Knowledge Network in Rural and Remote Dementia Care

Healthcare Delivery Across the Continuum for Rural and Remote Seniors with Dementia

2nd Annual Summit October 29th & 30th, 2009 Saskatoon, SK









Final Report



Mark your calendars now for the 3rd Annual Knowledge Network in Rural and Remote Dementia Care Summit

October 28th & 29th 2010 Saskatoon

Contents

Welcome from Dr. Debra Morgan	2
Introduction and Summit Summary	3
Summit Agenda	4
Group Homework Discussion Piece	5
Project Discussion Group Notes: Policy and Longterm Care	7
Project Discussion Group Notes: Telehealth Delivered Exercise Intervention	8
Project Discussion Group Notes: Dementia Diagnosis and Management	9
Project Discussion Group Notes: Caring for a Family Member with Dementia	10
Following up and Supplemental Resources Available	11
Event Evaluation Feedback Response Summary	12
Appendix A - Selected Research Team Publications	15
Appendix B - Decision Maker Contact Information	19
Appendix C - Researcher Contact Information	23



Dear Decision Maker Advisory Council members:

I would like to extend my thanks to everyone who participated in the 2nd annual Summit of the Knowledge Network in Rural and Remote Dementia Care, held in Saskatoon in October, 2009. The Summit is linked to an Applied Chair in Health Services and Policy Research, funded by the Canadian Institutes of Health Research and the Saskatchewan Health Research Foundation (2009-2014). The title of the Applied Chair program is *Healthcare Delivery Across the Continuum for Rural and Remote Seniors with Dementia.* Your input into the research, education, and knowledge exchange activities of this Chair are most appreciated.

This report summarizes the activities of the meeting on Friday October 30th, 2009. A separate document was created with copies of the posters presented at the wine and cheese reception and scientific poster session on Thursday October 29th. Copies of this document are available by contacting us (see page 11).

We will be holding the 3rd annual Summit on Thursday October 28th and Friday October 29th, 2010 in Saskatoon. Once again, the wine and cheese poster session and the fullday Summit will be held at the Sheraton Hotel. We look forward to seeing you there.

Thank you again for you invaluable contributions to our team's ongoing research program. It is a pleasure to work with you as we all strive to improve dementia care in rural and remote areas.

Sincerely,

Leber Mongon

Debra Morgan

Introduction and Summary

This report summarizes the activities of the 2nd annual Summit of the Knowledge Network in Rural and Remote Dementia Care held in Saskatoon on the 29th and 30th of October 2009.

This second meeting continued to build on the opportunities for the exchange of ideas between the invited decision makers and researchers. Hosted as an integral part of the activities of the Applied Chair in Health Service and Policy Research Program (funded by the Canadian Institutes of Health Research and the Saskatchewan Health Research Foundation), the Summit provided an arena to foster research and knowledge exchange between participants. Attendees included members of the Rural and Remote Dementia Care research team (founded 2003 through a CIHR New Emerging Team grant) and Decision Makers who work "in the field" to plan and provide care to people affected by dementia, their families, and communities.

Hosted at the Sheraton Cavalier Hotel in downtown Saskatoon, the first evening of the Summit opened with a welcome from Dr. Debra Morgan and a screening of a short documentary about the Rural and Remote Memory Clinic. The main activity of the evening was an informal wine and cheese reception and poster session highlighting new and ongoing dementia care research and programs in Saskatchewan (copies of the poster session booklet are available, please see page 11 for information on how to request a copy).

The second day began with opening remarks and Summit overview from Debra Morgan. The keynote speaker, Dr. Anthea Innes from the Dementia Services Development Centre at the University of Stirling, Scotland, then took the podium to share her knowledge and experience with the group with her presentation: *Dementia care in rural Scotland: Policy, practice and research issues.* After a networking break, participants were invited to review a summary of responses collected ahead of the Summit via email from decision makers concerning the kinds of dementia-related information they would like to hear more about (a copy of this summary document follows on page five). This information will help the Summit group plan future events, and will help to inform future newsletters and communications with the group. Tracy Danylyshen-Laycock and Anita Bergen presented their experiences in selecting and implementing a resident-centered care program in a rural long-term facility. The morning session ended with Dr. Anthea Innes returning to provide a brief overview of educational opportunities available through the Dementia Services Development Centre at the University of Stirling.

After lunch, four small group discussion stations were arranged, each anchored by a research team member who is developing a new study related to rural dementia care. In small groups, Summit attendees circulated to each discussion station for 'hands on' time with the project lead and research team members at each station. These discussions were an opportunity for the researchers to discuss the research questions, methods, and study logistics with the Decision Makers present. This unique opportunity for sharing of expertise was invaluable for the four researchers who have used this input to refine their study plans (please see their Project Discussion Group Notes on pages seven through ten). Participants also rated this activity highly in the evaluation (page 12).

The day ended with an evaluation of the meeting and discussion of next year's Summit. A suggested meeting time of the last Thursday and Friday of October 2010 was identified as a time that would best suit the majority of participants. Subsequent to the event, October 28th & 29th, 2010 have been confirmed as the dates for the next Summit group meeting.

Summit Agenda

Agenda

Knowledge Network in Rural and Remote Dementia Care 2nd Annual Summit October 29th & 30th Sheraton Hotel – Saskatoon

Thursday, October 29th - Sheraton Hotel – South Room

7:00 pm – 10:00 pm Registration, Wine and Cheese Poster session and informal networking. Please join us in the South room to review posters which highlight a variety of projects from summit attendees. Appetizers will be served, and a cash bar will be available.

