdraw from the research project for any reason, at any time,

without penalty of any sort. If you withdraw from the research project at any time, any data that you have contributed will be destroyed at your request.

Questions: If you have any questions concerning the research project, please feel free to ask at any point; you are also free to contact the researcher at the number provided if you have other questions. This research project has been approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board (Beh 11-192). Any questions regarding your rights as a participant may be addressed to that committee through the Ethics Office (966-2084). Out of town participants may call collect.

Follow-up: The findings will be used to develop a Team Grant in Community-based Primary Healthcare and submitted to the Canadian Institutes for Health Research in January, 2012. As well, the findings will be made available to the public and the media in a summary report.

Consent to Participate: I have read and understood the description provided; I have had an opportunity to ask questions and my/our questions have been answered. I consent to participate in the research project, understanding that I may withdraw my consent at any time.

Name of participant

Date

Signature of participant

Signature of Researcher

If you have any questions concerning the study, please contact Dr. Debra Morgan, at the Canadian Centre for Health and Safety in Agriculture, by calling collect 1-306-966-7905, or email debra.morgan@usask.ca

Appendix F: Focus Group Questions

The main purpose of the small groups is to get the information we need for the Team Grant proposal—a good picture of the gaps in rural dementia primary healthcare, and models of CBPHC that we would propose to implement.

Morning

Thinking of people with dementia and their caregivers in rural and remote areas:

1. What are the gaps in primary healthcare* (i.e., pressing issues or challenges)?
2. What are the reasons for these gaps?
3. How can these gaps be resolved?

Afternoon

Thinking of people with dementia and their caregivers in rural and remote areas:

1. What objectives should be kept in mind when designing services to provide primary healthcare to this group? (at the level of patient, caregiver, healthcare professionals, health region, etc.).
2. What would an ideal model of rural primary healthcare look like? Which specific interventions should be included in this model?

*CIHR's definition: "CBPHC includes health promotion and disease prevention, the diagnosis, treatment, and management of chronic and episodic illness, rehabilitation support, end-of-life care, and care coordination among others. These services can take place in a wide range of community settings, including people's homes, long-term care facilities, hospices, community health centres, walk-in clinics, and physicians' offices, and can be delivered by a number of different healthcare professionals (e.g. nurses, social workers, pharmacists, dieticians, family physicians, and others).

Appendix G: Consent to Participate in Survey

CONSENT TO PARTICIPATE IN SURVEY

You are invited to participate in a research study entitled *Dementia Care Models in Saskatchewan Rural and Urban Primary Healthcare*.

Researchers: The study researchers from the University of Saskatchewan are Drs. Debra Morgan, Julie Kosteniuk, Megan O’Connell, Margaret Crossley, Andrew Kirk, Carl D’Arcy, and Norma Stewart. The researchers also include Drs. Anthea Innes from the University of Stirling, John Keady from the University of Manchester, Vanina Dal Bello-Haas from McMaster University, and Dorothy Forbes from the University of Alberta.

Purpose and Procedure: We hope that this study will improve our understanding of community resources and primary healthcare models for rural patients with dementia and chronic diseases. This questionnaire will take approximately 15 minutes to complete.

Potential Benefit: The potential benefit of responding to this survey is an increase in our knowledge regarding primary healthcare models for rural patients with dementia and chronic diseases. This benefit is not necessarily guaranteed.

Potential Risks: There are no known risks to you associated with completing this survey.

Storage of Data: The survey questionnaires will be stored in the office of Dr. Debra Morgan (Room 3614, Wing 3E), in the Canadian Centre for Health and Safety in Agriculture, Royal University Hospital for a period of five years upon completion of the study. No participants’ names will appear in any publication of results. If you withdraw from the study at any time, any data that you have contributed will be destroyed at your request.

Confidentiality: Answer only the questions with which you are comfortable. Your name is never connected to your answers in any way. Survey questionnaires will be kept strictly confidential. Direct quotations from participants’ answers will be used when reporting study results; however, any information that may identify a participant or a participant’s community will be removed to guarantee anonymity.

Right to Withdraw: Your participation is voluntary, and you can answer only those questions that you are comfortable with. There is no guarantee that you will personally benefit from your involvement. The information that is shared will be held in strict confidence and discussed only with the research team. You may withdraw from the research project for any reason, at any time, without penalty of any sort. If you withdraw from the research project at any time, any data that you have contributed will be destroyed at your request.

Questions: If you have any questions concerning the research project, please feel free to ask at any point; you are also free to contact the researcher at the number provided if you have other questions. This research project has been approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board (Beh 11-192). Any questions regarding your

rights as a participant may be addressed to that committee through the Ethics Office (966-2084). Out of town participants may call collect.

Follow-up: The findings will be used to develop a Team Grant in Community-based Primary Healthcare and submitted to the Canadian Institutes for Health Research in January, 2012. As well, the findings will be made available to the public and the media in a summary report.

Consent to Participate: I have read and understood the description provided. I have had an opportunity to ask questions and my/our questions have been answered. I consent to participate in the research project, understanding that I may withdraw my consent at any time.

Name of participant

Date

Signature of participant

Signature of Researcher

If you have any questions concerning the study, please contact Dr. Debra Morgan, at the Canadian Centre for Health and Safety in Agriculture, by calling collect 1-306-966-7905, or email debra.morgan@usask.ca

Appendix H: Survey

1. Please indicate your role during this Planning Session (you may check more than one):

- ☐ Family Caregiver
- ☐ Health Region Director (e.g., Director of Primary Healthcare)
- ☐ Family Doctor
- ☐ Nurse Practitioner
- ☐ Researcher
- ☐ Other, please specify:

2. What are the most important issues in primary healthcare for people with dementia and their caregivers in the rural and remote areas of your health region (or your community)?

3. What types of interventions would you like to see implemented in primary healthcare for people with dementia and their caregivers in the rural and remote areas of your health region (or your community)?

4. In your health region or community, what might be the challenges to implementing the interventions that you identified in Question 3?

5. What might be some solutions to the challenges that you identified in Question 4?

6. Would you be willing to provide a letter of support for Dr. Debra Morgan's CBPHC Team Grant to the Canadian Institutes for Health Research (CIHR)?

