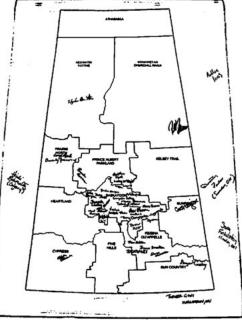
## The Seventh Annual Summit

of The Knowledge Network in Rural and Remote Dementia Care October 21 & 22, 2014 Saskatoon, SK

















## Save the Date.

Be sure to mark your calendar, and plan to attend the 8th Annual Summit in Saskatoon. October 27th and 28th, 2015

This report summarizes the activities of Summit 7, the Seventh Annual meeting of the Knowledge Network in Rural and Remote Dementia Care in Saskatoon on October 21<sup>st</sup> & 22<sup>nd</sup>, 2014.

Funding to make this Summit possible was provided by Canadian Institutes of Health Research and Saskatchewan Health Research Foundation.

Support provided by the University of Saskatchewan, and the Canadian Centre for Health and Safety in Agriculture.

Most photos from the Summit used in this report were taken by Debra Marshall with some provided by CCHSA.

University of Saskatchewan Saskatoon, Saskatchewan June, 2015

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## Welcome

Dear Knowledge Network Members,



On October 21<sup>st</sup> and 22<sup>nd</sup> 2014 we held our 7th Summit of the Knowledge Network in Rural and Remote Dementia Care in Saskatoon. This year's Summit was a bit different, as it was held in conjunction with the 7th International Symposium: Safety and Health in Agricultural and Rural Populations (SHARP)—a scientific conference that is held every five years in Saskatoon, hosted by the Canadian Centre for Health & Safety in Agriculture at the University of Saskatchewan. Holding the Summit at the same time provided an opportunity to raise awareness about issues in rural and remote dementia care among a larger audience, and highlight the important and exciting research that is being done to improve the care of people with dementia and to support their caregivers.

The Summit started with a Wine and Cheese poster session on the evening of October 21<sup>st</sup> (where 30 Summit posters were on display along with 50 SHARP Symposium posters at the Bessborough). A full-day program followed on October 22<sup>nd</sup>. Dr. Anthea Innes, Director of the Bournemouth University Dementia Institute in England, gave a keynote presentation to the combined SHARP Symposium and Summit audiences, which was very well received. Dr. Innes was the keynote speaker at our 2nd Summit in 2009 and Summit participants have been asking us to bring her back ever since! We were pleased that the Honorable Greg Ottenbreit, Minister Responsible for Rural and Remote Health, took time to travel to Saskatoon to open the Summit meeting before Dr. Innes's presentation.

There was a full day of presentations about research conducted in the UK, Ontario, and Saskatchewan. Dr. Innes and PhD student Clare Culter from Bournemouth University presented on novel dementia research being conducted in the UK. RaDAR colleagues from the Northern Ontario School of Medicine presented on their research program aimed at understanding and improving dementia care among Aboriginal people. Participants also heard an update from the Alzheimer Society of Saskatchewan about development of Dementia Advisory Networks in Saskatchewan.

Most of the afternoon was spent working on recommendations from a recent RaDAR-Health Quality Council study of dementia incidence, prevalence, and service availability in Saskatchewan. Participants were very engaged in this discussion and debate about how the recommendations should be ranked and revised. The revised recommendations were included in the final report published in January 2015.

Thanks to everyone who made this event so productive and energizing. I know I speak on behalf of all RaDAR team members when I say how much we need and enjoy this opportunity to work together to improve dementia care in Saskatchewan.

I would like to acknowledge the support provided by a Saskatchewan Health Research Foundation "Research Connections Grant," and a Canadian Institutes of Health Research "Planning and Dissemination Grant."

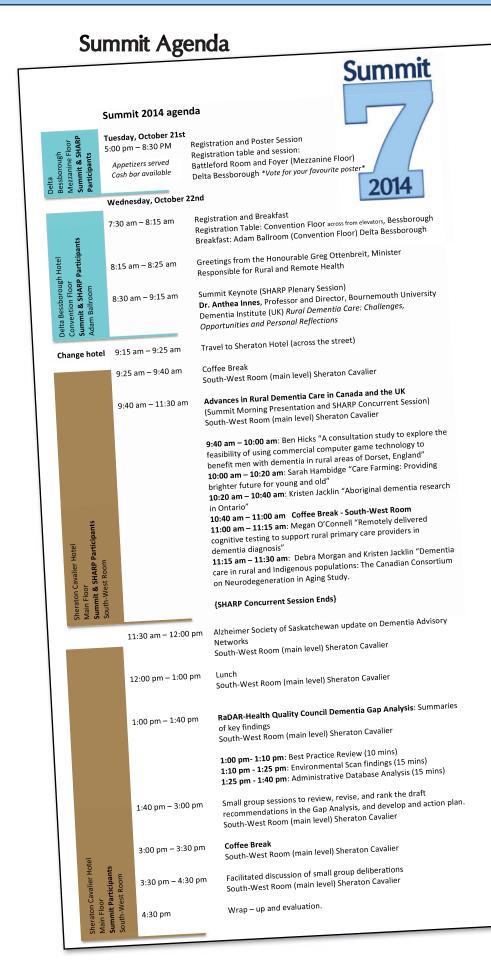
Leber Mayo

Debra Morgan



Final Report of the 7th Annual Summit of the Knowledge Network in

If you did not attend the 2014 Summit, and are interested in attending future meetings please contact Debra Morgan at: debra.morgan@usask.ca





This year's Summit was hosted in conjunction with the 7th International Symposium: Safety & Health in Agricultural and Rural Populations in downtown Saskatoon at both the Sheraton and Delta Bessborough hotels.



Participants of the Summit were provided with a binder of information, which included copies of some of the presentations and background information. If you would like to request a copy of this information, please see page 15.

#### Poster Session Delta Bessborough - Battleford Room



A full list of poster titles and authors as presented for the Summit is available in Appendix A, page 16 of this report. A booklet including all of the posters displayed is also available. Page 15 includes information about how to access the booklet.