Friday, October 30 th	- Sheraton Hotel – South & West Rooms
8:00 am - 8:25 am	Registration and Breakfast served in the South/West room
8:30 am - 8:45 am	Intro, welcome, and overview of day
8:45am - 9:45 am	Keynote by Dr. Anthea Innes from the Dementia Services Development Centre at the University of Stirling - Scotland
9:45 am - 10:15 am	Networking break and coffee
10:15 am - 10:45 am	Review and discussion of participant priorities identified at last year's summit, and of participant interest for further dementia-related information
10:45 am <i>–</i> 11:45 am	Presentations to highlight the programs available for staff training and resident care in Long Term Care facilities. Guest presenters will include: (1) Tracy Danylyshen-Laycock (Saskatoon) – Review of training/care programs (2) Anita Bergen (Rosthern)- Gentle Persuasive Approach (3) Cynthia Shelstad (Assiniboia) – Supportive Pathways The presentations will be followed with a group discussion.
11:45 am - noon	Dr. Anthea Innes will provide a brief overview of training programs offered at the Dementia Services Development Centre and potential opportunities for collaboration
Noon to 1:00 pm	Lunch served in the South/West room
1:00 pm - 1:45 pm	 Project overviews of developing research projects being lead by team members: a) Allison Cammer: Policy Analysis of Saskatchewan Long Term Care b) Vanina Dal Bello-Haas: Development of a Telehealth Delivered Exercise intervention c) Julie Kosteniuk: Dementia Diagnosis and Management: Advancing Strategies to Support Rural and Remote Primary Care Providers d) Debra Morgan: Caring for a Family Member with Dementia: Identifying the Support and Service Needs of Rural Family Caregivers
1:45 pm - 3:00 pm	Participants will have the opportunity to interact with project leads to explore the feasibility, quality and relevance of the proposed studies.
3:00 pm	Refreshment Break – cold drinks and snacks provided
3:10 pm - 3:30 pm	Wrap-up and evaluation of the 2 nd Annual Summit, communication strategies for attendees, and setting the date for the next Summit
3:30 pm	Adjourn – thank you for your participation and have a safe trip home





Due to H1N1 preparations, Cynthia was unable to present







Group Homework and Discussion Piece

Reproduced over the next two pages are the condensed responses collected from participants via email before the Summit. These responses were a part of the discussion held mid-morning on Friday to reflect on participants' identified research priorities from last year, and to provide direction for future information dissemination to the group.

	Summit 2009 Homework Assignment Responses
W	hat dementia-related information are you most interested in hearing about?"
. 1	Raising public awareness (dementia education) There needs to be grassroots people that are educatedand then people need to know who these people are in their communities. Education for the public. (I think that the television commercials are goodthere needs to be more, and not all "older " people.)
.]	Early diagnosis Are people getting diagnosed in the early stages?
.]	Dementia treatment and cure Hard evidence It is important to know the latest developments in the treatment (and cure) of dementia, along with information about the accessibility and the problems, concerns and side effects of these
	treatments. Who is taking the lead to require changes in practice? "Alternative" treatments available for those in need of dementia care
4.	Rural patients What is being done for these patients in a rural setting?
	Pain management Transition from patient living at home to having help to remain at home, to care home. What is or should be available to rural patients.
_	Communication between specialists, family doctors, patient, and family members
-	Gaps in care/opportunities to improve dementia care to complex patients in rural/remote
-	settings What impact will the increasing numbers of people living with dementia have on our current health care system in rural and remote areas?
- 5.	What pressures and problems are unique to rural Saskatchewan? Rural formal/informal caregiver support
-	Any information that can be shared with and provide support to caregivers both informal and professional who care with individuals suffering with dementia would be helpful. Supports for caregivers and families of those in need of dementia care (specific to rural and
-	remote environments) What is happening for the caregivers in the rural setting? The Alzheimer society are certainly there in the larger centers, but that doesn't reach the rural settings as easily!
	Who is taking the lead in the province for the education of caregivers in LTC?

6. Chair research projects

It is important to know about the research projects in place and new ones being planned. A
report on the current status and information gathered through these projects, as well as goals
for these projects and expected outcomes. (There may be occasions when the information
gathered will differ from the expectations and may require a change in the goals and
outcomes).

7. Health care system

- What are the priority areas for improvement in provincial dementia care?
- How can current dementia care be supported by the provincial/regional/organizational improvement initiatives happening within our system?
- What impact will the increasing numbers of people living with dementia have on our current health care system in rural and remote areas?

8. Government's role in dementia care Patient First Review

- Do those involved in dementia care in our province (particularly those in remote locations) see a link to priorities announced at the throne speech in response to the Patient First review?
- How can we leverage this report and recommendations to influence government to address the needs of people with dementia and their families who are living in rural and remote areas of the province?

Senior's Care Strategy

- Five Priority Areas have been identified by the Minister Of Health:
 - 1. Addressing Elder Abuse
 - Expanding Home Care Supports
 - 3. Preventing Falls among Seniors
 - 4. Improving Accessibility of Personal Care Homes
 - 5. Developing a Seniors Secretariat
- How do we work within this government identified priority to make sure that the voice of people with dementia and their caregivers are part of this priority process?

Rising Tide Report

 How can we utilize the Rising Tide Report that is under development by the Alzheimer Society of Canada to leverage support to make dementia a health care priority in Saskatchewan?

9. Innovations

- Innovations that have improved care in various regions.
- Details of successful programs to deliver dementia care to complex patients (eg. with behavioural issues or comorbidities) in rural/remote settings



Report of the 2nd Annual Knowledge Network in Rural and Remote Dementia Care Summit – October 29th & 30th, 2009

The Rising Tide Report is now available, turn to pagae II for more info

Project Discussion Group Notes Project Lead: Allison Cammer Policy and Long Term Care

Project Summary:

The subject of policy and long-term care was introduced at the 2009 Summit to engage with stakeholders on the topic and to gauge their level of interest in and perceived benefit of a study of the long-term care policy cycle within Saskatchewan. Policy is a somewhat nebulous term and can be used as a 'catch-all' for the governance structures, regulations, and procedures that guide the operation of long-term care facilities. Little is known about Saskatchewan's current long-term care policy cycle, what policy exists, how it is used, how new policies are initiated and determined, how they are implemented, accessed and evaluated, who the intended users are, and who actually uses formal policies within the continuum of care. These knowledge gaps provide a challenge: how to conduct research that will best address knowledge translation and efficiently and successfully put research into practice within long-term care practices at all levels: provincial, regional, local and facility. A better understanding of formal policy could help to direct future research and practice.