☐ Yes ☐ No

7. Would you be willing to be involved in a Primary Healthcare intervention in dementia care?

☐ Yes ☐ No ☐ Don't know/Unsure

If yes, please describe how you would like to be involved:

Appendix I: Whiteboard Data

FOCUS GROUP MORNING SESSION

Whiteboard Recorder Notes from five focus groups

Thinking of people with dementia and their caregivers in rural and remote areas:

1. What are the gaps in primary healthcare (i.e., pressing issues or challenges)?

Group 1

- Access
 - to point of entry care (anyone)
 - to primary health care provider (NP, MD)
 - to primary health care team
 - expanded professionals
 - special teams
 - interdisciplinary/multidisciplinary
- Knowledge and awareness
 - by community, facility
 - health professionals
 - disease awareness (stigma)
 - early identification
 - treatment - ongoing across disease process
- Care
 - mid-stage dementia - community based support
 - transportation
 - funding (PCH's)
 - availability (family support, relief for caregivers to remain at home)
 - management of competency issues
 - access to appropriate interventions and treatment
 - culturally appropriate care
- End stage
 - insufficient LTC beds
 - types of solutions to solve lack of beds need to be innovative as we won't have more LTC facilities in appropriate place

Group 2

- Diagnosis
 - Early
- Accessibility
 - transportation
 - access to services
 - funding
- Education
 - caregivers
 - family
 - person with dementia

- Regional boundaries - permeability!!!
- Resources
 - funding - public, charitable, community
 - human resources
 - respite - in home, in facilities
- Home Care support
- Telehealth
- Safety and security
- Transitions
 - to diagnosis and loss of independence
 - to res housing and total dependence
- Palliative care
- Prevention of abuse
- Housing
 - LTC beds
 - assisted living

Group 3

- Access
 - knowledge / education
 - services
- Awareness / lack of knowledge
- Travel issues
 - distance
 - driving
- Telehealth/facilities
- Caregiver support program

Group 4

- Diagnosis, lack of
 - early diagnosis
 - public awareness
 - knowledge
- Stigma
- Qualifying for treatment
- Risk reduction
- Determinants of health
- Long Term Care Facilities - Adult Day Care / Respite
- Lack of training for "informal" caregivers
- Low number of trained caregivers
- Funding for personal care homes
- Community based support for families
- Telehealth
- Lack of training for "formal" caregivers

Group 5

- Lack of services
- Lack of education/knowledge for staff, families, patients, HCP's
- Lack of awareness of importance of skill/education re dementia
- Lack of coordination/networks
- Limited formal education for HCP's
- Family reluctant to acknowledge dementia
 - family/friends not aware of services
- Need for public awareness (warning signs)
- Small population over large geographic area
- Difficulty in sustaining expertise
- Lack of resources for timely assessment
- Lack of knowledge of what defines "Normal Aging"
- Challenge of getting a diagnosis/early referral
- Stigma associated with dementia - putting loved one into LTC
- Lack of coverage for costs - transportation to care, meds
- Need to differentiate age-related dementias and services
- Services for early onset, younger patients, subtypes of dementia
- Need for appropriate living arrangements
- "Softer" services no longer available
- Types of services inconsistent in various locations
- Guidelines (eg. TLR) are not client friendly and lead to dependence
- Lack of support to families due to stringent policies

Thinking of people with dementia and their caregivers in rural and remote areas:

2. What are the reasons for these gaps?

Group 1

- Inadequate # and appropriate type of health professionals
- Inadequate opportunity for CME for rural physicians
- Not full use of telehealth
 - inadequate sites (better but need more)
 - inadequate training to use
- nature of rural medicine itself
 - reluctance to live & work
 - lack of incentive/support for rural physicians
 - quality of life issues
- Health Science education on dementia and initial health sciences education interdisciplinary
- Trend to move medicine/care into urban centres with lack of incentives and support for rural
- Regional jurisdictions - unnecessary bureaucracy, eg. lack of common language and region boundaries
- Family cycle is such that immediate and extended families not in close proximity, scattered geographically
- Loss of ability to drive

- no family to drive
- geographical location
- Isolation
- Burn out
- Lack of home care fees on group to help maintain at home

Group 2

- What is diagnosis: early/late prognosis
- Lack of public education. Normal aging vs dementia.
- Service across the border - service isn't available 24/7
- How to navigate the system
- Crisis management vs prophylaxis
- Aren't the people available
- Can't find service (don't know about resources available)
- Alternative housing
- Moving people? When to do this? Is it disorientating? To larger community?
- Choices!
- Electronic monitoring? Ethics
- Geography
- Lack of certain therapeutics - patients

Group 3

- Availability: services, training
- Attitude: patient, community, prof.
- Mental Health
- Funding issues
- Training
- Transportation
- Screening
- Patient ownership

Group 4

- Bed blocking
- Travel providers
- Lack of recognition of warning signs
- Denial
- Screening tools
- Inconsistency between assessment/screening tools and coverage
- Lack of human resources. Caregivers are too busy providing acute care.
- Unrealistic expectations of drug therapy
- Physical access to health care providers (distance, weather)
- Limited Home Care services: staff, volunteers, distance, weather
- Family support: distance, mobility, jobs
- Centralization

Group 5

- Lack of funds/transportation to access services
- Processes to access services are cumbersome
- Rural/small community residents reluctant to drive in "cities"/larger centres
- In late diagnosed dementia, client/family too overwhelmed to effectively access services
- Decreased funding for soft services (shopping, housekeeping/maintenance, etc.)
- Sask elderly population increasing in rural locations (other provinces trend is elderly moving to cities)
- Decreased # of informal caregivers
- No provincial strategy (each HR allocates funds differently)
- Cost of institutionalization greater than individualized care delivery in home - but federal funding has been disseminated to provinces
- Lack of human resources (for consistent care delivery in home)
- Caring for the system rather than the client
- Fear based on infection issues (MRSA, VRE)
- No access to family physicians (decreased # of physicians)
- Professional territorialism

Thinking of people with dementia and their caregivers in rural and remote areas:

3. How can these gaps be resolved?

Group 1

- Telemedicine
- Telehealth
- Videoconferencing (e-health) - include families/caregivers
- Immediate assessment team
- Access to Geriatric assessment unit for those with multiple health conditions
- Remove regional boundaries hindering care, more permeable
- Increase distributive learning for students to work in rural areas
- Recruitment/retention packages for rural health care practitioners
- Appropriate staff for level of care needs
- Use the data we have to accurately allocate funds for service staff, eg. Inter RAI MDS/HC & LTC
- Increase sensitivity for boundaries so communities don't create care provider burnout, eg. no time off - grocery start
- Access to extensive day program
- Access to appropriate LTC beds and wander and behavior units
- Access to frequent behavior management consultants visits or consultants themselves

Group 2

- Physician role?? MRI, TSH, etc., depression
- Breaking the news - telling patient/family
- Expansion of R & R Memory Clinic
- Broader HC services

- Telehealth
- Day/night programs
- Travelling PHC
- Case management improvements
- Resources for case management
- Family and staff support 'Crash & burn'
- Alternative housing. Efficiency of services as available.
- Provision of equipment
- Care pathways. Navigators or translators - coordinators - case management
- More effort between home based and facility based care (respite)

Group 3

- Short term
 - More collaborative care
 - Better education of prof. people/community
 - Someone to coordinate
 - Regional directory
 - Road show
 - Algorithm - flow chart
 - Recruitment and retention
 - Chronic vs Mx and Acute bed use
 - Better discharge plan
 - Increased beds available in long term care
- Long Term

Group 4

- EI benefits, ??? for family caregivers
- Advocacy role - government supplement programs to help caregivers, raise awareness
- Client/patient/family centred care
- Research - make sure research is utilized and implemented
- Finances - priorities, conflicting resource demands
- Consolidating screening and diagnostic tools - more uniformity - standardization
- Trained Dementia Care Providers who are available
- Teaching risk reduction strategies
- Recognition of dementia as a chronic disease
- Telehealth
- Improved crisis management
 - with follow-up - home care, Alzheimer's Society,
 - referral
- Early intervention
- Strong communities
 - caring for others
 - neighbors/families/friends
 - remove stigma
 - coordination with other community groups
 - volunteer