On Tuesday participants registered for the Summit and enjoyed the scientific poster session and informal networking evening. The Summit poster session was hosted along with the official Poster Reception for the 7th International Symposium (SHARP). The ballroom was very full as Summit participants and SHARP delegates enjoyed the more than 50 SHARP posters, and 30 Summit posters (three of which were co-submitted to SHARP).



**Summit poster presenters included:** Juanita Bacsu, Anita Bergen, Camille Branger, Rachel Burton, Allison Cammer, Clare Cutler, Vanina Dal Bello-Haas, Tracy Danylyshen-Laycock, Joe Enright, Ben Gould, Leslie Holfeld, Paulette Hunter, Anthea Innes, Julie Kosteniuk, Kathleen Kulyk, Debra Morgan, Darrell Mousseau, Jennifer Nyarko, Megan O'Connell.

#### **Poster Award**

In keeping with the SHARP conference poster session style, the Summit held a Favourite Poster vote. All Summit attendees received a ballot when they registered, and then cast their vote for their favourite Summit poster. The winner was Camille Branger for her poster titled *Coping with Cognitive Impairment and Dementia: Rural Caregivers' Perspectives*.



Rural and Remote Dementia Care - Saskatoon, October 21 & 22, 2014

## Summit Meeting Welcome, and Greetings from the Honourable Greg Ottenbreit Minister Responsible for Rural and Remote Health

The SHARP conference had more that 250 delegates in attendance from across Canada, and around the globe who share an interest in the health of rural populations. SHARP delegates traveled to Saskatoon from a number of different nations including Australia, Uganda, India, Sweden, Poland, and Nigeria.

Wednesday morning's Summit meeting started off in different manner than previous Summits. Shared with the delegates of the SHARP conference, Wednesday morning's events were the start-off of the Summit meeting for Summit attendees, and the morning plenary session for the SHARP delegates. Over breakfast, Dr. Morgan welcomed the Summit attendees to the 7th Summit, and introduced herself and the Summit group to the SHARP delegates. She gave a very brief history of the Summit meetings to the group, and then introduced the Honourable Greg Ottenbreit, Minister Responsible for Rural



and Remote Health. The Minister brought greetings on behalf of the Government of Saskatchewan to the room of Summit and SHARP participants who together represented local, national, and international research interests in the health of rural populations.



#### Honourable Greg Ottenbreit - MLA for Yorkton Minister Responsible for Rural and Remote Health

Greg was first elected as the MLA for Yorkton in the 2007 provincial election and was re-elected in 2011. Born in Regina, Greg has lived in Yorkton for most of his life, and has always been involved in his community. Prior to being elected, Greg owned and operated Ottenbreit Waste Systems, a private environmental and waste disposal business. Greg has been married to his high school sweetheart, Leone, for over 26 years, and has two daughters, Katelin and Rayanne. In 1998, the couple started Brayden Ottenbreit Close Cuts for Cancer, an event that encourages volunteers to shave their head to raise money for cancer research and local initiatives. The charity, which has raised almost \$700,000, is

named in honour of their son Brayden who lost his battle with cancer in 2000 at age 5. Greg and Leone received the Saskatchewan Centennial Medal in 2005 for their community involvement and volunteerism. Greg was recognized in 2012 with the Hal Rogers Fellow Award, the highest honour presented by the Kinsmen of Canada.

Greg has served as the Legislative Secretary to the Minister of Social Services, Community Based Organizations initiative and as Legislative Secretary to the Minister of Environment, Recycling. In June 2010, he was appointed as Legislative Secretary to the Premier for Vulnerable Youth. Greg has served as Chair of the caucus' standing policy committee on human services and the Chair of the legislature's Standing Committee on Human Services. He has served as Deputy Government Whip and was appointed as Whip in May of 2012. Greg was appointed Minister Responsible for Rural and Remote Health on September 24, 2014.

#### Summit Keynote - Dr. Anthea Innes

Dr. Anthea Innes of Bournemouth University Dementia Institute (BUDI), Bournemouth, England, was the Summit 7 Keynote presenter as well as the SHARP conference morning plenary presenter. Dr. Innes participated in the 2009 Summit meeting as our guest presenter, and it was exciting to welcome her back to Saskatoon for Summit 7.

Dr. Innes provided the audience with background information about the prevalence of dementia in the United Kingdom (UK) and the rurality of the population of the UK. She then spoke about her research work in dementia care in rural and remote settings in Scotland and in England, highlighting key issues and challenges in dementia care in this context.

Dr. Innes took some time to consider the strengths of rural and remote settings that help drive innovations in dementia care. She then highlighted some of the research interventions that she and her team have employed over the years that aim to support people with dementia and their family and caregivers living in rural and remote settings in the UK. An overview of some of the BUDI initiatives aimed at promoting an inclusive and supportive society for people affected by dementia then followed. Some of these initiatives were explored later in the morning at the SHARP concurrent session.



#### Dr. Anthea Innes – Director, Bournemouth University Dementia Institute, UK

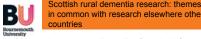
Professor Anthea Innes is the Director of the Bournemouth University Dementia Institute launched in May 2012. She previously worked at the Dementia Services Development Centre, University of Stirling where, as inaugural programme director, she was responsible for the development and delivery of the first world wide online post-graduate programme

in Dementia Studies. As a social scientist she brings a distinct approach to understanding dementia and her work with people with dementia. She is passionate about improving the lives of those with dementia and their families, as well as enabling care professionals to provide high-quality support and services. Her research interests within the area of dementia are: rural service provision; technology; dementia friendly environments; the views and experiences of people with dementia and their family members; and diagnostic and post-diagnostic support. She uses mixed methods in her research and has particular skill in the use of interviews and focus groups as well as observation methods including Dementia Care Mapping (DCM). For more information about Dr. Innes' research visit http://goo.gl/XX8L6t









- Diagnostic processes (Australia, Canada, US, Republic of Ireland, UK)
- Staff education and support needs (US, Australia, Canada, Ireland)
- In person v's remote delivery (US, Australia, Canada)
- Staff perceptions and experiences of dementia care delivery in rural areas
- Morgan, D., Innes, A. and Kostenisek, J. (2010) Formal Dementia care in rural and remote settings: A systematic review Maturities doi:10.1016/j.maturitias.2010.00.008 Innes, A. Morgan, D. and Kostenieuk, J. (2010) Informal dementia care in rural and remote settings:



#### Working towards dementia inclusiv societies and communities: What can a University do?

Involvement and engagement •Collaborative approach – BUDI intentional acronym to demonstrate a 'buddy' or collaborative approach •Work with others locally – BUDI part of the Dorset Dementia Partnership, nationally and

 Listen to and work to address the needs and concerns of our partners and stakeholders through our work
 Promote change through our research, knowledge exchange, and



Inter-disciplinary team, involving range stakeholders in University and wider community

## Morning session: Advances in Rural Dementia Care in Canada and the UK



After Dr. Anthea Innes' morning keynote presentation there was a break to allow participants to move between hotels for the next presentations. The morning's first five presentations followed a format that matched the SHARP conference presentations format. These five presentations were integral to the Summit and attended by all Summit 7 participants and they were also open to SHARP delegates.