The small group discussions at the Summit yielded much information. Decision-makers noted that formal policy per se has not been central to long-term care since the early 1980s; instead, the focus has been guidelines and standards of care. They explained that formal policy is often difficult to mandate in long-term care given the emphasis on resident-directed philosophy of care and wide variation in facility resources and in residents. All agreed that it would be beneficial to have a more thorough understanding

of the complex policy process, but indicated that it will be a difficult undertaking. Though the focus of discussion was primarily on formal policy, we know that informal policy dictates much of practice and is also of interest.

Summit Feedback:

The term 'policy' can be intimidating and implies something written in stone which doesn't fit with the flexibility encouraged in long-term care. May want to address 'standards of care' rather than 'policy'.



- A clear and concise definition of policy will need to be determined before engaging with people; policy can be understood very differently and can have more than one meaning, especially among different categories of provider.
- Saskatchewan Association of Healthcare Organizations has been working on a long-term care policy document for ~ 5 years and is close to having a draft for public release.
- Regional variation will have to be addressed as well as the difference between urban and rural long-term care facilities.

The scope of a potential research project examining long-term care policy in Saskatchewan requires narrowing and focusing. The information and suggestions provided by decision makers at the Summit meeting will be invaluable in determining specific research questions that can adequately address policy and long-term care.

<u>Project Discussion Group Notes</u> <u>Project Lead:</u> Vanina Dal Bello Haas Development and Evaluation of a Telehealth Delivered Exercise Intervention for Rural-Dwelling Individuals with Memory Problems and Their Caregivers

Project Summary:

Exercise is considered to be an important non-pharmacologic intervention for people diagnosed with cognitive impairment. We are developing and evaluating a Telehealth-delivered exercise intervention for rural, community-dwelling individuals with cognitive impairment and their caregivers. To tailor the exercise intervention, we will first obtain stakeholder feedback from Rural and Remote Memory Clinic (RRMC) patients with cognitive impairment and their caregivers. In the *Survey Development* phase, we plan to interview RRMC patients and caregivers regarding physical activity and exercise, accessible services that are currently available in their home communities, intervention needs, unmet intervention needs and preferences regarding exercise interventions. Trends from these interviews will be used to refine specific questions for a survey that will be mailed out to current RRMC patients and their caregivers for the *Survey Administration* phase. The results from these surveys will be used to develop a pilot exercise intervention program that can be delivered over Telehealth. To examine the **feasibility** and **acceptability** of this novel Telehealth delivered exercise intervention program, we will implement the program with RRMC patients and caregivers who reside in the Kelsey Trail and Prince Albert Parkland Health Regions.

Summit Feedback:

- We received several suggestions about questions/types of questions that we could use in the survey including: familiarity with and access to computers, high-speed internet and the Nintendo Wii Fit; and comfort level in exercising with others with similar memory problems.
- We were encouraged to highlight the social aspect of the exercise program as an added incentive to get individuals to participate. Other incentives could include prizes or certificates of participation.
- We discussed Telehealth and other teleconference options that could be available or explored in Saskatchewan communities. It was recommended that we also gauge the interest of conducting an exercise program through the internet.
- We were encouraged to examine the Saskatchewan Parks and Recreation Association and FIT for Active Living resources as an initial first step to help us identify existing community resources.



We received several suggestions about family and community involvement through supervision and participation in the exercise intervention.

During the *Survey Development* phase we implemented many of the suggestions and feedback we received from the Summit participants during the small group discussions. We are currently reworking some of these questions for the survey and we are also using the feedback groups' suggestions to locate community resources more readily.

For future stages of the project, we are planning to facilitate participant socialization in the program through coffee and conversation while encouraging caregivers and other family members to participate in the exercise intervention as well. Overall, we received a great deal of positive and extremely useful feedback that we will continue to implement in the next phases of our study. It was very beneficial to be able to hear from such a wide variety of stakeholders prior to initiating our research study.

<u>Project Discussion Group Notes</u> <u>Project Lead:</u> Julie Kosteniuk Dementia diagnosis and management: Advancing strategies to support rural and remote primary care providers

Project Summary:

The objective of this project is to identify the needs of primary care providers (PCPs) to assess and manage dementia, with a particular focus on the needs of rural and remote primary care providers. Our project will ask whether PCPs report practicing quality dementia care in terms of detection, diagnosis, treatment, specialist referral, and follow-up, based on the guidelines of the Third Canadian Conference on the Diagnosis and Treatment of Dementia. Also, we will examine PCP attitudes, knowledge, confidence, and support needs regarding provision of dementia care.

This project will be carried out in three phases. In Phase 1, we will conduct focus groups with 50-100 PCPs across the province. Primary care providers include family physicians, nurse practitioners, and primary health care team members. In Phase 2, we will survey approximately 100 PCPs across the province, to pilot test a questionnaire for the final phase. In Phase 3, we will survey PCPs across Alberta, Saskatchewan, and Manitoba.

Summit Feedback:

The small group discussions of this research project generated several suggestions, such as:

- Including Home Care assessors/coordinators, Occupational Therapists, and Emergency personnel in our sample of PCPs.
 - Exploring length of time to get a diagnosis, level of impairment at time of diagnosis, diagnosis screening instruments used by PCPs, types of diagnoses (i.e. specific and general), and time required to perform diagnoses.
- Inviting family members to participate in this research project.
- PCPs will be more likely to participate in research project if it includes an education component or credit for attendance, if the value of the project is clearly articulated to PCPs, and if the survey is brief.
- Focus groups will likely be difficult to conduct in small towns where privacy is an issue, and where there are few or only one practicing PCP.