Group 5

- Info/education specific to various groups: physicians, families
 - Public access - language, reading level
- Contact person(s) in each town/area
- Early formal referral to services
- Intersectoral access to continuum of care (tax rebate to families purchasing services)
- Consistent provincial/federal strategy
- Role of NPs - points of access
- Entry level/ongoing education for healthcare professionals
- Remote technology in all regions (needs expansion)
- Subsidized services
- Support for family caregivers
- Other healthcare professionals? role
- System navigation
- Expanding circle of care - includes non-traditional community partners
- Specific person to help patient navigate system
 - "case worker"
 - effective individualized case management

FOCUS GROUP AFTERNOON SESSION

Whiteboard Recorder Notes from five focus groups

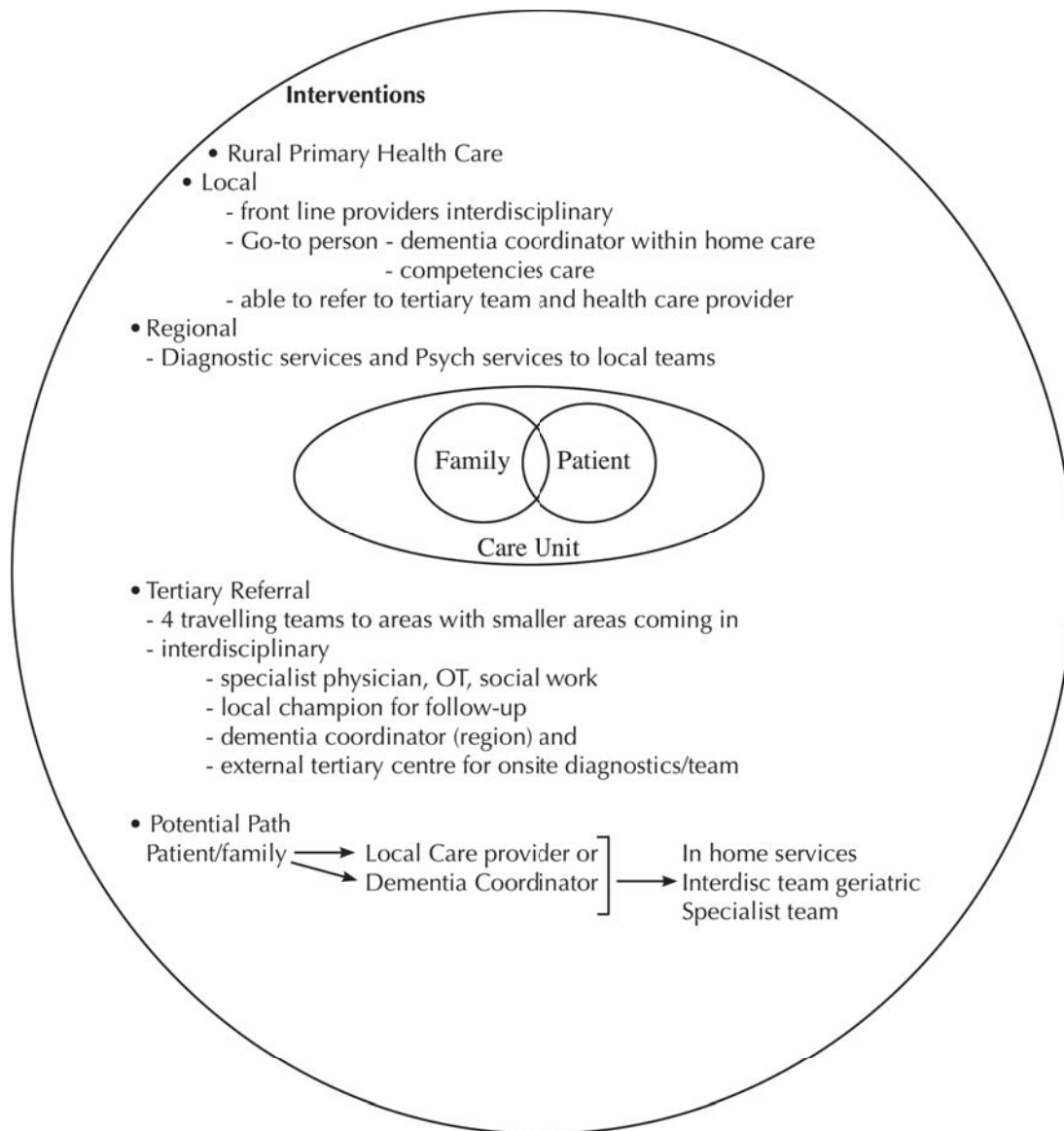
Thinking of people with dementia and their caregivers in rural and remote areas:

- 1. What objectives should be kept in mind when designing services to provide primary healthcare to this group? (at the level of patient, caregiver, healthcare professionals, health region, etc.).**
- 2. What would an ideal model of rural primary healthcare look like? Which specific interventions should be included in this model?**

Group 1 Objectives

- services to provide PHC to dementia and caregivers
- fair, ethical assessment of competency (protect patient and society)
- multifaceted, multi and interdisciplinary approach
- seamless (no boundaries)
- honor principles of Canada's Health Act - accessible, portable, universal
- evidence-based algorithm/pathway for dementia diagnosis and treatment
- increase public awareness re: early diagnosis of dementia through education, eg. blue book, red book, etc.
- Prevention programs
 - education re warning signs
 - focus on baby boomers for sake of their parents and for themselves later (Public Health?)
- Proposed model decrease transportation issues as services come to them
 - require Drive Able program from AB
 - SGI standardized assessment compulsory
- \$ for resources

Group 1 Model



Group 2 Objectives

- Patient/family centred care
- Stigma - normalizing dementia - patient/caregiver/family
- “Normalizing” dementia
- Services need to be accessible
- Ensure family can make informed decisions with patients
- Medical records that travel with patient
- Prevention focus and early intervention
- Health economist on research team
- Continuity of care
- Accessibility to care and services
- Recognition of dementia as a chronic disease
- Wellness clinics - screening for dementia