> "A consultation study to explore the feasibility of using commercial computer game technology to benefit men with dementia in rural areas of Dorset, England" ~ Ben Hicks Ben Hicks was unable to travel to attend the Summit 7 meeting, and so Dr. Anthea Innes led his presentation. Ben is a PhD student who joined Bournemouth University Dementia Institute (BUDI) in 2012. His PhD research explores the use of commercial computer game technology [such as Nintendo Wii, Nintendo DS, Microsoft Kinect, and iPad] with older men with dementia in rural Dorset. He aims to develop and implement an initiative using technology gaming systems, explore the impact this has for men with dementia in rural Dorset, and produce final guidance documentation for practitioners. Ben's presentation focused on his consultation work with stakeholders in Dorset which aimed to collect information to inform his wider PhD project. Participants in the consultation were excited to engage in something novel, and showed a willingness to learn more about technology. Some of the identified benefits of the technologies were: mild exercise, cognitive stimulation, and social interaction.

#### "Care Farming: Providing brighter future for young and old" ~ Sarah Hambidge

Sarah Hambidge was unable to travel to attend the Summit 7 meeting. However, her colleague Clare Cutler from BUDI was able to attend in her place and led Sarah's presentation. Sarah is a PhD student at BUDI and her work explores the impact of care farming on both younger people with behavioural, emotional, and social difficulties as well as older people living with dementia. Sarah cites background research that suggests men who have retired from rural occupations are at greater risk of mental health problems, and evidence that suggests keeping mentally, physically, and socially active can reduce the risk of dementia, or slow its progression. These are important considerations in her research with older people with dementia. Her research is in progress, and has implications for future programming opportunities for older persons in the UK.

## BUBCkground

- Consultation to find out what stakeholders wanted as phase 1 of a wider PhD study/ initiative part funded by AgeUK (a local charity).
- Overall the PhD aims to:
- Develop and implement an initiative using commercially available technology gaming systems
  Explore the impact this has for older men with
- dementia (65 years+) in rural Dorset
- Produce final guidance documentation for

practitioners



#### Aim's of the consultation

- 1. Explore the feasibility of using the technology with older men with dementia
- 2. Gather information to support the development and implementation of the technological initiative
- 3. Highlight other related areas of interest the wider PhD study could explore

#### **BU** What is care farming?



 Use the whole or part of a farm
 Provide health, social or educational care services for one or a range of vulnerable groups of people

practices

A therapeutic use of farming

- Supervised, structured programme of farming-related activities
  - (Care Farming: UK, 2014)

**BU** Overview of the research

- Are there benefits from participating in care farming for older men with dementia and young people with behavioural, emotional and social difficulties (BESD)?
- What are the outcomes for each group?
- Do the benefits of participating in care farming differ between the two groups?
- Are there opportunities for intergenerational activity in care farming?
- What opportunities would intergenerational activity provide to care farming and individuals?

#### "Aboriginal dementia research in Ontario" ~ Kristen Jacklin

Dementia is an emerging health issue for Aboriginal populations in Canada. The research conducted by Dr. Jacklin and her team aims to improve understanding of Aboriginal peoples' experiences with dementia in diverse communities in Ontario. Her team's research explores how cultural understandings of dementia as well as history, policy, and geography shape health care seeking behaviours in diverse communities. This work has been conducted in partnership with Aboriginal communities in Ontario. This research indicates that for Aboriginal people, acquiring a diagnosis of dementia is influenced by three key factors: (1) cultural understandings and interpretations of the symptoms of dementia; (2) structural barriers to care including access to primary health care and specialist services, and the appropriateness of cognitive screening tools; and (3) patient and caregiver relationships with their health care provider. The relative importance of each of these factors in determining peoples' experience with seeking a dementia diagnosis varied between the urban, rural, and remote sites. The findings suggest that Aboriginal experiences with dementia diagnosis are unique in Canada; shaped by Indigenous cultural values, issues of cross cultural assessments and care, and geographic and jurisdictional issues.

#### "Remotely delivered cognitive testing to support rural primary care providers in dementia diagnosis" ~ Megan O'Connell

Neuropsychological services are generally rare and difficult to access, but geographic isolation compounds inaccessibility for rural primary care teams. Research on remotely delivered cognitive screening tests have demonstrated promise, but these screens do not provide sufficient cognitive information nor do they meet best practices in dementia diagnosis. To date, little research has been conducted on the psychometric equivalency of in person and remotely delivered neuropsychological test batteries. Dr. Megan O'Connell's project aims to capitalize on the large body of normative data and psychometric properties of a 30 minute neuropsychological battery delivered over the telephone in the Canadian Longitudinal Study on Aging (CLSA). She plans to use the CLSA neuropsychological battery and the dementia algorithm derived from the neuropsychological results in a novel way for rural primary care. As a result of this project, Dr. O'Connell anticipates increased ability of primary care teams to diagnose dementia due to Alzheimer disease. However, for dementia due to other etiologies she anticipates continued referrals to the Rural and Remote Memory Clinic for a full day in person interdisciplinary dementia assessment.