Where does the project go from here:

As a result of the Summit group discussions, we decided that rather than conducting focus groups, we will conduct semi-structured telephone interviews with PCPs. Also, our printed invitations to participate in this project explicitly remind family physicians that they can claim continuing education credits for educational activity such as research participation. We hope that these methods will increase research participation. Before designing our PCP interview guide, we will carefully consider all of the points raised in the Summit group discussions. Together with the findings from the PCP interviews, these points will also be very useful as we move forward from the pilot to the main study phase.

<u>Project Discussion Group Notes</u> <u>Project Lead:</u> Debra Morgan Caring for a Family Member with Dementia

Project Summary:

The purpose of this study is to provide evidence that informs health service policy and program planning for individuals with dementia and their caregivers, who reside in rural and remote communities. Despite the higher proportion of seniors in rural communities, little is known about the experiences of caregiving in rural settings, and how these experiences and needs change over time as dementia progresses. It is this gap that the current study will address.

At the October 2009 Summit the project team presented some initial ideas for conducting a pilot phase that would inform planning for a full-scale study. The proposed pilot study design was complex, involving interviews with caregivers of past Rural and Remote Memory Clinic patients (stratified by time since diagnosis and relationship to the patient) and interviews with caregivers of new patients attending the clinic. We planned to randomly assign caregivers to one of four interview methods (telephone, telehealth, face-to-face, or focus group) in order to evaluate the utility and feasibility of various data collection methods. A final objective was to invite international researchers with expertise in rural dementia care to participate in the study.

The small group discussions at the Summit were very helpful. We received suggestions on:

- Simplifying the study design.
- Refining the initial questions for the interview guide.
- When and how often to do follow-up interviews with caregivers.
- How to recruit caregivers who are not linked to the Rural and Remote Memory Clinic.

Where does the project go from here?

 As a result of the Summit group discussions, we have made changes to the study design. We will invite family members of new Rural and Remote



Memory Clinic patients to participate in the study. To help us understand their experiences as a caregiver, we will conduct an interview at:

- 1) the initial clinic (to learn about events leading up to their assessment at the clinic and their expectations of the day)
- 2) 6 months post-diagnosis (via telephone)
- 3) one year post-diagnosis (when most patients and caregivers return to Saskatoon for an in-person appointment).
- We will ask participants about the feasibility and acceptability of telehealth interviews.
- We are in the process of submitting the application for ethical approval and plan to start conducting interviews in March or April, 2010.
- We are developing international partnerships in rural dementia care research through the participation of Dr. Anthea Innes (University of Stirling, Scotland) as a co-investigator.
- Sheena Walls-Ingram, who had been on maternity leave for the past year, returned in January and is the Research Manager for this study.

Following up and Supplemental Resources Available

After the afternoon project discussion group sessions, the Summit closed with the collection of evaluation information and feedback from the participants. (Available on the next page)

The feedback and comments from attendees strongly supports continuing to meet face-toface on an annual basis. We have again secured our hotel bookings for the **third annual Summit, to be held October 28th & 29th, 2010**. Please watch for further communication opportunities over the year as we implement some of the suggestions made during the discussion.

If there was a particular individual you would like to contact, appendices B & C contain contact information for the individuals who attended this year's Summit.

If you would like to view the Rural and Remote Memory Clinic short documentary (5 minutes) that was screened on Thursday evening before the poster session, you can find it online at www.lifeandminds.ca/features/ and then choose Rural and Remote Memory Clinic from the list.

If you would like to learn more about this year's keynote presenter, Dr. Anthea Innes, or about the Dementia Services Development Centre at the University of Stirling you may visit their website at http://dementia.stir.ac.uk

If you would like a copy of the Alzheimer Society's Rising Tide report, you will find it online at www.alzheimer.ca/english/rising_tide/rising_tide.htm

If you did not attend the event this year, or if you did attend but would like more resources, we'd be happy to provide resources you may need. You may contact either Dr. Debra Morgan (email: debra.morgan@usask.ca or phone 966-7095), or Duane Minish, Research Assistant (email: duane.minish@usask.ca or phone: 966-4098) to request additional materials.

Supporting documents and supplemental information available includes:

- Biographies of Decision Makers and Researchers
- Bound copy of all the posters from Thursday's poster session
- The slideshows presented during the keynote, and throughout the day
- Any of the documents provided to attendees of the Summit

You are invited to contact us if you were not able to attend in 2009, but would like to be a part of the 3rd annual Summit.

Credit for many of the photos from the Summit used in this report belongs to Joe Wickenhauser and Duane Minish. Save the Date! The 3rd Annual Knowledge Network in Rural and Remote Dementia Care Summit October 28th & 29th, 2010 Saskatoon



Event Evaluation Feedback Response Summary

Knowledge Network in Rural and Remote Dementia Care 2nd Annual Summit – Saskatoon October 29th & 30th, 2009

EVALUATION FORM RESULTS

We	re you able to attend the <u>Reception & Poster Session</u> last night?	Yes (19)	No (2)
If	yes, did the event:		
a)	Provide you with an opportunity to learn about research and projects that are current and relevant to rural and remote dementia care in Saskatchewan?	Yes (19)	No (0)
b)	Provide you with an opportunity to meet Research Team members	Yes (19)	No (0)
c)	you had not met before? Provide you with good value for your time?	Yes (19)	No (0)

Comments on the Reception & Poster Session:

- Good opportunity to see the initiatives that are underway in dementia care.
- Excellent posters! More time to review the posters would be appreciated.
- I was unaware of comprehensive research that is happening! I am contemplating pursuing PhD studies and am exploring options.
- Food was excellent. The floor plan was a little confusing, ie flow wasn't very good, some posters facing back corner.
- Consider keeping posters up around the edge of the room on Friday.
- Excellent food and good discussion.
- Well organized session. I liked the set-up for the posters, allowed people to circulate. The food is always good at the Sheraton, recommend this venue continue to be used.
- This is sure a great way to see how the research comes about and how studies are done.
- I was very impressed with the variety of projects. I had the opportunity to increase my knowledge about research in Saskatchewan.
- I enjoy it. Time to think about it before sessions today. Like the idea of posters staying up the next day as well.
- Could leave posters up on Friday.
- As a poster presenter it was good to come early or stay after the poster session ended to see what others were presenting.
- Leave posters up the next day a good idea.