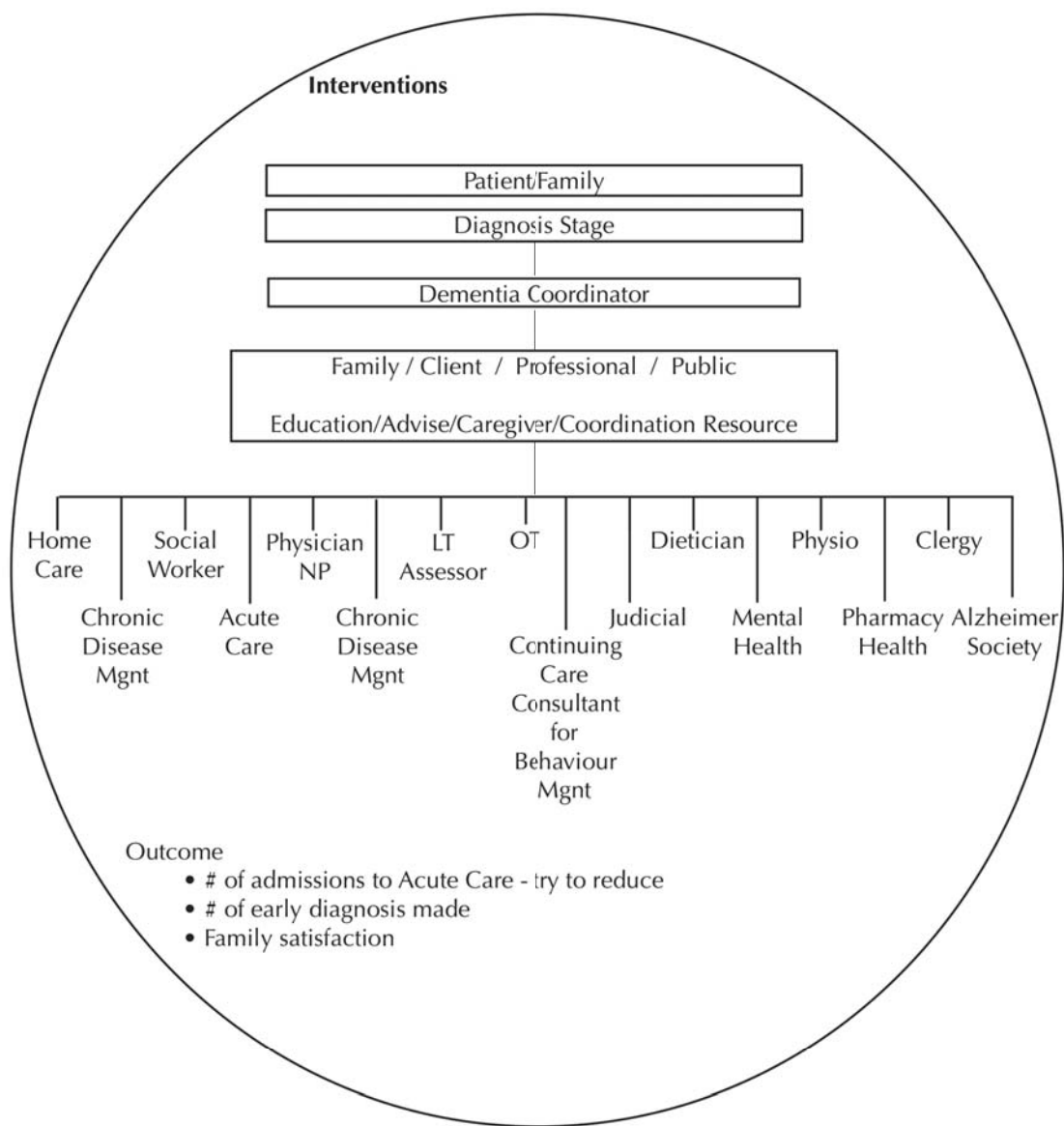
Group 2 Model



Group 3 Objectives

- Best possible care for client and family
- Client care should be in timely manner
- Care directed by client and family
- Keep costs down
- Integrate existing service to this care
- Awareness of cultural context - holistic care
- Patient/Client advocate for client care
- Communication between caregivers
- Development of standards of care and algorithms

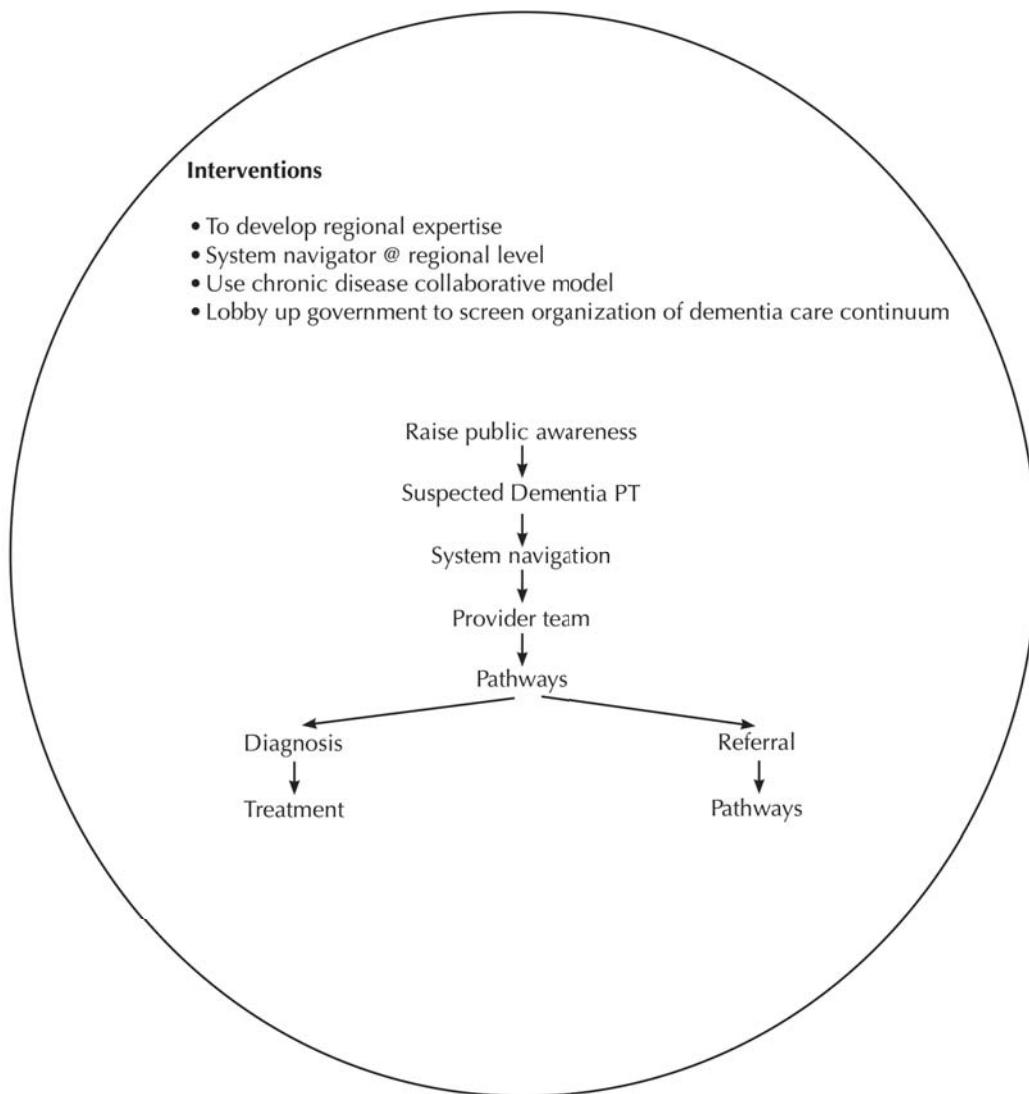
Group 3 Model



Group 4 Objectives

- To improve diagnosis
- To improve services after diagnosis
- To have Alzheimer's and dementia recognized as a chronic disease
- Improve public awareness about dementia
- Reduce long term cost burden for dementia care
- Recognition that dementia care needs to be "family centred" care
- To have government recognize dementia as a health care priority