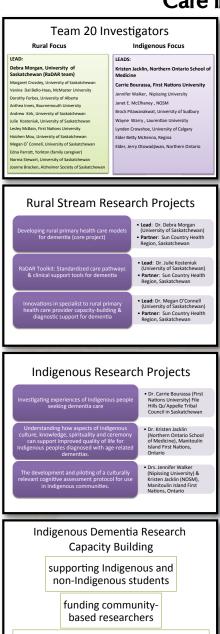
## Innovations in Specialist to Rural Primary Care Provider Capacity Building and Diagnostic Support

- for Dementia
- Rural seniors have less access to specialists
- The role of primary care is greatest in rural communities, but rural staff report limited dementia training
- We will explore how Rural and Remote Memory Clinic (RRMC) specialists can remotely offer rural primary health care providers with dementia care training and support

#### Why Provide Remote Neuropsychological Support

- To diagnose early stage dementia neuropsychological testing is critical, but this is a rare resource and almost completely inaccessible in rural Saskatchewan
- The psychometric properties of remotely delivered neuropsychological batteries have not been adequately addressed
- Any change to the way a neuropsychological test is administered requires creation of normative data and information regarding the validity of the test scores

## Morning session: Advances in Rural Dementia Care in Canada and the UK - *continued*



supporting the activities of International Indigenous Dementia Research Network

#### "Dementia Care in Rural and Indigenous Populations: The Canadian Consortium on Neurodegeneration in Aging (CCNA)"

#### ~ Debra Morgan and Kristen Jacklin

The Canadian Consortium in Neurodegeneration in Aging (CCNA) was established by the Canadian Institutes of Health Research in April 2014 to address the growing prevalence of neurodegenerative diseases affecting cognition, such as Alzheimer Disease and other dementias. CCNA brings together 340 researchers across 20 research teams, organized into three Themes (prevention, treatment, care). CCNA Team 20 brings together 23 researchers and decision makers from three provinces and the UK to focus on Issues in Dementia Care in Rural and Indigenous Populations. The Rural and Indigenous research streams are distinct but address three common research areas: community based primary healthcare (PHC), appropriate tools, and capacity building. Team synergies include the use of community based participatory methods; working within a health equity framework with communities that have elevated rates of and higher risk of chronic illness and reduced access to care; and the need for innovative adaptive solutions for equitable care in under serviced, under resourced and under studied populations. The Rural stream, led by Debra Morgan, includes three inter related projects. Project 1 will develop and evaluate effective and sustainable models of PHC for dementia by identifying current gaps in rural PHC for dementia, and working with PHC teams to adapt best practices to the local context. Project 2 will investigate the clinical support tools (e.g. assessment instruments, algorithms) needed by rural PHC providers and the best strategies for integrating these tools into rural PHC practice. Project 3 will explore strategies for specialist to rural PHC skills training and decision support. Within the Indigenous stream, co-led by Kristen Jacklin and Carrie Bourassa, Project 1 will examine pathways to dementia care for Aboriginal people and identify effective cultural approaches to care, to create appropriate PHC models. Project 2 will focus on development of appropriate measures and tools for understanding and providing



dementia care in Indigenous communities. Finally, this stream will focus on capacity building for age related Indigenous dementia research to build a cadre of new investigators. The Rural and Indigenous streams share an interest in virtual health care technologies, the influence of gender on outcomes, and integrated knowledge translation and exchange. The presentation by Debra and Kristen provided an overview of the CCNA initiative and outcomes of the early stages of Team 20 projects.

## Summit Morning Presentation: Alzheimer Society of Saskatchewan update on Dementia Advisory Networks

At Summit 6, in 2013, the Alzheimer Society of Saskatchewan (ASoS) presented about the then recent expansion of their First Link Program to a total of six health regions across the province. One of the goals of the expansion of the program was to develop a Dementia Advisory Network (DAN) in each of these six health regions, which would be anchored by the First Link Program Coordinator in each region. The goal of the DANs is to improve the care for people with dementia, their family, and caregivers by facilitating people and resources coming together to improve the system of care.

This year Trina Hodgson, ASoS Client Services Manager, and Joanne Michael, Director of Programs and Services, provided an update on the DANs in the province and their work to date. They reviewed some of the existing work that has already been done to support people with dementia - initiatives, studies, and reports that can support the work of each DAN. They also spoke about the work that each regional DAN will do to map the journey of care for people with dementia. This information will be used to identify gaps and strengths inter-regionally in the province, and will help the ASoS to identify themes in the journey and identify priority areas to improve the lives of people with dementia and their caregivers. In time for Summit 8 in 2015, the ASOS plans to have completed this work, and will provide a report of their findings.



## What is a Dementia Advisory Network (DAN)?

Goal:



 To improve the system of care for people with dementia and families and caregivers

 DAN made up of representatives from the region

**Alzheimer** Society

#### What has already been done?

- 2004 Strategy on Alzheimer disease and related dementia
- 🖊 Alzheimer Society response to the 2009 Patient First Review
- 2013 Ministry of Health Seniors Engagement Session
- 🖊 2013/2014 Council of the Federation
- 🛹 2014 RaDAR and Health Quality Council Report

#### Alzheimer Society



1st Link Program Coordinators from across the province met together at Summit 7.



## Summit Afternoon Presentation: RaDAR-Health Quality Council Dementia Gap Analysis - Summary of Key Findings and Participant Small Group Sessions





After lunch RaDAR team members Debra Morgan and Julie Kosteniuk, and Health Quality Council (HQC) senior researcher Jacqueline Quail started the afternoon with a presentation about the Final Report from the RaDAR-HQC Dementia Gap Analysis. Titled A Multi-Method Investigation of Dementia Related Services in Saskatchewan: Final Report and Recommendations, the report is the result of a multi-year partnership between HQC and the RaDAR team. The funding to support this work was provided from Dr. Debra Morgan's Applied Chair in Health Services and Policy Research (awarded jointly from CIHR and SHRF) with in-kind funding provided from HQC.

Going back to 2012, Summit participants have played an important role in shaping this study, and have been engaged in the process as the analysis progressed. At both Summit 5 and Summit 6, participants have had opportunities to learn more about the analysis, and to



provide input into study methods. As well, Summit participants have benefitted from early access to preliminary data and the opportunity to discuss findings and their relevance with all of the members of the research team face-to-face.