Event Evaluation Feedback Response Summary - continued

<u>Today's Summit</u> - Please rate your satisfaction with the following (*circle appropriate response*):

	Strongly Agree	Agree	Disagree	Strongly Disagree	Did not answer question
The time allotted for agenda items was sufficient	12	8			1
The time allotted for breaks was enough that I was able to network	12	7	1		1
Overall, I enjoyed the meeting rooms, food, and amenities of the Sheraton	14	6			1
There was a good flow to the order of events during today's meeting	14	6			1
Overall, I feel like I was able to share my opinions and ideas	13	7			1
Overall, I believe that we were able to meet today's objectives	13	7			1
It was worth my time to attend the Summit today	15	4	1		1

The elements of today's Summit that I liked best were:	
 Research project consultation with Decision Makers. Had a Dr. come from the North. Keynote speaker: Anthea Innes. Violence in workplace presentation. Diverse crowd. I can't speak of anything that stands out – totally enjoyed everything. Variability of topics as well as the variability of people at the sessions. Violence Awareness Programming presentation – Tracy Danylyshen-Laycock. Keynote speaker – very relevant to situations in Sask. Variety in presentations – all very good. The discussion groups at the end of the day. Poster presentations. I always like the "brainstorming" sessions. The presentations – Anthea Innes and Tracy Danylyshen-Laycock. Small group exercise on 4 research projects. The food/comfort were top notch. I like the hours for start and finish. Sharing ideas in the afternoon. The variety of topics/speakers and audience participants. 	 Feedback sessions on research proposals – very useful to me as lead. Excellent talks and good informal discussion. Great presentations and great duration. Enjoyed hearing about current/future projects. The presentation from Dr. Innes was excellent. I feel Dr. Morgan and her team are doing an excellent job and I hope there is funding available to continue the Clinic. The groups to discuss each research project/proposal were excellent – could have been longer as it takes at least 5-10 minutes to get started and comfortable. The interdisciplinary participation. Discussion. The Gentle Persuasion approach presentation was excellent and engaging. Presentations from good guest speakers. Small groups, Presentations on GPA – partly due to the topic and partly due to passion of the speaker.

Event Evaluation Feedback Response Summary – continued

During today's Summit there were elements I did not particularly enjoy, they were:				
Nothing	• Involve, if possible, people with dementia – maybe not			
 Would be great to have more people here – perhaps 	in this format but somehow to make sure they have a			
some caregivers (family caregivers).	voice.			
All were informative and well presented.	The room was cold.			

If I were planning next year's Summit I would make sure that:			
• I continue to engage in the research consultation.	I like the Thursday evening wine and food poster		
Have a keynote speaker.	presentation.		
Government involvement.	• Tables rotated – people sat at different tables after each		
 Posters up all day on Friday. 	break to promote mix/mingling.		
Work group stations.	• Could the posters be left up.		
• Same format would be good.	• If posters were left up the next day and more time for		
• Great workshop.	group discussion of projects – include a few family		
• All activities are in the same place as you did this year.	members or individuals with dementia.		
• Would not plan an event in the evening leading up to	• I don't know that I would change anything.		
the Summit. Would suggest that posters and	Political involvement.		
networking happen over lunch and coffee breaks.	• Open poster session and Summit to private community.		
• Nothing to add – very well organized and informative.	Include provincial government.		
Other comments:			
Eantastic and Rich Experience	• The Sheraton as a one-ston convention center is a		

Other comments.	
Fantastic and Rich Experience.	• The Sheraton as a one-stop convention center is a
 Good job by all involved. 	wonderful idea.
 A good mix of international info and local research. 	• Continue yearly face to face meetings. Well done!
 Annual Summit face to face is excellent and I believe 	• Great event.
necessary.	 Soliciting input from everyone was great and the
 Invite Saskatchewan Health Representative to the 	process of getting feedback on prepared and upcoming
meeting.	research projects was good.
• I feel we are melding as a group and I am learning to	 Poster presentation provided an opportunity to reflect
understand and value research more with each Summit.	and process.
I consider it a privilege to be part of the Summit.	 All sessions with all participants attending is a good
• Excellent.	format.
 Excellent Summit – well organized. 	Well done!

By what other means would you find useful to communicate with the team? (check all that apply)

teleconferences - 3 emailed newsletters/updates - 19 online community (e.g. Sharepoint; Timeless) - 3 interactive online meetings (e.g. WebEx; Illuminate) - 4 videoconferencing (e.g. Telehealth) - 4 Other suggestions:

- E-mail with weblinks
- E-mail including info that could be printed for sharing

Appendix A – Selected Research Team Publications

If you are interested is receiving a copy of any of the following publications, please contact Duane Minish, Research Assistant at 966-4098.