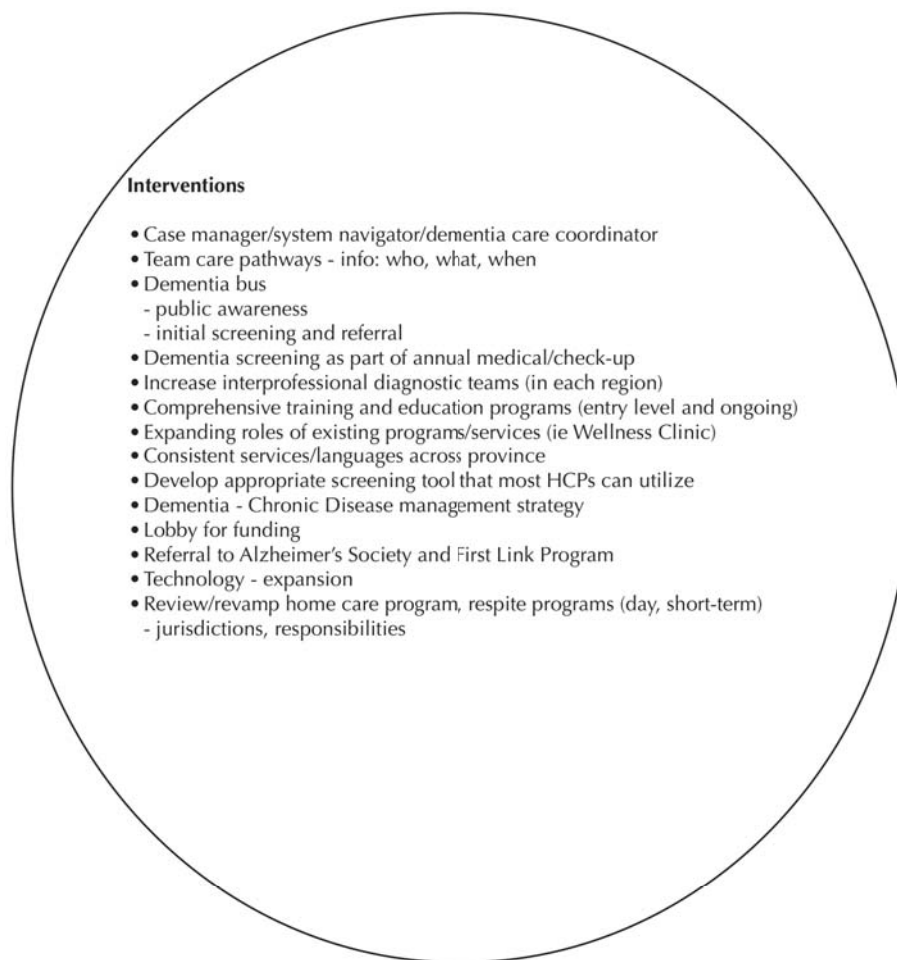
Group 4 Model



Group 5 Objectives

- Universal access to diagnosis, treatment, education support services regardless of \$, race, language, timely care, location, etc - across continuum to of care/disease
- Affordable and/or no cost to patient, family, caregiver
- Continuity/standardization of care across the province
- Sustainable
- HCPs: ongoing access to continuing education
- update/accurate information to professionals and family
- Research/evidence based
- Increase public awareness
- Keep patient with dementia in the community
- Unique individual dignity and respect
- Client-centred care (menu to choose from) - objectively accessing care needs
- Clearly identified resources to deal with system navigation
- Right service, by right person, at the right time and in the right place
- Change stigma associated with dementia

Group 5 Model



Appendix J: Survey Data

1. Please indicate your role during this Planning Session (you may check more than one):

Response	n	%
Family caregiver	4	8.9
Health region director	10	22.2
Family doctor	8	17.8
Nurse practitioner	7	15.6
Other specify	16	35.6
Total	45	100.0

Other role:

- Alzheimer Society
- Behavioral Consultant, Doctoral Student
- Client Care Coordinator with CPAS
- Community member, future nurse
- Continuing Care Consultant, Assistant Facility Manager
- Home Care Nurse
- Manager Rural Home Care
- Pharmacist - Rxfiles - Long Term Care Project
- Regional Telehealth Coordinator
- RN, Client Care Coordinator
- Rural Home Care Manager
- Senior Researcher, HQC
- VP Institutional and Emergency Care of Health Region and Family Caregiver

2. What are the most important issues in primary healthcare for people with dementia and their caregivers in the rural and remote areas of your health region (or your community)?

- Access - early diagnosis. After diagnosis, follow-up care. Lack of case manager/navigator. Education/awareness.
- Access - transportation, available professionals. Getting a diagnosis. Education. Support for caregivers. End of life care.
- Access of resources.
- Access of service to diagnose the condition. Lack of service availability for those who need help.
- Access to 'coordinated' care. Early diagnosis. Support for care that sees institutions as last option not first choice.
- Access to accurate and timely diagnosis. Support to the person with the disease.

Family caregivers following the diagnosis.

- Access to care - be that medical personnel, home care, medication, travel to specialists, public education.
- Access to diagnosis, specialist support. Post-diagnostic support for caregivers. LTC access at end-of-spectrum dementia.
- Access to diagnostic services. Access to information, education support.
- Access to diagnostic services. Caregiver/homecare support. Long term care bed access, especially personal care home as many people with dementia may be deemed too healthy for long term care.
- Access to early diagnosis. Support and information throughout the continuum of the disease process.
- Access to evidence-based diagnosis. Family support based on chronic disease principles (informal). Education and support of formal caregivers. These 3 areas all require continuing research into the disease, the family and community dynamics and the most appropriate models of care for Saskatchewan.
- Access to services including Home Care, in home assessment, timely and geographically convenient Doctor or NP appointments and specialist appointments. Smooth transitions through levels of care.
- Access to services provided by well informed dementia care providers. Removal of the stigma of dementia so that people are not afraid to seek service. Public education that a dementia diagnosis is not a death sentence and that there is effective treatment available to slow the trajectory.
- Access to timely care. Cost of therapy. Access to knowledgeable caregivers.
- Access. Diagnosis. Standard treatment/support. Lack of staff to carry out support.
- Accessibility. Lack of support to client/family once diagnosed.
- Accurate and timely diagnosis. System navigation. Services that are designed for client, not client to fit into existing services.
- Being identified with early diagnosis. Appropriate/timely interventions to all. That all patients will have services available to them at no cost. Home care be revisited and services from H/C be integrated into their protocols (they are not at present).
- Caregiver support - alleviate caregiver burden. Education for patients and families re disease progression, medications, non-pharm options, support programs.
- Diagnosis and treatment currently lacking.
- Diagnosis. Care strategies. Access to services. Stigma in community. Cost of treatment. Health care provider numbers and turn around.
- Early diagnosis, treatment, interventions and support services. This includes education about their disease and what they can do to help themselves/their family member to live well with dementia.
- Early diagnosis. Access to appropriate services for family and patient as the disease progresses.
- Education of family.
- I would think listening to the conversations today that accessibility to all aspects of care, services are limited. How can we get dementia on the provincial health radar? How can we remove the stigma associated with this disease? I also heard that there is a great deal of variation from region to region in the quality of care that can be provided. How can we "shine a light" on this inequity?