At Summit 7 the presenters reviewed the background of the Gap Analysis with a focus on the three components of the study: a best practice review, administrative health data analysis including prevalence and incidence of dementia in province by health region, and the findings of an environmental scan of dementia related services by health region.

After the presentation the presenters asked Summit participants to use their skills and knowledge in the field of dementia care in





Saskatchewan to help with the report by reviewing and revising the draft recommendations generated from the study. They were also asked to identify and rank their top five recommendations, and suggest action plans for each. Summit participants broke into small discussion groups that were each facilitated by one of the co-authors of the study. After the small group discussions, a moderated discussion was held with each group reporting back on their top five recommendations and action plans.



Gap Analysis – Recommendations
10 Recommendations
Policy
<ol> <li>Revisit and update the Provincial Strategy for Alzheimer Disease and Related Dementias in Saskatchewan released in 2004</li> </ol>
2. Improve access to a timely diagnosis
<ol><li>Increase access to health and community services for individuals living in rural communities</li></ol>
4. Ensure that family caregivers are adequately supported
<ol> <li>Include dementia in the provincial Chronic Disease Management Quality Improvement Program</li> </ol>
Gap Analysis – Recommendations
10 Recommendations
Research         6. Track quality indicators of dementia care provincially and by health region         7. Increase investment in the First Link referral program provided by the Altheimer Society of Saskatchewan         Knowledge Translation and Exchange         8. Partner with television and newspaper media to raise public awareness         9. Establish and maintain continuing education programs for health care professionals         10. Increase awareness of early onset dementia (younger than 65 years)
Since the Summit the Final Report from the RaDAR- HQC Dementia Gap Analysis has been released. You can download a copy from the RaDAR team's website using this

Thank-you & safe travels

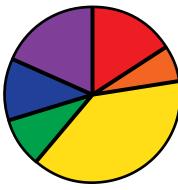
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## 2014 Summit Evaluation

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~	Combining the Second with the					

We asked participants to identify their role(s) as Summit attendees. Their responses are graphed below.



How would you describe your role?

Researcher
Family
Student
Other
Work with people with dementia
Administrative work in dementia care

Of the sixty-eight participants, 38 completed and returned a Summit evaluation at the end of the meeting. This feedback is invaluable to the team as we assess the 2014 Summit and plan for the meeting in 2015.

The majority of respondents felt that the poster session evening provided ample opportunities to learn about research as well as interact with researchers in the field of rural and remote dementia care. All of the evaluations indicated that the poster session provided good value for participant's time. There was also a lot of positive feedback about the combination of the Summit Poster evening and the SHARP Conference Poster reception: respondents generally enjoyed the larger event and opportunity to see other research from the SHARP conference, and Summit poster presenters enjoyed the broader audience for their posters.

Overall, respondents 'Strongly Agreed' that the Summit meeting on Wednesday was a good use of their time, and that there was a good flow to events of the day.

We learned that overlapping the Summit meeting with the SHARP conference was something that the majority of evaluation respondents 'Agreed' was a benefit to the meeting overall. Most felt that there were additional opportunities for networking and knowledge exchange and that it provided a nice change from previous Summit meetings. However, a few participants did note that it was a bit confusing at times.

Participants this year enjoyed: Dr. Anthea Innes' keynote presentation; the interactive group work and group discussion in the afternoon; and the organization to the day.

We learned that next year participants would appreciate if Summit 8: included additional participants from other areas of the province, as well as persons with dementia; included a follow-up report from the small-group discussions from this year's Summit; kept the format of the meeting the same, and continued to remain on-time and on-task throughout the busy day.

"I always learn so much" "... a well organized, thought provoking event" "This was my first Summit and it was a wonderful " experience ... a great forum to discuss, network & learn"

... it was amazing to see so many intelligent & dedicated people in one room"

"Efficient usage of time, very productive day. Great job organizing several activities into a small amount of time.

"This is a priority to attend in my calendar. I always go home eager to find different things to do

"... the wide range of people"

## **Supplemental Resources**

Attendees of the Summit come from a variety of backgrounds but all share a common interest in rural and remote dementia care. Page 16 of this report includes contact information for the attendees of Summit 7.

Copies of participant binders, the poster booklet from Tuesday, and information provided during this year's Summit are available. Please contact Duane Minish, Research Assistant, at duane.minish@usask.ca or phone: 306-966-4098.

### Web Based Resources

The RaDAR team has updated the research team website, and it includes a great selection of links to other excellent dementia-related web sites under the Resources tab www.cchsa-ccssma.usask.ca/ruraldementiacare



Resources available on the RaDAR Team website include the full report from the RaDAR-HQC Dementia Gap Analysis as mentioned on pages 12 & 13 in this report, and the RaDAR Team newsletter. Visit the RaDAR site to download a copy.

The Gateway for Rural International Initiatives in Dementia (GRIID) - a website that connects rural based research and services from around the world and invites users to contribute content and share rural initiatives from their area.

www.ruraldementia.com

The Summit keynote presenter, Dr. Anthea Innes, is the director of the Bournemouth University Dementia Institute (BUDI) in Bournemouth, UK. The BUDI website has more information about the work that Dr. Innes and her team undertake, and highlights current research and projects at the institute.

http://blogs.bournemouth.ac.uk/dementia-institute

The Alzheimer's Society in the United Kingdom has authored a report *Building dementia-friendly communities: A priority for everyone*. You can download a copy of this report from the Society's website.

www.alzheimers.org.uk

Alzheimer's Disease International has published an important report Improving dementia care worldwide: Ideas and advice on developing and implementing a National Dementia Plan. The report provides an outline of important content, development, and implementation considerations for countries developing their own national plan.

www.alz.co.uk/dementia-reports-policy-briefs









## Appendix A - Summit Participant Contact Information

Contact information for individual attendees has been removed from this version of the report posted on-line.

Please contact Debra Morgan at the University of Saskatchewan email: debra.morgan@usask.ca or phone 306-966-7905 for assistance contacting any of the decision makers.