Selected Research Team Publications

Morgan, D., Crossley, M., Kirk, A., McBain, L., Stewart, N., D'Arcy, C., Forbes, D., Harder, S., Dal Bello-Haas, V., Basran, J. Evaluation of telehealth for pre-clinic assessment and follow-up in an interprofessional rural and remote memory clinic. *Journal of Applied Gerontology*. (accepted Feb 14, 2010)

Stewart, N., D'Arcy, C., Kosteniuk, J., Morgan, D., Forbes, D., MacLeod, M., Kulig., J., & Pitblado, R. Moving on? Predictors of intent to leave among rural and remote RNs in Canada. *The Journal of Rural Health*. (accepted January 2010)

Andrews, M.E., Morgan, D., & Stewart, N. Awareness of dementia in northern nursing practice. *Canadian Journal of Nursing Research* (accepted Jan 7, 2010).

Peacock, S., Forbes, D., Markle-Reid, M., Hawranik, P., Morgan, D., Jansen, L., Henderson, S., & Leipert, B. The positive aspects of the caregiving journey with dementia: Using a strengths-based perspective to reveal opportunities. *Journal of Applied Gerontology. Available at On-Line First, Aug 25, 2009.*

Kulig, J., Stewart, N., Forbes, D., Morgan, D., & Emerson, P. (2009). Community attachment and satisfaction: Perspectives of rural and remote registered nurses. *Public Health Nursing*, *26*(5), 430-439.

Estabrooks, C., Hutchinson, A., Squires, J., Birdsell, J., Cummings, G., Degner, L., Morgan, D., & Norton, P. (2009). Translating Research in Elder Care: An Introduction to a Study Protocol Series. *Implementation Science*, *4*, 51.

Rycroft-Malone, J., Dopson, S., Degner, L., Hutchinson, A., Morgan, D., Stewart, N., & Estabrooks, C. (2009). Study protocol for the Translating Research in Eldercare (TREC) : Building context through case studies in long-term care project (project 2). *Implementation Science*, *4*, 53.

Morgan, D., Crossley, M., Kirk, A., D'Arcy, C., Stewart, N., Biem, J., Forbes, D., Harder, S., Basran, J., Dal Bello-Haas, V., & McBain, L. (2009). Improving Access to Dementia Care: Development and Evaluation of a Rural and Remote Memory Clinic. *Aging & Mental Health*, *13*(1), 17-30.

Crossley, M., Morgan, D., Lanting, S., Dal Bello-Haas, V., & Kirk, A. (2008). Interdisciplinary research and interprofessional collaborative care in a memory clinic for rural and northern residents of Western Canada: A unique training ground for clinical psychology graduate students. *Australian Journal of Psychology*, 43(4), 231-238.

Penz, K., Stewart, K., D'Arcy, C., & Morgan, D. (2008). Predictors of job satisfaction for rural acute care registered nurses in Canada. *Western Journal of Nursing Research*, *30*(7), 785-800.

Steve, T., Kirk, A., Crossley, M., Morgan, D., D'Arcy, C., Biem, J., Forbes, D., & Stewart, N. (2008) Medication use in patients presenting to a rural and remote memory clinic (peer-reviewed letter to the editor). *Canadian Journal of Neurological Sciences*, *35*, 669-671.

McEachern, W., Kirk, A., Morgan, D., Crossley, M., & Henry, C. (2008). Utility of telehealth in following cognition in memory clinic patients from rural and remote areas. *Canadian Journal of Neurological Sciences*, *35*, 643-646.

Hogan, D., Bailey, P., ., Black, S., Carswell, A., Chertkow, H., Clarke, B., Cohen, C., Fisk, J., Forbes, D., Man-Son-Hing, M., Lanctôt, K., Morgan, D., Thorpe, L. Diagnosis and treatment of dementia: 5. Nonpharmacologic and pharmacologic therapy for mild to moderate dementia. *Canadian Medical Association Journal*, *179*(10), 1019-1026.

Hogan, D., Bailey, P., ., Black, S., Carswell, A., Chertkow, H., Clarke, B., Cohen, C., Fisk, J., Forbes, D., Man-Son-Hing, M., Lanctôt, K., Morgan, D., Thorpe, L. (2008) Diagnosis and treatment of dementia: 4. Approach to management of mild to moderate dementia. *Canadian Medical Association Journal*, *179*(8), 787-793.

Forbes, D., Forbes, S., Morgan, D., Markle-Reid, M., Wood, J. &, Culum, I. (2008). Physical activity programs for persons with dementia. *Cochrane Database of Systematic Reviews* 2008, Issue 3. Art. No.: CD006489. DOI: 10.1002/14651858.CD006489.pub2.

Forbes, D., Markle-Reid, M., Hawranik, P., Peacock, S., Kingston, D., Morgan, D., Henderson, S., Leipert, B., & Jansen, L. (2008). Availability and acceptability of Canadian home and community-based servcies: Perspectives of family caregivers of persons with dementia. *Home Health Care Services Quarterly*, 27(2), 75-99.

Forbes, D., Janzen, L., Markle-Reid, M., Hawranik, P., Morgan, D., Henderson, S., Leipert, B., Peacock, S., & Kingston, D. (2008). Gender differences in use and availability of home and community-based health services for people with dementia. *Canadian Journal of Nursing Research*, 40(1), 38-59.

Morgan, D., Crossley, M., Stewart, N., D'Arcy, C., Forbes, D., Normand, S., & Cammer, A. (2008). Taking the hit: Focussing on caregiver "error" masks organizational-level risk factors for nursing aide assault. *Qualitative Health Research*, *18*(3), 334-346.

Kulig, J., Andrews, M.E., Stewart, N., Pitblado, R., Bentham, D., Forbes, D., MacLeod, M., Morgan, D., Smith, B., & Remus, G. (2008). How do registered nurses define rurality? *Australian Journal of Rural Health*, *16*, 28-32.