- Information - what services are available. Access - when and how do I get those services. Travel - can the services required be offered in the rural not urban setting. Cost - Is there or can there be funding to patients to receive services.
- Isolation. Lack of knowledge. Lack of resources.
- Keeping people at home and providing support.
- Lack of appropriate services for early diagnosis and treatment. No services available for ongoing support of family caregivers. Travelling and associated costs.
- Lack of Home Care services, ie. in-home respite care. Lack of information re dementia progression/treatment. Expectation that family is able/capable of providing support. This is often not realistic and doesn't happen.
- Lack of knowledge, accessibility, interventions, support
- Lack of resources for assessment, treatment, education and family support.
- Lack of services. Population spread over large geography – no critical mass. Difficulty accessing diagnosis and treatment – few family physicians and even fewer with knowledge and expertise. No care pathways that support clients/families.
- Lack of specialized services (geriatricians, psychiatrists). Lack of caregiver services (counseling, support groups, available options for travel and respite).
- Limited access to specialized services/resources. Limited access to education for HCP and public about illness. Lack of interdisciplinary team approach to care (having coordinator of services for dementia).
- Limited access to support and education for the carer in the home (family and patient). Almost no access to therapies (PT, OT, SLP, exercise therapy). Home Care - limited menu of services and limited capacity to provide in-home support. Inefficient detection, diagnosis and access to services.
- Maintaining privacy, maintaining dignity, maintaining quality of life. So many times P/t the persons and dementias behaviour - they become reclusive - they lose contact with friends, therefore decreased support. Dispelling the fear of disease and education. Patients that fall between the cracks - not mental health, not long term care, therefore out in the community living at risk.
- No adequate respite or emergency care if needed. 12 bed unit for dementia for a very large area. Support group and community education lacking.
- No diagnosis. Delayed treatment resulting in earlier long term care admission. Isolation. Limited family support due to family moved away. Lack of education to community, family, formal caregivers.
- Proper diagnosis. Follow up care. Standardized treatment.
- Stigma in attending and seeking help. Lack of time in medical practice. Lack of hospice support of end-stage dementia.
- The provision of services (home care, support services, and LT care availability). The ability to access (navigate) the services.
- Timely access to diagnosis and care. Education – professional caregivers, informal caregivers, public.
- Transportation. Coordination of care. Facilities with the proper environment. Lack of sufficient Continuing Care Consultants-Behavioural Management. No access for care pathways. Education of public, staff, physicians.

3. What types of interventions would you like to see implemented in primary healthcare for people with dementia and their caregivers in the rural and remote areas of your health region (or your community)?

- A dementia navigator or coordinator. Equal access. Dementia care made a provincial/national strategy. Increased dementia education for all HCWs involved. Increased access to telemedicine.
- Algorithm for care. Dementia coordinator. Education to care providers.
- Area dementia coordinators. Can there be a travelling CT bus to assist with diagnosis. Incorporate dementia screening with wellness clinics.
- Available support from Home Care and other agencies to provide care for clients in their own homes (ie. Sunday am respite, overnight respite).
- Better access to primary health care. System navigation help through whole process (go-to person). Specialist help that are timely and local (transport a big issue). Caregiver support programs. Improved home care services.
- Better access to specialized care. Respite care for caregivers in home. Algorithms for care based on best practice.
- Better diagnostic services. A continuum of care strategy that provides not only education and awareness for people with dementia and their caregivers and also assistance in order to be proactive rather than reactive and awaiting a "crisis" in order to access services.
- Case management from diagnosis to end of life. Education of communities re prevention and signs and symptoms. Increased access to specialty services through telehealth. I reference to LTC - Increased \$ so can have recreational activities appropriate to dementia. Funding for specialty dementia care to assist in management of those with behaviour management issues.
- Communication strategies enhanced to include all stakeholders in a timely way (eg. telehealth, teleconference). Development (or "stealing") of good material to assist clients/families and caregivers. Transportation "made easy".
- Community-based early detection services (somewhat similar to breast cancer awareness, screening). Could be a provincial program and visit communities every 2 or 3 years in a blitz. Community or at least regional dementia care coordinator.
- Coordinated services across the region and province. Screening for dementia as part of routine checkups (eg. at Wellness Clinics, apply dementia screening tool when checking BP, etc). Increased home-based services to support clients remaining in their homes.
- Dementia care coordinator with appropriate responsibility and authority.
- Dementia care coordinator(s) for each Health Region as "expert" as educator as advocate.
- Dementia Care Coordinators. Standards of Care and Algorithms after diagnoses across the province. Based on existing primary health care teams and enhance communications. Education.
- Dementia case manager/navigator of the same role/function as in the Shetland Islands system. A deliberate education - skill development process for those providing front-line care - point of this can be case driven.
- Develop core "PHC teams" that are multidisciplinary, embed case management into core PHC teams. Expand use of technology - particularly telehealth and

videoconferencing.

- Easier access. More primary health care programs that allow early access to info and resources. A team of individuals in the rural areas who are knowledgeable and can be available on a consult basis.
- Education (presentations, interactive, written materials) in their language exploring every facet of the disease (include associated costs).
- Education, support through the community, early diagnosis.
- Focused \$\$ - knowledge/education/awareness - public/community/caregivers. Navigator. Home Care. Social programs, ie not just day care. Focus on diagnosis - care for client and family. More screening (accessibility/availability to all - even in smaller communities).
- Go to person with complete support team for timely diagnosis, treatment and support. Support team can be through e-health but increased home care support is definitely a requirement. Keeping dementia people at home is best.
- Holistic care - collaborative approach from health care professionals, including Alzheimer Society programs and services. More resources available in rural areas.
- I would like to see how "dementia" can be a "test disease" for examining how PHC re-design in remote and rural areas works. A collaborative model may be beneficial to test small ideas of change in different regional contexts and quickly spread that learning of how/why these changes improve care through SK. This model also helps quickly learn what doesn't work and why so that resources are not wasted.
- Improved transportation (not ambulance). Affordable. Caregiver support with adequate funding. Multidisciplinary approach to care. Increase in NPs so continuity of care will be improved.
- Increase access to interprofessional diagnosis team. Continuity of services throughout province. System navigation/dementia care coordinator.
- Increase prevention and promotional activities. Education. Early assessment. Treatment modalities. Multidisciplinary interventions and follow-up.
- Increased numbers of specialists, geriatrician, family physicians and nurses in dementia care. Research into what works and what doesn't. Difficulty of patients and families travelling to attend appointments.
- Increased resources/support.
- Increased respite services - whether it be in the home to provide caregiver relief or improved day care/night care - where persons with dementia can have a room with bed to go to lie down/rest/toilet. Increased education re the disease process - to informal and formal support.
- Interprofessional diagnostic teams to improve diagnosis. Education and support for family caregivers. Improved access to respite and home care services.
- Memory Clinics accessible in rural areas, telehealth or travelling teams or both. Reduce travel to urban areas.
- More discussions with Doctor in what next step will be.
- More resources both human and financial to implement a model where actual dedicated professional would be available in many locations of the province/region to assist in getting help to client/caregiver.
- Navigators/coordinators/facilitators. Community awareness. Help for family caregivers.