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## Appendix B - List of Posters Presented at Summit

Poster Presenter	Authors & Poster Titles
Juanita Bacsu	Bacsu J, Viger M, Abonyi S, Jeffery B
	Rural Older Adults' Perceptions of Cognitive Health
Anita Bergen	Nein L, Bergen A, Evjen T
	Accurate assessment, effective care planning and quality improvement for better resident outcomes
Camille Branger	Branger C, Burton R, O'Connell ME, Stewart N, Morgan D
	Coping with Cognitive Impairment and Dementia: Rural caregivers' Perspectives
Rachel Burton	Burton R, O'Connell ME
	Recruiting individuals diagnosed with dementia due to Alzheimer's disease for cognitive rehabilitation: Ethical tension between the clinician and investigator roles
Allison Cammer	Cammer A, Whiting S, Morgan D
	The Intersection of Resident-Centered Care and Best Practices for Nutrition Care in Long-term Care
Vanina Dal Bello-	Dal Bello-Haas V, Crossley M, O'Connell ME, Morgan D, Kirk A
Haas	Characteristics of Falls in Community Dwelling Older Adults with Early Memory Problems
Vanina Dal Bello-	Dal Bello-Haas V, O'Connell ME, Morgan D
Haas	Fitness and Physical Activity Levels of Individuals Attending a Rural and Remote Memory Clinic
Tracy Danylyshen- Laycock	Danylyshen-Laycock T, Morgan D
	Examining the Relationship Between Leadership and Sustainability of a Dementia Training Program in Long- Term Care
Ben Gould	Gould B, Enright J, O'Connell ME, Morgan D
	Reliable Change (RCI) on Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) in a Dementia Sample
Sarah Hambidge	Hambidge S
	Care farming: providing brighter futures for young and old
Ben Hicks	Hicks, B
	An exploration of commercial gaming technology as a leisure activity for older men with dementia in rural Dorset
Leslie Holfeld	Holfeld L, Morgan D, O'Connell ME, Crossley M, Kirk A, Stewart N, Dal Bello-Haas V, McBain L, Cammer A, Minish D, Beever R, Kosteniuk J
	Rural And Remote Memory Clinic – Update (March 2004 – June 2014)
Paulette Hunter	Hunter P, Hadjistavropoulos T, Thorpe L, Malloy D
	The influence of individual and organizational factors on person-centred dementia care
Paulette Hunter and	Berger J, Blevins L, Evjen T, Gelowitz K, Nein L, Nowlan D, Tiedjens A, Werle J
Anita Bergen	myPLAN 1.0: Resident Centred Care Planning In Long Term Care
Paulette Hunter and	Hunter P, Bergen A, Berger H, Blevins L, Evjen T, Gelowitz K, Nein L, Nowlan D, Tiedjens A, Werle J
Anita Bergen	myPLAN 1.0: Evaluation Framework
Paulette Hunter and	Hunter P, Fick F
Anita Bergen	myPLAN 1.0: Staff Perceptions

Poster Presenter	Authors & Poster Titles		
Anthea Innes	Innes A, Page S, Cutler C, Crossen-White H, Cash M, McParland P		
	Dementia Friendly Tourism		
Anthea Innes	Cutler C, Innes A		
	Tech Club: What are the benefits of a technology group on the quality of life for people with dementia living within the community?		
Anthea Innes	Cutler C, Heward M, Hambidge S, Innes A		
	Dementia Friendly Communities: Dorset		
Anthea Innes	Innes A, Reynolds L		
	A musical ensemble: evaluation of a Bournemouth Symphony Orchestra /Bournemouth University Music initiative for people with dementia and their carers		
Anthea Innes	O'Malley, M		
	Dementia Friendly Architecture		
Anthea Innes	Cutler C, Palma P		
	Tales of the sea: Engaging people with dementia in maritime archaeology		
Kathleen Kulyk	Kulyk K, Stewart N, Peacock S, Morgan D, O'Connell ME, Kosteniuk J		
	Evaluating the Construction and Validity of a Questionnaire Assessing Healthcare Provider Perceptions of Rural Dementia Care Pathways		
Debra Morgan	Morgan D, Kosteniuk J, Crossley M, O'Connell ME, Kirk A, Stewart N, Dal Bello-Haas V, Forbes D, Innes A, McBain L, Mou H, Parrott E		
	Team 20 of the Canadian Consortium on Neurodegeneration in Aging (CCNA): Rural Dementia Action Research (RaDAR)		
Darrell Mousseau	Nyarko J, Fehr K, Pennington P, Maley J, Mousseau D		
	A simple test for mutations in the presenilin-1 gene revealed a mutation that can protect against Alzheimer disease		
Jennifer Nyarko	Wei Z, Nyarko J, Pennington P, Fernyhough P, Baker G, Mousseau D		
	Phosphorylation of the insulin receptor substrate-1 regulates monoamine oxidase-A in primary and immortalized neuronal, but not glial, cultures		
Megan O'Connell	O'Connell ME, Burton R, Michael J		
	From Research to Practice: Collaboration with the Alzheimer Society of Saskatchewan for a Telehealth Delivered Frontotemporal Dementia Caregiver Support Group		
Posters presented as part of the 7th International Symposium: Safety & Health in Agricultural & Rural Populations: Global Perspectives (SHARP)			
Allison Cammer	Cammer A, O'Connell ME, Morgan D, Whiting S		
	Nutrition Care Needs of Alzheimer Disease versus non-Alzheimer Disease Dementia Patients		
Joe Enright	Enright J, O'Connell ME		
	An Evaluation of a Reminiscence Intervention via Telehealth Videoconferencing for Caregivers of Persons with Dementia		
Julie Kosteniuk	Kosteniuk J, Morgan D, Quail J, Teare G, Kulyk K, O'Connell ME, Kirk A, Crossley M, Stewart N, Dal Bello-Haas V, McBain L, Mou H, Forbes D, Innes A, Bracken J, Parrot E		
	Analysis of dementia prevalence, incidence, and care gaps in Saskatchewan: A mixed methods study		

## Appendix C - RaDAR Research Team Selected Publications

#### PEER REVIEWED PAPERS

#### Published/In Press/Accepted:

Enright, J., O'Connell, M. E., MacKinnon, S., & Morgan, D. (accepted November 22, 2014) Predictors of completion of executive functioning tasks in a memory clinic dementia sample. *Applied Neuropsychology: Adult.* 

Forbes, D.A., Strain, L., Blake, C., Peacock, S., Harrison, W., Woytkiw, T., Hawranik, P., Thiessen, E., Woolf, A., Morgan, D., Innes, A., & Gibson, M. (in press, 2015). Dementia care evidence: Contextual factors that influence use in northern home care centres. *Online Journal of Rural Nursing and Health Care*, *15*(1).