Hogan, D., Bailey, P., Carswell, A., Clarke, B., Cohen, C., Forbes, D., Man-Son-Hing., M., Lanctôt, K., Morgan, D., Thorpe, L. (2007). Management of mild to moderate Alzheimer's Disease and dementia. *Alzheimer's and Dementia: The Journal of the Alzheimer's Association, 3*, 355-384.

Morgan, D., Funk, M., Crossley, M., Basran, J., Kirk, A., & Dal Bello-Haas, V. (2007). The potential of gait analysis to contribute to differential diagnosis of early stage dementia: Current research and future directions. *Canadian Journal on Aging*, 26(1), 19-32.

Penz, K., D'Arcy, C., Stewart, N., Kosteniuk, J., Morgan, D., & Smith, B. (2007). Barriers to participation in continuing education among rural and remote nurses: Results from a national survey. *Journal of Continuing Education in Nursing*, *38*(2), 58-68.

Forbes, D., Forbes, S., Markle-Reid, M., Morgan, D., Taylor, B., & Wood, J. (2007). Physical activity programs for persons with dementia (Protocol). *Cochrane Database of Systematic Reviews, Issue 2*, Art. No.: CD006489. DOI: 10.1002/14651858.CD0066489.

Kulig, J., Stewart, N., Morgan, D., Andrews, M.E., Macleod, M., & Pitblado, R. (2006). Aboriginal nurses: Insights from a national study. *Canadian Nurse*, *102*(4), 16-20.

Forbes, D.A., Morgan, D., Janzen, B., & Biem, H.J. (2006) Rural and urban Canadians with dementia: Use of health care services. *Canadian Journal on Aging*, 25(3), 321-330.

McBain, L., & Morgan, D. (2006). Telehealth, geography, and jurisdiction: Issues of health care delivery in northern Saskatchewan. *Canadian Woman Studies*, 24(4), 123-129.

Jansen, S., Forbes, D., Duncan, V., & Morgan, D. (2006). Melatonin for cognitive impairment. *The Cochrane Database of Systematic Reviews*, Issue 1, Art. No. CD003802. LOI: 10.1002/14651858.CD003802.pub3.

Morgan, D., Stewart, N., D'Arcy, C., & Cammer, A. (2005c). Creating and sustaining dementia Special Care Units in rural nursing homes: The critical role of nursing leadership. *Canadian Journal of Nursing Leadership*, *18*(2), 74-98.

Forbes, D., Peacock, S., & Morgan, D. (2005). Nonpharmacological management of agitated behaviours associated with dementia. *Geriatrics & Aging*, 8(4), 26-30.

Morgan, D., Stewart, N., D'Arcy, C., Forbes, D., & Lawson, J. (2005b). Work stress and physical assault of nursing aides in rural homes with and without dementia special care units. *Journal of Psychiatric & Mental Health Nursing*, *12*, 347-358.

Forbes, D., Jansen, S., Duncan, V., & Morgan, D. (2005). Melatonin for cognitive impairment (Protocol). *The Cochrane Database of Systematic Reviews*, Issue 2. Oxford: Update Software.

Morgan, D., Stewart, N., Crossley, M., D'Arcy, C., Biem, J., Kirk, A., & Forbes, D. (2005a). Dementia care in rural and remote areas: The first year of a CIHR New Emerging Team. *Canadian Journal of Nursing Research*, *37*(1), 177-182

Andrews, M.E., Stewart, N., Pitblado, R., Morgan, D., Forbes, D, &D'Arcy, C., (2005) Registered nurses working alone in rural and remote Canada. *Canadian Journal of Nursing Research*, *37*(1), 14-33.

Stewart, N., D'Arcy, C., Pitblado, R., Morgan, D., Forbes, D., Remus, G., Smith, B., Andrews, M.E., Kosteniuk, J., Kulig, J., & MacLeod, M. (2005). A profile of registered nurses in rural and remote Canada. *Canadian Journal of Nursing Research*, *37*(1), 122-145.

Forbes, D.A., Morgan, D.G., Bangma, J., Peacock, S., Pelletier, N, & Adamson, J. (2004) Light therapy for managing sleep, behaviour, and mood disturbances in dementia. (Cochrane Review). In: *The Cochrane Library*, Issue 2. Chichester, UK: John Wiley & Sons, Ltd.

Morgan, D., Stewart, N., D'Arcy, C., & Werezak, L. (2004). Evaluating rural nursing home environments: Dementia special care units vs. integrated facilities. *Aging and Mental Health*, 8(3), 257-266.

Forbes, D., Stewart, N., Morgan, D., Anderson, M., Parent, K., & Janzen, B. (2003). Individual determinants of home care nursing and housework assistance. *Canadian Journal of Nursing Research*, 35(4), 14-36.

Morgan, D., Semchuk, K., Stewart, N., & D'Arcy, C. (2003). The physical and social environments of rural nursing homes: Assessing supportiveness for residents with dementia. *Canadian Journal on Aging*, 22(3), 283-296.

Biem, J., Hadjistavropoulos, H., Morgan, D., Biem, H., & Pong, R. (2003). Breaks in continuity of care and the rural senior transferred for medical care under regionalization. *International Journal of Integrated Care, 3* (September 29), ISSN 1568-4145.

Werezak, L., & Morgan, D. (2003). Creating a therapeutic psychosocial environment in dementia care: A preliminary framework. *Journal of Gerontological Nursing*, 29(12), 18-25).

Forbes, D., Morgan, D., Bangma, J., Peacock, S., Campbell, T., & Adamson, J. (2003). Light therapy for managing sleep, behavior, mood, and cognitive disturbances associated with Alzheimer Disease (Protocol for a Cochrane Review). *Cochrane Library*, Issue 4. Oxford: Update Software.

Morgan, D., & Stewart, N. (2002). Theory building through mixed-method evaluation of a dementia special care unit. *Research in Nursing and Health*, 25(6), 479-488.