- Outreach teams - multidisciplinary approach - via telehealth if necessary.
- Public education and professional evaluation. Financial assistance for medications for borderline people. Assistance for families dealing with dementia in their own hands.
- Regional/local coordinated diagnosis and treatment.
- Scaling care - increasing Home Care and respite to keep patients in home longer.
- Standardize and appropriate screening. Recognition as a CD so that there is a more positive focus on the disease to promote better outcomes for the person/family. Access to education for caregivers, community groups - could be via travelling Dementia bus, telehealth @ convenient and optional times. Presentations at seniors groups, church groups, economic development groups.
- Standardized pathway so regions could use as model to better dementia care. Government funding for training coordinators/HCP in programs that address disease (HQC model). Support models for family/caregivers.
- Steps to diagnose early help with flow chart and regional directory of names to access. Support services available for caregivers.
- Subsidized in home care relief for caregivers. Education for caregivers on the physiological/cognitive/behavioral changes with respect to dementia. Counselling for caregivers. Transportation to appointments. Streamlined process for diagnosis.
- To utilize our Chronic Disease provider in the most efficient way possible. Due to Dr. shortage and no "emergency" care our NPs are over worked with daily care. No time for "prevention" and health promotion.
- Training for local health providers. Dedicated case managers (one on one with patient and family caregivers). Local specialist services.
- We need to have dementia incorporated into a provincial strategy that recognizes it as a chronic disease, to increase awareness and surveillance and to address the impact of co-morbidity.

4. In your health region or community, what might be the challenges to implementing the interventions that you identified in Question 3?

- \$\$ - lack of. Shortage of resources. Provincial focus is on acute care vs. community primary health care service.
- Additional personnel would be needed - Skill set. Strategy to assure education was actually accessed by the front-line care providers - i.e., mode of delivery, timing and place, mandatory vs optional. Philosophical orientation of nurses and doctors and managers so they interact with client and families rather than limited interaction and primarily staying at office or desk.
- Costs. Human resources - can we reduce the barriers, ie collective agreement that restricts # of call in lists, staff can be on. ? Is it good utilization for SCA to work in housekeeping (because she will get her 8 hours there). Building structures- respite, mental health group homes,
- Culture change. Funding.
- Dementia care is not a provincial government priority, therefore money is not available for services - ideas are there, funding is not. Recruitment and retention of rural specialists + LTC staff, physicians, RNs.
- Dollars. Human resources. Travel/weather conditions.
- Dr. shortage. Nursing shortage as per budget. As not wanting overtime or extra hours -

- care levels exceed manpower at times.
- Education and knowledge about diagnostic process – specifically Canadian Consensus Guidelines. False belief that there are no benefits in giving a diagnosis - nothing that you can do. Lack of recognition of the important role that family caregivers provide in the health care team.
 - Education to care providers. Only those interested attend inservices - this consistency still a problem.
 - Family support is not available. Young people leave community for jobs and leave elderly.
 - Fragmented health care system - lack of a team approach which interrupts continuity of care. Care of elderly and persons with dementia is low on the list of priorities.
 - Funding for the positions of Coordinator. Development of standards of care.
 - Funding.
 - Funding. Staff resources (feet on the ground) - primary care, home care, specialists. Stigma of the illness.
 - Funding. Having the MOH view dementia as a priority. Retention of HCW's.
 - Funding. Staffing. Resources.
 - Having the resources (i.e., people, \$) to make materials and deliver them.
 - How to provide this specialized care - telehealth? mobile health? transportation to?
 - Human resources and dollars.
 - Human resources, funding.
 - Human Resources. Lack of collaboration region to region to Ministry. Lack of awareness about seriousness of the problem.
 - Human resources. Public denial of issue. Geographic and weather challenges.
 - Isn't a culture that funds and does research. Difficulty in recruitment to rural Family Medicine. Isn't same availability of taxis/community transit to rural clients as there is for aboriginal clients.
 - Isolation, lack of staff, lack of education.
 - Lack of \$. Lack of regional direction at VP level. Lack of resources. Lack of willingness by individuals and family to access primary services at an early dementia stage - often they wait until a crisis occurs.
 - Lack of dollars. Lack of personnel. Lack of will by senior leaders to make this a priority.
 - Lack of human and financial resources. Enthusiasm of provincial government for implementing a province wide strategy.
 - Lack of manpower, short of doctor, short of homecare nursing time, short of OT availability.
 - Lack of personnel for home visits. Lack of funding to improve the knowledge base. Education funds used in acute care - not home care or LTC. Tending to be reactive not proactive.
 - Lack of personnel trained in dealing with dementia patients especially in the earlier stages. Lack of programs for pre nursing home patients.
 - Lack of resources - human and financial.
 - Lack of rural staff. Inadequate funding to Home Care. Reluctance from the client to accept services.
 - Lack of staff. Would require additional personnel.

- Large geographical area - health region - people have many responsibilities. Not a priority for MoH (ie SOD document). Limited \$\$\$. Lack of resources - some communities without physician or RN/NP.
- Need designated funding.
- Prioritization. Human resources. Lack of public awareness.
- Privacy concerns, fragmented technology, lack of standard documentation, cross border "buy-in" (specialist often outside health region). Open source communication. All disciplines should be working together and contributing to the patient's care plan and medical file.
- Recognizing/knowing what resources already exist, and filling in the gaps. Funding.
- Resources - financial/human. Support/direction from Government.
- Resources - our community has only 1 NP, an MD for 5 hours/week, a home care RN 2 days/week.
- Services. A coordinated continuum of care.
- Stigma, lack of education of health care professionals to the need for early diagnosis.
- There is a need for a provincial commitment to providing services for clients with dementia. Funding or other financial considerations (e.g., tax rebates) are needed if family members choose to leave the work force while caring for a client with dementia.
- We need a "bottom-up" approach to 'testing' evidence-based practice to improve dementia care. However, unless we have government directive (ie Ministry of Health) setting this as a priority, the sustainability of this research may be compromised.