Kosteniuk, J., Wilson, E., Penz, K., MacLeod, M., Stewart, N., Kulig, J., Karunanayake, C., & Kilpatrick, K. (Firstview published online, March 19, 2015) Development and psychometric evaluation of the Primary Health Care Engagement (PHCE) Scale: a pilot survey of rural and remote nurses. *Primary Health Care Research and Development*, doi:10.1017/S1463423615000158

Kosteniuk, J., Morgan, D., O'Connell, M. E., Crossley, M., Kirk, A., Stewart, N., & Karunanayake, C. (2014). Prevalence and covariates of elevated depressive symptoms in rural memory clinic patients with mild cognitive impairment or dementia. *Dementia and Geriatric Cognitive Disorders Extra*, 4(2), 209-220. doi:10.1159/000363226

Morgan, D., Kosteniuk, J., Stewart, N., O'Connell, M. E., Karunanyake, C., & Beever, R. (2014). The Telehealth Satisfaction Scale (TeSS): Reliability, validity, and satisfaction with telehealth in a rural memory clinic population. *Journal of Telemedicine and eHealth, 20*(11), 997-1003. doi:10.1089/tmj.2014.0002

O'Connell, M. E., Dal Bello-Haas, V., Crossley, M., & Morgan, D. (2015). Attitudes toward physical activity and exercise: comparison of memory clinic patients and their caregivers and prediction of activity levels. *Journal of Aging and Physical Activity, 23*(1), 112-119. doi:10.1123/japa.2013-0035

Dal Bello-Haas, V., Cammer, A., Morgan, D., Stewart, N., & Kosteniuk, J. (2014). Rural and remote dementia care challenges and needs: perspectives of formal and informal care providers residing in Saskatchewan, Canada. *Rural and Remote Health*, 14, 2747. Available from www.rrh.org.au

Stewart, N., Morgan, D., Karunanayake, C., Wickenhauser, J., Cammer, A., Minish, D., O'Connell, M., & Hayduk, L. (online before print, January 26, 2014). Rural caregivers for a family member with dementia: Models of burden and distress differ for women and men. *Journal of Applied Gerontology*. doi: 10.1177/0733464813517547

Morgan, D., Crossley, M., Stewart, N., Kirk, A., Forbes, D., D'Arcy, C., Dal Bello-Haas, V., McBain, L., O'Connell, M. E., Bracken, J., Kosteniuk, J., & Cammer, A. (2014). Evolution of a community-based participatory approach in a Rural and Remote Dementia Care Research Program. *Progress in Community Health Partnerships: Research, Education, and Action, 8*(3), 337-345. doi:10.1353/cpr.2014.0040

Branger, C., Burton, R., O'Connell, M., Stewart, N., & Morgan, D. (online before print June 20, 2014). Coping with cognitive impairment and dementia: Rural Caregivers' Perspectives. *Dementia: The International Journal of Social Research and Practice*. doi: 10.1177/1471301214539956

Branger, C., O'Connell, M., & Morgan, D. (ePub ahead of print, Jan 30, 2014). Factor Analysis of the 12-item Zarit Burden Interview in caregivers of persons diagnosed with dementia. *Journal of Applied Gerontology*. doi: 10.1177/0733464813520222

O'Connell, M., Dal Bello-Haas, V., Crossley, M., & Morgan, D. (2014). Clinical correlates of awareness for balance, function, and memory: Evidence for the modality specificity of awareness. *Journal of Aging Research*, 2014, 1-12. doi: 10.1155/2014/674716

2014

Kosteniuk, J., Morgan, D., Bracken, J., & Kessler, P. (2014). Adventures in rural and remote health services innovation: the role of researcher as collaborator [editorial]. *Rural and Remote Health, 14,* 2898. Available from www.rrh.org.au

Morgan, D., Walls-Ingram, S., Cammer, A., O'Connell, M., Crossley, M., Dal Bello-Haas, V., Forbes, D., Innes, A., Kirk, A., & Stewart, N. (2014). Informal caregivers' hopes and expectations of a referral to a memory clinic. *Social Science and Medicine*, *102*, 111-118. doi: 10.1016/j.socscimed.2013.11.023

Kosteniuk, J., Morgan, D., Innes, A., Keady, J., Stewart, N., D'Arcy, C., & Kirk, A. (2014). Who Steers the Ship? Rural Family Physicians Views on Collaborative Care Models for Patients with Dementia. *Primary Health Care Research & Development*, *15*(1), 104-110. doi:10.1017/S146342361300011X

O'Connell, M., Crossley, M., Cammer, A., Morgan, D., Allingham, W., Cheavins, B., Dalziel, D., Lemire, M., Mitchell, S., & Morgan, E. (2014). Development and evaluation of a Telehealth videoconferenced support group for rural spouses of persons diagnosed with atypical early-onset dementias. *Dementia: The International Journal of Social Research and Practice, 13*(3), 382-395. doi:10.1177/1471301212474143

Burton, R., Enright, J., O'Connell, M. E., Lanting, S., & Morgan, D. (first published online December 3, 2014). RBANS embedded measures of suboptimal effort in dementia: Effort scale has a lower failure rate than the effort index. *Archives of Clinical Neuropsychology*. doi:10.1093/arclin/acu070

Dal Bello-Haas, V., O'Connell, M. E., & Morgan, D. (2014). Maintaining health and wellness in the face of dementia: an exploratory analysis of individuals attending a rural and remote memory clinic. *Rural and Remote Health, 14*, 2722. Available from www.rrh.org.au

Dal Bello-Haas, V., O'Connell, M. E., Morgan, D., & Crossley, M. (2014). Lessons learned: feasibility and acceptability of a telehealth delivered exercise intervention for rural-dwelling individuals with dementia and their caregivers. *Rural and Remote Health*, 14, 2715. Available from www.rrh.org.au

Forbes, D., Blake, C., Thiessen, E., Finkelstein, S., Gibson, M., Morgan, D., Markle-Reid, M., & Culum, I. (2013). Dementia care knowledge sharing within a First Nations community. *Canadian Journal on Aging. 32*(4), 360-374. doi: 10.1017/S0714980813000457

Kosteniuk, J., Morgan, D., & D'Arcy, C. (2013). Use and perceptions of information among family physicians: sources considered accessible, relevant, and reliable. *Journal of the Medical Library Association*, *101*(1), 32-37. doi:10.3163/1536-5050.101.1.006

Saleh, S., Kirk, A., Morgan, D., & Karunanayake, C. (2013). Less education predicts anticholinesterase discontinuation in dementia patients. *Canadian Journal of Neurological Science*, 40(5), 684-690.