Morgan, D., Semchuk, K., Stewart, N., & D'Arcy, C. (2002). Rural families caring for a relative with dementia: Barriers to use of formal services. *Social Science & Medicine*, 55(7), 51-64.

Morgan, D., Semchuk, K., Stewart, N., & D'Arcy, C. (2002) Job strain among staff of rural nursing homes: A comparison of nurses, aides, and activity workers. *Journal of Nursing Administration*, *32*(3), 152-161.

Stewart, N., Hiscock, M., Morgan, D., Murphy, P., & Yamamoto, M. (1999). Development and psychometric evaluation of the Environment-Behavior Interaction Code (EBIC). *Nursing Research*, 48(5), 260-268.

Morgan, D., & Stewart, N. (1999). The physical environment of special care units: Needs of residents with dementia from the perspective of staff and family caregivers. *Qualitative Health Research*, 9(1), 105-118.

Morgan, D., & Stewart, N. (1998a). High vs. low density special care units: Impact on the behavior of elderly residents with dementia. *Canadian Journal on Aging*, *17*(2), 143-165.

Morgan, D., & Stewart, N. (1998b). Multiple-occupancy vs. private rooms on dementia units. *Environment and Behavior*, 30(4), 487-503.

Morgan, D., & Stewart, N. (1997). The importance of the social environment in dementia care. *Western Journal of Nursing Research*, 19(6), 740-761.

Morgan, D., & Laing, G. (1991). The diagnosis of Alzheimer's disease: Spouse's perspectives. *Qualitative Health Research*, 1(3), 370-387.

For assistance accessing any of these publications please contact: Duane Minish Research Assistant (306) 966-4098 duane.minish@usask.ca

Appendix B: Decision Makers Contact Information - Updated

Jame	Position & Location	Contact info	
nita Bergen	Contact information 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.		
Auriel Beutler			
oanne Bracken			
Dr. Stephen Britton			
aylor Bassingthwaithe			
Dr. Peter Butt			
Charlene Chipeur			
Barb Church- Staudt			
Hazel Crosson			

Name	Position & Location	Contact info	
Carol Dyck	Contact information 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.		
Diania Daigneault			
Ira Dales			
Heather Dyck			
Kelvin Fisher			
Dave Gibson			
R. Turner Goins			
Carol Gregoryk			
Beverly Greenwood			

Name	Position & Location	Contact info
Elaine Halvorsen	Contact information has been re Please contact Debra Morgan at email: debra.morgan@usask.ca for assistance contacting any of	
Anthea Innes		
Jean Nelson		
Janet Keim		
Janet McVicar		
Glenda Montgrand		
Edna Parrott		
Dr. Kurt Roelens		
Dr. Heidi Schmaltz		

Cynthia Shelstad

Name	Position & Location	Contact info		
Brenda Walsh		Contact information 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.			

Dr. Tom Smith-Windsor

Elizabeth Waterer

Network Members and Gue	sts	
Name	Position & Location	Contact info

Tracy Danylyshen-Laycock

Sara Finkelstein

Nuelle Novick

Brenda Person

Juanita Tremeer

Name	Department	Phone	E-mail
Basran, Jenny	Div. of Geriatric Medicine	(306) 655-8925 pager 80363	jenny.basran@saskatoonhealthregion.ca
Beever, Rob	Applied Research/Psychiatry	(306) 966-8772	beev.99@usask.ca
Cammer, Allison	Canadian Centre for Health and Safety in Agriculture (CCHSA)	(306) 966-6075	allison.cammer@usask.ca
Crossley, Margaret	Psychology	(306) 966-5923	margaret.crossley@usask.ca
D'Arcy, Carl	Applied Research/Psychiatry	(306) 966-8769	carl.darcy@usask.ca
Dal Bello Haas, Vanina	School of Physical Therapy	(306) 966-6570	vanina.dalbello-haas@usask.ca
Elash, Freda	Applied Research	(306) 966-8767	freda.elash@usask.ca
Ellingboe, Carole	CCHSA	(306) 966-6645	cle702@mail.usask.ca
Forbes, Dorothy	School of Nursing – U. of Western Ontario	(519) 661-2111 ext 86575	dforbes6@uwo.ca
Haugrud, Nicole	Psychology	(306) 966-5925	nah843@mail.usask.ca
Holfeld, Leslie	CCHSA	(306) 966-2109	leslie.holfeld@usask.ca
Karunanayake, Chandima	CCHSA	(306) 966-1647	chandima.karunanayake@usask.ca
Kirk, Andrew	Neurology	(306) 966-8372	drew.kirk@usask.ca
Kosteniuk, Julie	Applied Research/Psychiatry/CCHSA	(306) 966-8773	julie.kosteniuk@usask.ca
McBain, Lesley	First Nations University - PA	(306) 931-1800 ext 7509	lmcbain@firstnationsuniversity.ca
Minish, Duane	CCHSA	(306) 966-4098	duane.minish@usask.ca
Morgan, Debra	CCHSA	(306) 966-7905	debra.morgan@usask.ca
O'Connell, Megan	Clinical Psychology	(306) 966-2496	megan.oconnell@usask.ca
Poock, Jocelyn	Psychology	(306) 664-6658	jocelyn.poock@usask.ca
Remmen, Moira	Clinical Health Psychology	(306) 655-2343	moira.remmen@saskatoonhealthregion.ca
Stewart, Norma	College of Nursing	(306) 966-6254	norma.stewart@usask.ca
Wagner, Flo	School of Physical Therapy	(306) 966-2110	flo.wagner@usask.ca
Walls-Ingram, Sheena	CCHSA	(306) 966-6154	sheena.walls@usask.ca
Wickenhauser, Joe	CCHSA	(306) 966-7885	joe.w@usask.ca

To request additional documentation or Summit resources, please contact Duane

Knowledge Network in Rural and Remote Dementia Care Summit 2009



