5. What might be some solutions to the challenges that you identified in Question 4?

- A National or at least a Provincial strategy of care for the elderly and persons with dementia. Senior managers need to recognize a coordinated systematic team approach is necessary to offset crisis management approach we seem to have at present.
- Accessible education and "normalizing" dementia. Provincially directed programs. Increased awareness of "the rising tide".
- Aggressive retention/recruitment strategies to attract and keep HCWs in rural settings. Lobbying the government to see this as a priority.
- Awareness about the beliefs of diagnosis - including \$ factor, the people who go undiagnosed cost the health care system more because they access at point of crisis. Some provinces have developed Caregiver Recognition Acts/specific programs. Fund and expand Alzheimer Society First Link program. Financial supports for caregivers.
- Campaigning government to recognize as a priority. Discussion and collective agreement. Incorporating room for respite in new/existing structures.
- CME, other continuing education in their community. Again reduce travel.
- Contact with staff or private care providers, instead of relying solely on Home Care. Work with private agencies to provide affordable services, subsidize financially. Increase funding for Home Care, and make respite-in-home services a priority.
- Corporate sponsorship. Public education. Establishment of a CDM-like collaborative to educate, engage and empower primary caregivers.
- Culture change. Funding.
- Dementia as a chronic disease collaborative. Dementia as an issue in government

- priorities. Dementia awareness campaign.
- Designated and accountable funding.
 - Easy access via telehealth for specialist advice. Recognition by the Ministry of Health as a chronic disease.
 - Education of our decision-makers (people who spend healthcare dollars). Education of caregivers (family and friends and community). Education of health care providers (diagnosis/screening/treatment options).
 - Education regarding the promotion of early diagnosis and the caregiver and community's role in providing support and services to the person diagnosed.
 - Global medical files (E-health records). Scaling access according to provider needs. Provincial documentation standards.
 - Government puts dementia as a priority. Tap into existing resources - OT, Chronic Disease NPs, Home Care Wellness Clinics, Visiting programs via church groups.
 - Government support. Public awareness to increase knowledge and thus increase demand for better services (through increased government funding).
 - Government understanding of the growing need for dementia care.
 - If all areas were allowed to perform their regular duties and not pick up all the extra baggage the system may run smoother.
 - In an ideal world there would be more funds for more people trained to help specific needs.
 - Increased telehealth sites.
 - Integrating all existing services.
 - Listed as priority for SK Health. Use technology, ie Telehealth, access to more "specialists" through Telehealth.
 - Lobby to government to look at the benefit of supporting dementia care as long as possible in the home therefore saving dollars on the acute and LTC side.
 - Make a financial case for early intervention. Public awareness to make patients/families more likely to lobby for more care.
 - Mandatory inservice to anyone (professional) who cares for dementia clients. Algorithm of care to guide practitioners to standardized care.
 - Marketing. Centralized "core PHC teams" into hubs and spoke services ? Use "others", ie non health care disciplines in novel and creative ways to lobby for change.
 - Mobile services. Dementia case worker. Increased Home care resources for screening and caregiving.
 - Pilot projects. Community grant.
 - Political action to bring about change. People are not vocal enough. Medical school education in geriatrics. Geriatric Nurse Practitioner Training.
 - Possibly by aligning dementia care with the PHC (Provincial) re-design efforts. Need to include health economic aspect to program - comparative effectiveness (eg. usual care vs. alternative models).
 - Preplanning with family members of what to do/when updating plan. This would mean "in the event that " then this would happen.
 - Provincial commitment to establish an infrastructure of coordinated services. Paradigm shift that will shift some funding that is currently dedicated to acute care to providing increased community-based services.
 - Provincial directions with financial statements. Having dementia recognized with

CDM so that someone can assume some umbrella of responsibility and their funding can be allocated. Now no one to champion the cause.

- Provincial recognition of dementia issues (politically).
- Refocus Ministry of Health. Rural recruitment and retention incentive packages standard across the province so one region does not compete with the other.
- Regional teams to provide support and education rather than provincial support.
- Resource allocation, screening programs conducted by primary healthcare providers, eg. homecare, nurses, nurse practitioners, public nurses, RNs in health centres and ?
- Restructuring of current programs. Lobby for funding for dementia care.
- Results from research projects like this taken forward to the Ministry identifying the need for dementia to be classified as a chronic condition. This would then bring forward as a higher priority and allow quicker funding for programs.
- Training students and residents in rural areas. Continued research by HQC and U of S. Improved rural transportation systems of patients and families. Reminders by mail/e-mail of appointment times.
- Use of videoconferencing and "recognition" rewards for care aids to reward to attaining additional knowledge. Some component - health care education to value and emphasize relationship building with the patient/client. Government review of Home Care scope of services and adequacy of our approach to helping those with dementia.
- Working with Ministry of Health to develop standards of care and care pathways. If SUN Partnership funds continues – Coordinator positions may come from that.

6. Would you be willing to provide a letter of support for Dr. Debra Morgan's CBPHC Team Grant to the Canadian Institutes for Health Research (CIHR)?

Response	n	%
No	2	4.4
Yes	31	68.9
Missing	11	24.4
Do not know	1	2.2
Total	45	100.0

7. Would you be willing to be involved in a Primary Healthcare intervention in dementia care?

Response	n	%
Yes	28	62.2
Missing	3	6.7
Do not know	14	31.1
Total	45	100.0

If yes, please describe how you would like to be involved:

- Alzheimer Society programs and services include: First Link - direct referral program where families affected by dementia are referred to ASOS for information and support. Education - some provided by Telehealth. Support for persons with dementia (if appropriate) and family members (often by phone). Caregivers support groups.
- Alzheimer Society, First Link program being included in circle of care for persons with dementia and family. Whatever other way we can to support the program/intervention in early stage of development.
- As a physician to screen patients opportunistically at my clinic, by providing a questionnaire and then invite them for proper organised consultation.
- Building/expanding on case management. Implementing programs/screening in existing clinics/programs. Building partnerships with all core providers.
- Contingent upon discussions with my Primary Health Care Manager regarding my involvement in initiatives outside of my clinical practice. Given the restraints of time and local resources.
- Demands on time are an issue, very NB project. ? consultative role.
- Depending on time and funding.
- Depends on current commitments and ability to dedicate time/energy to another initiative.
- Depends on the need and how that would fit.
- Developing and providing education and materials to patients/families and healthcare professionals. Handouts, presentations, anything related to the treatment (pharm or non-pharm).
- Group meetings.
- I would like to be part of a multidisciplinary team that works in rural and remote areas of Sask. To bring services to the people rather than bring the people to the service. Rural resource mobile service?
- If I could bring to Wellness Clinics - screening, information to raise public awareness I would love to see how we could do this.
- Implementing and monitoring strategies, gathering data, sharing experiences, panel discussions.
- In the capacity as a family physician. Participate in research.
- Local planning, periodic consultation.
- My office will be closed but: I am prepared to work with LTC in Prince Albert. I am ready to work with Family Medicine residents in PA. I work regularly in Nipawin and would be happy to encourage them there.
- No idea. I work in a Medical Clinic. Screening of clients in community?
- Not sure - as a caregiver.
- Not sure at this time. Pilot site for Dementia Care Coordinator.
- Not sure how? Open to suggestions.
- Not sure how. Willing to explore possibilities and capacity to help. ? steering process/focused discussions.
- Piloting.
- Role that the NFP sector/Alzheimer Society can play as part of the health care team.
- To help improve services and education to my region and team members.

- We'll leave it to my Manager to decide how involved we can be.
- Would be more than willing to help with screening/diagnosis if provincial pathway/algorithm was in place.
- Would depend at present how much time this would take and if we would benefit in some way. I hate to say no but there is only so many hours in the day and so many initiatives that we are involved with already.
- Would like to see First Link coordinators and referrals be part of the interdisciplinary team to inform people with dementia and their caregivers as to ASOS services at time of diagnosis.