Estabrooks. C., Poss, J., Squires, J., Teare, G., Morgan, D., Stewart, N., Doupe, M., Cummings, G., & Norton, P. (2013). A profile of residents in prairie nursing homes. *Canadian Journal on Aging*, *32*(3), 223-231. doi: 10.1017/S0714980813000287

Cammer, A., Morgan, D., Stewart, N., McGilton, K., Rycroft-Malone, J., Dopson, S., & Estabrooks, C. (ePub July 15, 2013). The hidden complexity of long-term care: How context mediates knowledge translation and use of best practices. *The Gerontologist*, doi:10.1093/geront/gnt068

O'Connell, M., Germaine, N., Burton, R., Stewart, N., & Morgan, D. (2013). Degree of rurality is not related to dementia caregiver distress, burden, and coping in a predominantly rural sample. *Journal of Applied Gerontology,* 32(8), 1015-1029. doi:10.1177/0733464812450071

Meng, X., D'Arcy, C., Morgan, D., Mousseau, D. (2013). Predicting the risk of dementia among Canadian seniors: A useable practice-friendly diagnostic algorithm. *Alzheimer Disease & Associated Disorders 27*(1) 23-29. doi:10.1097/WAD.0b013e318247a0dc

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## Appendix C - RaDAR Research Team Selected Publications - continued

McCormack, B., Roberts, T., Julienne, M., Morgan, D., & Boscart, V. (2012). Appreciating the 'Person' in long-term care. International Journal of Older People Nursing. 7, 284-294. doi:10.1111/j.1748-3743.2012.00342.x

Forbes, D., Finkelstein, S., Blake, C., Gibson, M., Morgan, D., Markle-Reid, M., Culum, I., & Thiessen, E. (online 2012). Knowledge exchange throughout the dementia care journey by rural community-based health care practitioners, persons with dementia, and their care partners: an interpretive descriptive study. *Rural and Remote Health*, *12*, 2201.

Cranley, L., Birdsell, J., Norton, P., Morgan, D., & Estabrooks, C. (2012). Insights into the impact and use of research results in a residential long-term care facility: A case study. *Implementation Science*, *7*, 90 doi:10.1186/1748-5908-7-90

Lacny, C., Kirk, A., Morgan, D., & Karunanayake, C. (2012). Predictors of cognitive impairment severity in rural patients at a memory clinic. *Canadian Journal of Neurological Science*, 39(6), 774-781.

Kosteniuk, J., Morgan, D., & D'Arcy, C. (2012). Diagnosis of anxiety and depression in clinical scenario patients: Survey of Saskatchewan family physicians. *Canadian Family Physician, 58*, 144-151.

Kosteniuk, J., Morgan, D., & D'Arcy, C. (2012). Treatment and follow-up of anxiety and depression in clinical scenario patients: Survey of Saskatchewan family physicians. *Canadian Family Physician, 58*, 152-158.

Slaughter, S., & Morgan, D. (2012). Functional outcomes of nursing home residents in relation to features of the environment: Validity of the Professional Environmental Assessment Protocol. *Journal of the American Medical Directors Association*, *13*(5), 487.e1-487.e7. doi: 10.1016/j.jamda.2012.01.003

#### **Technical Reports**

Kosteniuk, J., Morgan, D., Quail, J., Teare, G., Kulyk, K., O'Connell, M. E., Kirk, A., Crossley, M., Stewart, N., Dal Bello-Haas, V., McBain, L., Mou, H., Forbes, D., Innes, A., Bracken, J., & Parrott, E. (2015). A Multi-Method Investigation of Dementia and Related Services in Saskatchewan: Final report and Recommendations. Report printed at the University of Saskatchewan (160 pages).

Morgan, D., & Minish, D. (July 2014). Summit 6 final report. Final report from the sixth annual summit of the knowledge network in rural and remote dementia care, October 24th & 25th 2013. Report printed at the University of Saskatchewan (24 pages).

Kosteniuk, J., Morgan, D., & Dal Bello-Haas, V. (July 2014). *Dementia learning needs assessment for Sun Country Health Region: Survey Report*. Report printed at the University of Saskatchewan (31 pages).

Morgan, D., & Minish, D. (Feb 2013). Summit 5 final report. Final report from the fifth annual summit of the knowledge network in rural and remote dementia care, November 15th & 16th 2012. Report printed at the University of Saskatchewan (26 pages).

Forbes, D., Harrison, W., Strain, L., Peacock, S., Morgan, D., Hawranik, P., Woytkiw, T., & Blake, C. (March, 2012). Contextual Factors within Northern Home Care Centres that Influence the Spread and Uptake of Research Evidence: A Pilot Study. Report printed at University of Alberta (39 pages).

Morgan, D., & Minish, D. (February, 2012). *Knowledge network in rural and remote dementia care: Final Report, 4th Annual Summit Oct 27th and 28th, 2011*. Report printed at the University of Saskatchewan (28 pages).

If you would like assistance accessing any of these publications, or if you would like more information about research conducted by the team, please contact Duane Minish, Research Assistant: duane.minish@usask.ca or by phone at 306-966-4098





The RaDAR Team maintains a website with information about team members, team research projects, dementia-specific resources and contact information.

The site also features reports and photos from past Summit events. Be sure to visit:

www.cchsa-ccssma.usask.ca/ruraldementiacare



Report from the Knowledge Network in Rural and Remote Dementia Care Summit 2014 For more information: debra.morgan@usask.ca